Postoperative behaviour changes and pain in children, 2 to 12 years, following inpatient and day case surgery

By

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Declaration

I, Nina Mary Power, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: 

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Abstract

Children may suffer negative outcomes following admission to hospital. Previous research in the USA, Finland, Sweden and Australia has shown that up to 54% of children exhibit problematic behaviours (PB) 2 weeks post-discharge and 16% at one month. Risk factors included higher child/parent pre-operative anxiety, child temperament, pre-surgical behavioural disturbances, younger age, premedication, and pain at home. The incidence of post-hospital PB in British children is not known and potential influencing variables have not been examined.

The aims of this study were to describe and compare children's post-hospital PB following day case or inpatient surgery and to examine the association of parent, child, pre-operative and in-hospital factors with parent and child anxiety, preparation for surgery and child post-hospital PB and postoperative symptoms.

A descriptive, repeated measures study design was used, involving self-report questionnaires, direct observation of behaviour and post-discharge questionnaire follow-up. Children, 2 to 12 years, scheduled for general, ENT and urology surgery under general anaesthesia were invited to participate.

73.3% children exhibited PB and 93.4% were in some pain (≥1, 0-10 NRS) on day 2 post-discharge from hospital. The incidence of PB and pain decreased significantly over the follow-up period with 31.8% children exhibiting PB and 25.2% experiencing pain at the end of week 4. PB and pain were associated with families taking additional time off work/school and increased follow-up healthcare. Following multivariate regression analyses, factors associated with PB were parents' level of preparation for their child's care at home, higher parent education, younger child age, the child's previous pain experience, children who did not attend pre-admission clinics, child and parent anxiety, children who stayed overnight in hospital, and higher child pain intensity at home. The findings suggest

that poorer parent self-efficacy in caring for their child in hospital and at home are associated with increased child negative outcomes at home.

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Abbreviations

AA	aggression toward authority
ACCN	Association of Chief Children's Nurses
APAIS	Amsterdam Pre-operative Anxiety and Information Scale
ASA	American Society of Anesthesiologists
A-TQPM	Adapted Total Quality Pain Management questionnaire
AW	apathy-withdrawal
BQS	Baseline Questionnaire Set
CI	confidence interval
CONSORT	Consolidated Standards for Reporting Trials
COREC	Central Office for Research Ethics Committee
CRD	Centre for Reviews and Dissemination
DCQ	Demographic and Clinical Questionnaire
EA	eating disturbances
EASI	Emotionality Activity Sociability and Impulsivity Instrument of Child Temperament
ENT	Ear Nose and Throat
FLACC	Faces Legs Cry and Consolability
GA	general anxiety and regression
GP	General Practitioner
HES	Hospital Episodes Statistics
IMD	Index of Multiple Deprivation
IPP	Index of Parent Participation
IQR	inter-quartile range
MBSS	Monitor Blunter Style Scale
MeSH	Medical Subject Headings
MRC	Medical Research Council
mYPAS	modified Yale Pre-operative Anxiety Scale

N	number
NHS	National Health Service
NMC	Nursing Midwifery Council
NRES	National Research Ethics Service
NRS	numeric rating scale
NS	not significant
NSF	National Service Framework
PB	problematic behaviour/s
PBS	Parent Beliefs Scale
PCS	Pain Catastrophizing Scale
PHBQ	Post-Hospital Behaviour Questionnaire
PISP	Parent Information Needs and Satisfaction with Preparation
R&D	Research and Development
REC	Research Ethics Council
SA	separation anxiety
SD	standard deviation
SDQ	Strengths and Difficulties Questionnaire
SL	anxiety about sleep
STAI	State Trait Anxiety Inventory
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TPAG	Thames Paediatric Anaesthetists Group
UCL	University College London
UK	United Kingdom
USA	United States of America

Chapter 1
Introduction

1.1 Introduction

This chapter provides an overview of the challenges faced by children admitted to hospital for surgery and the associated negative short and long-term outcomes. A summary of the existing body of research is provided, gaps in knowledge are presented, followed by the study aims and objectives and how these were addressed by the study methodology.

1.2 Surgery in British children

Admission to hospital for surgery can be a significant event in the formation of children's attitudes towards hospitals and health care, including their relationships with health care workers. One in 10 to 15 British children are admitted to hospital each year and the Hospital Episode Statistics (HES) report for 2008/09 indicates that 6% of the 9.3 million operations were performed in children 0 - 14 years of age (Hospital Episodes Statistics 2009). Children's experience of hospitalisation and surgery can promote positive views of hospitals and health care professionals, leading to future proactive engagement with services, or can lead to anxiety and fear, phobias and avoidance of healthcare encounters. The long term implications in terms of reduced population health or health care costs are potentially great but unknown at this time.

1.3 The problem

Hospitalisation for surgery has been recognised as a stressful healthcare event in a child's life for a number of decades (Caldas et al. 2004;Goslin 1978;Thompson et al. 1993;Vernon et al. 1993;Watson et al. 2003). Long-term negative outcomes include problematic behaviours (PB) and pain and immediate negative outcomes include child and parent pre-

operative anxiety, (Kain et al. 1996c;Karling et al. 2007;Kotiniemi et al. 1997;Stargatt et al. 2006).

1.3.1 Problematic behaviours in children following admission to hospital for surgery

A significant proportion of children are thought to suffer persistent physical and psychosocial problems as a result of hospital encounters. PB may include: attention seeking, temper tantrums, waking up at night, and eating problems as well as fear of doctors and hospitals (Kain et al. 1999b;Kotiniemi et al. 1997). Research in the USA, Finland, Sweden, and Australia has shown that up to 54% children may exhibit new negative behaviours up to two weeks following discharge (Kain et al. 1996c), 16% one month after surgery (Stargatt et al. 2006), and 20% up to six months later (Kain et al. 1996c).

Risk factors for PB have been identified as younger child age, child temperament factors, children with pre-operative behavioural disturbances, children and parents who were more anxious pre-operatively, staying over night in hospital, and pain at home (Carson et al. 1991;Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007;Lumley et al. 1993;Stargatt et al. 2006;Tuomilehto et al. 2002).

Interventions aimed at reducing child post-hospital PB over the last two decades have had mixed results and have included: parent presence during induction of anaesthesia, pre-operative preparation programmes, administration of premedication, modes of anaesthesia induction, and changes to the theatre environment.

1.3.2 Postoperative pain and other symptoms at home

In addition to children exhibiting new PB at home following surgery, they also experience pain, nausea and vomiting (Amanor-Boadu et al. 1997;Gedaly-Duff et al. 1994;Kokinsky et al. 1999;Kotiniemi et al. 1997;Morgan et al. 2001;Reid et al. 1995;Tuomilehto et al. 2002;Wang et al. 2000;Wilson et al. 2006). Pain is reportedly worst in the first three postoperative days and decreases significantly thereafter (Gedaly-Duff et al. 1994;Reid et al. 1995;Tuomilehto et al. 2002). Child cues used by parents to assess pain include behavioural and verbal expressions, i.e. not eating or drinking, tiredness / changes in sleep, crying, grimacing and hand gestures (Gedaly-Duff et al. 1994;Reid et al. 1995). Postoperative pain has been identified as a significant predictor of post-hospital PB at 4 weeks (2 - 4 weeks after pain had resolved) and adversely affected children's attitudes towards doctors and nurses (Kotiniemi et al. 1997). Parents have reported feeling ill-equipped to deal with pain and other postoperative symptoms and experience high levels of anxiety, causing further distress to the child and prompting parents to seek medical advice (Hughes et al. 2004). Recent research has identified that 71% of children following routine tonsillectomies received less than one half of the possible doses of analgesia they could have received at home (Fortier et al. 2009b). Most parents have the potential to effectively manage their child's postoperative pain at home, as long as they are appropriately equipped to do so with a planned approach to discharge preparation and appropriate support (Bastable et al. 2005). Parents in the UK have expressed a desire for more information regarding their child's postoperative pain and the management thereof (Simons et al. 2001;Simons 2002).

1.3.3 Pre-operative anxiety

Most children exhibit some degree of pre-operative anxiety that increases significantly from admission to induction of anaesthesia (Caldwell-Andrews et al. 2005;Kain et al. 1996c;Kain et al. 2000). Risk factors for heightened child pre-operative anxiety have been identified as: anxious parents, parent coping style, child temperament factors, poor previous medical encounters, children not offered premedication, and the timing of pre-

operative preparation (Davidson et al. 2006;Kain et al. 1996c;Kain et al. 1996a;Kain et al. 2000;Kain et al. 2006b). Child pre-operative anxiety has also been identified as a risk factor for child PB two weeks following discharge from hospital (Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007) and has been associated with higher child self-reported pain scores post-discharge (Kain et al. 2006a).

1.3.4 Pre-operative preparation

There is a body of knowledge on pre-operative techniques that can prevent or reduce post-hospital PB, pain and other symptoms in children undergoing surgery (McCann et al. 2001;Vernon et al. 1993). The main mechanisms of action of pre-operative preparation are thought to be: (i) anxiety reduction in the pre-operative period, for the child directly or by reduction of parental anxiety; (ii) increased sense of control and self-efficacy through improved knowledge and coping skills; and (iii) desensitisation through non-threatening exposure to the peri-operative environment (McCann et al. 2001;Vernon et al. 1993). The effectiveness of pre-operative preparation for children is highly dependent on the involvement of parents. In a recent randomised controlled trial in the USA, a family-centred preparation for surgery programme improved child peri-operative outcomes: children exhibited a lower incidence of emergence delirium after surgery, required less analgesia in the recovery room and were discharged from the recovery room earlier (Kain et al. 2007a). Research in Canada has shown that parents may be inhibited from fully participating in pre-operative preparation with children because of their pre-existing attitudes and beliefs about the need for pre-operative preparation or communication difficulties with healthcare staff (Tourigny et al. 2005). Additionally, the effectiveness of pre-operative preparation may be moderated by a number of factors and it is not clear which of these are most beneficial in adequately preparing children and parents and reducing postoperative symptoms and post-hospital PB (McCann et al. 2001;Vernon et al. 1993). One randomised controlled trial in the UK examined the effect of pre-operative preparation on parental knowledge, anxiety and satisfaction on the day of surgery (Spencer et al. 2005). In this study parents who received an anaesthetic information leaflet within

two weeks of their child's surgery had a 10% increase in knowledge but there were no differences in parental anxiety or satisfaction based on method or timing of information delivery, however a slight majority of parents preferred to receive the information in the pre-operative assessment clinic. Interviews with British children, aged 7 to 11, reveal that children have many queries regarding their admission to hospital and planned surgery and obtain information from a variety of sources (Smith et al. 2005). In a more recent study conducted in the USA, 7 to 17 year olds expressed a desire for information about their surgery including information about pain and anaesthesia, procedural information and information about possible complications (Fortier et al. 2009a).

1.3.5 The influence of parents on children's admission to hospital

Parents who have been educated regarding expected child post-hospital PB and who have been given instructions on how they can assist in the care of their children have reported less negative mood states, less depression and fewer negative outcomes in their children (Melnyk et al. 2004). Maternal anxiety and participation in their child's care are mediating factors on the effect of child behaviour information on the child's post-hospital PB (Melnyk et al. 2001). A systematic review of the literature on parent participation in the care of hospitalised children revealed that parents want to participate in the care of their children but are not always sure of what they can and should do (Power et al. 2008). In studies where parents have been educated regarding how they can participate in their child's care and when parent and nurse roles have been defined; parents have been found to be competent to care for their children, they feel more in control and have lower levels of anxiety (Power et al. 2008).

1.4 Knowledge deficit

There is a compelling need for and suggested evidence of the effectiveness of intervention programmes to reduce children's post-hospital PB but these cannot be implemented in the

UK until the incidence of postoperative symptoms and post-hospital PB in British children, who did not receive any intervention, following surgery is known.

Descriptive detail is lacking in the current literature regarding whether or not parents are provided with information/preparation for their child's admission to hospital for surgery and how this relates to the parent and child's pre-operative anxiety and child behaviour outcomes at home. More information is also needed in terms of parent coping style, previous experience with hospitalisation for surgery and pain and how these factors relate to their information needs and satisfaction with preparation and child outcomes.

The current level of provision of pre-operative preparation must be characterised in more detail so that systematic, multi-centre evaluation of the effectiveness of the various methods of pre-operative preparation for children and parents can be done. There are no common measures with which hospitals can audit their performance. Nevertheless there are believed to be substantial costs incurred in the provision of pre-operative preparation services and this money may be wasted because the current services are ineffective or are not being provided to the children and parents who need them most.

1.5 Study aims, objectives and methodology

The aims of this research were to describe and compare children' post-hospital PB following day case or inpatient surgery and to examine the association of parent, child, pre-operative and in-hospital factors with parent and child anxiety, preparation for surgery and child post-hospital PB and postoperative symptoms. The specific study objectives were:

1. To determine the level of post-hospital PB in children after surgery;
2. To examine the associations between demographic, baseline and pre-operative psychological factors, pre-operative preparation factors, in-hospital factors and children's post-hospital PB;
3. To determine the level of post-hospital pain and other postoperative symptoms in children after surgery;

4. To examine the associations between demographic, baseline and pre-operative psychological factors, pre-operative preparation factors, in-hospital factors and children's postoperative symptoms at home;
5. To determine the level of child and parent pre-operative anxiety;
6. To examine the associations between demographic, baseline psychological factors, pre-operative preparation factors and child and parent pre-operative anxiety;
7. To determine the level of parent and child pre-operative preparation and satisfaction with information regarding the child's admission to hospital for surgery;
8. To determine the level of parent participation in the care of their children who spent at least one night in hospital after surgery;
9. To determine the level of parent satisfaction regarding their child's postoperative pain management for children who spent at least one night in hospital;
10. To determine which parent factors, child factors, in-hospital and home factors are potentially predictive of child post-hospital PB.

The study design chosen to meet these objectives was a descriptive, prospective, repeated measures study design involving self-report questionnaires (parent and child > 8 years), direct observation of pre-operative anxiety (child) and post-discharge follow-up of the child (as reported by the parent) through completion of self-report questionnaires or telephonic completion of questionnaires.

1.6 Conclusion

This chapter provided a brief introduction of the existing body of research on the negative outcomes related to a child's admission to hospital for surgery. PB at home, postoperative pain and other symptoms, child pre-operative anxiety, pre-operative preparation and parent participation in their child's inpatient care were briefly discussed. The gaps in knowledge,

specifically in the UK, were highlighted and the study aims and objectives were presented. A brief description of the study methodology was provided.

The following chapters provide greater detail in terms of the existing body of knowledge related to the negative outcomes associated with a child's admission to hospital for surgery (Chapter 2 – Literature review); a theoretical framework for the study is presented following a review of the literature and relevant theories (Chapter 3 – Theoretical framework); details of the study methodology, data analyses and ethical considerations (Chapter 4 – Methodology); descriptive and exploratory results (Chapter 5 – Results: descriptive and exploratory); the results of multivariate regression analyses (Chapter 6 – Results: logistic regression); and finally a discussion of the study results in relation to the wider context of prior research, the study's strengths and limitations as well as recommendations for clinical practice and future research (Chapter 7 – Discussion).

Chapter 2
Literature Review

2.1 Introduction

Chapter one provided an introduction and brief background to the study. This chapter provides details of an extensive systematic literature review of all the current research on children's post-hospital behaviour changes and the factors that are associated with these changes. Other areas highlighted in the systematic review were children's pre-operative anxiety and postoperative pain and other symptoms in the home setting. Specific chapter aims were to describe the methodology and the results of the review and to discuss the field of research to date with recommendations for future research.

2.2 Methods

2.2.1 Searching

A literature search was performed in the electronic databases of MEDLINE, CINAHL, PsycINFO and Web of Science between February 2009 and April 2009. Key papers (Kain et al. 1996c;Karling et al. 2007;Kotiniemi et al. 1997;Stargatt et al. 2006) that were known to be significant in the field of study prompted the inclusion of search terms such as pre-operative anxiety (parent and child), pre-operative preparation and postoperative symptoms, i.e. pain, nausea and vomiting. Terms used in the final search included recognised Medical Subject Heading (MeSH) terms and non-MeSH terms for **child behaviour** (child behaviour (MeSH) or child behaviour/behaviour or behaviour/behavior change), **postoperative symptoms** (signs and symptoms (MeSH) or postoperative/post-operative symptoms or pain or postoperative nausea and vomiting (MeSH) or pain, postoperative (MeSH)), **emotions** (emotions (MeSH) or anxiety or child anxiety or parent anxiety or fear), **surgery** (surgical procedures, operative (MeSH)), **pre-operative preparation** (pre-operative/preoperative/presurgical/pre-surgical

information/education/preparation, preparation program*), **general anaesthesia** (anesthesia, general (MeSH) or general anaesthesia/anesthesia or general anaesth*/anesth*) and **hospitalisation/day case** (child hospitalized (MeSH) or outpatients (MeSH)). MeSH terms / other relevant terms were exploded. Where narrower terms were searched for when exploding broader terms, these terms were not searched again i.e. nausea covered by exploding 'symptoms'. The Web of Science search did not allow limits for 'child' to be set, therefore the search was refined to anaesthesiology, nursing, surgery or paediatrics, which meant that studies on adults were included in the final result. A conservative approach was taken to retrieve all studies that could possibly be included in the review and to hand pick the studies that were eligible from the final merged search result. There were no restrictions on publication date or study design. Reference lists of key papers were hand-searched and a citation search of authors from identified key papers was performed in the Web of Science database to reveal any publications that were not found in the initial search. Relevant studies collected by experts in the field that were not retrieved by the search methods described were added to the final sample.

2.2.2 Selection

Search results from each database were merged using Reference Manager Software version 11 (ISI ResearchSoft, Carlsbad, CA). The titles and abstracts listed in the search results were examined and any duplicates or studies that were obviously irrelevant were removed. Based on the abstracts, the full texts of all studies that related in any way to the topic of interest were retrieved. Studies were selected for inclusion in the review if they met the following criteria: children 0-18 years (population) admitted to hospital for surgery under general anaesthesia (intervention) and any behaviour change (outcome) exhibited once the child was at home. Studies that focused on potential influencing variables, such as pre-medication, induction technique, and pre-operative preparation programmes aimed at children and/or parents were also included in the review if there was any record of child behaviour at home. Other studies that were included were those that had outcomes of pre-operative anxiety and postoperative pain, nausea and vomiting at home, even if behaviour

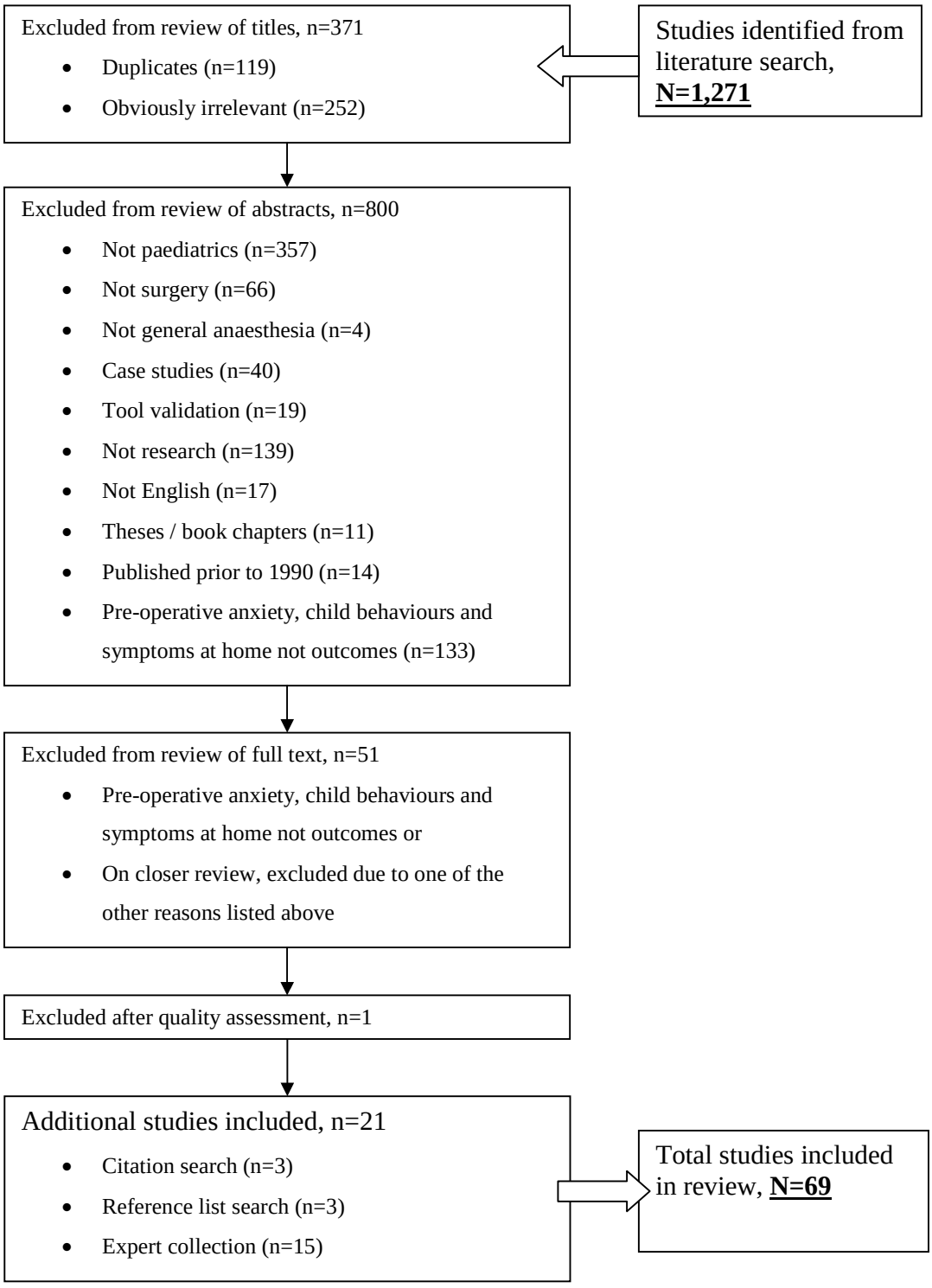
change at home was not an outcome, as it became clear from the search that these factors were strongly related (Kain et al. 1996c;Kain et al. 1999b;Kain et al. 2002;Kain et al. 2006a;Karling et al. 2007;Kotiniemi et al. 1997;Lumley et al. 1993;MacLaren et al. 2008). Studies were excluded if they focused on parent outcomes only, i.e. parent anxiety or experiences, with no reference to how these related to child behavior change, pre-operative anxiety or postoperative pain, nausea or vomiting at home. Studies were also excluded if the full text was not available in the English language as there is often insufficient information in an abstract (where only the abstract was published in English) to adequately judge the validity of the study and the outcome measures/results.

2.2.3 Search results

The search yielded a total of 1,271 citations. The titles and abstracts were reviewed and full texts of all citations meeting the inclusion criteria (or where it was unclear) were obtained and reviewed. A review of the full text articles further eliminated a number of citations in relation to the exclusion criteria. A review of the reference lists of key papers and a citation search resulted in the inclusion of six additional studies. A further 15 studies were added to the final sample from expert collection. A final sample of 69 studies (38 descriptive and 31 intervention) was included in the review.

Figure 2.1 provides a breakdown of the citations retrieved and how the sample included in the review was accrued.

Figure 2.1 Flow chart of included studies



The search revealed two meta-analyses (Thompson et al. 1993;Vernon et al. 1993) that analysed findings from studies up to 1990 that used the post hospital behaviour questionnaire (PHBQ) to determine whether hospitalisation resulted in PB changes. The PHBQ is the most widely used measure of child behaviour at home, following admission to hospital with/without surgery. It is a 27-item list of possible problem behaviours that children could exhibit and each child's behaviour is compared to his/her behaviour prior to hospital / surgery. The focus of the first meta-analysis was to examine behaviour changes in children who received no special experimental interventions, i.e. participants in correlation studies or the control group participants in experimental studies (Thompson et al. 1993). The second meta-analysis addressed a related question of whether or not experimental interventions help children, i.e. psychological preparation and parental presence, had benefits in relation to the occurrence of PB changes after hospitalisation (Vernon et al. 1993).

2.2.4 Critique of meta-analyses

The search strategy was the same for both meta-analyses and consisted of an extensive search of citation indices using Vernon et al (Vernon et al. 1966), the original published description of the PHBQ, as the target citation; a combination of electronic (CINAHL, MEDLINE) and non-electronic (other abstracting and indexing services) databases; published and unpublished reviews; personal communication with investigators and bibliographies of research reports. The keywords used were "hospitals, children" and "hospitalised children". Unlike the current review, the focus of these meta-analyses was on child behaviour following hospitalisation including but not restricted to children who had been hospitalised for surgery under general anaesthesia. The meta-analyses provide details of the calculation of effect sizes for each of the included studies and how these were analysed to identify factors that accounted for variability in the effect sizes, i.e. factors associated with more or less PB change.

Twenty six studies were included in the first meta-analysis (Thompson et al. 1993) examining the effect of hospitalisation on child PB without experimental interventions. The significant results were as follows:

- Hospitalisation resulted in negative behaviour change (mean weighted effect size = +.24).
- PB changes increased significantly after discharge but decreased with time and were largely disappeared by two weeks: mean effect size when measured within 2 weeks of discharge = +.34 and after 2 weeks = -.09.
- Length of stay was a significant contributor to PB change but did not follow a dose effect, i.e. children hospitalised for two to three days had the most PB change (+.46) followed by those hospitalised for one day (+.28) and then those hospitalised for longer periods (four to eight days) (+.09).

Twenty two studies comprised the sample of the second meta-analysis (Vernon et al. 1993) examining the effect of experimental interventions on child PB after hospitalisation. Significant results are summarized as follows:

- Children exposed to experimental interventions had less PB change than those not exposed (mean weighted effect size = +.44).
- Studies that had true experimental designs (versus quasi-experimental) demonstrated a significantly greater effect at decreasing PB changes (+.54 vs. +.17).
- Two types of general experimental interventions were identified, i.e. mothers' presence and preparation, which were equally effective at reducing PB.
- Stress point preparation, e.g. intervention before and after stressful procedures and training in coping strategies, was significantly more effective (+.88) than simple dramatic (+.41), e.g. film, or multi-component presentations (+.20) which consisted of one or more of the following: video, puppets, verbal description on one occasion or extended over time.

- Preparation before admission (-.01) was significantly less effective than after admission (+.54) and preparation both before and after admission (+.61).
- Children ≥7 years benefited from experimental interventions significantly more than children ≤ 6 years (+.63 vs. +.15).
- Interventions were significantly more effective in children hospitalised for two to three days (+.62) versus one day (+.27) or four to eight days (+.41).

Although these meta-analyses were meticulous in their study selection and calculation of effect sizes, they only included studies that used the PHBQ. At the time of the reviews, the PHBQ had only been preliminary validated in one study (Vernon et al. 1993). The possibility of measurement bias could therefore not be eliminated, given the fact that parents consented to participate in an experimental intervention designed to benefit their children and were then asked to rate their child's behaviour change. The authors noted that the results of their analyses could not be generalized to all hospitalised children as 95% of the children in the included studies were hospitalised briefly for elective surgery or invasive diagnostic procedures and that no studies were found that included children who were repeatedly hospitalised for serious medical conditions or for extended periods.

2.2.5 How the current review differs and why it is important

The current systematic review sought to describe all research (descriptive and experimental) investigating children's behaviour post-hospital, irrespective of the measures used to describe the child's behaviour. It followed on from the two meta-analyses described above in relation to the publication date of the included studies, i.e. the meta-analyses included studies published before 1990 and the current systematic review includes studies published from 1990 onwards. Unlike the meta-analyses, the current systematic review does not synthesize the results of included studies quantitatively using meta-analysis due to the varying measures used and the way in which the studies' results were presented. Instead, a qualitative synthesis of results was used so as to include as many studies as possible of varying designs, using a number of different outcome measures. The current

systematic review was more specific in the selection of studies where children were hospitalised for surgery under general anaesthesia.

Another area where the current systematic review differed from the meta-analyses is the quality assessment of each of the included studies. Quality assessment of the individual studies added to the methodological rigour of the review by reducing the potential for bias as a qualitative synthesis of results is inherently more subjective than a meta-analysis (University of York NHS Centre for Reviews and Dissemination 2009).

The current systematic review was vital in the design of the current study. It is the only systematic literature review that describes child behaviour after hospitalisation for surgery under general anaesthesia and explores all possible factors that influence behaviour change, specifically pre-operative anxiety and postoperative pain and other symptoms. This was ensured by the extensive search using a number of search terms (MeSH and other).

2.2.6 Quality assessment

According to the Centre for Reviews and Dissemination (CRD) the development of a quality checklist ensures that all studies assessed for inclusion in a review are critically appraised in a standardised way (University of York NHS Centre for Reviews and Dissemination 2009). The report suggests that a combined checklist be developed where the review includes more than one study design, as is the case in the current review. A quality assessment checklist, which was developed and used successfully in a prior systematic review (Power et al. 2008), was used to assess studies selected for inclusion in this review. The checklist was developed to evaluate key study quality components within the domains of sampling, intervention/study procedures and outcome measurement following the guidelines and example coding instructions from the CRD Report 4 (2009). The Cochrane Centre's recommended reporting guidelines: CONSORT for reporting of randomised controlled trials and STROBE for reporting of observation studies in epidemiology (cohort, case-control and cross-sectional studies) and two other research

appraisal references (Cochrane Library 2004;Burns et al. 2001;Greenhalgh 2000) were used in the development of the checklist. Each of the domains was graded as adequate or inadequate depending on whether or not the quality criteria were met. Criteria were rated as unclear/unknown if they were not reported so as not to exclude studies due to report failings but rather only when it was clear that a criterion was not met (University of York NHS Centre for Reviews and Dissemination 2009). Each of the three domains (sample, intervention/study procedures, and outcomes/main measures) was given the lowest quality rating assigned to the listed criteria within that domain. Studies were included if each of the three domains were rated as adequate. Studies were included, but results interpreted with caution, if one domain was adequate, two were unclear; one domain was adequate, one unclear, one inadequate; two domains were adequate, one unclear; or if two domains were adequate, one inadequate. Studies were excluded if two or more domains were rated as inadequate. See Table 2.1 for explanations of the quality domains and criteria.

2.2.7 Data extraction

A data extraction form was used to identify key data from all the studies selected for inclusion in the review. The form was adapted from examples provided in the CRD and The Cochrane Handbook. Items included were those relevant to the question/s of the review. Table 2.2 provides details of the data extracted from included studies.

Studies included in the review were not restricted to a particular design. Specific participant characteristics were all children (0-18 years) admitted to hospital for day case or inpatient surgery under general anaesthesia. Outcomes of interest were any record of child pre-operative anxiety, behaviour at home after surgery and any changes (improved or problematic) in behaviour compared to normal/usual behaviour prior to the child's admission to hospital and any reports of child pain and / or other symptoms (nausea and vomiting) at home. Interventions included were those aimed at improving on child pre-operative anxiety and / or behaviour and symptoms at home.

2.2.8 Data synthesis

A narrative approach to synthesis of the data was followed to allow for variations in study design, interventions and outcomes. The CRD recommends a narrative approach to data synthesis where studies are diverse and cannot be combined in a meta-analysis (University of York NHS Centre for Reviews and Dissemination 2009). Studies were grouped according to their reports of behaviour changes at home, pre-operative anxiety, and symptoms at home, i.e. incidence of; risk factors for; specific behaviour changes/symptoms; within study group comparisons; and pre-operative anxiety, behaviour changes and symptoms following specific experimental interventions. Due to the numerous ways in which study results were presented, not all details are provided in the text but are available in Tables 2.5 and 2.6.

2.3 Results

Results are presented under the main outcomes identified in the studies, i.e. behaviour changes (problematic and improved); pain, nausea and vomiting at home; and child pre-operative anxiety.

2.3.1 Samples and settings

Included studies were conducted in the USA (18 descriptive, 17 intervention), Canada (2 descriptive, 3 intervention), Ireland (1 intervention), UK (4 descriptive, 3 intervention), Lebanon (1 intervention), France (1 intervention), Italy (1 intervention), Turkey (1 intervention), Finland (3 descriptive, 1 intervention), Sweden (2 descriptive), Israel (1 descriptive), Iceland (1 descriptive), South Africa (1 descriptive, 1 intervention), Nigeria (1 descriptive), China (1 descriptive, 1 intervention), Taiwan (1 descriptive), Australia (2 descriptive) and New Zealand (1 descriptive).

Children between the ages of 1 and 16 years participated in the descriptive studies and children between the ages of 1 and 14 years participated in the intervention studies. The study sample sizes ranged from 7 to 1,224 participants in the descriptive studies and from

24 to 408 participants in the intervention studies. The total number of children who participated in the descriptive studies was 6,528 and in the intervention studies was 3,414. Children who participated in the studies were admitted for day case surgery (20 descriptive, 27 intervention), inpatient surgery (5 descriptive, 3 intervention) and a combination of day case and inpatient surgery (8 descriptive). In six studies it was unclear whether children were admitted for day case or inpatient surgery (5 descriptive, 1 intervention). The studies included children admitted for surgery under mixed specialties (17 descriptive, 25 intervention), ENT surgery (18 descriptive, 4 intervention), orthopaedic (1 descriptive), urology (1 descriptive, 1 intervention), dental (1 descriptive) and general surgery (1 intervention).

2.3.2 Methods and measures

Studies included in the review used a variety of validated measures of behaviour change, pre-operative anxiety, pain and other symptoms. Studies also included instruments specifically designed for the study, i.e. interviews and questionnaires. Table 2.3 provides details of all the measures used in the studies.

2.3.3 Quality assessment

Forty eight studies were given "unclear/unknown" quality ratings for sample size estimation because no information was provided in the published report. Eighteen of these studies (Amanor-Boadu et al. 1997;Bal et al. 2006;Bevan et al. 1997;Calipel et al. 2005;Keaney et al. 2004;Kotiniemi et al. 1996b;Lamontagne et al. 1997;Li et al. 2003;Lynch 1994;Margolis et al. 1998;McCluskey et al. 1994;McGraw et al. 1998;Patel et al. 2006;Patel et al. 1997;Payne et al. 1992;Payne et al. 1994;Rossen et al. 1996;Tuomilehto et al. 2002) were also given "unclear/unknown" or "inadequate" quality ratings for aspects of sample, intervention/study procedures or main measures, but the studies were not excluded from the review as they received "adequate" quality ratings for other criteria. Details of "inadequate" or "unclear/unknown" quality ratings are provided where appropriate in the text and results have been interpreted with caution. Table 2.4

provides a summary of the assessment of methodological quality for all of the studies included in the review. Only one study (Brophy et al. 1990) was excluded from the review following quality assessment. This study received an adequate rating for sample, an unclear rating for sample size estimation and exclusions/refusals/withdrawals and an adequate rating for behaviour change tool. However, an inadequate rating was given for follow-up as behaviour change was measured between two and six weeks after discharge and analysed as a group, which meant that the results could not be included in the results of the review, because prior research has shown that children's behavior changes substantially over this interval (Kain et al. 1999b;Kotiniemi et al. 1997;Thompson et al. 1993).

2.3.4 Descriptive studies

Thirty eight descriptive studies (39 articles) were identified for inclusion in the review that reported levels of child behaviour change, pre-operative anxiety, pain and postoperative symptoms at home and associated risk factors. Twenty three studies reported behaviour change outcomes only, 5 reported pre-operative anxiety outcomes only, 6 reported pain and postoperative symptoms only and 4 reported a combination of outcomes. Results from the 43 studies have been synthesized and described under the main topics of behaviour change, pre-operative anxiety and symptoms at home. Detailed results are provided in Table 2.5.

2.3.4.1 Behaviour change

Twenty six studies were identified for inclusion in the current review that described children's behaviour changes after surgery. These studies used variations of the PHBQ as well as other validated child behaviour measures.

2.3.4.1.1 Problematic behaviour change

2.3.4.1.1.1 Incidence of problematic behaviour change

2.3.4.1.1.1.1 Measured by the PHBQ

The incidence of PB change (%) was reported in eight studies (Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007;Kotiniemi et al. 1997;Lumley et al. 1993;Schmidt 1990;Stargatt et al. 2006;Tuomilehto et al. 2002) and ranged from 18% (Tuomilehto et al. 2002) to 53.8% (Kain et al. 1996c) within the first two weeks post-discharge; 9% (Kotiniemi et al. 1997) to 16% (Stargatt et al. 2006) one month after surgery; 20% at six months and 7% one year later (Kain et al. 1996c). PB change decreased significantly over time ($p<.001$) (Kain et al. 1999b;Kotiniemi et al. 1997).

Out of a possible 0 to 27 PB, the number of PB changes reported was generally low: range 1 to 2 (Kain et al. 1999b;Lumley et al. 1993), median 3 (Kain et al. 1999b;Kotiniemi et al. 1997), mean 1.17 (Kain et al. 1999b;Karling et al. 2007) at week 2; median 3 (Stargatt et al. 2006) at one month. All six of the PHBQ subscales were represented as areas of problematic change across the studies, i.e. general anxiety and regression, separation anxiety, anxiety about sleep, aggression toward authority, apathy/withdrawal and eating disturbances (Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007;Lumley et al. 1993;Stargatt et al. 2006).

Identified risk factors for PB change in the first 2 weeks after discharge were: younger child (Karling et al. 2007;Lumley et al. 1993;Stargatt et al. 2006;Tuomilehto et al. 2002), child temperament (Carson et al. 1991), children with no siblings (Kain et al. 1996c), children with ≥ 2 older siblings (Stargatt et al. 2006), children with pre-operative behavioural disturbances (Carson et al. 1991), children who were more anxious (Kain et al. 1996c;Kain et al. 1999b), children who had a discussion with an anaesthetist pre-operatively (Stargatt et al. 2006), maternal overindulgence, state and trait anxiety (Carson

et al. 1991;Stargatt et al. 2006), staying over night in hospital (Stargatt et al. 2006), moderate to severe pain at home, living in a one-adult family and not living in a rural area (Karling et al. 2007). Risk factors for PB change at one month were: younger child (Kotiniemi et al. 1997;Stargatt et al. 2006), longer hospital stay, a difficult previous anaesthetic, reading about the anaesthetic (Stargatt et al. 2006), severe pain at home on day 0 and hospital-influenced play (Kotiniemi et al. 1997). At six months younger child age remained a predictor and children whose mothers were more anxious in the anaesthetic holding area (Kain et al. 1996c). Table 2.5 provides details of significance levels.

2.3.4.1.1.1.2 Measured by other measures

Two studies described children's post-discharge PB change using other validated tools (Issa et al. 1999;Millar et al. 2006). Using the Paediatric Symptom Checklist (PSC), Issa et al. (1998) reported PB changes in 9.3% of children 6 weeks after surgery with a mean score of 11.56 ± 7.16 (possible range 0-64, higher scores indicating poorer adjustment). Children's psychological morbidity, measured by the Revised Rutter Scale for School-Age Children (completed 48 hours and 1 week after surgery), increased (non-significantly) from 48 hours to 1 week after discharge with parents reporting attention-seeking, tantrums, crying, waking up at night and nightmares in 8-21% children (Millar et al. 2006). Children answered questions on the Modified Child Dental Anxiety Scale (MCDAS) and revealed that they had higher anxiety 48 hours after surgery than before (Millar et al. 2006).

Only two studies used a qualitative methodology. In interviews one week after surgery, parents were asked about any behaviour changes in their children (Rossen et al. 1996) and more generally about their child's postoperative course (Amanor-Boadu et al. 1997). Nineteen children (of 23) were reported to have distressed behaviour including sleeping and eating disturbances, irritability, separation anxiety, regression in behaviour and withdrawal from family members (Rossen et al. 1996). Children were described by their parents as being restless/fretful (13.5%) and suffering from sleeplessness (6.7%) (Amanor-Boadu et al. 1997). Results from these interviews should be interpreted with caution as the sample in

the first study (Rossen et al. 1996) was selected by convenience and the latter study (Amanor-Boadu et al. 1997) was given an "unclear/unknown" quality rating for main measure as there was no mention of the tool used for the interview, i.e. how or when was it developed and/or analysed.

2.3.4.1.1.1.3 Summary

Children exhibit problematic change in their behaviour at home after inpatient or day case surgery compared to their behaviour prior to surgery. However, there does not appear to be any consensus with regard to the frequency of PB across the studies at the various time-points. The widest variability was reported within the first two weeks after discharge, i.e. 18 to 53%. Children continue to exhibit PB changes up to one month after surgery, a small percentage up to one year after surgery, even though the number of PB remains relatively low and decreases over time.

Child risk factors for PB change identified in more than one study were: pre-operative behaviour and anxiety, child age, length of stay in hospital and pain at home. There was some disagreement regarding the risk factor of number of siblings: 1 study identified no siblings and another identified ≥ 2 siblings as being risk factors for PB. Parent anxiety and socioeconomic status were additional risk factors for PB. There was no apparent pattern in the reporting of PB by study publication date or country of origin.

2.3.4.1.1.2 Problematic changes in sleep post-surgery

Changes in children's sleep after surgery were investigated in three studies by the same research group (Caldwell-Andrews et al. 2006;Kain et al. 2002;MacLaren et al. 2008). Using actigraphy, a device used to measure the amount and quality of sleep using motion detection, and the sleeping disturbance subscale of the PHBQ, Kain (2002) reported that 47% children experienced sleep disturbance (diagnosed by either actigraphy or the PHBQ) in the first five nights postoperatively. Children with sleep problems diagnosed by actigraphy only had higher pain scores that decreased more slowly over time; they had

lower baseline sociability scores for temperament and were more anxious pre-surgery than children whose sleep problems were diagnosed by the PHBQ only (Kain et al. 2002). In a later study that diagnosed sleep problems with actigraphy only (Caldwell-Andrews et al. 2006) 22% children were diagnosed with problems in the first five nights postoperatively. Risk factors identified were: pre-operative sleep disturbance, postoperative pain, parent baseline anxiety and child aggressive behaviour (Caldwell-Andrews et al. 2006). The third study (MacLaren et al. 2008) reported that children's sleep efficacy decreased postoperatively when compared to sleep prior to surgery, with significantly lower sleep efficacy during the first postoperative night in hospital compared to nights 2 to 5 at home. 30.9% Children were diagnosed as having significant sleep decrements at home, i.e. significantly less effective sleep postoperatively than pre-operatively. Predictors of poor sleep efficacy were: child anxiety during induction, lower child temperament sociability and greater parent-report of postoperative pain at home (MacLaren et al. 2008).

2.3.4.1.1.2.1 Summary

The studies examining children's sleep in the first week at home following surgery consistently found sleep problems. Child pre-operative sleeping patterns, pre-operative behaviour/temperament and anxiety, pain at home and parent pre-operative anxiety were consistently found to be associated and may be risk factors.

2.3.4.1.1.3 Within study group comparisons

Three studies described the similarities / differences in PB changes between two sub-groups, neither of which received an intervention as part of the study (Kain et al. 2006a;Kotiniemi et al. 1996b;Payne et al. 1994).

Using a behaviour change tool modified from the PHBQ Payne et al. (1994) compared behaviour change between children admitted for day case and inpatient surgery and found that 56.6% and 62.5% respectively exhibited PB at home but the difference between the two groups was not significant. The influence of length of stay on PB change was also

explored by Kotiniemi et al. (1996) who reported an incidence of 68% in children who were treated as day cases compared to 46% in children who spent at least one night in hospital. The difference between these groups was also not significant. Both of these studies contained possible confounding variables, i.e. children received different care (private vs. public) (Payne et al. 1994) and the extent of surgery and child age were different in each group, which influenced the length of hospital stay (Kotiniemi et al. 1996b).

In a study conducted by Kain et al. (2006) children were divided into two groups according to their pre-operative anxiety scores. Within the first three postoperative days, children in the high anxiety group had significantly more generalised anxiety, separation anxiety and difficulty falling asleep and children in the low anxiety group had more improvements in eating (Kain et al. 2006a).

2.3.4.1.1.3.1 Summary

The influence of length of hospital stay and child pre-operative anxiety was examined within studies to determine the effect these factors might have on PB change. Child pre-operative anxiety was the only factor that appeared to negatively influence PB change. Because of flaws in the research designs, no conclusions can yet be drawn about the effects of day case versus inpatient surgery or length of hospital stay on post-hospital PB.

2.3.4.1.2 Improved behaviour

2.3.4.1.2.1 Incidence of improved behaviour

2.3.4.1.2.1.1 Measured by the PHBQ

Previous research has investigated behavior improvements as well as behavior problems in children following surgery. Within the first two weeks after discharge, two studies found that 18% (Lumley et al. 1993) to 21% (Schmidt 1990) of children had improved behaviour. One month after surgery, improvements were reported in 17% children (Kotiniemi et al.

1997). Only one study reported the median number of improvements: 1 (range 0-16) at 4 weeks (Kotiniemi et al. 1997). Kain et al. (1996) reported a range of 0-9% improvements in the PHBQ subscales with the greatest improvements in eating behaviours.

2.3.4.1.2.1.2 Studies evaluating other symptoms

Post-traumatic stress symptoms (PTSS), depression and anxiety were measured at one and six months after surgery in a study conducted by Ben-Amitay (Ben-Amitay et al. 2006). All scores were mild/not clinically significant with significant improvements reported in PTSS and depression between 1 and 6 months after surgery (Ben-Amitay et al. 2006). Rossen et al.'s (1996) interviews with parents one week after surgery revealed that 17.4% children were less irritable and more energetic. Only one study (Lamontagne et al. 1997) examined child characteristics in terms of better coping with surgery but the sample was selected by convenience and therefore results may be biased. Children described as vigilant-copers who had a concrete-objective focus had the most favourable activity outcomes at 3, 6 and 9 months after discharge (Lamontagne et al. 1997).

2.3.4.1.2.2 Associated factor – type of surgery

Six studies were identified that described behaviour changes in children after tonsillectomy and adenoidectomy (T&A), all of which reported improved behaviour (Galland et al. 2006;Goldstein et al. 1998;Goldstein et al. 2002;Li et al. 2006;Mitchell et al. 2005;Wei et al. 2007). There were significant improvements in child behaviour as measured by the Behavioural Assessment System for Children (BASC) (Galland et al. 2006;Mitchell et al. 2005), the Child Behaviour Checklist (CBCL) (Goldstein et al. 1998;Goldstein et al. 2002;Li et al. 2006) and Conner's Parent Rating Scale-Revised Short Form (CPRS-RS) (Wei et al. 2007). Improvements in children's sleep were reported by Galland et al. (2006) and Wei et al. (2007) after parents completed a sleep and breathing questionnaire and the Paediatric Sleep Questionnaire (PSQ) respectively. Other significant improvements were found in children's attention and reactivity using measures of Continuous Performance Test (CPT) (Galland et al. 2006) and Tests of Variables of Attention (TOVA) (Li et al. 2006).

Significant improvements were also reported for most subscales of the above-described measures and are detailed in Table 2.5.

2.3.4.1.2.3 Summary

Some children do exhibit improved behaviour at home following admission to hospital for surgery. The incidence of improved behaviour is lower than the incidence of PB when measured by the PHBQ. Type of surgery, i.e. tonsillectomy with/without adenoidectomy has been associated with improved behaviour. However, none of the studies that reported improved behaviour after these surgeries used the PHBQ to measure behaviour changes and the follow-up time-points were on the whole later than the studies that reported PB change, i.e. three and six months following surgery. It is possible that problem behaviour would have been detected at earlier follow-up time-points or if the PHBQ (a list of problem behaviours) had been used to measure behaviour change.

2.3.4.2 Postoperative symptoms at home

Nine studies (Amanor-Boadu et al. 1997;Gedaly-Duff et al. 1994;Kain et al. 2006a;Kokinsky et al. 1999;Morgan et al. 2001;Reid et al. 1995;Tuomilehto et al. 2002;Wang et al. 2000;Wilson et al. 2006) described children's pain and/or other symptoms (nausea and vomiting) at home following surgery. Only one study (Amanor-Boadu et al. 1997) was given an unclear/unknown quality assessment rating for pain assessment tool; all other studies used validated self-report and observation pain assessment measures.

2.3.4.2.1 Pain at home

A number of studies reported that children experienced pain at home up to two weeks following surgery as measured by child self-report (Kokinsky et al. 1999;Wilson et al. 2006) and parent-report (Amanor-Boadu et al. 1997;Gedaly-Duff et al. 1994;Kokinsky et al. 1999;Morgan et al. 2001;Reid et al. 1995;Tuomilehto et al. 2002;Wang et al. 2000).

Four studies measured the incidence of pain in children within the first 24 hours (Kokinsky et al. 1999), 48 hours (Wilson et al. 2006), 5 days (Amanor-Boadu et al. 1997) and 3 weeks (Tuomilehto et al. 2002) after discharge. Fifty four percent of children had no/mild pain (score 1-2, 1-6 parent-report NRS / 1-6 child-report faces scale) within the first 24 hours at home, 39% had moderate pain (score 3-4) and 6% had severe pain (score 5-6) (Kokinsky et al. 1999). Child-reports of pain were significantly higher than parent-reports (difference in scores not reported) ($p<.01$) (Kokinsky et al. 1999). Within the first 48 hours after discharge, Wilson et al. (2006) reported an incidence of 38-47% children who had significant pain (score ≥3, 0-5 faces scale) following tonsillectomies when not swallowing and 75% who had significant pain when swallowing (46% reported pain scores of 4 or 5). Pain was significantly higher when swallowing than when not swallowing ($p=.005$) (Wilson et al. 2006). An increase in pain while swallowing (eating and drinking) following tonsillectomies was also reported in an earlier study by Gedaly-Duff et al. (1994) but the difference in pain scores was not reported. Tuomilehto et al. (2002) reported an incidence of 91% of the children who were in pain during the first week at home and 37% of the children who were in severe pain (score 4, 1-4 verbal rating scale).

Pain was worst in the first 2 to 3 days at home (Gedaly-Duff et al. 1994;Reid et al. 1995;Tuomilehto et al. 2002) and significantly decreased by the end of day 3, with children able to resume normal activities by day 5 (Gedaly-Duff et al. 1994). Gedaly-Duff et al. (1994) reported pain scores of 8-9 (0-10 NRS) within the first 36 hours at home that decreased to 3 by day 4 or 5. The number of pain cues that parents reported in their children decreased significantly from 2.4 on day 1 and 2.3 on day 2 to 1.5 on day 3 ($p<.001$) (Reid et al. 1995). Tuomilehto et al. (2002) measured pain in children in the first 3 weeks following discharge and found that children were mostly pain-free by day 3 (range 0-8 days post-discharge).

Morgan et al. (2001) reported a decrease in pain scores after the children were given analgesia: 2.93 ± 1.57 decreased to 0.99 ± 1.32, $p<.001$ (0-6 scale) (Morgan et al. 2001). A

decrease in pain scores after analgesia was also reported in Gedaly-Duff et al.'s (1994) study but the difference in scores was not reported.

Child cues used by parents to assess pain were reported in two studies (Gedaly-Duff et al. 1994;Reid et al. 1995). These cues were a combination of behavioural and verbal expressions and included: not eating or drinking, tiredness / changes in sleep, crying, grimacing and hand gestures.

One study (Kain et al. 2006a) explored the association of pain and pre-operative anxiety and found that children classified as having a high anxiety (score ≥30 on 0 to 100 mYPAS) had significantly higher pain scores that declined significantly slower over time than children with lower pre-operative anxiety. Children with high pre-operative anxiety also had significantly higher self-reported pain scores than children with low pre-operative anxiety (Kain et al. 2006a).

In interviews with parents, Amanor-Boadu et al (1997) reported that on day 5 after surgery 14 children (18.9% of sample) complained of pain, of which 13 had not received intra-operative analgesia. Only 1 of 19 children that did receive intra-operative analgesia complained of pain on day 5 (Amanor-Boadu et al. 1997). This study was given an "unclear/unknown" rating for the interview measure, which included questions regarding pain, as there was no mention of how/when the interview tool was developed and/or analysed.

2.3.4.2.2 Nausea and vomiting

Three studies (Amanor-Boadu et al. 1997;Kokinsky et al. 1999;Wang et al. 2000) reported the incidence of nausea and vomiting at home. Up to 41% children experienced nausea and 33% had vomiting at home following surgery (Wang et al. 2000). Wang et al. (2000) examined the association between postoperative pain, nausea and vomiting (within the first 24 hours at home) and pre-operative anxiety. Results showed that children who had

vomited were older (mean age 9.5±3.2 vs. 7.8±2.6, p=.04) and had lower pre-operative (30±3 vs. 33±5, p=.02, 20-80 State Trait Anxiety Inventory for Children (STAIC)) and trait anxiety scores (33±5 vs. 38±7, p=.04, 20-80 STAIC)(Wang et al. 2000). No association was found with nausea and vomiting and pain.

2.3.4.2.3 Summary

The research on children's symptoms at home following surgery consistently found that children experience pain at home following surgery. Over a third of children (38-47%) experience moderate to severe pain within the first 48 hours at home. Pain scores were most severe (scores 8-9, 0-10 NRS and 4, 1-4 verbal rating scale) in the first three postoperative days and decreased significantly within the first postoperative week at home (3, 0-10 NRS and 1, 1-4 verbal rating scale). None of the studies included in the review reported an incidence of pain later than two weeks following discharge.

Pain does decrease with analgesia but may increase with specific procedure-related activities, such as eating or drinking after tonsillectomy. Parents may under-estimate children's pain as child self-report of pain is generally higher. Children who are more anxious pre-operatively have worse pain (intensity and duration) at home. Some children experience nausea and vomiting at home.

2.3.4.3 Pre-operative anxiety

Seven descriptive studies (Caldwell-Andrews et al. 2005;Davidson et al. 2006;Kain et al. 1996c;Kain et al. 2000;Kain et al. 2006b;Kain et al. 2006a;Li et al. 2003) that were identified for inclusion in the current review described children's pre-operative anxiety as the primary outcome of interest. All studies used validated tools to measure pre-operative anxiety.

2.3.4.3.1 Associations and risk factors

Factors associated with pre-operative anxiety were described in seven descriptive studies (Caldwell-Andrews et al. 2005;Davidson et al. 2006;Kain et al. 1996c;Kain et al. 2000;Kain et al. 2006b;Kain et al. 2006a;Li et al. 2003) and four intervention studies (Bevan et al. 1990;Ellerton et al. 1994;Kain et al. 2004;Margolis et al. 1998). Most children exhibited some degree of pre-operative anxiety and scores increased significantly from the anaesthetic holding area to induction of anaesthesia: 37±2.3 increased to 57±2.6, 0-100 VAS (Kain et al. 1996c); 23 (range 23-46) increased to 56 (range 23-100), 0-100 modified Yale Pre-operative Anxiety Scale (mYPAS) (Kain et al. 2000); 38±18.3 increased to 58.9±28.7, 0-100 mYPAS (Caldwell-Andrews et al. 2005). Child pre-operative anxiety was strongly negatively correlated with child age (Caldwell-Andrews et al. 2005;Kain et al. 2000;Kain et al. 2006b) and positively correlated with parent anxiety (Ellerton et al. 1994;Kain et al. 1996c;Kain et al. 2000;Li et al. 2003). Ellerton et al (1994) reported significantly higher child pre-operative anxiety in children whose parents were experienced with day case surgery and Caldwell-Andrews et al (2005) reported an association between parents' high desire to be present during the child's induction of anaesthesia and child pre-operative anxiety. A high correlation with child pre-operative anxiety and poor compliance during the induction of anaesthesia was reported in one study (Li et al. 2003). Caldwell-Andrews et al (2005) examined the association between child pre-operative anxiety and parents' beliefs about preparation and coping skills and reported that strong parent beliefs correlated with lower child anxiety. Lower child pre-operative anxiety was also reported to be associated with children admitted via a day-stay ward and children (with an ASA status >1) who were given a sedative premedication (Davidson et al. 2006).

Five studies (Davidson et al. 2006;Kain et al. 1996c;Kain et al. 1996a;Kain et al. 2000;Kain et al. 2006b) conducted regression analyses to identify risk factors associated with child-pre-operative anxiety. Identified risk factors were: anxious parents (Davidson et al. 2006;Kain et al. 1996c;Kain et al. 2000;Kain et al. 2006b), parent coping style (Kain et al. 2000), child temperament factors (Kain et al. 1996c;Kain et al. 1996a;Kain et al. 2000),

poor previous medical encounters (Kain et al. 1996c;Kain et al. 2006b), children not enrolled in day-care and not offered premedication (Kain et al. 1996c), older children (Davidson et al. 2006), younger children (Kain et al. 1996c), timing of pre-operative preparation (Kain et al. 1996a) and children with a history of more than five previous hospital admissions (Davidson et al. 2006).

2.3.4.3.2 Summary

The research indentified in this review consistently found that children are anxious pre-operatively, that their anxiety levels tend to increase from admission until the induction of anaesthesia and may affect their compliance during induction of anaesthesia. Children and / or their parents' experience with previous hospitalisation and surgery appear to have a negative effect on child pre-operative anxiety. Child and parent anxiety scores were consistently found to be highly correlated.

2.3.4.4 Overall summary of descriptive studies

Children who are hospitalised for surgery exhibit PB, pre-operative anxiety and pain and other symptoms at home. These negative outcomes often co-occur.

There is a lack of consensus regarding the incidence of PB across the studies and over the various time-points. Although the number of individual PB that children exhibit is low and decreases significantly over time, research shows that some children continue to exhibit PB up to one year following surgery. Specific behavioural problems include general anxiety and regression, separation anxiety, sleep and eating problems.

Researchers concur on a number of risk factors for PB: younger child age, temperament, PB prior to surgery, higher child and parent pre-operative anxiety, longer length of stay in hospital and higher pain intensity at home.

Studies that reported behaviour change (problematic or improved) using the PHBQ reported higher incidences of PB than improved behaviours and no factors associated with improved behaviour were reported. Studies that examined behaviour change following tonsillectomy with or without adenoidectomy used different tools than those used to describe PB and measured behaviour change much later, i.e. 3 to 6 months versus within the first month following surgery. Behaviour changes measured specifically after tonsillectomy and adenoidectomy were much improved than prior to surgery.

In addition to PB, children experience pain at home, which is most severe in the first three postoperative days. Children who are more anxious pre-operatively have worse pain (intensity and duration) at home. Some children experience nausea and vomiting at home.

The level of children's pre-operative anxiety increases from admission until the induction of anaesthesia. Younger children are at greater risk for experiencing pre-operative anxiety and may not respond to anxiolytics. Previous exposure to anaesthesia, i.e. direct experience or participant modelling as part of a preparation programme is negatively associated with pre-operative anxiety particularly in younger children. Child and parent anxiety scores are highly correlated.

On the whole, the descriptive studies included in the review were of good quality. Only two studies (Amanor-Boadu et al. 1997;Payne et al. 1994) received unclear ratings for their main measures; all other studies used validated tools to measure behaviour change, pre-operative anxiety, postoperative pain, nausea and vomiting at home. Other unclear ratings for quality were assigned to study sampling and mostly due to lack of detail provided in the article regarding sample size estimation and/or exclusions, refusals and withdrawals.

There was no apparent pattern in the reporting of problematic or improved behaviours, pre-operative anxiety or symptoms at home by study publication date or country of origin.

2.3.5 Intervention studies

Thirty one intervention studies were identified for inclusion in the current review. Seven studies reported behaviour change outcomes only, 10 reported pre-operative anxiety outcomes only and 14 reported a combination of outcomes. These studies all reported child's post-discharge behaviour (primary or secondary outcome) using variations of the PHBQ as well as other validated child behaviour measures to describe children's behaviour changes after surgery. All measures used to record pre-operative anxiety and symptoms were validated. Detailed results are provided in Table 2.6.

2.3.5.1 Parent presence

2.3.5.1.1 Behaviour change

Three studies used the PHBQ to describe any changes in children's behaviour after allowing parents to be present during induction of anaesthesia (Bevan et al. 1990;Kain et al. 1996b) and during emergence from anaesthesia (Tripi et al. 2004). Allowing parents to be present during their child's induction of anaesthesia versus standard care (separating parents from their children at the theatre door) showed no significant group differences in children's behaviour one week, two weeks or six months after surgery (Bevan et al. 1990;Kain et al. 1996b). In the study conducted by Bevan et al (1990), children in both groups had significantly more PB change at one week compared to scores completed at their pre-operative assessment clinic (3.1±0.2 vs. 1.8±0.4, 0-28 PHBQ) but there were no significant differences between groups (Bevan et al. 1990). In the study conducted by Tripi et al. (2004) standard care involved parents being present during their child's induction of anaesthesia and the intervention allowed parents to be present during their child's emergence from anaesthesia in the post-anaesthetic care unit. No group differences were found in children's behaviour at one and four weeks following surgery (Tripi et al. 2004).

2.3.5.1.2 Pre-operative anxiety

The studies that investigated changes in pre-operative anxiety after allowing parents to be present (versus not present in the control groups) during induction of anaesthesia had conflicting results: Bevan et al (1990) found that children of anxious parents were significantly more anxious if there parents were present (4.5±1.5 vs. 3.4±1.5, 1-7 Global Mood Scale (GMS)) but no significant differences were found in child pre-operative anxiety in the study conducted by Kain et al. (1996b).

2.3.5.1.3 Summary

Parent presence during induction of anaesthesia has no effect on the incidence of children's behaviour changes following surgery when compared to children whose parents were not present. Children's pre-operative anxiety is negatively affected when parents are present during induction, especially if the parents are highly anxious (mean difference 1.1, 1-7 GMS).

2.3.5.2 Pre-operative preparation

2.3.5.2.1 Behaviour change

Preparing children for surgery was investigated as an intervention in four studies (Brewer et al. 2006;Kain et al. 1996a;Margolis et al. 1998;Zahr 1998). Children in the control groups, who did not receive formal pre-operative preparation, in all but one of these studies (Kain et al. 1996a) had more PB change following surgery. Kain et al (1996) reported similar mean total scores on the PHBQ at two weeks: 81 ± 3 vs. 82 ± 7 (p=NS) (score of 81 = no change in behaviour). In Zahr et al. (1998), the intervention involved children being invited to play freely in the playroom after admission followed by an informal puppet show specific to the child's surgery with puppets representing a doctor, nurse, the child and the parents. Children in the control group did not receive any preparation for surgery and had significantly higher frequencies of PB change than children in the intervention group in all six subscales of the PHBQ: general anxiety and regression (26 vs. 4), separation anxiety

(16 vs. 8), anxiety about sleep (8 vs. 2), eating disturbances (14 vs. 6), aggression toward authority (20 vs. 10) and apathy-withdrawal (8 vs. 2) (Zahr 1998). In another study, children were reported to be significantly less aggressive than their pre-operative baseline score (8.4 decreased to 8.0) (PHBQ subscale) following surgery after having received an interactive pre-operative teaching book with tactile, olfactory and visual sensations of the anaesthetic room one to three days prior to surgery compared to children in the control group, who had an increase in aggressive scores (8.8 increased to 9.0) (Margolis et al. 1998). The fourth study that tested pre-operative preparation used the Child Drawing: Hospital (CD:H) tool to measure child anxiety at their follow-up appointment following surgery (Brewer et al. 2006). Preparation in this study was by a child life specialist and consisted of a 20 minute tour, developmentally appropriate explanations of the surgery process and exploration of and rehearsal with medical equipment on the day of surgery (Brewer et al. 2006). Brewer et al. (2006) reported that children in the intervention group had significantly better anxiety score changes from pre-surgery to follow-up (difference in scores not reported).

2.3.5.2.2 Pre-operative anxiety

Six studies compared pre-operative anxiety scores between children who received formal pre-operative preparation and those that did not (Brewer et al. 2006;Ellerton et al. 1994;Kain et al. 1996a;Li et al. 2007;Lynch 1994;Rice et al. 2008). Formal preparation consisted of a slide-show/video, a tour of the theatre areas, familiarisation with theatre equipment, e.g. anaesthetic mask, pulse oximeter, and/or role rehearsal. Only one of these studies (Brewer et al. 2006) offered formal preparation on the day of surgery; the rest were offered 1 to 2 weeks prior to surgery. Four of the studies (Ellerton et al. 1994;Li et al. 2007;Lynch 1994;Rice et al. 2008) that offered preparation 1 to 2 weeks prior to surgery reported significantly lower pre-operative anxiety scores: Ellerton et al. (1994) reported an incidence of 13% children with high anxiety, as measured by the 7-point Brieri self-report faces scale (actual scores were not reported), in the intervention group compared to 25% children with high anxiety in the control group; pre-operative anxiety scores were lower in

the pre-operative holding area (2.2 vs. 3.1), as measured by a self-report 5-point faces scale and on separation from parents to theatre (1.4 vs. 2.8), as measured by the 5-point manifest upset scale (MUS)(Lynch 1994); Rice et al. (2008) measured pre-operative anxiety using the 0-100 mYPAS and reported lower anxiety in the intervention group in the waiting area (23 (23-62) vs. 37 (23-74)); and lower anxiety scores were self-reported by children on admission (34.36±8.09 vs. 38.60±8.53, on the 20-60 Chinese State Anxiety Scale for Children (CSAS-C)) (Li et al. 2007).

Mixed results were reported in Kain et al. (1996) when pre-operative anxiety scores were analysed according to child age: younger children (2 to 3 years) were more anxious in the pre-operative holding area (46±17 vs. 25±14, 0-100 VAS) and older children (> 6 years) were less anxious on separation from their parents to theatre if they received preparation 5 to 7 days before surgery (47±13, 0-100 VAS), intermediate if they did not receive preparation (54±14) and most anxious if they received preparation 1 day prior to surgery (63±22) (Kain et al. 1996a). Significantly higher pre-operative anxiety scores were also reported in children who received formal preparation on the day of surgery (89±20 vs. 80±21, maximum score 160 on the child drawing: hospital instrument (CD:H))(Brewer et al. 2006).

Other pre-operative preparation interventions consisted of a preparation book given to children at their pre-operative clinic (Margolis et al. 1998) and a theatre-related puppet show on the day of surgery (Zahr 1998). The increase in pre-operative anxiety scores from admission to induction of anaesthesia was slightly higher in children 2 to 4 years after receiving a preparation book compared to the control group (no preparation book) (1.6±1.1 increased to 2.2±1.5 vs. 1.4±0.6 increased to 1.8±1.1, 1-7 GMS) and slightly lower in children 4 to 6 years compared to the control group (1.5±0.8 increased to 1.8±0.9 vs. 1.7±1.1 increased to 2.0±1.1, 1-7 GMS) but neither of these changes were significantly different (Margolis et al. 1998). In Zahr et al.'s (1998) study children who were shown a puppet show on the day of surgery were compared to children not shown a puppet show and pre-operative anxiety was assessed at the time of the child's injection with

premedication. Anxiety scores were significantly lower in children who watched the puppet show (2.52±1.28 vs. 3.76±1.16, 1-5 manifest upset scale (MUS)) (Zahr 1998).

Kain et al. (2007) examined the effect of a multi-component behavioural preparation programme directed at parents, administered five to seven days prior to surgery, on pre-operative anxiety compared to three other groups: one group given midazolam 0.5mg/kg, another group had parents present during induction of anaesthesia and the third group was a control group with no premedication/parents present/formal preparation. The intervention in this study prepared parents by showing them a video of pre-operative procedures, i.e. the journey to theatre and induction of anaesthesia, and provided parents with instructions on how they could manage their own and their child's anxiety, how they could distract their child and teach them how to perform the required behaviours in theatre. Children who received midazolam had significantly lower anxiety scores than all other groups in the anaesthetic holding room (31±12 vs. 36±16 control, 35±16 parent presence and 37±17 midazolam, 0-100 mYPAS) and children who received the preparation programme had similar anxiety scores to the midazolam group during induction but significantly lower anxiety than the control or parent present groups (43±23 intervention and 40±24 midazolam vs. 52±26 control and 50±26 parent presence) (Kain et al. 2007a).

2.3.5.2.3 Summary

Formal pre-operative preparation programmes that involve a slide-show/video, a tour of the theatre areas, familiarisation with theatre equipment, e.g. anaesthetic mask, pulse oximeter, and/or role rehearsal, had a positive effect on child behaviour changes at home. Three of the 4 studies included in the review reported a decrease in PB following surgery. The frequency of PB in the subscales of the PHBQ were 2 to 6 times lower for children who received the preparation intervention in one study but only slightly lower in the aggression toward authority subscale only (mean difference 0.4) in another study.

Formal pre-operative preparation appears to lower child pre-operative anxiety if provided 1 to 2 weeks prior to surgery except in 2 to 3 year olds (as reported in 1 study). Lower pre-operative anxiety scores were reported on a number of self-report and observational measures. Mean differences reported were 0.9 to 1.4 on 5-point scales and 4 to 14 on 40 to 100 point scales respectively. When parents are prepared and given instructions on how to prepare their children and coach them during stressful procedures children exhibited lower pre-operative anxiety scores (mean difference 4-6, 0-100 mYPAS).

An increase in anxiety scores was reported in 1 study when children received formal preparation on the day of surgery (mean difference 9, 14-160 CD:H), and in another study when children > 6 years were offered formal preparation the day before surgery compared to 5 to 7 days prior to surgery (mean difference 19, 0-100 VAS). Lower anxiety scores were however reported in children during injection with premedication following a procedure-related puppet show on the day of surgery (mean difference: 1.24, 1-5 MUS).

2.3.5.3 Premedication

2.3.5.3.1 Behaviour change

Four studies recorded behaviour changes in children after comparing the administration of midazolam as a premedication to placebos (Bevan et al. 1997;Kain et al. 1999a;McCluskey et al. 1994;McGraw et al. 1998). PHBQ scores indicated that PB change 1 to 2 weeks after surgery were significantly lower for children who received midazolam compared to those who received placebos in two studies: incidence ± 30% in the intervention group compared to ± 60% in the control group 1 week after discharge (Kain et al. 1999a) and 17% in the intervention group compared to 52% in the control group 2 weeks after discharge (McCluskey et al. 1994). However, after telephonic structured parent interviews with forced choice questions regarding PB conducted at week one McGraw et al. (1998) reported a significantly higher incidence of PB in children who received midazolam compared to children who received a placebo (54% vs. 23%). In another study that interviewed parents one week after surgery no differences between groups was found in

terms of behaviour changes (Bevan et al. 1997). The development and structure of the interview tool used in this study was not reported and the study was therefore given an "unclear/unknown" quality rating for main measure (Bevan et al. 1997).

Two studies compared different types of premedications (Patel et al. 1997;Payne et al. 1992). Payne et al. (1992) compared oral trimeprazine, intramuscular midazolam and oral midazolam and found that children who received midazolam (intramuscular or oral) had less PB change at night, two weeks after discharge, than those who received trimeprazine (32.8% vs. 51.6%) but these results should be interpreted with caution as the tool used to measure behaviour change was adapted from the PHBQ and no psychometrics were reported. Similar results were reported by Patel et al. (1997): children who received trimeprazine had more PB change than the combined groups of children who received midazolam and diazepam (75% vs. 45.5%).

In two studies (Calipel et al. 2005;Patel et al. 2006) premedication (midazolam/placebo) was compared to alternate treatments/distraction. Patel et al. (2006) compared the administration of midazolam as a premedication 20 minutes before being taken to surgery to allowing children to play with a self-selected video game in the 20 minutes before surgery and during induction of anaesthesia. Both interventions were compared to standard care which involved parents being present until their child was anaesthetised and results showed no significant group differences at baseline, follow-up 7 to 10 days after surgery or between baseline and follow-up (Patel et al. 2006). In a study conducted by Calipel et al. (2005) children were given a placebo premedication 30 minutes prior to surgery and an anaesthetist established a hypnotic state which was maintained until the induction of anaesthesia. The hypnotized children had significantly less PB changes on day 1 (30% vs. 62%) and 14 (26% vs. 44%) after discharge, they were less aggressive towards their parents (day 1: 0% vs. 18% and 14: 4% vs. 29%) and showed less fear of separation (day 7: 4% vs. 30%) compared to children who received the placebo premedication (Calipel et al. 2005).

2.3.5.3.2 Pre-operative anxiety

Children who received midazolam pre-operatively were significantly less anxious than those who received a placebo on arrival in the anaesthetic room (anxiolysis effective in 96% children in midazolam group vs. 44% in placebo group, 1-4 anxiety scale) and during induction (88% vs. 33%, 1-4 anxiety scale) (McCluskey et al. 1994). Similar results were reported in a study conducted by Kain et al. (1999); children who received midazolam had significantly lower pre-operative anxiety scores, as measured by the mYPAS, when compared to children who received a placebo at separation to theatre, entrance to theatre and introduction of the anaesthetic mask (no scores reported). Midazolam was also found to be a more effective anxiolytic when compared to alternate premedications (diazepam-droperidol/trimeprazine) on arrival in the anaesthetic room (anxiolysis effective in 90% children in midazolam vs. 79% in diazepam-droperidol group and 62% in trimeprazine group, 1-4 anxiety scale) and during induction (83% vs. 55% and 40%, 1-4 anxiety scale) (Patel et al. 1997). In a fourth study, children given midazolam were no more or less anxious at any of the pre-operative measurement time-points than those given placebos pre-operatively in a study conducted by Bevan et al. (1997) but the sample in this study was small (n=24) which may have affected the results.

One study (Kain et al. 2007b) compared children who responded to premedication of midazolam 0.5mg/kg with decreased anxiety scores to children who did not respond. Children classified as non-responders (score of ≥72.91, 22-100 mYPAS, an a priori score defined by authors as non-response to premedication) were significantly more anxious in the anaesthetic holding area (49±22.9 vs. 38.3±19.1, 22-100 mYPAS). Younger child age and high child temperament emotionality were found to be predictors of non-response to midazolam (Kain et al. 2007b).

In a study conducted by Kain et al. (2004) pre-operative anxiety was the only outcome of interest when comparing the administration of midazolam 0.5mg/kg to interactive music therapy administered by one of two music therapists in theatre and a control group who

received neither premedication nor music therapy. Children who received midazolam were significantly less anxious during induction than children in the music therapy or control groups (mean score 35 vs. 52 and 53, 0-100 mYPAS) (Kain et al. 2004).

Children who were hypnotised versus children who were offered a placebo premedication were significantly less anxious during induction (23 (score range 23-78) vs. 28 (23-75), 0-100 mYPAS) (Calipel et al. 2005). Patel et al. (2006) compared pre-operative anxiety scores between children who were given a video game, children who were given Midazolam and children whose parents were present only. Children who were given a video game demonstrated a decrease in anxiety from baseline to induction of anaesthesia (median change -3, 0-100 mYPAS) which was significantly different to the increase in anxiety scores demonstrated in the parent present group (+7.3, 0-100 mYPAS) (Patel et al. 2006). Golden et al. (2006) measured pre-operative anxiety outcomes only after an intervention that consisted of giving a child a toy shortly after admission. Children in the intervention group had significantly lower anxiety scores during the administration of premedication (midazolam) compared to the no-toy control group (23 (score range 23-24) vs. 42 (28-52), 0-100 mYPAS) (Golden et al. 2006). Anxiety scores during premedication decreased significantly from earlier scores in the intervention group (33 (23-47) decreased to 23 (23-24)), whereas children in the control group had a significant increase in anxiety scores from baseline to premedication (28 (23-35) increased to 42(28-52))(Golden et al. 2006).

2.3.5.3.3 Summary

Two studies reported improved child behaviour at home, as measured by the PHBQ, when the children were given midazolam versus placebos. The incidence of PB in children who were given midazolam was ≤ half the incidence of PB in children who were given placebos within the first two weeks after discharge. When PB were measured through parent interviews mixed results were reported; children who were given midazolam had double the incidence of PB compared to children given placebos in one study and no difference in the

incidence of PB in another study. When the effects of midazolam/other benzodiazepines on post-hospital behaviour were compared to the effects of alternate premedications children had two thirds of the incidence of PB if given midazolam/other benzodiazepines. However, one study compared PB between children who were hypnotized pre-operatively and children who were given midazolam and reported that hypnotized children had half the incidence of PB than children given midazolam.

Improved child anxiety was reported at a number of pre-operative time-points when children who were given midazolam/other benzodiazepines were compared to children who were given placebos/alternate premedications. Lower anxiety was reported as a higher incidence of effective anxiolysis (range of 10-43% higher in the midazolam groups). Lower mean scores on the mYPAS were reported in children who responded to midazolam versus children who didn't (mean difference 10.7, 0-100 mYPAS). When midazolam/placebos were compared to diversionary activities/hypnosis, lower pre-operative anxiety scores were reported in the latter group: mean difference 5, 0-100 mYPAS (hypnosis vs. placebo premedication), mean difference 19, 0-100 mYPAS (toy vs. midazolam) and a decrease in anxiety scores over the pre-operative period (score difference -3, 0-100 mYPAS) versus an increase in anxiety scores (+7.3, 0-100 mYPAS) (video-game vs. midazolam). However, music therapy was a less effective diversionary activity when compared to midazolam (mean difference 17, 0-100 mYPAS).

2.3.5.4 Induction of anaesthesia

2.3.5.4.1 Behaviour change

Kotiniemi et al. (1996) compared routes of induction of anaesthesia, i.e. intravenous with thiopentone, inhalation with halothane and rectal with methohexitone. PHBQ scores failed to identify any group differences. However, in the same study structured, open-ended questions regarding children's memories of hospitalisation showed that children who received inhalation induction of anaesthesia had more negative memories of hospital and anaesthesia than children in either of the other groups (61% vs. 28% and 38%) (Kotiniemi

et al. 1996a). Both the intravenous and inhalation induction groups had more hospital-influenced play than children in the rectal induction group (28% and 18% vs. 3%) (Kotiniemi et al. 1996a). Aguilera et al. (2003) compared intravenous induction with thiopental to inhalation induction with sevoflurane and also found no group differences with regard to PHBQ scores at two weeks after discharge. Bal et al. (2006) compared inhalation induction with sevoflurane (alone and followed by a dose of propofol) to intravenous induction with propofol. Children who had intravenous induction had no nightmares/fear of the dark at one week after surgery whereas children in the inhalation induction groups did (N=0 vs. N=6 and 8) and significantly fewer children in the intravenous induction group wanted to sleep with their parents (N=2 vs. N=10 and 5) (Bal et al. 2006). Two studies (Kain et al. 2005;Keaney et al. 2004) compared two inhalation induction drugs: sevoflurane versus halothane. No group differences in behaviour changes were found in PHBQ scores (total or subscales) (Kain et al. 2005;Keaney et al. 2004) or sleep variables as measured by actigraphy in the first five nights postoperatively (Kain et al. 2005).

2.3.5.4.2 Pre-operative anxiety

Only one study was found that examined the effects of induction technique on pre-operative anxiety. Children who received intravenous induction of anaesthesia were significantly more anxious than children who received inhalation induction; 46% children in the intravenous group received unsatisfactory anxiety scores versus 10% in the inhalation group (1-4 anxiety scale) (Aguilera et al. 2003).

2.3.5.4.3 Summary

Three studies compared the effects that routes of anaesthesia (inhalation/intravenous/rectal) had on children's behaviour at home. Two studies that measured behaviour change using the PHBQ failed to detect a difference in behaviour but a third study did with children in the inhalation group experiencing more sleeping disturbances than children in the intravenous group (29 vs. 2), as measured by the PHBQ. In interviews with children more

negative memories of hospital were identified in children who had received inhalation induction of anaesthesia (versus intravenous or rectal) and more children who had received rectal induction of anaesthesia displayed hospital-influenced play at home (versus intravenous or inhalation). No significant group differences were found in child behaviour when two studies compared different types of inhalation induction drugs.

Only one study compared the effects that routes of anaesthesia (inhalation/intravenous) had on children's pre-operative anxiety and found that more than four times the number of children in the intravenous group had unsatisfactory pre-operative anxiety scores during induction than children in the inhalation group. This is contrary to the effects on post-hospital behaviour change.

2.3.5.5 Changes to the theatre environment

2.3.5.5.1 Behaviour change

One study (Kain et al. 2001) examined the effect of lower sensory stimulation in theatre on behaviour changes at home compared to the normal theatre environment. The incidence of behaviour changes did not differ between groups at any of the follow-up time-points (Kain et al. 2001).

2.3.5.5.2 Pre-operative anxiety

Lower sensory stimulation in theatre resulted in significantly lower anxiety scores on entrance to theatre (±36 vs. ±47, 0-100 mYPAS) and during induction (±33 vs. ±60, 0-100 mYPAS) (Kain et al. 2001).

Two studies (Golan et al. 2009;Vagnoli et al. 2005) examined the effect of the presence of clowns in theatre on children's pre-operative anxiety. In the study conducted by Vagnoli et al. (2005) children in the intervention group were accompanied by their parents and clowns into theatre where the clowns interacted with the children up to and including induction of anaesthesia. Children in the intervention group had significantly lower anxiety scores

during the induction of anaesthesia compared to the control group (parent presence only) (37.50±21.48 vs. 68.25±28.42, 0-100 mYPAS) and scores did not change significantly from the holding room to induction whereas the control group had a significant increase in anxiety between these time-points (35.95±15.64 increased to 68.25±28.42) (Vagnoli et al. 2005). Golan et al. (2009) compared pre-operative anxiety scores between children who had clowns present in theatre to children who received midazolam and children who had neither (control). Children in the clown group had significantly lower anxiety scores than the control group in the anaesthetic room (28.3±4.6 vs. 38.4±12.7, 0-100 mYPAS) and on entering theatre (37.3±12.3 vs. 50±17.4) but anxiety scores were not significantly different to those in the midazolam group (42±10.6) at this time (Golan et al. 2009).

2.3.5.5.3 Summary

Changing the theatre environment, either through lower sensory stimulation or distraction with the presence of clowns has positive effects on child pre-operative anxiety; mean anxiety scores in the intervention groups were 11 to 31 lower than anxiety scores in the control groups at various pre-operative time-points in the intervention group. However, one of these studies compared the presence of clowns in theatre to the administration of midazolam as premedication and found no significant difference in pre-operative anxiety scores.

2.3.5.6 Overall summary of intervention studies

Five types of experimental interventions were identified from the review and include: parent presence during induction of anaesthesia, pre-operative preparation programmes, administration of premedication, modes of anaesthesia induction, and changes to the theatre environment.

Interventions that had a positive effect on child behaviour change at home were pre-operative preparation programmes that involved exposure to aspects of the surgical experience, i.e. sensory features, role-play, tours of the surgical areas, and the

administration of midazolam (versus other premedications or placebos) pre-operatively. Inhalation induction of anaesthesia (versus intravenous induction) had a negative effect on behaviour change at home.

Interventions that had a positive effect on child pre-operative anxiety were the administration of midazolam pre-operatively, offering the children some form of distraction, child hypnosis prior to and during induction of anaesthesia, inhalation induction of anaesthesia (versus intravenous) and lower sensory stimulation or distraction in theatre prior to and during induction of anaesthesia. Interventions tested but that proved to be ineffective under certain conditions were parent presence in theatre and during induction of anaesthesia, especially if the parents were highly anxious and pre-operative preparation programmes if conducted too close to the surgery date and with younger children.

For the scope of this review (1990 to 2009) experimental interventions consisted of premedications, modes of induction and parent presence between 1990 and 1997. Pre-operative preparation interventions were introduced in 1998, distraction interventions in 2001 and pharmacological experiments (premedication, induction, and anaesthesia) continued however 4 of these 9 studies compared premedication of midazolam to different forms of distraction.

2.4 Discussion

2.4.1 Descriptive studies

In their meta-analysis on children's behaviour after hospitalisation Thompson et al. (1993) reported a significant decrease in PB with time that largely disappeared by two weeks. Although the current review also reports a significant decrease in PB over time, several studies reported PB at 1 month (Kain et al. 1996c;Kotiniemi et al. 1996b;Kotiniemi et al. 1997;Stargatt et al. 2006;Tuomilehto et al. 2002), 6 months (Ben-Amitay et al. 2006;Kain et al. 1996c) and 1 year (Carson et al. 1991;Kain et al. 1996c) following hospitalisation for surgery. More is now known about the risk factors for post-hospital behaviour problems.

Thompson et al. (1993) reported a contribution of the child's length of stay in hospital to PB at home but stated that this was not a dose-response relationship with children hospitalised for 2 to 3 days having most PB followed by children hospitalised for 1 day and then those hospitalised for 4 to 8 days. Eight of the 38 descriptive studies included children admitted for both day case and inpatient surgery. Only one of these studies (Stargatt et al. 2006) reported an influence of length of stay on PB at home. Staying over night was found to be a risk factor for PB on day 3 post-discharge and longer hospital stay was a risk factor for PB on day 30 (Stargatt et al. 2006). Other child and parent factors identified as risk factors for PB in the current review were: child age, temperament, the child's number of siblings, pre-operative behavioural disturbances, child pre-operative anxiety, preparation/information, mother's anxiety, pain at home, one-adult homes, living in urban areas and a difficult previous anaesthetic for the child. Research since 1990 has explored more potentially influencing variables on PB post-discharge.

The current review identified 12 studies that described child pre-operative anxiety. Child anxiety increased from admission until the induction of anaesthesia and was highly correlated to mother's anxiety. Other factors associated with pre-operative anxiety were child age, temperament, children not given premedication and previous anaesthesias. Although preparation programmes may decrease pre-operative anxiety, an increase in anxiety was seen in younger children who received pre-operative preparation programmes and in older children who received preparation the day before surgery (Kain et al. 1996c). Pre-operative anxiety was not discussed in Thompson et al.'s (1993) meta-analysis and this is most likely because the meta-analysis was not restrictive to children having surgery, however two later review-type papers (Caldas et al. 2004;Watson et al. 2003) highlighted the inextricable link between pre-operative anxiety and maladaptive behaviours at home following surgery.

Postoperative symptoms were described in nine studies. Children experience pain, nausea and vomiting at home following surgery. Pain intensity is reportedly most severe in the first three postoperative days and decreases thereafter. Children's pain at home has been

related to both pre-operative anxiety (Kain et al. 2006a) and PB at home (Karling et al. 2007;Kotiniemi et al. 1997). In addition, two studies (Gedaly-Duff et al. 1994;Reid et al. 1995) reported behavioural cues that parents used to identify their child's pain and these behaviours are similar to those reported in descriptive studies of PB at home including: general anxiety, eating and sleeping disturbances.

2.4.2 Intervention studies

Vernon et al.'s (1993) meta-analysis on the effect of experimental interventions on children's behaviour after hospitalisation reported significantly less PB in children exposed to interventions than those who were not. Two primary types of intervention were included in the meta-analysis: parent presence (versus absence) and preparation. In the current review parent presence was examined as an intervention in the context of induction of anaesthesia and had a negative effect on child pre-operative anxiety if the parent was anxious (Bevan et al. 1990) and no effect on child behaviour following surgery (Bevan et al. 1990;Kain et al. 1996b;Tripi et al. 2004). Preparation as an intervention was carried out pre-operatively and mixed results were reported in terms of pre-operative anxiety. Preparation programmes conducted on the day of surgery (Brewer et al. 2006) and with younger children (Margolis et al. 1998) had negative effects on pre-operative anxiety while pre-operative preparation in the form of a therapeutic play session conducted a week prior to surgery (Li et al. 2007) and a puppet show the day before surgery (Zahr 1998) had positive effects on pre-operative anxiety. Three studies (Brewer et al. 2006;Margolis et al. 1998;Zahr 1998) reported beneficial effects of pre-operative preparation on PB at home. Vernon et al. (1993) reported negative effects of preparation for hospitalisation on behavioural outcomes in children younger than six years.

Stress-point preparation was reported as significantly more effective than simple dramatic or multi-component presentations (video, puppets, verbal description) and preparation after admission was reportedly more effective than prior to admission in Vernon et al.'s (1993) meta-analysis. No studies involving preparation both before and after admission/surgery or

at various stress points were identified for inclusion in the current review. It is therefore unknown if this type of preparation, that was so successful in children's hospitalisation not restrictive to surgery, would be more beneficial in terms of the effects on child pre-operative anxiety and behaviour at home.

Other types of interventions identified in the current review that were new and specific to children hospitalised for surgery were pharmacological interventions (premedications, induction agents and anaesthetics) and changes to the theatre environment. Midazolam was effective at reducing both pre-operative anxiety (Kain et al. 1999a;Kain et al. 2004;McCluskey et al. 1994;Patel et al. 1997) and behaviour changes at home (Kain et al. 1999a;McCluskey et al. 1994;McGraw et al. 1998;Patel et al. 1997;Payne et al. 1992). Distraction techniques such as video-games (Patel et al. 2006) and toys (Golden et al. 2006) provided to children also improved pre-operative anxiety but there are no reports regarding the effect that these had on behaviour change at home. Hypnosis prior to and during induction of anaesthesia had beneficial outcomes on both pre-operative anxiety and behaviour changes at home (Calipel et al. 2005). A number of studies examined the effect of inhalation versus intravenous induction of anaesthesia and reported that children who had inhalation induction had higher pre-operative anxiety (Aguilera et al. 2003) scores but fewer PB at home (Bal et al. 2006;Kotiniemi et al. 1996a). Changes to the theatre environment by lowering sensory stimulation or by providing distraction with trained clowns present had positive effects on pre-operative anxiety (Golan et al. 2009;Kain et al. 2001;Vagnoli et al. 2005) but no effect on behaviour at home (Kain et al. 2001).

2.4.3 Knowledge gained

From this systematic review of the literature it is clear that children continue to exhibit pre-operative anxiety, as well as symptoms (primarily pain) and PB at home, as measured by a number of validated tools. The incidence of these problems appears not to have been reduced by research on interventions aimed at improving these outcomes. Numerous child factors influence pre-operative anxiety and/or PB at home. Interventions that improve pre-

operative anxiety outcomes do not necessarily improve PB outcomes and vice-versa. There is research evidence that both outcomes can be improved by pre-operative preparation (depending on type and timing of programme) and administration of midazolam as a premedication. It is also clear from the review of the research that pre-operative anxiety negatively affects both pain and behaviour changes at home. Previous exposure to pre-operative procedures, i.e. anaesthesia, either through direct experience or formal preparation can have a detrimental effect on both pre-operative anxiety and behaviour change outcomes. Child and parent pre-operative anxiety are highly correlated and both predict child PB at home.

2.4.4 Knowledge lacking and necessary future research

The current review excluded studies that focused on parent outcomes without any reference to child outcomes and only one study was identified that focused on preparing parents of children admitted to hospital for surgery and how this related to child pre-operative anxiety (Kain et al. 2007a). This study reported favourable pre-operative anxiety outcomes but no reports on child behaviour at home (Kain et al. 2007a). In an early review paper on hospitalization as a life crisis for the pre-school child, Goslin (1978) synthesized the findings of three studies in which the interventions consisted of time spent with the accompanying parent and providing support and information at various stress-points. All three studies reported favourable outcomes in parent and child peri-operative anxiety, child cooperation and child behavioural outcomes at home (Goslin 1978). Descriptive detail is lacking in the current literature regarding whether or not parents are provided with information/preparation for their child's admission to hospital for surgery and how this relates to the parent and child's pre-operative anxiety and child behaviour outcomes at home. More information is also needed in terms of parent coping style, previous experience with hospitalisation for surgery and pain and how these factors relate to their information needs and satisfaction with preparation and child outcomes. Information is also lacking regarding the provision and uptake of pre-operative preparation and

information of/for children without experimental interventions and how this relates to child outcomes.

Visintainer et al.'s (1975) stress-point preparation of the parent was highlighted as a significantly effective intervention on children's behaviour following hospitalisation in Goslin's (1978) review paper and Vernon et al.'s (1993) meta-analysis yet no research in the current literature was identified that examined the effect of stress-point preparation of the parent before and after the child's surgery from 1990 to 2009.

Only one study (Brewer et al. 2006) included in the current review described a theoretical framework on which the study was based, i.e. Lazarus and Folkman's theory of stress and coping. This theory was referred to in the background of a another study included in the review (Lamontagne et al. 1997) but was not explicitly stated as a theoretical framework for the study. Goslin (1978) highlighted the lack of theoretical basis for research in this field up until 1978. The meta-analyses by Vernon et al. (1993) and Thompson et al. (1993) did not provide any detail on theoretical frameworks that their included studies were based on. It appears that little progress has been made in this area. In agreement with Goslin (1978), preparation studies appear to be based on Bandura and Walters modelling theory which asserts that subjects tend to imitate the response of a model exposed to an experience but this has not been confirmed in any of these intervention studies.

Only five types of experimental interventions were identified from 31 intervention studies. Interventions included parent presence during induction of anaesthesia, pre-operative preparation programmes, administration of premedication, modes of anaesthesia induction, and changes to the theatre environment. Although some of these interventions report improved child pre-operative anxiety other influencing factors of PB at home and child pre-operative anxiety that were identified in the descriptive studies do not seem to have been taken into account, e.g. younger children, length of hospital stay, parent pre-operative anxiety, child temperament factors and pre-operative PB. These factors were identified as risk factors for both child pre-operative anxiety and PB at home. Only three intervention

studies included children who spent at least one night in hospital; a significant predictor of post-hospital behaviour problems. The total number of children included in the intervention studies was much smaller than the total number included in the descriptive studies (3,414 vs. 6,528) and the sample sizes were generally smaller (largest sample 408 vs. 1,224).

2.4.5 Strengths of the review

This review systematically identified all research conducted since 1990 that focused on child behaviour change outcomes following admission to hospital for surgery. Child pre-operative anxiety and symptoms at home were additional noteworthy outcomes identified from the literature search and were described in isolation as well as in relation to child behaviour change outcomes. Results from this review provide an updated incidence of child pre-operative anxiety and behaviour changes at home and clarifies the predictors for these outcomes. A synthesis of interventions that successfully improve these outcomes has been provided.

2.4.6 Limitations of the review

The aim of this review was to include all studies that reported child behaviour change outcomes at home, pre-operative anxiety and postoperative symptoms at home irrespective of the tools and methods used to measure these outcomes. Although this enabled a thorough description of the field of research from 1990 it may be considered a limitation that a more robust synthesis of data, i.e. a meta-analysis could not be performed. The quality assessment of each of these studies ensured the exclusion of any study that did not meet a defined list of methodological criteria however, the conservative approach chosen to include studies that were rated as ‘unclear’ or even ‘inadequate’ in a quality criterion, if all other criteria were rated ‘adequate’ may have resulted in biased findings.

The inclusion of studies that focused only on child pre-operative anxiety and/or postoperative symptoms at home add to the knowledge base of these particular outcomes but their relationship to child behavioural outcomes at home can only be inferred.

2.5 Conclusion

This chapter provided a detailed systematic review of the literature on child behaviour change outcomes at home following discharge from hospital for surgery over two decades (1990 to 2009). An online search of relevant electronic databases, expert collection of research articles, references lists and citation searches of key papers and authors resulted in the inclusion of 69 studies: 38 descriptive and 31 intervention studies. The total number of children included in the studies was 9,942 and children ranged in age from 1 to 16 years. The methodological quality appraisal and data extraction procedures for each of the included studies were described in detail.

Results of the review were presented by study type, i.e. descriptive and intervention. The incidence of behaviour changes in children following admission to hospital for surgery and any identified associations and/or predictors were detailed. Additional findings of child pre-operative anxiety and postoperative symptoms were also described and wherever possible related to behaviour change outcomes. Results from the intervention studies were presented under the main types of interventions.

The chapter was brought to a close with a discussion of how this review confirms or disputes findings from previous reviews, areas where knowledge is lacking and further research is required was described and the strengths and limitations of the review acknowledged. Chapter three will present a theoretical framework on which the current study was based following a thorough review of the literature and relevant theories.

Table 2.1 Quality assessment tool

Quality domain	Coding	Explanation of quality criterion
Sample	A, Adequate I, Inadequate U, Unclear/unknown	Adequate: • Eligibility criteria explained. • Sampling methods detailed and appropriate to study design. • Sample size estimation / rationale for sample size. • Matching criteria (for matched studies) and number of controls per case detailed. • Explanations of exclusions, refusals and withdrawals. Inadequate: • Inappropriate sampling for study design e.g. sample selected by convenience or by non-random method (alternation, case record number, birth date, or similar procedures). • Sample size too small for study design e.g. insufficient statistical power in quantitative study or saturation of results not met in qualitative study. Unclear: • Sample selection (eligibility, recruitment methods, size) was not explained. • Exclusions, refusals and withdrawals not detailed.
Intervention / study procedures	A, Adequate I, Inadequate U, Unclear/unknown	Adequate: • Study procedures explained and appropriate to design and intended outcomes. • Details provided of setting, relevant dates of recruitment, exposure and follow-up. • Randomization: explanations of appropriate sequence generation, allocation and implementation. • Blinding of participants, those administering the intervention and those assessing the outcomes. • Precise and replicable explanation of intervention/s described.

		• The identical intervention was used throughout the study. • There was no risk for the intervention to change over the course of the study or threat to blinding. • Details provided of how (any) bias was addressed. Inadequate: • Procedures did not relate to the study aims or outcomes. • Participants in the intervention did not get the intervention or received a different intervention to that intended. • Inadequate group concealment/no blinding. • Evidence of assessor bias. Unclear: • The terms 'randomised' or 'randomly allocated' used with no further details provided. • No statements on procedures and not deducible. • Procedures for ensuring consistent intervention throughout the study were not explained. • No indication of assessor blinding.
Outcomes/main measures	A, Adequate I, Inadequate U, Unclear/unknown	Adequate: • Clearly defined primary and secondary outcomes that are appropriate to research aims/questions. • Evidence of internal consistency, reliability and validity. • Details of outcome measurement provided i.e. upper/lower limits for scales, unit of measurement. • Summary of results for each outcome (for each group at all relevant time-points) and the estimated effect size and its precision e.g. 95% confidence interval. • Explanations given of how missing data were dealt with.

		Inadequate: • Not appropriate to study population and / or design. • Outcome measure not tested or reliable/valid. Unclear: • Measures developed / adapted for the study and no psychometrics were reported. • Not all results given.
Decision for inclusion in review	Inc, include Inc*, include but interpret results with caution Exc, exclude from review	Inc • All criterion rated adequate Inc* • One criterion adequate, two unclear • One criterion adequate, one unclear, one inadequate • Two criterion adequate, one unclear • Two criterion adequate, one inadequate • Three criterion unclear Exc • Two or more criterion inadequate

Table 2.2 Data extraction form

General Info	**Study characteristics**	**Participant characteristics**
1.Researcher 2.Date	1.Aim/objectives	1.Total number
3.Study ID 4.Author	2.Design	2.Sample size calculation: Y/N
5.Title	3.Duration	3.Age 4.Gender
6.Country of origin	4.Inclusion/exclusion criteria	5.Ethnicity
7.Confirm eligibility	5.Recruitment procedures/group allocation/blinding	6.Socio-economic status/other important background
8.Funding		information
9.Correspondence required: Y/N		7.Surgery type
Missing:	Missing:	Missing:
Intervention and setting	**Outcomes and results**	**Quality** (refer to Table 2.1 for coding)
1.Total number of interventions groups	1.Number of participants at each time-point	Sampling:
2.Methods used to allocate participants to groups	2.Definition of outcome in study	Intervention/study procedures:
3.Number of participants in each group	3.Measurement tool/method	Outcomes/main measures:
4.Description of intervention(s) and control(s)	4.Unit of measurement	
	5.For scales: upper and lower limits, high or low is good	
	6.Statistical techniques used	
	7.How was missing data dealt with	
	8.Estimate of effect with confidence intervals; p-value	
Missing:	Missing:	Decision for inclusion/exclusion:

Table 2.3 Main measures used in included studies

Type of study	Methods designed for studies	Validated measures
Descriptive	Behaviour change: • Interviews Symptoms: • Questionnaire regarding pain intensity (4-point likert scale) and duration • Questionnaires / telephonic interviews including questions about pain, nausea, vomiting and journey home from hospital • Interview regarding pain experiences at home.	Pre-operative anxiety: • Child Anxiety Rating Scale (CARS) • Anxiety Visual Analogue Scale (VAS) • Venham Picture Test (VPT) • Modified Yale Pre-operative Anxiety Scale (mYPAS) • Bieri Faces Scale • Chinese State Anxiety Scale for Children (CSAS-C) • Manifest Upset Scale (MUS) Behaviour change: • The Competent Scales of Youth Self-Report and Profile (YSR) to assess usual activities. • Post-Hospital Behaviour Questionnaire (PHBQ) • Paediatric Symptom Checklist (PSC) • Actigraphy (sleep disturbance) • The Child's Post-traumatic Stress Reaction Index (CPTS-RI) • Children's Depression Inventory (CDI) • Revised Children's Manifest Anxiety Scale (RCMAS) • Behaviour Assessment System for Children (BASC) • Conner's Parent Rating Scale-Revised Short Form (CPRS-RS) • Paediatric Sleep Questionnaire (PSQ) • Test of Variables of Attention (TOVA) • Child Behaviour Checklist (CBCL) • Obstructive Sleep Apnoea – 18 (OSA-18)

		• Continuous Performance Test (CPT) • Revised Rutter Scale for School-age Children • Modified Child Dental Anxiety Scale (MCDAS) Symptoms: • Postoperative Pain Measure for Parents (PPMP) • Pain: Bieri Faces Scale • Pain: Wong Baker FACES Pain Rating Scale • Pain: Visual Analogue Scale (VAS) • Pain: Numeric Rating Scale (NRS) (Parent-report from behaviour / observation) • Postoperative nausea and vomiting: VAS • Toddler-Preschooler Postoperative Pain Scale (TPPPS)
Intervention	Behaviour change: • Interviews • Behaviour questionnaire adapted from the Post-Hospital Behaviour Questionnaire (PHBQ) • Structured, open-ended questionnaire	Pre-operative anxiety: • 4-point anxiety rating scale (1-tearful/combative, 2-anxious/easily reassured, 3-calm, 4-asleep). • Yale Pre-operative Anxiety Scale (YPAS) • Modified Yale Pre-operative Anxiety Scale (mYPAS) • Child Anxiety Rating Scale (CARS) • Global Mood Score (GMS) • Manifest Upset Scale (MUS) • Chinese State Anxiety Scale for Children (CSAS-C) Behaviour change: • Post-hospital behaviour questionnaire (PHBQ) • Hospital Fears Index (HFI) • Child Drawing: Hospital (CD:H) • Actigraphy (sleep disturbance)

		Symptoms: • Pain: Visual Analogue Scale (VAS) • Pain: Oucher scale

Table 2.4 Assessment of methodological quality

Year, author and country	Sample	Design	Intervention / study procedures	Main measures	Quality decision
1990 Bevan JC et al. Canada	A: S, ERW U: SSE	Non-randomised trial	A: SPEAD, SF, GA, IRM, AB – not possible.	A: VT PA, BC and fear	U+A+A = Inc*
1990 Schmidt CK USA	A: S, ERW U: SSE	Experimental design	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1991 Carson DK et al. USA	A: S, ERW U: SSE	Single group pre-test post-test	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1992 Payne KA et al. South Africa	A: S U: SSE, ERW	RCT	A: SPEAD, SF, GA, IRM, AB	U: Adapted BC no psychometrics reported.	U+A+U = Inc*
1993 Lumley MA et al. USA	A: S, ERW U: SSE	Prospective cohort	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1994 Ellerton ML et al. Canada	U: S, SSE, ERW	Retrospective study	A: SPEAD, SF	A: VT PA	U+A+A = Inc*
1994 Gedaly-Duff V et al. USA	A: S, SSE, ERW	Inductive qualitative study	A: SPEAD, SF	A: VT pain	A+A+A = Inc
1994 Lynch M et al. USA	A: S, ERW U: SSE	Comparative study	A: SPEAD, SF	A: VT PA	U+A+A = Inc*
1994 McCluskey A et al. UK	A: S U: SSE, ERW	Prospective randomised double-blind placebo-controlled trial	A: SPEAD, SF, AB, IRM U: GA	A: VT PA BC*	U+U+A = Inc*
1994 Payne KA et al. South Africa	A: S U: SSE, ERW	Two-group comparison study	A: SPEAD, SF	U: Adapted BC no psychometrics reported.	U+A+U = Inc*

1995 Reid GJ et al. Canada	A: S U: SSE	Prospective study	A: SPEAD, SF	A: VT pain	U+A+A = Inc*
1996a Kain ZN et al. USA	A: S U: SSE, ERW	Cross-sectional study	A: SPEAD, SF	A: VT PA and BC	U+A+A = Inc*
1996b Kain ZN et al. USA	A: S, SSE, ERW	RCT	A: SPEAD, SF	A: VT PA and BC	A+A+A = Inc
1996c Kain ZN et al. USA	A: S U: SSE, ERW	Prospective longitudinal study	A: SPEAD, SF	A: VT PA and BC	U+A+A = Inc*
1996a Kotiniemi LH et al. Finland	A: S, SSE, ERW	RCT	A: SPEAD, SF, GA, IRM, AB	A: VT BC	A+A+A = Inc
1996b Kotiniemi LH et al. Finland	A: S, ERW U: SSE	Two-group comparison study	A: SPEAD, SF	A: VT BC	U+U+A = Inc*
1996 Rossen, BE et al. Canada	I: S – convenience U: ERW, SSE	Qualitative study	A: SPEAD, SF	A: Interview questions derived from clinical experience, observations and literature review.	I+A+A = Inc*
1997 Amanor-Boadu SD Nigeria	A: S U: SSE, ERW	Prospective study	A: SPEAD, SF	U: no mention of tool used for interview, i.e. how/when developed and/or scored.	U+A+U = Inc*
1997 Kotiniemi LH et al. Finland	A: S, ERW U: SSE	Prospective multi-centre survey	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1997 LaMontagne LL et al. USA	I: S – convenience U: ERW, SSE	Prospective cohort	A: SPEAD, SF	A: VT BC, coping	I+A+A = Inc*

1997 Bevan JC et al. Canada	A: S U: SSE, ERW	Randomised placebo-controlled trial	A: SPEAD, SF, AB, IRM U: GA	A: PA U: telephone interview development and structure not detailed.	U+U+U = Inc*
1997 Patel D et al. UK	A: S, ERW U: SSE	RCT	A: SPEAD, SF, IRM U: GA, AB	A: VT PA BC*	U+U+A = Inc*
1998 Goldstein NA et al. USA	A: S, ERW U: SSE	Prospective study	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1998 Issa A et al. UK	A: S, ERW U: SSE	Single group pre-test post-test	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
1998 Margolis JO et al. USA	A: S, ERW U: SSE	RCT	A: SPEAD, SF, GA, IRM U: AB	A: VT PA BC	U+U+A = Inc*
1998 McGraw T et al. USA	A: S U: SSE, ERW	Two-part RCT	A: SPEAD, SF, IRM, GA, AB	U: BC	U+A+U = Inc*
1998 Zahr LK Lebanon	A: S, SSE, ERW	Two-group experimental design	A: SPEAD, SF, IRM, GA AB - not possible	A: VT PA and BC	A+A+A = Inc
1999a Kain ZN et al. USA	A: S, SSE, ERW	Double-blind RCT	A: SPEAD, SF, GA, IRM, AB	A: VT PA, BC and pain	A+A+A = Inc
1999b Kain ZN et al. USA	A: S, SSE, ERW	Longitudinal study	A: SPEAD, SF	A: VT BC	A+A+A = Inc
1999 Kokinsky E et al. Sweden	A: S, ERW U: SSE	Prospective survey	A: SPEAD, SF	A: VT pain	U+A+A = Inc*
2000 Kain ZN et al. USA	A: S, ERW U: SSE	Prospective cohort	A: SPEAD, SF	A: VT PA	U+A+A = Inc*

2000 Wang SM et al. USA	A: S U: SSE, ERW	Cross-sectional study	A: SPEAD, SF	A: VT symptoms	U+A+A = Inc*
2001 Kain ZN et al. USA	A: S, SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB not possible	A: VT PA and BC	A+A+A = Inc*
2001 Morgan J et al. UK	A: S U: SSE, ERW	Prospective study	A: SPEAD, SF	A: VT pain	U+A+A = Inc*
2002 Goldstein NA et al. USA	A: S, ERW U: SSE	Before-after study	A: SPEAD, SF	A: VT BC, quality of life	U+A+A = Inc*
2002 Kain ZN et al. USA	A: S, SSE, ERW	Longitudinal cohort-controlled study	A: SPEAD, SF	A: VT sleep disturbances and sleep-related BC	A+A+A = Inc*
2002 Tuomiletho H Finland	A: S U: SSE, ERW	Prospective study	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
2003 Aguilera JM et al. UK	A: S, SSE, ERW	RCT	A: SPEAD, SF, IRM U: GA and no AB	A: VT PA BC*	A+U+U = Inc*
2003 Li HCW et al. China	I: S – convenience U: SSE, ERW	Pre and post test design	A: SPEAD, SF	A: VT PA	I+A+A = Inc*
2004 Kain ZN et al. USA	A: S, SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB not possible	A: VT PA	A+A+A = Inc
2004 Keaney A et al. Ireland	A: S, ERW U: SSE	RCT	A: SPEAD, SF, IRM, GA U: AB	A: VT BC	U+U+A = Inc*
2004 Tripi PA et al. USA	A: S, SSE, ERW	RCT	A: SPEAD, SRF, IRM, AB not possible	A: VT BC	A+A+A = Inc
2005 Caldwell-Andrews AA et al. USA	A: S, ERW U: SSE	Prospective cohort	A: SPEAD, SF	A: VT PA	U+A+A = Inc*

2005 Calipel S et al. France	A: S, ERW U: SSE	RCT	A: SPEAD, SF, IRM, AB not possible. U: GA	A: VT PA and BC	U+U+A = Inc*
2005 Kain ZN et al. USA	A: S, SSE, ERW	Double-blind RCT	A: SPEAD, SF, GA, IRM, AB	A: VT BC, VT sleep disturbances	A+A+A = Inc
2005 Mitchell RB et al. USA	A: S, SSE, ERW	Prospective cohort	A: SPEAD, SF	A: VT BC	A+A+A = Inc
2005 Vagnoli L et al. Italy	A: S U: SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB not possible	A: VT PA	U+A+A = Inc*
2006 Bal N et al. Turkey	A: S, ERW U: SSE	RCT	A: SPEAD, SF, IRM, GA U: AB	A: VT BC	U+U+A = Inc*
2006 Ben-Anitay G et al. Israel	A: S, ERW U: SSE	Prospective cohort	A: SPEAD, SF	A: VT post-traumatic stress, depression and anxiety.	U+A+A = Inc*
2006 Brewer S et al. USA	A: S, ERW U: SSE	Double-blind, alternate assignment intervention	A: SPEAD, SF, GA, IRM, AB	A: VT anxiety	U+A+A = Inc*
2006 Caldwell-Andrews AA et al. USA	A: S U: SSE, ERW	Cohort-controlled study	A: SPEAD, SF	A: VT sleep disturbance	U+A+A = Inc*
2006 Davidson AJ et al. Australia	A: S, SSE, ERW	Prospective cohort study	A: SPEAD, SF	A: VT PA	A+A+A = Inc
2006 Galland BC et al. New Zealand	A: S, ERW U: SSE	Before-after study	A: SPEAD, SF	A: VT BC, visual and auditory	U+A+A = Inc*
2006 Golden L et al. USA	A: SSE U: S, ERW	RCT	A: SPEAD, SF, IRM, GA, AB not possible	A: VT PA	U+A+A = Inc*

2006a Kain ZN et al. USA	A: S U: SSE, ERW	Controlled cohort study	A: SPEAD, SF	A: VT PA, BC and pain	U+A+A = Inc*
2006b Kain ZN et al. USA	A: S, SSE, ERW	Prospective cohort study	A: SPEAD, SF	A: VT PA	A+A+A = Inc
2006 Li HY et al. Taiwan	A: S, SSE, ERW	Prospective interventional	A: SPEAD, SF	A: VT BC, attention and sleep	A+A+A = Inc
2006 Millar K et al. UK	A: S, SSE, ERW	Two-group comparison study	A: SPEAD, SF	A: VT anxiety and psychological morbidity.	A+A+A = Inc
2006 Patel A et al. USA	A: S, ERW U: SSE	Prospective RCT	A: SPEAD, SF, GA, IRM, AB - not possible U: GA	A: VT PA and BC	U+U+A = Inc*
2006 Stargatt R et al. Australia	A: S, SSE, ERW	Prospective cohort	A: SPEAD, SF	A: VT BC	A+A+A = Inc
2006 Wilson ME et al. Iceland	A: S U: SSE, ERW	Prospective descriptive	A: SPEAD, SF	A: VT pain	U+A+A = Inc*
2007a Kain ZN et al. USA	A: S, SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB	A: VT PA	A+A+A = Inc
2007b Kain ZN et al. USA	A: S, ERW U: SSE	Cross-sectional controlled study	A: SPEAD, SF	A: VT PA	U+A+A = Inc*
2007 Karling M et al. Sweden 2007 Karling M et al. Sweden	A: S, ERW U: SSE	Prospective cohort	A: SPEAD, SF	A: VT BC	U+A+A = Inc*
2007 Li HCW et al. China	A: S, SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB	A: VT PA	A+A+A = Inc

2007 Wei JL et al. USA	A: S, ERW U: SSE	Prospective non-randomised study	A: SPEAD, SF	A: VT BC and sleep	U+A+A = Inc*
2008 MacLaren et al. USA	A: S, ERW U: SSE	Cohort-controlled study	A: SPEAD, SF	A: VT sleep disturbance	
2008 Rice M et al. UK	A: S, ERW U: SSE	Prospective observational study	A: SPEAD, SF	A: VT PA	U+A+A = Inc*
2009 Golan G et al. USA	A: S U: SSE, ERW	RCT	A: SPEAD, SF, IRM, GA, AB	A: VT PA	U+A+A = Inc*

A adequate; U unclear; I inadequate, S sample described, SSE sample size estimation reported, ERW exclusions/refusals/withdrawals explained, RCT randomized controlled trial, SPEAD study procedures explained and appropriate to design, SF setting and follow-up detailed, GA group allocation detailed, IRM intervention replicable and maintained throughout study, AB assessor blinding, Inc included, Inc* included with caution, Exc excluded, VT validated tool, PA pre-operative anxiety, BC behaviour change

* Confirmed through correspondence with authors

Table 2.5 Summary of descriptive studies

Year, author and country	Surgery type (specialty, day case/inpatient)	Sample	Procedures / Measures	Key findings
1990 Schmidt CK et al. USA	Mixed specialties Day case	60 (62% M/38% F) 2 to 10 yrs (no mean age given)	PHBQ completed 7-10 days after surgery	Behaviour change: • 48% children showed change in behaviour. • 55% (of 48%) showed mild PB and 45% had improved behaviour. • 58 children (96.7%) received some form of preparation for surgery (verbal n=40, read book n=5, played n=2, toured hospital n=3, combination n=8). • Only children who played with hospital equipment (n=2) had significantly less behaviour changes post-hospital (p<.05).
1991 Carson DK et al. USA	ENT (tonsillectomies) Inpatient	47 (63.8% M/36.2% F) 4 to 12 yrs (mean age: 6.5)	PHBQ (28-item) collected pre-surgery, 7-10 days and 1 year after surgery. Higher score indicate poorer adjustment.	Behaviour change: • Mean behaviour change at 7-10 days was 51.39 ± 10.53 and at 1 year 47.86 ± 8.19. Significant improvement in behaviour at 1 year (p<.05). • Correlations: post-hospital PB were negatively correlated to child's in-hospital behaviour rating (pain behaviour, cooperation and distress during hospital procedures – PPRS) (p<.001); child temperament characteristics were positively correlated with PB: rhythmicity, approach, adaptability and mood (p<.001) as measured by BSQ (3-7 yr olds) and MCTQ (8-12 yr olds); subscales of MCRE (overprotective p<.01, overindulgent p=.01

				and rejection of children p<.05) and mother's trait anxiety (p<.01) correlated to PB. • Risk factors/predictors for PB at 7-10 days (including pre-hospital adjustment and child age in forward stepwise regression): pre-hospital PHBQ scores (p<.001), child temperament (mood) (p<.01), maternal overindulgence and trait anxiety (negatively predictive) (p<.01). • Risk factors/predictors for PB at 7-10 days (including child age in forward stepwise regression): child temperament (adaptability p<.001, mood p<.05, rhythmicity p<.05) and maternal overindulgence (negatively predictive) (p<.05).
1993 Lumley MA et al. USA	ENT Day case and inpatient	37 (64.7% M/35.3% F) 4 to 10 yrs (mean age: 6.9)	PHBQ (27-item) completed 2 weeks post-surgery. CBCL completed prior to surgery	Behaviour change: • 22% children had no change in behaviour. • 78% children had changes: 41% PB, 21% improved behaviours and 38% had both. • Most children had 1 or 2 (of 27) changes in behaviour items and these were moderate (±1). • 4 children (3 boys, 1 girl) developed intense PB: 4 had increased separation anxiety, 3 were more aggressive and 2 had sleep problems and apathy/withdrawal. • Younger children were more likely to experience PB (p=0.02) • Children with increased scores on the CBCL (pre-surgery) had more PB post-surgery (p=0.063). • In a regression analysis, there was a significant interaction between pre-operative distress and staying over night (p=0.002)

				and pre-operative heart rate and staying over night (p=0.05). • No children received any premedication or preparation for surgery.
1994 Gedaly-Duff V et al. USA	ENT Day case	7 4 to 8 yrs (no details regarding child gender provided) (mean age: 6)	Interview regarding child's experience of pain at home and pain NRS (0-10) conducted 2 to 4 weeks after surgery.	Symptoms: • Children experienced pain up to 2 weeks following surgery. • Pain was worst 12 to 36 hours after discharge but decreased by 3 to 5 days. • Children's normal activities had resumed by 5 to 7 days. • Pain decreased after analgesia and increased with drinking and eating. • Children's pain was estimated to be between 8-9 during the first 36 hours at home and about 3 by the 4^{th} or 5^{th} day. Parents reported that pain scores were worse than they had expected. • Cues that parents used to identify their child's pain: not eating or drinking, facial grimacing and hand gestures, crying and tiredness.
1994 Payne KA et al. South Africa	ENT Day case and inpatient	62 1 to 10 yrs (% gender not given) Group 1, n=30 (mean age: 4.9) Group 2, n=32 (mean age: 5.5)	Behaviour questionnaire (adapted from PHBQ) completed at 2 weeks after discharge. Scores: 1-4 (unchanged, less, little more, much more). Group 1: private hospital,	Behaviour change: • 56.6% children in group 1 had PB at 2 weeks and 62.5% in group 2. No significant difference between groups. • Apathy was reported in 20% children in group 1 and no children in group 2 (p<.001). • Climbing into parents' beds occurred in 23% children in group 1 and no children in group 2 (p<.001). • Children in both groups regressed in toilet-training and nocturnal enuresis and both groups had an increase in waking

			day case. Group 2: government hospital, inpatients.	and crying at night. • Group 1 parents remained with children up to the theatre door and they were rejoined on returning to the ward. Group 2 parents left their child shortly after admission, the day before theatre, and next saw their child during visiting hours the following evening, after surgery. Children were discharged the day after surgery.
1995 Reid GJ et al. Canada	Mixed specialties Day case	176 (58% M/42% F) 2 to 12 yrs (mean age: 5.8)	Pain VAS (100mm) and pain cues completed at home on the day of surgery (day 1) and 2 days (day 2 and 3) after surgery.	Symptoms: • Mean number of pain cues reported on day 1: 2.4, day 2: 2.3 and day 3: 1.5. • Significantly less pain cues were reported on day 3 than on day 1 or day 2 ($p<.001$). • Verbal report was the most common pain cue reported, followed by loss of appetite. Other pain cues reported: level of activity, sleep quality, visible/audible discomfort and physiological observations. • Appetite pain cues were reported significantly more in older children (mean age: 6.4) than younger children (5.5) ($p<.05$). • Significantly lower pain intensity was reported by parents who reported positive illness behaviour cues on day 1 ($p<.001$) and day 2 ($p<.01$). • Significantly higher pain intensity was reported by parents using negative illness behaviour cues on day 1, 2 and 3 ($p<.01$). • Significantly higher pain intensity was also reported by parents using negative normal behaviour cues on day 1 ($p<.01$), day 2

				(p<.001) and day 3 (p<.01). • Normal behaviour cues (appetite, sleep, activity, alertness, emotional state). • Illness behaviour cues (verbal report, discomfort, physiological observations, protective/regressive behaviour, request/refusal of medication).
1996c Kain ZN et al. USA	Mixed specialties Day case	163 (68% M/32% F) 2 to 10 yrs (mean age: 4.91)	CARS (0-5 likert scale) measured at separation from parents. Anxiety VAS (100mm line) observed pre-surgery and at separation from parents. VPT (12 pictures) measured pre-surgery. PHBQ (27-item) collected pre-surgery and 2 weeks, 6 months and 1 year after surgery.	Pre-operative anxiety: • Mean anxiety VAS pre-surgery 37±2.3 • Risk factors for PA: older children, anxious parents, low temperament activity, child history of poor medical encounters (p=.007). • Mean anxiety VAS increased significantly at separation from parents to 57±2.6 (p=.001). • Risk factors for anxiety at separation from parents: low temperament activity, children not enrolled in day-care, children who did not receive premedication (p=.001). Behaviour change: • 53.8% (N=119) children exhibited PB at 2 weeks (33.5% had 1-3 behaviour change items), most common changes: bad dreams/waking up crying (21.8%) and getting upset when left alone for a few minutes (19.3%). • 20% (N=110) had PB at 6 months and 7% (N=95) at 1 year. • Throughout 1-year follow-up period, most common PB were: separation anxiety, eating problems, increased fear of physicians and hospitals, bad dreams and nightmares, aggression to

				authority and temper tantrums. • Reported improvements in 27 behaviour items at 2 weeks ranged from 0-9.2% (better appetite). 73.1% improvements were in children who had myringotomy and grommets. • Risk factors at 2 weeks: children with no siblings (OR: 2.7, CI 1.4-5.4) and children who were more anxious at separation from parents (OR 1.4, CI 1.1-3.4). • Risk factors at 6 months: younger children (OR 4, CI 1.1-5.2) and children whose mothers were more anxious in holding area (OR 3.2, CI 1.2-4.2). • Risk factors for subscales at 2 weeks: SA: child < 4yrs (OR 9.4, CI 1.2-39), not enrolled in day-care (OR 6.6, CI 1.2-29), anxious mother (OR 3.4, CI 1.2-6.7), no siblings (OR 3.5, CI 1.3-9.6); GA: child < 4 yrs (OR 3.3, CI 1.1-7.8), very impulsive child (OR 2.7, CI 1.1-6.8); AW: anxious mother (OR 6.6, CI 1.6-19.1); SL: anxious mother (OR 3.9, CI 1.1-14); EA: anxious child (OR 4.2, CI 1.3-8.7)/ • Risk factors for subscales at 6 months: no siblings for SA (OR 2, CI 1.1-3.5), GA (OR 3, CI 1.4-6.9), AA (OR 2, CI 1.1-4.1); anxious child for EA (p=.04); anxious mother for SL (OR 4.8, CI 1.2-20.4).
1996b Kotiniemi LH et al. Finland	ENT Day case and inpatient	85 2 to 10 yrs Group 1, n=55 (47.5% M/52.5% F)	PHBQ (23 item) completed on day 1 and at 1 week and 1 month after surgery.	Behaviour change: • Children in group 2 were older than those in group 1 and the types of operations were different due to admission criteria. • 61% children had PB, 23% had no behaviour changes, 33% had

		(mean age: 3.4) Group 2, n=52 (62.5% M/37.5% F) (mean age: 6.2)	Group 1: day case adenoidectomies on children ≤7 yrs. Group 2: inpatient tonsillectomies and all other children who lived more than an hour's drive / 100km away from the hospital.	improvements in behaviour and 17% had both. • Younger children (<3.5yrs) had more PB than older children (p<.01). • PB decreased significantly from 59% to 32% in the first month (p<.001). • Improved behaviour did not differ between age groups or observation times. • Due to differences in mean age between groups, data were analysed excluding the extremes of age (<3 and >7): PB occurred in 68% children in group 1 and 46% children in group 2 (95% CI for difference: -6% to 51%). • PB in more than 10% children were reported on 7 of 23 behaviour items. • 8 of the 15 children who had problems with eating were after tonsillectomy.
1996 Rossen BE et al. Canada	ENT Day case and inpatient	23 (47.8% M/52.2% F) 3 to 6 yrs (mean age:4.4)	Interview at home 1 week after discharge. Questions derived from clinical experience, observation and literature review. (1 question addressed behaviour change)	Behaviour change: • 4 children (all day case) had improved behaviour: less irritable, more energetic and more helpful. • 19 children had distressed behaviour: sleeping and eating disturbances, irritability, separation anxiety, regression in behaviour, withdrawal from family members. • 11 children attended a pre-admission programme – no differences in behaviour noted.
1997 Amanor-	Mixed specialties Day case	62 (90.3% M/9.7% F)	Interview at outpatient clinic 5 days after	Behaviour change: • 13.5% children had restlessness/fretfulness and 6.7% suffered

Boadu SD et al. Nigeria		0 to 13 yrs (no mean age given)	surgery. Questions asked about postoperative course in general and specifically about any complications.	from sleeplessness. • Pain was associated with fretfulness in 5 patients (8.1%) Symptoms: • 14 (18.9%) children complained of pain: 13 of these children did not receive intra-operative analgesia. • Of the 19 children that received intra-operative analgesia, only one complained of pain. • 30% children who were intubated during anaesthesia complained of sore throat compared to 16% children who had anaesthetic mask only. • 20% children experienced nausea / vomiting.
1997 Kotiniemi LH et al. Finland	ENT Day case	551 (59.9% M/40.1% F) 0 to 13 yrs (mean age: 3.8)	PHBQ (17-item) collected on day 0, 1, 2, 3 and week 4 after surgery.	Behaviour change: • 44% children had no behaviour changes at any of the follow-up time points. • 47% children had PB at least once during the observation time, median number of changes = 3 (range 1-13) on day 0 and 3 (range 0-13) at week 4. • 17% had improved behaviour, median number of changes = 0 (range 0-7) on day 0 and 1 (range 0-16) at week 4. • Significantly more PB than positive on day 0 ($p<.001$). • 6% had both PB and improved behaviours. • PB were most common on day 0 and decreased over the 4 weeks: 46% to 9% ($p<.0001$). • Younger children ($p=.0001$), pain at home day 0 (mild and severe) ($p<.0001$) and a difficult experience in primary health

				care (p=.017) effected PB on day 0. • Younger children (p=.039), severe pain at home day 0 (p=.0005) and hospital influenced play (p=.002) effected PB at week 4.
1997 LaMontagne LL et al. USA	Orthopaedics Inpatients	97 (29% M/71% F) 8 to 17 yrs (mean age: 13.8)	Competence scales of the Youth Self-Report and Profile (YSR) to assess usual activities the day before surgery and 3, 6 and 9 months after discharge. Coping was measured by Preoperative Mode of Coping Interview	Behaviour change: • Children who focused on the concrete-objective aspects of surgery had the most positive activity outcomes (p<0.01), followed by children with an emotion-focus (p<0.02). • Vigilant copers who had a concrete-objective focus of attention had the most favourable activity outcomes at all time points. • All children received pre-operative teaching provided by the hospital staff
1998 Goldstein NA et al. USA	ENT Unclear if day case and/or inpatient	36 (67% M/33% F) 2 to 18 yrs (mean age: 4.6)	CBCL pre-operatively and at 3 months after surgery	Behaviour change: • The mean CBCL total problem score was 7.5 points lower after surgery indicating a significant improvement (p<.001). • Scores were also lower for internalizing subgroup (p<.001) and individual syndrome scales of withdrawn (p<.001), somatic complaints (p=.009), anxious/depressed (p=.003), attention problems (p=.002) and thought problems (p=.007).
1998 Issa A et al. UK	ENT (grommets) Day case	32 (59.4% M/40.6% F) 4 to 11 yrs (mean age: 7)	PSC (34-item) completed on the day of surgery and 6 weeks later.	Behaviour change: • 90.7% children had significantly improved behaviour (p<.001) • 9.3% had PB (mean score at 6 weeks = 11.56 ± 7.16) (possible range of 0-64, higher scores indicating poorer adjustment). • Significant improvement in 3 of the most common pre-operative

				behaviour problems: trouble concentrating (improved by 57%), being fidgety (50%) and easily distracted (27%). • Other improvements of ≥ 50%: school grades, interest in school, feeling 'down' and 'hopeless'.
1999b Kain ZN et al.USA	Mixed specialties Day case	91 (63.5% M/36.5% F) 1 to 7 yrs Received preparation (mean age: 5.3) No preparation (mean age: 4.7)	PHBQ (27-item) collected pre-surgery and on day 1, 2, 3, 7 and 14 after surgery.	Behaviour change: • 67% children had PB on day 1, 45% of these children still had PB on day 2 and 23% of these on day 14. • Specific PB: bad dreams/ waking up crying, disobeying parents, separation anxiety, temper tantrums and an increased fear of doctors and hospitals. • Children who were more anxious had more PB; for every postoperative day following surgery children exhibited fewer PB (OR 0.56/day, 95% CI 0.46-0.68, p=.0001); and children who had grommets inserted were less likely to have PB (OR 0.17, 95% CI 0.10-0.60, p=.006).
1999 Kokinsky E et al. Sweden	Urology and minor general surgery. Day case	202 (80.7% M/19.3% F) 4 months to 16 yrs (median age: 5)	Child self-assessment of pain: Faces rating scale for pain (1-6) Parent behavioural /observation NRS for pain (1-6) Completed every 3 hours for 24 hours after discharge.	Symptoms: • 54% children had no or mild pain (score 1-2), 39% had moderate pain (score 3-4) and 6% had severe pain (score 5-6) at home on the day of surgery and the following day. • On day 3, pain was noted by 17 patients (2 had severe pain). • For all surgery types, mean pain scores increased at home on the day of surgery ($p<.05$) and decreased the following day. • Parents were instructed to give analgesics at home if pain was rated ≥2: 56% children received some analgesia at home, 82% of the children with moderate to severe pain received analgesia.

				• Pain in 46% children was assessed by the faces scale and 54% by NRS. • Pain reports were higher for self-assessment than for behavioural/observation in hospital and at home (p<.01). • 20% experienced nausea / vomiting at home, including transport home. • Incidence of nausea / vomiting was significantly higher for children given fentanyl (p<.05).
2000 Kain ZN et al. USA	Mixed specialties Day case	56 3 to 10 yrs (47% M/53% F) (mean age: 6)	mYPAS (27-item) measured pre-operatively on admission, on separation from parents and during induction.	Pre-operative anxiety: • Child anxiety increased significantly over the 3 measurement time-points [23 (23-46); 46 (23-76); 56 (23-100)] (p<.05). • Child anxiety was significantly related to child age (r=-.27), temperament activity (r=-.21), temperament sociability (r=-.25), social skills (r=-.38) cognitive ability (r=.29) and parent anxiety (r=.33) and monitoring style (r=-.25) (p<.05). • Predictors of child PA: parent anxiety, child's social adaptive capabilities and child temperament (p=.003) while controlling for child age, cognitive abilities and parent coping style. • All children underwent a behavioural pre-operative preparation programme consisting of information, orientation tour and modelling using dolls by child-life specialists.
2000 Wang SM et al. USA	Mixed specialties Day case	51 5 to 16 yrs (80% M/20% F) (mean age: 8.4)	PONV VAS (0-100mm) measured at home 24 hr after surgery.	Symptoms: • 41% children developed nausea and 33% developed vomiting in the first 24 hours after surgery. • Children who developed PONV were less anxious pre-

				operatively than those that did not develop PONV (p=.02) and also had lower trait anxiety scores (p=.04). • Children who developed PONV were older than those who did not (9.5±3.2 vs. 7.8±2.6, p=.04). • Pain scores did not differ significantly between those with PONV and those without.
2001 Morgan J et al. UK	Mixed specialties Day case	42 1 to 6 yrs (no details regarding child gender provided) (median age: 4.1)	Adapted TPPPS (0-6) completed on the evening of discharge, 3 times on day 1 after surgery, before and 30 min after analgesia and if the child woke up at night.	Symptoms: • Pain scores recorded before analgesia were significantly higher than scores recorded after analgesia (2.93±1.57 vs. 0.99±1.32, p<.0001). • 21% children consistently scored 0 while at home. • 69% children scored ≥3 at least once after discharge. • 7% children scored a maximum 6 once at home.
2002 Goldstein NA et al. USA	ENT Unclear if day case and/or inpatient	64 (56.3% M/43.7% F) 2 to 18 yrs (mean age: 5.8)	OSA-18 and CBCL pre-operatively and at 3 months after surgery	Behaviour change: • Significant change was found in quality of life (OSA-18) (small impact in 63 children and moderate impact in 1 child) (p<.001). • CBCL scores improved after surgery (p<.001): internalizing and externalizing subgroups and in all but 2 (total competence and social problems) of the individual syndrome scales. • Changes in the classification of CBCL were significant for the total problem score (p<.001), anxious/depressed (p=.02), thought problems (p=.007) and sleep problems (p=.01). • Changes in OSA-18 scores were correlated with changes in total CBCL total problem scores (r=.54, p<.001), internalizing subgroup (r=.5, p<.001) and externalizing subgroup (r=.49,

				p<.001). • Predictors for changes in CBCL scores: parents who w ere school and colleague graduates (p=.01) and mean OSA-18 scores (p<.001).
2002 Kain ZN et al. USA	ENT, minor general surgery. Day case	92 † (52.2% M/47.8% F) 3 to 9 yrs (mean age: 6.7) 77 healthy controls recruited from local and neighbouring towns and did not have surgery.	Actigraphy collected every night for 5 nights before and 7 nights after surgery. Scores: % actual sleep time during total sleep period) PHBQ (sleep subscale only) completed pre-surgery and days 1-5 after surgery.	Behaviour change: • 47% children experienced postoperative sleep disturbances (14.4% diagnosed by actigraphy): POD 1 = 26%, POD 2 = 21%, POD 3 = 17%, POD 4 = 14%, POD 5 = 13%. • On POD 1: 60% children had 1 PHBQ sleep item change, 30% had 2 changes, and 10% had 3 changes. • 21% children with PHBQ-diagnosed sleep problems also had problems diagnosed by actigraphy. • On POD 1 children who had PHBQ-diagnosed sleep problems slept for a shorter duration (502 ± 61 min vs. 568 ± 61 min, p=.0001). • Children who had actigraph-diagnosed sleep problems had more postoperative pain (p=.047) and pain scores in this group decreased more slowly over the 5 postoperative days (p=.002). • These children also had lower baseline sociability (EASI) scores (p=.04) and their anxiety in the holding area and during induction increased faster and became higher (p=.03).
2002 Tuomilehto H et al. Finland	ENT Day case	300 (59.7% M/40.3% F) 1 to 10 yrs (mean age: 3.8)	PHBQ (24-item) completed day before surgery, at week 1 and 3 post discharge.	Behaviour change: • At week 1: 1-18% children had equal change in PB and improved behaviours. Most change was in the physical domain e.g. headaches, stomach ache.

			Questionnaire regarding pain intensity (4-point verbal rating scale) and duration completed at week 1 post discharge.	• At week 3: more positive behaviours than PB compared to baseline (pre-surgery). Only 1-4% showed large worsening in any domain. • Factors affecting PB: child age ($p<.05$) for all domains, worst pain at rest ($p=.04$) and when swallowing ($p=.02$) observed in PACU for daytime functional disturbances. Fear of separation from parents ($p=.03$) for sleep disturbances. Symptoms: • 91% children had pain at week 1 post discharge. • 37% reported severe pain (4, 1-4 verbal rating scale). • Mean time for pain cessation was 3 days (range 0-8) • All children were discharged on a proactive pain treatment programme.
2003 Li HCW et al. China	Urology Day case	112 7 to 12 yrs (no details regarding child gender or mean age provided)	CSAS-C measured pre-operatively on admission	Pre-operative anxiety: • Children's mean PA score was 38.77±7.52. • There was a high negative correlation between children's PA and cooperation during induction of anaesthesia ($r=-.710$, $p=.01$). • Child and parent PA were moderately correlated ($p=.01$).
2005 Caldwell-Andrews AA et al. USA	Mixed specialties Day case	289 2 to 12 (63% M/27% F) (mean age: 5)	mYPAS (27-item) measured pre-operatively in anaesthetic room, on entrance to theatre and during induction of anaesthesia	Pre-operative anxiety: • Child anxiety increased significantly over the three measurement time-points ($p=.0001$). • Children whose mothers had higher desire and to entre theatre were significantly more anxious ($p=.006$). • Children whose mothers had higher hesitancy to entre theatre

				were significantly less anxious (p=.034). • Children whose mothers had high beliefs about preparation and coping skills were less anxious in the anaesthetic room (p=.016) and during induction (p=.001).
2005 Mitchell RB et al. USA	ENT Unclear if day case and/or inpatient	52 (56% M/44% F) 2.5 to 15 yrs (mean age: 7.1)	BASC completed pre-operatively and at 4 to 6 months after surgery.	Behaviour change: • Pre-operative mean BASC T-scores for behavioural scales and composite scores were greater than 50. • Behavioural scales: aggression, atypicality, depression, hyperactivity and somatisation improved after surgery (p≤.001).
2006 Ben-Anitay G et al. Israel	Mixed specialties Day case and inpatient	40 (52.5% M/47.5% F) 6 to 18 yrs (mean age: 13.1)	CPTS-RI Scores: 0-11 doubtful, 12-24 mild, 25-39 moderate, 40-59 severe, 60-80 very severe post-traumatic stress. CDI Scores: ≥ 11 significantly depressed. RCMAS Scores: ≥ 18 significant anxiety symptoms All measures collected on the day of surgery, 1 and 6 months after surgery.	Behaviour change: • Mean PTSS were doubtful at 1 (7.4 ± 2.8) and 6 (5.3 ± 3.1) months after surgery with a significant decrease in symptoms between the two time-points (p<.001). PTSS subscales (recall, avoidance, arousal) also decreased significantly between time-points (p=.02, p=.04, p<.001). • Depressive symptoms decreased from 1 (4.2 ± 2.8) to 6 (3.8 ± 3.1) months after surgery (p=.056) and scores were higher for boys than for girls (p<.05). • Anxiety scores were low at 1 (10.6 ± 4.9) and 6 (10.3 ± 5) months. • Type of surgery was not significantly correlated to any postoperative scores (p>.05). • Child anxiety and depression were correlated with mother's anxiety and depression at 1 month (p<.05). • Child anxiety and depression were correlated with father's

				anxiety at 1 month (p<.05). • Child PTSS, anxiety and depression were correlated with mother's anxiety and depression at 6 months (p≤.01) • Child anxiety and father's anxiety were correlated at 6 months (p=.04)
2006 Caldwell-Andrews AA et al. USA	Mixed specialties Day case	52 (61% M/39% F) 4 to 10 yrs (mean age: 6.9)	Actigraphy collected every night for 5 nights before and 5 nights after surgery. Scores: % actual sleep time during total sleep period	Behaviour change: • 22% children experienced actigraph-diagnosed sleep problems. • Predictors (accounting for 82% variance): child's pre-operative sleep patterns (60%, p=.000); postoperative pain (8.2%, p=.034); parent anxiety/worry (9%, p=.016); child aggressive behaviour (5%, p=.045). • Children with higher aggressive behaviour scores (p=.021) and whose parents had higher levels of anxiety/worry (p=.09) were more likely to experience poor sleep.
2006 Davidson AJ et al. Australia	Mixed specialties Day case and inpatient	1224 3 to 12 yrs HA group (59% M/41% F) (mean age: 7.2) LA group (55% M/45% F) (mean age: 7.9)	mYPAS (22-item) measured immediately prior to induction of anaesthesia	Pre-operative anxiety: • 50.2% children had a mYPAS score < 30 prior to induction. • Predictors of PA: younger child age (p<.001), history of >5 hospital admissions (p<.001), parent anxiety at induction (p<.001). • Admission via day stay ward (p<.001) and sedative premedication if ASA status >1 (p=.023) were associated with lower anxiety.
2006 Galland BC et al. New	Tonsillectomy and adenoidectomy. Unclear if day case	61 (57.4% M/42.6% F) 4 to 11 yrs	BASC, CPT and sleep and breathing questionnaire completed	Behaviour change: • Significant improvements in sleeping after surgery: difficulty in breathing (p<.0005), snoring (p<.0001), sleeping with mouth

Zealand	and/or inpatient	(mean age: 7)	1 week pre-operatively and at 3 months after surgery	open (p<.0001), snorting (p=.01), difficult to wake (p=.001), daytime sleepiness (p=.004), restless sleep (p<.0001) and drenching sweats (p=.035). • All BASC variables significantly improved after surgery (except conduct problems): externalizing behaviours (p=.003), hyperactivity (p=.001), aggression (p=.003), internalizing behaviours (p<.0001), anxiety (p=.01), depression (p<.001), somatisation (<.0001), atypicality (p=.008), withdrawal (p<.001), attention problems (p=.006) and behavioural symptom index composite (p=.001). • Scores for commission (indicator of impulsivity and inattention) and detectability (indicator of inattention) obtained from visual CPT improved after surgery (p=.04 and p=.006 respectively). • AHI pre-operatively was significantly positively associated with BASC hyperactivity (p=.03)
2006a Kain ZN et al. USA	ENT Day case	241 5 to 12 yrs HA group (49% M/51% F) (mean age: 5.9) LA group (54% M/46% F) (mean age: 6.3)	mYPAS (27-item) measured pre-operatively. PHBQ (27-item) completed on postoperative days 1, 2, 3, 7 and 14. PPMP (15-item) completed on postoperative days 1, 2,	Pre-operative anxiety: • 197 children had high anxiety (60±14) and 44 had low anxiety (30±8). • Parent anxiety was significantly lower in the LA group pre-operatively and during induction of anaesthesia (p<.001). Behaviour change: • Children in the HA had significantly more generalised anxiety over first 2 postoperative days (p=.043), separation anxiety over first 3 postoperative days (p=.025) and difficulty falling asleep and staying asleep on postoperative day 3 (p=.04).

			3, 7 and 14 Bieri Faces Scale (7-item)	• LA children had more improvements in eating on postoperative days 1 and 2 (p=.02). Symptoms: • Parents reported higher pain scores and a slower decline in HA children compared with LA children (p<.05). • HA children self-reported consistently higher levels of pain in the first 72 hours at home than LA children (p<.05).
2006b Kain ZN et al. USA	Mixed specialties Day case	426 2 to 12 (64% M/36% F) (mean age: 4.9)	mYPAS (27-item) measured pre-operatively on admission, on entrance to theatre and during induction of anaesthesia.	Pre-operative anxiety: • Child age and anxiety during induction were strongly correlated (r=-.537, p=.01) • Younger children were significantly more anxious during induction than older children (6.9±2.8 vs. 2.6±2, p=.0001). • Predictors of anxiety during induction: child age (p=.0001), behaviour during previous medical visits (p=.001), child PA (p=.007), parent state anxiety (p=.001), parent's locus of control (p=.036).
2006 Li HY et al. Taiwan	ENT Unclear if day case and/or inpatient	40 (90% M/10% F) 5 to 12 yrs (mean age: 8.4)	Polysomnography, TOVA and CBCL completed pre-operatively and at 6 months after surgery	Behaviour change: • AHI, TOVA and 8 of the 9 domains of CBCL (all except aggressive behaviour) improved after surgery (p<.001, p<.001 and p<.05 respectively). • AHI and TOVA were not correlated which means that the change was not simply attributable to sleep apnoea events. • CBCL domain improvements: depression/anxiety 11.5%, thought/obsession 10.9%, somatic complaints 9.6%, social withdrawal 9.8%, hyperactivity 6.3%, delinquent behaviour

				5.8%, internalizing behaviour 13.2% and externalizing behaviour 6.3%. • 18 of the 26 children who had ADHD scores below the normal range increased into the normal range after surgery (p<.001). • TOVA response time improved after surgery (p<.001).
2006 Millar K et al. UK	Dental Day case	48 † (47.9% M/52.1% F) 5 to 10 yrs (mean: 6.47) 48 controls who had dental examinations and not surgery	MCDAS (behavioural and affective assessment). Completed pre-operatively and at 48 hours after surgery. Revised Rutter Scale for School-age children completed at 1 week after surgery.	Behaviour change: • At 48 hours: bed wetting (2%), waking up at night (4%), reluctant to go to bed (2%), tantrums (2%), crying (16%) and seeking attention (15%) were reported by parents. • At 1 week: bed wetting (4%), waking in the night (13%), nightmares/terrors (10%), tantrums (8%), crying (15%) and seeking attention (21%) remained problems. • There was a NS increase in problems from 48 hours to 1 week. • Children rated their dental anxiety significantly higher (p<.01) at 48 hours (13.3 ± 6.63) than prior to surgery (11.7 ± 5.76).
2006 Stargatt R et al. Australia	Mixed specialties Day case and inpatient	1027 3 to 10 yrs Significant NBC (57% M/43% F) (mean age: 7.6) No significant NBC (57% M/43% F) (mean age: 7.2)	PHBQ (27-item) completed pre-surgery and days 3 and 30 post-surgery.	Behaviour change: • 24% children had significant PB (negative change in ≥ 7 behaviour items on PHBQ) on day 3 post-surgery, 16% children had significant PB on day 30. • Mean number of PB items on day 3 was 4.4, median 3, IQR 1-6. Mean PB items on day 30 was 3.4, median 3, IQR 1-5. • 33% children who had PB on day 3 continued to have PB on day 30. • 9% with no PB on day 3 had developed PB by day 30. • Common PB were general anxiety, separation anxiety, apathy

				and withdrawal. • Risk factors/predictors for PB at day 3: increased parent state anxiety, younger age, lower birth order, children with ≥ 2 older siblings, staying over night in hospital, a discussion with an anaesthetist and younger age (p<.05). • Risk factors/predictors for PB at day 30: longer hospital stay, younger age, a difficult previous anaesthetic and reading "I am going to have an anaesthetic" (p<.05). • When compared to sibling controls, patients were more likely to experience PB at day 3 (p=.05) but not at day 30 (p=.7).
2006 Wilson ME et al. Iceland	ENT (Tonsillectomies) Inpatient	68 3 to 7 yrs (50% M/50% F) (mean age: 5)	Wong Baker FACES pain scale measured at home, 3 times a day for the first 2 postoperative days.	Symptoms: • At least 75% children had pain when swallowing of ≥3 (0-5) on postoperative day 1 and 2 at home. • More than 46% children reported pain of 4 or 5 when swallowing on postoperative day 1 and 2 at home. • 38%-47% reported significant pain when not swallowing of ≥3. • Pain was significantly higher when swallowing than when not swallowing (p=.005).
2007 Karling M et al. Sweden 2007 Karling M et al. Sweden	Mixed specialties Day case and inpatient	340 (59% M/41% F) 2 to 13 yrs (mean age:7)	PHBQ (25-item) collected 2 weeks after discharge.	Behaviour change: • For PHBQ total score: 71% children had no or improved behaviour changes and 28.5% children had PB (score >75 on 25-item questionnaire). • 10% children had changes in the general anxiety subscale, 13.5-15% had changes in the subscales of: separation anxiety, eating and sleeping disturbances, apathy/withdrawal and aggression

				towards authority. • 34.4% children had PB in at least one behaviour change item (mean: 1.17) and 27.3% had new improved behaviours. • Greatest risk factor for PB was moderate to severe pain at home (OR 6.36, CI 3.53-11.6), children > 5yr (OR 2.4, CI 1.4-4.0), living in one adult family (OR 4.4, CI 1.6-12.6) and not living in a rural area (OR 1.6, CI 1.0-2.6). Other risk factors: previous PB, nausea, child anxiety at induction of anaesthesia, post-op nausea and distress, previous hospitalisations.
2007 Wei JL et al. USA	ENT Day case	117 (47.9% M/52.1% F) 2 to 17 yrs (mean age: 6.5)	CPRS-RS and PSQ completed pre-operatively and at 6 months after surgery. Children divided into groups depending on pre-operative CPRS-RS scores: Group 1 ≤ 50 Group 2 50.1-60.9 Group 3 61-70 Group 4 > 70	Behaviour change: • There were significant reductions in mean T-scores, i.e. improvements in all behaviour categories of CPRS-RS after surgery (p<.001). • T-scores decreased by close to 10 points after surgery, which is considered clinically significant. • PSQ scores significantly improved after surgery (p<.001). • Correlations between PSQ and CPRS-RS scores were significant pre-operatively for ADHD index and cognitive problems (p=.004) and oppositional behaviour (p=.008) and postoperatively for cognitive problems (p=.049) and oppositional behaviour (p=.03). • Higher CPRS-RS T-scores pre-operatively were associated with larger changes in T-scores in all 4 domains: oppositional behaviour, cognitive problems or inattention, hyperactivity and ADHD index.

2008 MacLaren et al. USA	ENT Inpatient	55 6 to 12 yrs (32.7% M/67.3% F) (mean age: 8.1)	Actigraphy collected every night for 5 nights before and 5 nights after surgery (1 in hospital, 4 at home).	Behaviour change: • Total sleep time was greater after surgery than before. • Significantly more long awake times (>5 min) after surgery than before resulted in a lower average sleep efficacy (p<.001). • There was a significantly lower sleep efficacy on the first postoperative night in hospital compared to the 4 postoperative nights at home (p<.001). • No significant differences for sleep efficacy on nights 2-5 at home. • Mean change in sleep efficacy (average sleep pre-surgery subtracted from average sleep post-surgery) was -3.83%. • 30.9% children had significant sleep decrements at home (sleep efficacy > 1SD less than pre-surgery sleep efficacy). • Predictors of sleep decrements: child anxiety during induction, lower temperament sociability and greater parent-report of postoperative pain at home (p<.01).

PB problematic behaviour/s, PA pre-operative anxiety, PHBQ post-hospital behaviour questionnaire, HA high anxiety group, LA low anxiety group, SA separation anxiety, GA general anxiety, EA eating disturbances, AA aggression toward authority, AW apathy/withdrawal, SL sleep disturbances, PPRS Paediatric Patient Rating Scale, BSQ The Behavioural Style Questionnaire, MCTQ Middle Childhood Temperament Questionnaire, MCRE Mother-Child Relationship Evaluation, PSC Paediatric Symptom Checklist, CPTS-RI The Child's Post-traumatic Stress Reaction Index, CDI Children's Depression Inventory, RCMAS Revised Children's Manifest Anxiety Scale, PTSS post-traumatic stress symptoms, EASI Emotionality, Activity, Sociability, Impulsivity instrument of child temperament, IQR inter-quartile range, BASC Behavioural Assessment System for Children, CPRS-RS Conner's Parent Rating Scale-Revised Short Form, PSQ Paediatric Sleep Questionnaire, TOVA Test of Variables of Attention, CBCL Child Behaviour Checklist, AHI apnoea-hypopnoea index, OSA obstructive sleep apnoea, CPT Continuous Performance Test, MCDAS Modified Child Dental Anxiety Scale, CARS Clinical Anxiety Rating Scale, VAS visual analogue scale, VPT venham picture test, PPMP Postoperative Pain Measure for Parents, mYPAS modified Yale Pre-operative Anxiety Scale, PONV Postoperative Nausea and Vomiting, TPPPS Toddler-Preschooler Postoperative Pain Scale, MUS Manifest Upset Scale † only children who had surgery were included in results of the review (control group did not have surgery)

Table 2.6 Summary of intervention studies

Year, author and country	Surgery type (specialty, day case/inpatient)	Sample and Intervention	Procedures / Measures of behaviour change	Key findings
1990 Bevan JC et al. Canada	Mixed specialties Day case	134 2 to 10 yrs (M:F 1.73:1) Control, n=67 Intervention, n=67	GMS (7-point scale) measured pre-operatively on admission and during induction of anaesthesia. PHBQ (28 item) Scores: 1-5 ("behaviour never present" to "behaviour present most of the time"). HFI (8-item) Scores: 1-5 ("no fear" to "very much") Both measurers completed at pre-operative assessment clinic and at 1 week post-surgery Intervention: parents present at induction of anaesthesia. Control: parents separated from child at theatre door.	Pre-operative anxiety: • Anxiety scores increased significantly from admission to induction ($p<.0001$). • Younger children were more anxious ($p=.001$). • Children of anxious parents (mean anxiety VAS 77.2±16.7) were significantly more anxious in the intervention group than in the control ($p<.05$). Behaviour change: • Mean PB at 1 week after surgery: 3.1 ± 0.2. • Significantly more PB at 1 week than pre-surgery $p<.0001$. • No significant group differences pre-surgery or at 1 week. • Mean HFI at 1 week: 2.2 ± 0.8. • Risk factors for PB at 1 week: parent anxiety post-induction ($p<.05$).

				• Risk factors for HFI at 1 week: HFI at pre-operative assessment clinic (p<.001), child age (p<.05) and parent anxiety in the reception area (p<.05)
1992 Payne KA et al. South Africa	Inguinal hernia repair Inpatient	136 1 to 10 yrs Only males Group 1, n=31 (mean age: 4.7) Group 2, n=31 (mean age: 5) Group 3, n=31 (mean age 4.5) Control, n=31 (mean age: 4.9)	Behaviour questionnaire (adapted from PHBQ) completed at 2 weeks after discharge. Scores: 1-4 (unchanged, less, little more, much more) Group 1: Oral premedication of trimeprazine tartrate 2mg/kg, methadone 0.1mg/kg and droperidol (0.15mg/kg) Group 2: Intramuscular midazolam 0.15 mg/kg Group 3: Oral midazolam 0.45mg/kg Control: no premedication.	Behaviour change: • 22% children had no change in behaviour at 2 weeks, no children had improved behaviour. • 78% children had PB. • 71.5% children had negative night-time behaviour changes, 25% of which were rated as “much more” in intensity. • 52% had disturbed sleep (waking, crying, restlessness or vocalising) and 32.5% had increased dreaming, often hospital-related. • 51.2% children had negative day-time behaviour changes, 87% of which also reported changes in night behaviour. • Children in group 2 and 3 had significantly less night crying (p<.05). Children in group 3 had less night waking (p<.05). Children < 5yrs had a higher incidence of regression in toilet training (p<.05).

1994 Ellerton ML et al. Canada	Mixed specialties Day case	75 (no details regarding child gender provided) Group 1, n=23 3 to 12 yrs (mean age: 5.4) Group 2, n=52 (mean age: 6.8)	Child-report anxiety: Bieri Faces Scale (7-point) completed post-surgery about anxiety pre-operatively on admission and in theatre just prior to induction. Group 1: attended a formal pre-operative preparation programme Group 2: non-attendees	Pre-operative anxiety: • Mean anxiety score pre-operatively on admission: 1.69 and in theatre: 2.44. • There were significantly less highly anxious children in group 1 in theatre ($p<.04$). • 13% children in group 1 reported high anxiety (4-7) in theatre and 25% in group 2. • There was a strong and positive association between child and parent total anxiety ($p<.004$). • 35% children whose parents were experienced with day case surgery versus 16% whose parents were inexperienced reported high anxiety in theatre ($p<.05$).
1994 Lynch M et al. USA	Mixed specialties Day case	30 3 to 10 yrs Group 1, n=15 (53% M/47% F) (mean age: 5.5) Group 2, n=15 (73% M/27% F) (mean age: 5.5)	MUS completed as the child was taken to theatre. Self-assessment faces scale completed on admission. Group 1: attended a formal pre-operative preparation programme. Group 2: did not attend the programme.	Pre-operative anxiety: • Children in group 1 had significantly less anxiety than children in group 2 ($p<.0001$). • Children's self-report of anxiety was significantly less in group 1 than in group 2 ($p<.05$). • 5 parents in group 1 and 3 parents in

				group 2 reported reading their child a story about going to hospital.
1994 McCluskey A et al. UK	Mixed specialties Day case	54 1 to 10 yrs Control, n=27 (79.2% M/20.8% F) (mean age: 5.4) Intervention, n=27 (66.7% M/33.3% F) (mean age: 4.8)	4-point anxiety scale measured on arrival in the anaesthetic room and during induction. PHBQ completed at 2 weeks after surgery. Intervention: children given midazolam as premedication. Control: children given a placebo as premedication.	Pre-operative anxiety: • Anxiolysis was observed in significantly more children in group 1 than in group 2 on arrival in the anaesthetic room (96% vs. 44%, p<.001). • Anxiolysis was also significantly more effective in group 1 than in group 2 during induction of anaesthesia (88% vs. 33%, p<.001). Behaviour change: • Significantly more children in the control group (52% control vs. 17% intervention) had PB at week 2 (p<.05). • Most frequently reported PB in the control group were temper tantrums (n=6) and nightmares/night cries (5). Other changes: nocturnal enuresis (1), fear of dark/difficulty getting child to bed (3), poor appetite (3), disobedience (1), crying or upset if left alone (3), shyness/fear of strangers (4). • PB in intervention group were

				nightmares/night cries (n=1), poor appetite (1), disobedience (2), crying or upset if left alone (1). • Only 3 children in each group were prepared for surgery by formal preparation programme.
1996a Kain ZN et al. USA	Mixed specialities Day case	143 (64% M/36% F) 2 to 10 yrs Group 1 (mean age: 5.1) Group 2 (mean age: 5)	CARS (0-5 likert scale) measured at separation from parents. Anxiety VAS (100mm line) observed pre-surgery and at separation from parents. VPT (12 pictures) measured pre-surgery. PHBQ (27-item) completed 2 weeks after surgery. Scores: 27-80 = improved behaviour 81= no change 82-135 = NBC Group 1: received formal pre-operative preparation. Group 2: did not receive pre-operative preparation.	Pre-operative anxiety: • Child self-report anxiety (VPT) was similar between groups (2.5±0.5 vs. 2.8±0.5, p=NS). • On separation from parents, children's anxiety and cooperation (VAS) was also similar between groups (43±34 vs. 47±29, p=NS). • Younger children (2 to 3 yrs) were more anxious (VAS) pre-operatively in group 1 (46±17 vs. 25±14, p=.001). • Children > 6 yrs were least anxious if they received formal preparation > 5 to 7 days prior to surgery (47±13), intermediate if they did not receive formal preparation (54±14) and most anxious if they received formal preparation one day prior to surgery (63±22) (p=.04).

				• All children with prior hospitalisation / surgical experience were more anxious at separation from their parents if they received formal preparation (p=.03). • Children with high temperament emotionality were more anxious if they received formal preparation pre-operatively (p=.03) and at separation from their parents (p=.01). • Multiple regression analyses confirmed that timing of formal preparation, child age and child temperament activity predicted PA (p=.001). Behaviour change: • Behaviour changes (mean ± SD) at 2 weeks were similar for the group of children that received the preparation programme and those that didn't (81 ± 3 vs. 82 ± 7, p=NS).
1996b Kain et al. USA	Mixed specialties Day case	84 1 to 6 yrs Intervention, n=43 (60% M/40% F) (mean age:3.6) Control, n=41	Anxiety VAS measured pre-operatively on admission, entrance to anaesthetic room and during induction. YPAS measured at induction of anaesthesia. CARS measured at induction of anaesthesia. PHBQ (27-item) completed at 2 weeks and 6	Pre-operative anxiety: • There were no significant differences between groups in any of the anxiety scores pre-operatively. • Predictors of PA (child serum cortisol): younger children (p=.001), parent

		(66% M/34% F) (mean age: 3.2)	months after surgery. Intervention: parents accompanied their child to the anaesthetic room and remained with their children during induction of anaesthesia. Control: parents separated from their children before entering the anaesthetic room.	baseline anxiety (p=.004) and higher child temperament activity (p=.014). Behaviour change: • No significant group differences were found for PB at week 2 (83±4 control, 83±7 intervention, p=NS) and at 6 months (82±4 control, 83±10 intervention, p=NS).
1996 Kotiniemi LH et al. Finland	ENT Day case	86 2 to 7 yrs Group 1, n=29 (48.2% M/51.8% F) (mean age: 3.6) Group 2, n=28 (75% M/25% F) (mean age: 4.2) Group 3, n=29 (69% M/31% F) (mean age: 4.3)	PHBQ (23-item) and structured open-ended questionnaire to elicit child's memories of hospitalisation. Completed on day 1, week 1 and month 1 after surgery. Group 1: intravenous induction of anaesthesia with thiopentone. Group 2: inhalation induction of anaesthesia with 50% N_2O in O_2 followed by halothane. Group 3: rectal induction of anaesthesia with 10% methohexitone 15mg/kg. All groups received rectal premedication 30 min before induction.	Behaviour change: • 51% children had PB on day 1 and this decreased significantly to 34% at one month after surgery (p<.001). • No significant differences between groups. • 60% children who had a calm induction and 69% children who had a stormy induction had at least one PB (p=NS). • 30% children had improvements in behaviour, equally common in all groups at all observation times. • More children in group 2 had negative memories of the hospital in general and of the anaesthesia: group 1 vs. group 2 (-48% to 2%, 95% CI for the difference); group 2 vs. group 3 (9% to

				37%). • More children in group 1 and 2 showed hospital-influenced play at home: group 1 vs. group 3 (6% to 42%); group 2 vs. group 3 (-1% to 30%).
1997 Bevan JC et al. Canada	Mixed minor specialties Day case	24 2 to 7 yrs Control, n=12 (66.7% M/ 33.3% F) (mean age: 4.25) Intervention, n=12 (58.3% M/41.7% F) (mean age: 4.67)	4-point anxiety scale measured pre-operatively. Telephone interview regarding adverse effects of surgery conducted 6 to 7 days after discharge. Intervention: children given midazolam as premedication. Control: children given a placebo as premedication.	Pre-operative anxiety: • 25% children exhibited mild anxiety pre-operatively and 23% during induction of anaesthesia. • No significant difference in anxiety scores over time or between groups. Behaviour change: • Both groups took 1 (0-5) day to return to normal activity, 2 days after minor symptoms had disappeared such as nausea and vomiting, crying and upset, loss of appetite, listlessness and pain.
1997 Patel D et al. UK	Mixed specialties Inpatient	87 2 to 12 yrs Group 1, n=29 (65.5% M/34.5% F) (mean age: 6.6) Group 2, n=29 (72.4% M/27.6% F) (mean age: 6.8)	4-point anxiety scale measured on arrival in the anaesthetic room and during induction. PHBQ completed at 2 weeks after surgery Group 1: Premedication of midazolam 0.5mg/kg Group 2: Premedication of diazepam 0.25mg/kg with droperidol 0.25mg/kg Group 3: Premedication of trimeprazine 2mg/kg	Pre-operative anxiety: • Anxiolysis was observed in 90% children in group 1, 79% in group 2 and 62% in group 3 on arrival in the anaesthetic room. • Anxiolysis was observed in 83% children in group 1, 55% in group 2 and 40% in group 3.

		Group 3, n=27 (65.5% M/34.5% F) (mean age: 5.8)	All premedication given 30-90 minutes pre-surgery	• Anxiolysis was significantly more effective in group 1 than in group 3 on arrival in the anaesthetic room (p<.05) and more effective in group 1 than in group 2 (p<.05) and group 3 (p<.001) during induction of anaesthesia. Behaviour change: • There was a trend for children in group 1 and 2 to have fewer PB than children in group 3. • When results for group 1 and 2 were combined they had significantly less PB than group 3 (p<.05). • No group differences for children who were prepared for surgery by formal preparation programme.
1998 Margolis JO et al. USA	Mixed specialties Day case	102 2 to 6 yrs Control, n=46 (66% M/ 44 % F) (mean age:3.67) Intervention, n=56 (70% M/30% F) (mean age: 4.03)	GMS (7-point scale) measured pre-operatively on admission, on entrance to anaesthetic room and during induction. PHBQ (28-item) completed at pre-operative screening clinic and at week 2 post surgery. Intervention: Interactive pre-operative teaching book given at pre-operative clinic. Book included tactile, olfactory and visual sensations of the	Pre-operative anxiety: • Children's anxiety increased from admission, to entrance of anaesthetic room and again during induction (p<.0001). • The increase in anxiety scores in the control group for 4 to 6 yr old children was slightly higher than the intervention group (p=NS).

			anaesthetic room. Control: Children were given a non-medical colouring book. All children receive routine pre-operative information regarding fasting times and summary of anaesthetic induction.	• The increase in anxiety scores in the intervention group for 2 to 4 yr old children was slightly higher than the control group (p=NS). Behaviour change: • Children in the control group showed a slight increase in aggressive behaviour while children in the intervention group were less aggressive (p=.05). • Increase in aggressive behaviour was more pronounced in younger children (2-4yrs) (p<.008). • Control group children who had previous surgery were more aggressive that intervention group children who had previous surgery (p<.008). • 83% parents in intervention group said the teaching book was helpful and 87% said it helped their child cope better with the peri-operative situation.
1998 McGraw T et al. USA	Mixed specialties Day case	70 1 to 10 yrs (no details regarding child gender provided)	Telephonic structured interview with forced choice questions regarding PB conducted at week 1 and 4 after surgery. Control group: given placebo pre-surgery	Behaviour change: • At week 1 significantly more children in the intervention group than the control group exhibited PB (54% vs. 23%, p<.02).

		Control, n=35 (mean age: 3.1) Intervention, n=35 (mean age: 3.7)	Intervention group: premedication of midazolam 0.5mg/kg given prior to surgery.	• PB at week 1 included: nightmares (n=15), food rejection (n=3), fussiness (n=3), anxiety (n=2), negativity (n=3) and bed-wetting (n=1). • There were no significant differences between children younger and older than 3 yrs. • PB had mostly resolved by week 4.
1998 Zahr LK et al. Lebanon	Mixed specialties Inpatient (admitted day before surgery)	100 3 to 6 yrs Control, n=50 (56% M/44% F) (mean age: 4.7) Intervention, n=50 (64% M/36% F) (mean age:5)	MUS (5-point scale) PHBQ (27-item) completed within 2 weeks after surgery. Intervention: children invited to playroom to play freely after admission. Informal puppet show specific to child's surgery given day before. Puppets represented doctor, nurse, the child and parents. Child allowed to play with puppets, equipment and encouraged to ask questions and re-enact play. Areas of confusion were clarified. Routine care/control: No preparation given.	Pre-operative anxiety: • Mean MUS scores were significantly higher in the control group during injection with premedication for surgery ($p<.001$). Behaviour change: • Children in the intervention group had significantly less PB in all six subscales of the PHBQ: GA $p<.01$, SA $p<.05$, SL $p<.05$, EA $p<.05$, AA $p<.01$, AW $p<.05$
1999a Kain ZN et al. USA	Mixed specialties Day case	86 2 to 7 yrs Group 1, n=43 (72% M/28% F) (mean age: 4.8)	mYPAS (27-item) measured pre-operatively on admission, on separation from parents, entrance to anaesthetic room and induction of anaesthesia. PHBQ (27-item) completed on days 1, 2, 3, 7 and 14 after surgery.	Pre-operative anxiety: • Group 1 had significantly lower anxiety scores than group 2 at separation from parents, entrance to anaesthetic room and during induction ($p<.05$).

		Group 2, n=43 (61% M/39% F) (mean age: 5.1)	Parent-report pain VAS completed on days 1, 2, 3, 7 and 14 after surgery Group 1: premedication of midazolam 0.5mg/kg mixed with 15mg/kg acetaminophen Group 2 (control): Tylenol (acetaminophen) 15mg/kg None of the children were accompanied by their parents during induction of anaesthesia.	Behaviour change: • NBC decreased significantly over the follow-up time-points (p=.0001) and were worse in group 2 (p=.0001). • On days 1, 2, 3 and 7 after surgery, fewer children in group 1 had NBC but at day 14 (week 2), although an overall decrease, there were no group differences. • Subscales with significant group differences were SA and EA (p<.05). Symptoms: • Parent-reported pain scores did not differ between groups on any of the follow-up time-points.
2001 Kain ZN et al. USA	Mixed specialties Day case	70 2 to 7 yrs Control, n=37 (73% M/23% F) (mean age: 5.2) Intervention, n=33 (73% M/23% F) (mean age: 5.1)	mYPAS (27-item) measured pre-operatively in anaesthetic holding room, on separation from parents, on entrance to theatre and during induction. PHBQ (27-item) completed on days 1, 2, 3, 7 and 14 after surgery. Control: no changes to theatre routine. Intervention: lower sensory stimulation in theatre, involving dimmed lighting, background music,	Pre-operative anxiety: • No significant differences in anxiety scores in the anaesthetic holding room or on separation from parents. • Significantly lower anxiety scores in the intervention group on entrance to theatre (p=.03) and during induction (p=.003). • Children in the intervention group were significantly more compliant during

			limited conversation and no preparation of surgical instruments.	induction (p=.02). Behaviour change: • No significant differences between groups in the incidence of PB at any of the follow-up time-points.
2003 Aguilera JM et al. UK	ENT Inpatient	100 2 to 14 yrs Group 1, n=50 (54% M/46% F) (mean age: 7) Group 2, n=50 (62% M/38% F) (mean age: 7.2)	4-point anxiety scale measured on arrival in the anaesthetic room and during induction. PHBQ completed at 2 weeks after surgery Group 1: IV induction of anaesthesia with thiopental after topical anaesthetic cream applied to child's hand. IV cannula sited while child was distracted by a nurse. Group 2: Inhalation induction of anaesthesia with sevoflurane. Children were allowed to choose between a strawberry or bubblegum scented mask. All children were pre-medicated 30-45 min prior to surgery and were accompanied by their parents until they fell asleep.	Pre-operative anxiety: • No group differences in anxiety scores on arrival in the anaesthetic room. • 46% children had unsatisfactory anxiety scores in group 1 compared to 10% in group 2 during induction of anaesthesia (p=.0001). Behaviour change: • 28% children in group 1 and 47% children in group 2 had NBC at 2 weeks (p=NS). • No group differences for children who were prepared for surgery by formal preparation programme or for those children who had had previous inpatient surgery.
2004 Kain ZN et al. USA	Mixed specialties Day case	123 3 to 7 yrs Intervention 1, n=51	mYPAS (27-item) measured pre-operatively on admission, on separation from parents, on entering theatre and during induction.	Pre-operative anxiety: • No group differences in anxiety in the pre-operative holding area. • Anxiety scores significantly increased

		(64.8% M/35.2% F) (mean age: 5.6) Intervention 2, n=34 (64.7% M/35.3% F) (mean age: 5.1) Control, n=38 (64.1% M/35.9% F) (mean age: 5.5)	Intervention 1: children received interactive music therapy (by 1 of 2 therapists) in theatre. Intervention 2: children received oral midazolam 0.5mg/kg 30 min before surgery. Control: no music therapy or premedication.	in all groups over the 4 measurement time-points (p=.001). • Anxiety scores in the intervention 2 group were significantly less during induction than intervention 1 (p=.015) and the control group (p=.005). • Children's anxiety scores in intervention 1 were significantly different when controlling for therapists (p<.05).
2004 Keaney A et al. Ireland	Mixed specialties Day case	120 (details of age range not given) Group 1, n=63 (73% M/27% F) (mean age: 3.3) Group 2, n=57 (61.4% M/38.6% F) (mean age: 4)	PHBQ (27-item) completed at day 1, week 1 and month 1 after surgery. Group 1: induced with sevoflurane 8% for 4 minutes in 40%/60% O_2/N_2O Group 2: induced with halothane 5% for 4 minutes in 40%/60% O_2/N_2O	Behaviour change: • 58.3% children had PB on day 1 post discharge, 46.7% at the end of week 1 and 38.3% at the end of 1 month. • There was a significant decrease in PB over time (p<.03). • There was no relationship between anaesthetic agent and PB. • Children < 4 yrs were more likely to develop PB than children > 4 yrs (p<.005).
2004 Tripi PA et al. USA	General and urology Day case	92 1.5 to 9 yrs Control, n=46 (89% M/11% F)	PHBQ (27-item) completed at week 1 and 4 after surgery Intervention: Parents were permitted to be with	Behaviour change: • Mean PB in control group 1.9 ± 1.2 and intervention group 1.9 ± 1.3 (no details provided of PB at week 1 and week 4).

		(mean age: 3.4) Intervention, n=46 (91% M/9% F) (mean age:4.1)	their children during induction of anaesthesia, during emergence once off the ventilator and in the PACU. Control group: Parents were permitted to be with their children during induction of anaesthesia and in the PACU but not during emergence.	• No significant group differences (p=.8)
2005 Kain ZN et al. USA	Mixed specialties Day case	102 3 to 10 yrs Group 1, n=52 (60% M/40% F) (mean age: 6.9) Group 2, n=50 (56% M/44% F) (mean age: 7.1)	PHBQ (27-item) completed on postoperative days 1-5 and at week 1 Actigraphy collected every night for 5 nights before and 5 nights after surgery. Scores: % actual sleep time during total sleep period. Group 1: received sevoflurane as anaesthetic Group 2: received halothane as anaesthetic	Behaviour change: • 68% children in group 1 had 1 or more PB on day 1, 46.9% day 2, 28.6% day 3, 23.4% day 4, 17% day 5 and 14.6% at week 1. • 57.7% children in group 2 had 1 or more PB on day 1, 34.7% day 2, 27.5% day 3, 20% day 4, 12.3% day 5 and 14% at week 1. • No significant differences between groups. • PB decreased from day 1 postoperatively to week 1 (p=.0001). • No group differences in any of the PB subscales and no group-based differences based on the age of the child. • No group differences for any sleep variables as measured by actigraphy.

2005 Calipel S et al. France	Lower abdominal surgery Day case	50 2 to 11 yrs 80 %M/20% F Group 1, n=23 (median age: 4.5) Group 2, n=27 (median age: 5)	mYPAS (22-item) completed pre-operatively as children were admitted, at arrival in theatre and during induction of anaesthesia. PHBQ (26-item) completed pre-operatively and on day 1, 7 and 14 after surgery. Group 1: a placebo premedication was administered 30 min before surgery. An anaesthetist practising hypnosis entered the child's room and established a hypnotic state which was maintained until the induction of anaesthesia. Group 2: midazolam was given as a premedication 30 min before surgery.	Pre-operative anxiety: • Anxiety scores in group 1 decreased from admission to induction of anaesthesia (NS). • Anxiety scores in group 2 increased significantly from admission to induction (p=.03). • There were significantly fewer anxious children in group 1 than in group 2 during induction (39% vs. 68%, p=.04). Behaviour change: • 30% children in group 1 had NBC on day 1, 26% on day 7 and 26% on day 14. • 62% children in group 2 had NBC on day 1, 59% on day 7 and 44% on day 14. • There were significant group differences on day 1 and 14 (p=.01). • On day 1 and 14 children in group 1 had significantly less aggression towards their parents and on day 7 children in group 1 showed less fear of separation (p<.05).

2005 Vagnoli L et al. Italy	Mixed specialties Day-surgery	40 5 to 12 yrs Intervention, n=20 (75% M/25% F) (mean age: 7.3) Control, n=20 (70% M/30% F) (mean age: 6.9)	mYPAS (22-item) measured pre-operatively in the holding room and during induction. Intervention: children were accompanied by clowns and a parent and interacted with them in the pre-operative area including during induction of anaesthesia. Control: children were accompanied by a parent only in the pre-operative area.	Pre-operative anxiety: • Child anxiety scores were significantly lower in the intervention group than in the control group during induction (p=.001). • No group differences for child anxiety in the holding room. • Child anxiety scores in the control group increased significantly from the holding room to induction of anaesthesia (p=.001). There was no significant difference in anxiety measures for the intervention group. • Child anxiety scores within the intervention group were highly correlated between the holding room and induction (r=.93, p<.001).
2006 Brewer S et al. USA	ENT Day case	142 5 to 11 yrs Control, n=80 (57% M/ 43% F) (73% 5-7yrs) Intervention, n=62 (44% M/56% F)	CD:H (anxiety measure) completed prior to surgery and at follow-up appointment on average 1 month after surgery (3-72 days) Intervention: After CD:H, child life specialist took child and parents on a 20 min tour of all relevant areas of day surgery and provided	Pre-operative anxiety: • PA scores were significantly higher in the intervention group (p<.05). Behaviour change (anxiety): • Anxiety score change, from pre-surgery to follow-up, was significantly better in the intervention group than the control

		(59% 5-7yrs)	developmentally appropriate explanation of surgery process. Children were formally assessed throughout preparation to determine their understanding of surgery. Child then prepared in room filled with medical equipment – children able to explore and rehearse. Questions answered and misconceptions alleviated. Control: After CD:H child was escorted to a room with diversionary activities e.g. movies, arts and crafts.	group (p=.04). • Males who underwent minor surgery had a significant increase in anxiety scores from pre-surgery to follow-up (p=.04), males who underwent major surgery had a small NS decrease in anxiety (p=.74).
2006 Bal N et al. Turkey	ENT Unclear if day case and/or inpatient	120 2 to 12 yrs Group 1, n=40 (52.5% M/47.5% F) (mean age: 6.1) Group 2, n=40 (55% M/45% F) (mean age: 6.45) Group 3, n=40 (57.5% M/42.5% F)	PHBQ completed pre-operatively and at 1 week after surgery. Group 1: received sevoflurane induction of anaesthesia. Group 2: received IV propofol induction of anaesthesia. Group 3: received sevoflurane induction followed by a sub-hypnotic dose of propofol (1mg/kg). Groups 1 and 3 were ventilated by face mask before IV catheter placement. Local anaesthetic was applied to child's hand 30-45min pre-operatively. No premedication given and no parents present during induction in any groups.	Behaviour change: • No children in group 2 had nightmares / fear of the dark compared to 15% in group 1 and 20% in group 3 (p<.05). • 5% children in group 2 wanted to sleep with their parents compared to 25% in group 1 and 12.5% in group 3 (p<.05). • Children with increased anxiety on arrival to theatre had higher ratios of fear of the dark/difficulty going to bed (p=.008) and sleeping with parents (p=.028). • Children with increased anxiety during induction had higher ratios of nocturnal enuresis (p=.02), nightmares (p=.02,

				fear of the dark/ difficulty falling asleep (p=.05), crying during sleep (p=.002) and sleeping with parents (p=.01).
2006 Golden L et al. USA	Mixed specialties Day case	100 3 to 6 yrs Intervention, n=50 Control, n=50 (no details regarding child gender or mean age provided)	mYPAS (22-item) measured pre-operatively on admission (baseline), 3 minutes later and during administration of premedication of midazolam 0,5mg/kg Intervention: the child was given a toy immediately after first mYPAS was scored. Control: no toy was given to child. mYPAS scored at same intervals.	Pre-operative anxiety: • Anxiety scores at baseline and 3 min later were not statistically different between the intervention and control groups. • During administration of premedication, mean anxiety scores were significantly lower in the intervention group compared to the control group (23 vs. 42, p<.05). • Within group comparisons showed that mean anxiety scores in the control group were significantly higher than the first two scores during administration of premedication (p<.05) and in the intervention group were significantly lower (p<.05).
2006 Patel A et al. USA	Mixed specialties Day case	112 4 to 12 yrs Control, n=36 (61% M/39% F) (mean age:6.6)	mYPAS (22-item) measured pre-operatively on admission (prior to randomization) and during induction of anaesthesia. PHBQ (27-item) completed prior to surgery and 7-10 days after surgery.	Pre-operative anxiety: • Significant increases in anxiety scores were found in group 1 and the control group during induction (p<.01) but not in group 2.

		Intervention 1, n=38 (61% M/ 39% F) (mean age: 6.9) Intervention 2, n=38 (63% M/37% F)	Scores: difference in means from baseline to follow-up. Intervention 1: children were given midazolam in the holding area at least 20 min before being taken to theatre. Intervention 2: children were given a VG from a variety of 10 games at least 20 min before being taken to theatre. Children were allowed to play with the VG through the introduction of the anaesthetic mask. Routine care/control: All parents were given a written and verbal description of what to expect in theatre and remained with the child until he/she was anaesthetized.	• The change of anxiety scores in group 2 was significantly less than the change in the control group (p=.04). • 63% children in group 2 had no change or a decrease in anxiety scores, compared with 26% in group 1 and 28% in the control group (p=.01). • In 4 to 5 yr olds: no change / decrease in anxiety scores was seen in 50% group 2, 12% group 1 and 18% control (p=.04). • In 6 to 9 yr olds: no change / decrease in anxiety scores was seen in 78% group 2, 40% group 1 and 43% control (p=.05). • In 9 to 12 yr olds: difference was NS. Behaviour change: • Mean PB in control group at 7-10 days: 5.7 ± 0.6, group 1: 6.6 ± 0.6 and group 2: 6.1 ± 0.9. • No significant group differences at baseline, at follow-up or between baseline and follow-up.
2007a Kain ZN et	Mixed specialties Day case	408 2 to 12 yrs	mYPAS (27-item) measured at the pre-operative visit, in the anaesthetic waiting area and during	Pre-operative anxiety: • Children in group 2 had significantly

al. USA		Control, n=99 (60% M/40% F) (mean age: 5.4) Group 1, n=94 (69% M/31%F) (mean age: 5.5) Group 2, n=96 (62% M/38% F) (mean age: 5.6) Group 3, n=98 (60% M/40% F) (mean age: 5.5)	induction of anaesthesia. Control: standard care. No premedication given and parents not present during induction. Group 1: parents present during induction of anaesthesia. Group 2: children received multi-component behavioural preparation programme (anxiety-reduction, distraction, video modelling and education, parents present, no reassurance, coaching and exposure shaping) Group 3: premedication of midazolam 0.5mg/kg given 30 minutes prior to surgery.	lower anxiety scores in the anaesthetic waiting area than all the other groups (34.4±16 vs. 39.7±15, p=.007). • Children in group 2 were less anxious during induction that group 1 or control (44.9±22 vs. 51.6±25 and 53.6±25, p=.006) but similar to group 3 (42.9±24, p=NS).
2007b Kain ZN et al. USA	Mixed specialties Day case	262 2 to 10 yrs (57.8% M/42.2% F) (mean age: 5.7)	mYPAS (27-item) measured pre-operatively in the anaesthetic room and during induction. Group 1: responders to midazolam Group 2: non-responders to midazolam	Pre-operative anxiety: • All children were given premedication of midazolam 0.5mg/kg. • 57.4% children scored lowest possible score on mYPAS (22.9). • 14.1% were non-responders to anxiolytic (midazolam) (mYPAS ≥72.91). • Non-responders were significantly more anxious during induction of anaesthesia than responders to midazolam (p=.001).

				• Anxiety scores in the anaesthetic room and during induction were significantly correlated (rho=.340, p<.01). • Predictors of non-responders to midazolam: younger child age (p=.001) and child temperament emotionality (p=.001). • None of the children received formal pre-operative preparation.
2007 Li HCW et al. China	Mixed specialties Day case	203 7 to 12 yrs Intervention, n=97 (69.1% M/30.9% F) (mean age: 9.6) Control, n=106 (68.9% M/31.1% F) (mean age: 9.4)	CSAS-C (20-item) measured at pre-operative assessment clinic and pre-operatively on admission. Intervention group: received routine preparation and a session of therapeutic play 1 week prior to surgery. Children were taken on a tour of surgical areas, watched a demonstration of induction on a child-size manikin, children were encouraged to play with the equipment, followed by a questions session. Control group: routine pre-operative preparation comprised of a briefing of pre and postoperative care.	Pre-operative anxiety: • Mean anxiety scores increased from baseline to admission for both groups (p=.005). • Children in the intervention group had significantly lower anxiety scores on admission (intervention: 34.36±8.09 vs. control: 38.6±8.53, p=.02). • Child and parent anxiety scores were highly correlated at baseline (r=.67, p=.01) and moderately correlated pre-surgery (r=.45, p=.01).
2008 Rice M et al.	Mixed specialties Day case	94 2 to 16 yrs	mYPAS (22-item) measured pre-operatively on admission, in the pre-operative holding room and	Pre-operative anxiety: • Children in group 1 were significantly

UK		Group 1, n=21 (71% M/29% F) (median age: 4.9) Group 2, n=73 (68% M/32% F) (median age: 8.7)	during induction of anaesthesia. Group 1: attended a formal pre-operative preparation programme Group 2: non-attendees	younger than group 2 (p=.002). • 36% children in group 1 had a previous surgical experience compared to 47% in group 2. • All parents in group 1 accompanied their child during induction but 2 parents in group 2 chose not to. • Children's PA scores were lower in group 1 at all three time-points but only significantly lower in the pre-operative holding room (p=.007).
2009 Golan G et al. USA	Mixed specialties Day case	65 3 to 8 yrs (mean age: 4.5) (no details regarding child gender) Group 1, n=22 Group 2, n=22 Group 3, n=21	mYPAS (27-item) measured pre-operatively in anaesthetic room, entrance to theatre and during induction of anaesthesia. Group 1: no premedication or clown presence Group 2: children received a premedication of midazolam 0.5mg/kg 30 minutes before surgery. Group 3: two clowns specially trained in child distraction techniques were present on arrive to the anaesthetic room, on entrance to theatre and during induction.	Pre-operative anxiety: • Mean anxiety scores were significantly lower in group 3 than group 1 in the anaesthetic room (p.01). • Mean anxiety scores remained significantly lower in group 3 than group 1 but equally group 2 on entrance to theatre (p=.005). • No significant differences were detected between groups during induction. • Anxiety increased in all groups across the three measurement time-points but the largest increase was seen in group 3

PB problematic behaviour/s, PA pre-operative anxiety, ENT ear nose and throat, M male, F female, PHBQ post-hospital behaviour questionnaire, PACU post-anaesthetic care unit, SA separation anxiety, GA general anxiety, EA eating disturbances, AA aggression toward authority, AW apathy/withdrawal, SL sleep disturbances, VG video game, HFI hospital fears inventory, CD:H child drawing: hospital, NS non-significant, PP parent participation, GA general anaesthesia, MCDAS modified child dental anxiety scale, IV intravenous, CPRS-RS Conner's parent rating scale-revised short form, PSQ paediatric sleep questionnaire, ADHD attention-deficit/hyperactivity disorder, YPAS Yale Pre-operative Anxiety Scale, mYPAS modified Yale Pre-operative Anxiety Scale, GMS Global Mood Score, MUS Manifest Upset Scale, CARS Clinical Anxiety Rating Scale

Chapter 3
Theoretical Framework

3.1 Introduction

Chapter two provided the results of an extensive systematic literature review on children's post-hospital behaviour changes following admission to hospital for surgery. The incidence of behaviour changes (problematic and / or improved behaviour), the type of behaviour changes and the potential risk factors for behaviour changes were discussed. Other important outcomes related to behaviour changes after surgery, such as child pre-operative anxiety and postoperative pain at home, were explored in the literature search and discussed in the review. This chapter presents the development of a theoretical framework following identification of a number of theories related to children's hospitalisation and illness. The development of a theoretical framework is essential as it identifies, defines and operationalizes constructs and concepts, develops relational statements and expresses the statements in a hierarchical style. Interestingly, no study to date in the field of children hospitalised for surgery has presented a detailed framework (conceptual or theoretical) on which the field can progress. The theory chosen for this study best explained the context of the parent-child dyad when the child is admitted to hospital for surgery and the number of person and situational factors that affect how the dyad appraises the stress of hospitalisation and initiates coping strategies that result in immediate and long term coping outcomes.

3.2 Theory

Hospitalisation for surgery has been recognised as a stressful healthcare event in a child's life for a number of decades (Caldas et al. 2004;Goslin 1978;Thompson et al. 1993;Vernon et al. 1993;Watson et al. 2003). Negative outcomes of this healthcare event include child and parent pre-operative anxiety, pain and behaviour changes at home (Kain et al. 1996c;Karling et al. 2007;Kotiniemi et al. 1997;Stargatt et al. 2006). A number of child and parent factors have been identified as predictors of these negative outcomes and include: child age, temperament, pre-operative behaviour, parent coping style, and child and parent prior experience of hospitalisation for surgery and / or pain. Parent pre-

operative anxiety has been strongly correlated to child pre-operative anxiety (Ellerton et al. 1994;Kain et al. 1996c;Kain et al. 2000;Li et al. 2003) and is predictive of child PB at home up to six months following surgery (Kain et al. 1996c).

3.2.1 Theories identified from the relevant literature on children's illness and healthcare

Goslin (1978) highlighted the lack of a theoretical basis for research in the field of psychological upset in children following admission to hospital up until 1978. A few theoretical frameworks were implied in some of the studies included in Goslin's review (Goslin 1978). Anticipatory worry and social learning theory were thought to underpin research aimed at preparing children for hospital and surgery. For example, using the former, one would postulate that a certain amount of stress or worry would mobilise the ego's defences for coping and would reduce the effect of the actual stress. Using the latter, one would hypothesise that children exposed to a model who showed a favourable behavioural response in a stressful situation would tend to imitate the response (Goslin 1978).

Bandura's social learning theory (Bandura 1977) has been implicitly referred to in the literature, especially in intervention studies that involve demonstrations and participant modelling. Bandura (1977) explains human behaviour in terms of a continuous reciprocal interaction between cognitive, behavioural and environmental influences and people model their behaviour on other's through observation and imitation. Four factors that enable social learning are: attention to the behaviour, memory of the behaviour, the ability to replicate the behaviour, and the motivation to replicate the behaviour. Modelled behaviour that is learned through observation can take the form of a live model, which involves an individual demonstrating a particular behaviour; a verbal instruction, which involves a detailed explanation of the behaviour; and a symbolic model, which involves real or fictional characters that display behaviours in person, in books, on television or other forms of media.

Two other theories put forward by Goslin (1978) as being appropriate to the field of hospitalised children were developmental theory and Caplan's crisis theory. The younger child's susceptibility to become psychologically upset during crisis situations can be understood in terms of developmental theory, as their limited cognitive abilities mean that they cannot conceptualize to any significant degree and are more dependent on others for help with coping. As children mature and communication skills improve, language becomes an important mediator and regulator of behaviour and children are able to develop greater independent coping skills (Goslin 1978;Harbeck-Weber et al. 2003). Goslin (1978) suggests that during hospitalisation, separation of younger children from their mothers deprives the child of her/his primary source of feedback and interpretation of the hospital experience. In addition to younger children's developmental handicaps in being able to cope with medical-related stress, they lack the experience of stress exposure and learned coping skills. Problem-focused coping develops earlier in children, which can be explained by the fact that these strategies are more easily observed and therefore modelled by the child (Eiser 1993). As children mature they become more aware that their emotions can be brought under control, they are more likely to utilize a variety of coping resources and are better able to differentiate between situations that they can control and those that they can't (Eiser 1993;Harbeck-Weber et al. 2003).

Crisis theory relates to hospitalised children because the hospitalisation event provides either a danger or an opportunity to children who will: (i) learn adaptive new coping skills, (ii) learn mal-adaptive coping skills or (iii) emerge relatively unharmed as no new skills were required (Caplan 1961). It is the individual, i.e. the child's (and/or the parent's) interpretation of a situation that determines whether or not a stressor (hospitalisation) is a crisis and initiates coping mechanisms.

Theories that have been linked to children (and their parents) unexpectedly admitted to critical care are Johnson and Leventhal's self-regulation theory, Carver and Scheier's control theory and the emotional contagion hypothesis (Melnyk et al. 2007). Self-regulation theory asserts that concrete objective information provided to an individual who is about to undergo a stressful procedure facilitates the development of a cognitive schema similar to the real-life experience, which enhances coping through a decreased discrepancy

between what is expected and what occurs (Johnson et al. 1997). In Melnyk et al.'s (2007) intervention study information was provided to parents regarding their child's likely emotional and behavioural responses to hospitalisation with the expectation that information would strengthen parents' beliefs about their ability to understand and predict their child's behaviours and emotions which would lessen maternal anxiety and facilitate increased participation in their child's hospitalised care. Another component of the intervention was the provision of parent role information and activities which was guided by control theory. Control theory postulates that if there is a discrepancy between a standard and a current state behaviour the individual is motivated to reach the standard (Carver et al. 1999). Provision of parent role information would lessen the discrepancy between parents' usual / standard parenting and the way in which they could care for their child in hospital. Thirdly, the emotional contagion hypothesis contends that emotional states, especially anxiety, are transferred from one individual to another by being in each other's presence and modelling these emotions, which is similar to social learning theory (Gump et al. 1997). In Melnyk et al.'s (2007) study children in the intervention group were expected to have better outcomes than control children because of their parent's ability to cope effectively resulting in less anxiety.

One surprising finding of the systematic review of the literature (Chapter 2) was that only one study (Brewer et al. 2006) explicitly stated the theoretical framework on which the research was based: Lazarus and Folkman's theory of stress and coping. Brewer (2006) explained how the stressful events of admission to hospital for surgery, i.e. separation from family, fear of the unknown, loss of control and fear of pain contribute to a child's anxiety both before and after hospital and the child's cognitive appraisal of the event determines coping behaviours. Factors such as child age, developmental level, prior hospitalisations and prior encounters with the medical profession, child and parent coping styles and parenting style affect coping behaviours (Brewer et al. 2006). Thus the very basic concepts of stress and coping were identified, i.e. an individual's appraisal of the stress initiates coping, but no further explanation of the theory as it relates to the child and parent dyad was provided.

Although other studies included in the systematic literature review did not refer to specific theories, it was not uncommon for concepts of “stress” and “coping” to be mentioned in the reports. Intervention studies appear to have focused on enhancing coping methods by children and/or their parents or by averting children’s attention away from the stressors involved, which could mean that theories of stress and coping are taken for granted in this field of research. Intervention types have included education, modelling, teaching coping skills, behaviour therapy techniques and parent presence/participation (Harbeck-Weber et al. 2003). Although coping strategies have not been measured in these studies, the consistent use of outcomes of child behaviour at home and/or pre-operative anxiety is suggestive that these are a measure of child coping outcomes.

Theories of stress and coping have also been linked to children (and their parents) admitted to critical care (LaMontagne et al. 1995), children exposed to repeated invasive procedures (Slifer et al. 2002) and children with chronic illnesses (Eiser 1993;LaMontagne et al. 1995). Stress and coping theory will be discussed in greater depth below.

3.2.1.1 Summary

Eight theories were identified from related literature and briefly outlined in relation to children’s hospitalisation and illness. Anticipatory worry, self-regulation and control theories appear to fit best with intervention research where information is provided to individuals (i.e. parents) to initiate coping and/or decrease discrepancies between what is expected and what actually occurs in a stressful event such as the hospitalisation of a child. Social learning theory and the emotional contagion hypothesis explain how individuals (i.e. children) learn from and model their behaviour and/or emotions on a parent or other model who exhibits desired behaviour/emotions. Developmental theory explains how children of different ages appear to appraise and/or cope with the stress of hospitalisation differently and crisis theory explains how the stress can and does result in positive coping outcomes some of the time. Theories of stress and coping, although not always explicitly stated, appear to be the most widely referred to in the field of children’s hospitalisation and illness. It is important to develop a theoretical framework to guide future research and to delineate

which factors affect the appraisal of the stress, which factors measure the stress of hospitalisation for surgery and which factors are outcomes of coping.

3.2.3 Choosing a theory for the current study

Hospitalisation of a child for surgery is a stressful event for the parent-child dyad and this is best explained in terms of stress and coping theories as they relate to both the parent and the child. Other theories identified from the literature have related to either the parent (self-regulation theory, control theory) or the child (crisis theory, developmental theory, social learning theory/emotional contagion hypothesis). It is possible that elements of other theories exist within a framework of stress and coping, e.g. the high correlation between parent and child pre-operative anxiety could be explained in terms of social learning theory / emotional contagion hypothesis and self-regulation / control theory would explain how parents and (older) children might cope better with the stress of hospitalisation after adequate preparation. However, stress and coping covers the entire process from admission to hospital for surgery until follow-up after discharge. Parents and children enter the stressful encounter with or without personal experience, preparation and information about the surgery. These and other personal factors such as child developmental stage and temperament, parent education and socioeconomic status all influence how the stress is appraised. Immediate coping outcomes are evidenced by child and parent pre-operative anxiety levels and long term coping by child behavioural/emotional disturbances at home following discharge.

Lazarus and Folkman's theory of stress and coping (Lazarus et al. 1984) was chosen as the most appropriate theory of stress and coping on which to base the current study, as it best describes the psychosocial processes involved in a person's understanding and coping with stressful encounters, and the individuality of choosing and enacting various coping strategies. The theory is a generic one, offering an explanatory model for all types of human experiences that might be considered stressful. It is a state-oriented (versus trait-oriented) theory that explains how the parent-child dyad appraises the stress of hospitalisation for surgery as it unfolds instead of having trait coping strategies that pre-determine how they will cope. It is also contextual which means that person and situation variables jointly shape coping efforts.

3.3 Lazarus and Folkman's Theory of Stress and Coping

Cognitive appraisal and coping are two key processes in this theory that mediate how a stressful encounter relates to immediate and long term outcomes.

Through the process of cognitive appraisal, an individual evaluates a situation to determine if/how it will benefit/harm them. In primary appraisal the individual evaluates whether the encounter will be harmful or beneficial and in secondary appraisal the individual evaluates what can be done to overcome the posed harm or to improve benefit. These two methods of appraisal converge to determine whether an individual-environment relationship is regarded as significant for well-being and if so, if it is primarily threatening with the possibility of harm or loss or if it is challenging with the possibility of mastery or benefit.

Coping has been defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus et al. 1984, p.141). This definition has three key features:

1. It is process orientated. This means that it focuses on what the individual actually does and how behaviour changes as the stressful encounter unfolds. This contrasts with trait approaches which focus on what the individual usually does, i.e. stability rather than change.
2. It is contextual. Particular individual and situation variables influence the individual's appraisal of the situation and shape coping efforts.
3. There are no criteria for good or bad coping. Coping is the individual's attempt to manage the demands placed upon him/her in a stressful situation regardless of whether these attempts are successful.

The two major functions of coping are problem-focused coping and emotion-focused coping with attention focused on altering the individual-environment relation and regulating emotions respectively.

3.4 Substruction of Lazarus and Folkman's Theory of Stress and Coping in the context of children hospitalised for surgery

The process of substruction is a clarification of the links between theoretical (theory/constructs/concepts) and operational (empirical indicators/levels of measurement/scores or values) systems within a theoretical framework (Dulock et al. 1991). Substruction can provide a process for rigorous appraisal of the methodology and results of a study to determine if theory is supported or challenged by the findings.

Three constructs have been identified from Lazarus and Folkman's theory of stress and coping: cognitive appraisal, the stressful event and coping (outcomes). From a systematic review of the literature, various concepts have been identified as potential influencing factors regarding the way in which parents and / or their children appraise a stressful situation (admission to hospital for surgery), factors that affect the magnitude of the stressful situation and concepts that can be used to describe how the child coped.

3.4.1 Cognitive appraisal

Child age has already been identified as a significant factor in determining how children appraise and cope with a stressful event. It has also been established that exposure to a stress or related stimuli initiates a cognitive process that influences coping. Social learning theory indicates that children learn behaviour from observing others which explains the high correlation between child and parent pre-operative anxiety scores. An assumption can therefore be drawn that parent factors are equally important in determining their child's ability to cope as they are in determining their own ability to cope which would in turn influence their child's coping ability. Exploring both child and parent factors is essential in understanding how they influence child coping.

A number of descriptive studies have identified various child and parent factors as risk factors for child pre-operative anxiety and post-discharge PB. Child factors include younger age, number of siblings, temperament, pre-operative behaviour, previous

experience of hospitalisation for surgery and information/preparation provided prior to surgery (Carson et al. 1991;Davidson et al. 2006;Kain et al. 1996c;Kain et al. 1996a;Kain et al. 2006b;Karling et al. 2007;Kotiniemi et al. 1997;Lumley et al. 1993;Stargatt et al. 2006;Tuomilehto et al. 2002). Identified parent/family risk factors have included parent coping style, parent beliefs about preparation, parent state and trait anxiety, single parents and living in rural areas (Caldwell-Andrews et al. 2005;Carson et al. 1991;Kain et al. 2000;Karling et al. 2007;Stargatt et al. 2006).

Potential influencing factors for child coping outcomes that were of interest in the current study were: demographic factors (child age, gender, number of siblings, birth order, parent marital status, ethnicity, socio-economic status, education and employment), baseline psychological factors (child temperament, pre-operative behaviour, parent coping style, state and trait anxiety and beliefs about their role in the child's care and the child's behaviour) and factors related to child and parent prior exposure to the stress of hospitalisation for surgery (previous surgical experience, previous pain experience, formal preparation of the child for surgery, information provided to the parents and/or the child). Due to the inevitable pain that follows a surgical procedure, the influence that parent and child thoughts about pain would have on the child's coping were also of interest.

3.4.2 Stressful event

Two groups of intervention studies focus on minimizing the stress of the surgical procedure for the child either by providing premedication, particularly anxiolytics, or by averting the child's attention away from the stressors by providing some form of distraction. Six studies (Bevan et al. 1997;Kain et al. 1999a;McCluskey et al. 1994;McGraw et al. 1998;Patel et al. 1997;Payne et al. 1992) examined the effects of administering the anxiolytic, midazolam, to children pre-operatively on pre-operative anxiety scores and behaviour change outcomes at home. Favourable outcomes were reported in all but two of these studies (Bevan et al. 1997;McGraw et al. 1998). Bevan (1997) reported no significant difference in pre-operative anxiety scores and behaviour change outcomes in 2 to 7 year olds who were given midazolam compared to those that were given a placebo and McGraw (1998) reported worse behaviour change outcomes in 1 to 10 year old children who were given

midazolam. Both of these studies measured behaviour change at home through telephonic interviews with the parents and the development of the interview tools were not detailed.

All seven of the distraction intervention studies (Calipel et al. 2005;Golan et al. 2009;Golden et al. 2006;Kain et al. 2001;Kain et al. 2004;Patel et al. 2006;Vagnoli et al. 2005) identified from the literature review reported favourable outcomes in children's pre-operative anxiety scores. Of the three studies that reported behaviour change outcomes in these children, one reported improved behaviour change (Calipel et al. 2005) and two reported no significant difference in behaviour change (compared to controls who didn't receive distraction) (Kain et al. 2001;Patel et al. 2006). Distraction techniques in these studies included lower sensory stimulation in the theatre, music therapy, hypnosis, the presence of clowns in theatre and providing children with toys/video games. Proof is therefore found in these groups of studies that children appear to cope better irrespective of their age, if they are given an anxiolytic pre-operatively or if their attention is adequately averted from the stressors they are exposed to pre-operatively.

There are various peri-operative factors related to admission for surgery that affect child post-hospital behaviour outcomes and these have been identified in the literature as: whether or not children were given premedication, the type of induction of anaesthesia (inhalation or intravenous) and length of stay in hospital (Aguilera et al. 2003;Bal et al. 2006;Kain et al. 1996c;Kotiniemi et al. 1996a;Stargatt et al. 2006).

Therefore, peri-operative factors that were of interest in the current study as potential influencing variables on child coping outcomes were: whether or not children received premedication, the type of induction of anaesthesia and their length of hospital stay. Also of interest was the length of time that the child had to wait between admission to hospital and being taken to theatre, as it was assumed that prolonged exposure to the stressful pre-operative environment would either benefit or hinder the child's coping.

For the children who spent one night or more in hospital, levels of parent participation in their child's care and parent and child (> 8 years) satisfaction with in-hospital pain

management were explored as it was expected that parent participation would decrease the stress of hospitalisation for the child/parent and that lower satisfaction with pain management would be indicative of parents and children who rated the experience as more stressful.

3.4.3 Coping

3.4.3.1 Child coping

Four intervention studies (Brewer et al. 2006;Li et al. 2007;Margolis et al. 1998;Zahr 1998) were identified that focused on pre-operative preparation of children with the apparent aim of enhancing their coping skills. All four of these studies involved exposure of the child to surgery-related stimuli such as a teaching book (with tactile, olfactory and visual stimuli); a puppet show of doctors, nurses and a hospitalised child; a tour of the theatre areas; and a session of therapeutic play including a manikin model and induction equipment. In three of these studies (Brewer et al. 2006;Li et al. 2007;Zahr 1998) children were encouraged to re-enact procedures that had been demonstrated to them, they were coached with regard to how they should behave and were given the opportunity to ask any questions. Primary outcomes in these studies were children's pre-operative anxiety and/or post-hospital behaviour once at home. Results from these studies were mixed. Older children (7 to 12 years) who participated in a preparation programme a week or so prior to hospitalisation for surgery had lower pre-operative anxiety than their control-group peers (Li et al. 2007), but younger children (2 to 4 years) who were given a teaching book with sensory stimuli were more anxious pre-operatively than younger children who weren't given the book, but the differences in pre-operative anxiety scores was not statistically significant (Margolis et al. 1998). Children who participated in preparation programmes on the day of surgery had lower anxiety scores pre-operatively after watching puppets model surgery-related procedures (2 to 6 years) (Zahr 1998), but were more anxious after spending time with a child-life specialist (5 to 11 years) (Brewer et al. 2006). Children in both of these same-day preparation groups had improved behaviour outcomes at home compared to the respective control groups. It is clear therefore, that although children may benefit from being exposed to the theatre environment, watching models perform required behaviours and being given the chance to re-enact procedures, the age of the child is a vital consideration when planning the timing of these preparation programmes.

Another group of intervention studies that appear to enhance coping and/or to minimize stress exposure for children are the parent present versus absent studies. Three such studies were identified from a review of the literature (Bevan et al. 1990;Kain et al. 1996b;Tripi et al. 2004). Children as young as 1 year old were included in these studies. Results in two of these studies showed no significant difference in child pre-operative anxiety scores (compared to children who didn't have parents present) (Kain et al. 1996b), and no difference in behaviour outcomes at home (Kain et al. 1996b;Tripi et al. 2004). One study reported an increase in children's pre-operative anxiety during induction of anaesthesia if their present parents were anxious themselves (Bevan et al. 1990). A number of descriptive studies support the strong correlation between child and parent pre-operative anxiety scores (Davidson et al. 2006;Ellerton et al. 1994;Kain et al. 1996c;Kain et al. 2000;Kain et al. 2006b;Li et al. 2003). Although the main reason for allowing parents to remain with their child may be to minimize the stress of the surgical procedure to the child, it is detrimental to the child in terms of their coping abilities if their parents are overly anxious.

Only one study was identified that described children's coping strategies during admission to hospital for inpatient orthopaedic surgery and how it related to their behaviour at home once discharged. LaMontagne's (1997) study of 8 to 17 year olds found that children/adolescents that focused on the concrete-objective aspects of surgery (problem-focused) had significantly more positive activity outcomes 3, 6 and 9 months after discharge from hospital. Similar results were reported in studies of children with chronic medical illness. Eiser (1993) synthesized the results of a number of studies and reported that younger children were more likely to use problem-focused coping and children who favoured this coping strategy were better adjusted and accepting of the disease and tended to be more physically active.

No other studies identified from the literature on children's hospitalisation for surgery reported the coping strategies adopted by children. One reason for this is probably due to the difficulty in measuring the process of coping especially in younger children who do not have the cognitive or linguistic skills to explain how they cope. Older children with

chronic illnesses have participated in studies of this nature and have either been asked to explain how they coped or to identify coping strategies from a list of possible strategies such as the KIDCOPE tool developed by Spirito, Stark and Tyc (1989), which has been developed for use in children 7 to 18 years (Eiser 1993).

3.4.3.2 Parent coping

Parent involvement in preparation or indeed preparation of the parent has been the focus of three successful studies with excellent results in terms of child and parent outcomes (Kain et al. 2007a;Melnyk et al. 2004;Visintainer et al. 1975).

Visintainer and Wolfer's (1975) stress point preparation intervention consisted of a combination of systematic preparation (child and parent), rehearsal, and supportive care conducted prior to a number of stressful procedures during the child's admission to hospital for surgery. Results showed significantly less upset and more cooperation in children and their parents reported significantly greater satisfaction and less anxiety than children or parents in the other groups (a single-session preparation conducted after admission or consistent supportive care without systematic preparation or rehearsal) (Visintainer et al. 1975). This study provides evidence that parents, when guided through various stressful procedures during their child's admission to hospital for surgery, cope better and so do their children.

Melnyk et al (2007) designed an intervention aimed at increasing self-confidence of the parent whose child was unexpectedly hospitalised. The educational-behavioural intervention programme (COPE – Creating Opportunities for Parent Empowerment) focused on increasing the parents' knowledge of the range of behaviours and emotions young children typically display during and following hospitalisation. Parents were also directed regarding participation in their child's emotional and physical care. The results from this randomised controlled trial revealed that mothers who received the COPE programme reported significantly less stress, participated more in their child's care, reported less negative mood states, depression and fewer post-traumatic stress symptoms following their child's hospitalisation (Melnyk et al. 2007). Children, whose parents

received the COPE programme also had more favourable post-hospital outcomes than children whose parents were in the control group, with significantly fewer withdrawal symptoms at 6 months and fewer negative behavioural symptoms 12 months after discharge (Melnyk et al. 2007).

In the third parent-focused intervention study, Kain et al. (2007) tested the efficacy of a family-centred surgery preparation program consisting of anxiety reduction, distraction on the day of surgery, video-modelling, promoting family-centred care, parent coaching and exposure of the child via induction mask practice. Outcomes of interest were child and parent pre-operative anxiety scores, emergence behaviour, analgesic requirements and discharge time. Results showed that parents and children in the intervention group exhibited significantly lower pre-operative anxiety, children had a lower incidence of emergence delirium after surgery, required less analgesia and were discharged from the recovery room earlier (Kain et al. 2007a).

These studies provide evidence that parents are noteworthy participants in the preparation of their children for admission to hospital for surgery particularly when appropriately guided by healthcare professionals and can be of great assistance in facilitating their child's coping strategies, specifically through the process of modelling (Eiser 1993).

3.4.3.3 Coping outcomes

Following a rigorous review of the literature, 69 studies were identified that described children's post-hospital behaviour changes (problematic or improved) and child pre-operative anxiety as primary and/or secondary outcomes in the context of children admitted to hospital for surgery. These concepts have therefore been identified as indicative of child coping with the stress of hospitalisation for surgery with PB and higher pre-operative anxiety scores indicative of poorer coping and improved behaviour and lower pre-operative anxiety scores indicative of better coping.

As already discussed, child and parent pre-operative anxiety scores are highly correlated but they have also been identified as risk factors for post-hospital PB (Davidson et al.

2006;Kain et al. 1996c;Kain et al. 1996a;Kain et al. 1999b;Kain et al. 2000). Child and parent pre-operative anxiety are therefore both an immediate coping outcome and a potential influencing factor for behaviour change, a long-term coping outcome.

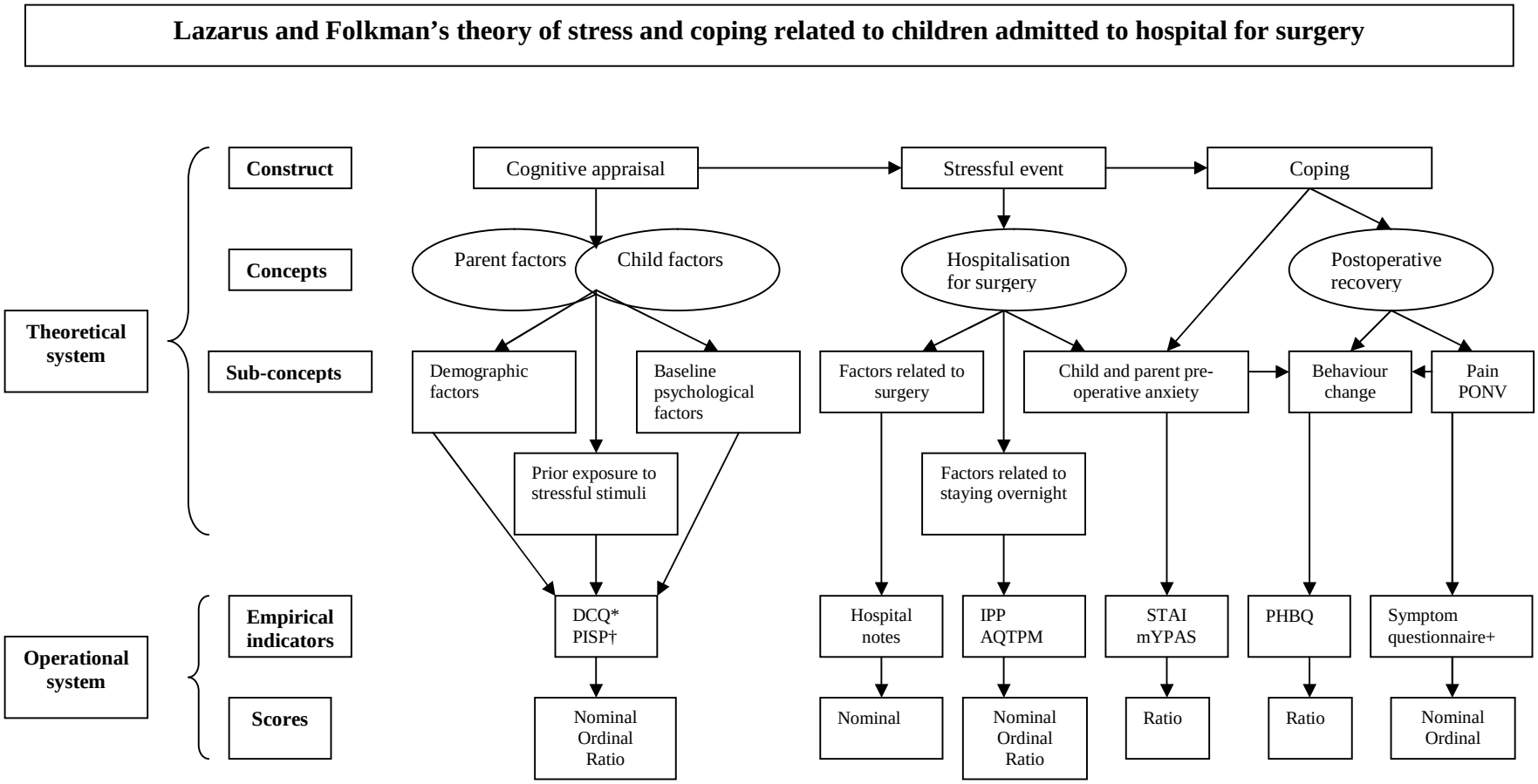
Another post-hospital factor that has been identified as a predictor of child PB is pain at home (Karling et al. 2007;Kotiniemi et al. 1997). There is also evidence to suggest that PB and the behavioural cues that parents use to assess their child's pain are similar (Gedaly-Duff et al. 1994;Reid et al. 1995). Pain has also been found to be significantly correlated to child pre-operative anxiety (Kain et al. 2006a).

The primary outcome of child coping identified for the current study was child behaviour at home following admission to hospital for surgery. Secondary outcomes included child and parent pre-operative anxiety and child pain at home. Long-term coping was assessed at the end of week four following discharge from hospital as literature suggests that up to 16% children continue to exhibit PB at this time.

3.4.4 Substruction model

Following a review of the literature and relevant theory the following model of child stress and coping with hospitalisation for surgery is presented (Figure 3.1).

Figure 3.1 Substructure of children admitted to hospital for surgery



PONV postoperative nausea and vomiting; DCQ demographic and clinical questionnaire; *includes questions on demographic details; previous experience with surgery/pain and baseline psychological measures of child/parent; PISP parent information needs and satisfaction with preparation; †includes questions on type of information/preparation received by child/parent; IPP index of parent participation; ATQPM adapted total quality pain management questionnaire; STAI state trait anxiety inventory; mYPAS modified Yale pre-operative anxiety scale; PHBQ post-hospital behaviour questionnaire; +includes questions on family's return to normal activities

3.5 Conclusion

This chapter briefly outlined a number of theories that were identified from relevant literature that have been related to children's hospitalisation and illness and described how children's psychological and behavioural upset at home following admission to hospital for surgery can best be explained in terms of Lazarus and Folkman's theory of stress and coping. This theory has been supported through evidence from intervention studies that have attempted to improve child coping and/or to minimize their exposure to stressful stimuli, with positive child pre-operative anxiety and post-discharge behavioural outcomes. Through the process of substruction, factors that influence children's cognitive appraisal of the stressful event of hospitalisation for surgery and their coping were discussed in relation to theory. In the following chapter the study methodology is presented with details of the specific study objectives and how the study design, participants and setting best address these objectives.

Chapter 4
Methodology

4.1 Introduction

In chapter three a theoretical framework, based on a systematic review of the literature and relevant theory, was presented. This chapter presents the specific study objectives and provides details of the study design, the participants and the setting. The measures used to quantify the study's primary and secondary outcomes are described. The second part of this chapter describes the data collection procedures, data analysis and ethical considerations for the study.

4.2 Specific study objectives

The specific objectives of the study were as follows:

1. To determine the level of post-hospital PB in children after surgery;
2. To examine the associations between demographic, baseline and pre-operative psychological factors, pre-operative preparation factors, in-hospital factors and children's post-hospital PB;
3. To determine the level of post-hospital pain and other postoperative symptoms in children after surgery;
4. To examine the associations between demographic, baseline and pre-operative psychological factors, pre-operative preparation factors, in-hospital factors and children's postoperative symptoms at home;
5. To determine the level of child and parent pre-operative anxiety;
6. To examine the associations between demographic, baseline psychological factors, pre-operative preparation factors and child and parent pre-operative anxiety;
7. To determine the level of parent and child pre-operative preparation and satisfaction with information regarding the child's admission to hospital for surgery;
8. To determine the level of parent participation in the care of their children who spent at least one night in hospital after surgery;

9. To determine the level of parent satisfaction regarding their child's postoperative pain management for children who spent at least one night in hospital;
10. To determine which parent factors, child factors, in-hospital and home factors are potentially predictive of child post-hospital PB.

4.3 Study design

A descriptive, prospective, repeated measures study design was used. The aim of descriptive research is to gain more information about a particular field of study and to provide an explanation of situations as they naturally occur (Burns et al. 2001). This study sought to describe children's PB at home following admission to hospital (day case or inpatient) for surgery under general anaesthesia, without any changes to current practice or manipulation of pre-operative care and/or in-hospital factors i.e. pre-operative preparation, administration of premedication or preparation of families for discharge. A prospective design was chosen because prospective studies collect data with greater confidence in reliability and accuracy as the outcome is not yet known thereby reducing possible sources of bias that may occur with retrospective designs (Burns et al. 2001). Children in this study were recruited from elective surgical lists 1 to 2 weeks prior to surgery and followed forward in time to the date of surgery and up to 4 weeks post-discharge from hospital. Repeated measures were collected in the form of a self-report questionnaire set measuring postoperative pain, other symptoms (nausea and vomiting) and PB and these questionnaires were given to parents to complete at four follow-up time-points (day 2 and at the end of week 1, 2 and 4 post-discharge). These time-points were similar to those used in previous research (Kain et al. 1999b;Kain et al. 1999a;Kain et al. 2006a) but day 1 and 3 were not included following discussions with the lead researcher of these studies who confirmed that they had found little difference in parental responses within the first three days post-discharge and recommended follow-up on day 2 only. The purpose of the repeated questionnaire set was to determine the incidence of PB, pain and other symptoms at four different time-points and to compare how these outcomes changed over the course of the first four weeks postoperatively. Research has shown that up to 16% children continue to exhibit PB four weeks after surgery (Stargatt et al. 2006) and there is a significant decrease in PB within the first month following discharge (Kain et al. 1999b;Kotiniemi et al. 1997).

4.4 Participants

London NHS hospitals with affiliations to the Association of Chief Children's Nurses (ACCN) and the Thames Paediatric Anaesthetists Group (TPAG) were approached to participate in this multi-site descriptive study. The ACCN is a group of senior nurses representing children's and young people's services and their purpose is to influence child health policy, strategy and nursing; to provide expert advice and support to its members and all those involved in the care of children; to influence and promote children's nursing; to work with professional bodies e.g. the Nursing Midwifery Council (NMC); and to raise the profile of health and welfare of children (Association of Chief Children's Nurses 2010). The aims of the TPAG, a clinical network of specialist and non-specialist consultant anaesthetists, are to provide a forum for discussion and the development of clinical guidelines; to provide a source of information for use in clinical practice, teaching and training; and to promote the highest level of peri-operative care for children in the Thames region (Thames Paediatric Anaesthetists Group 2009). Six hospitals (1 connected to the ACCN, 4 connected to the TPAG and 1 connected to both) that provide day case and inpatient surgery to a large proportion of the London paediatric surgical population initially volunteered to participate in the study. Three hospitals were included in the final sample with data collection at these sites overlapping and spanning 13 months. These hospitals were selected as they were the first to receive Research Ethics Committee approval and hospital-specific Research and Development clearance necessary for the study to commence. They also had the necessary resources available to assist with sending out study information to families and liaising with data collectors regarding participating children's surgery times, contact details and the whereabouts of medical notes for review following the children's discharge. One of the sites was a children's hospital and two were large general hospitals with dedicated paediatric surgery units. All children, 2 to 12 years of age, scheduled for planned general, ear nose and throat (ENT) or urology surgery, as inpatients or day cases, under general anaesthesia, and their parents, were eligible to participate in the study.

4.4.1 Child age

Children between the ages of 2 and 12 were selected for participation in this study. This age-group has been included in a number of descriptive and intervention studies on

children's behaviour change following admission to hospital for surgery (see Chapter Two, Tables 2.5 and 2.6). PB, pre-operative anxiety and postoperative pain and other symptoms have been measured in this age-group in other countries following inpatient and day case surgery (Davidson et al. 2006;Kain et al. 1996c;Kain et al. 2007a;Karling et al. 2007;Kotiniemi et al. 1996b;Reid et al. 1995). Parents of children in this age group are believed to be generally reliable informants about their child's usual behaviour (prior to surgery) and would be able to detect any differences in behaviour (improved or worsened) following discharge from hospital (Vernon et al. 1966). They would also be able to assess their child's temperament using validated tools (Buss et al. 1984) and provide a history of how their child had reacted during previous medical encounters with regards to their level of anxiety and any pain they may have felt.

In a systematic literature review conducted for the current study a number of researchers (Kotiniemi et al. 1997;Lumley et al. 1993;Stargatt et al. 2006;Tuomilehto et al. 2002) identified younger children as being at greater risk for developing PB than older children. This confirmed findings in an earlier review on pre-operative anxiety and postoperative behaviour conducted by Watson and Visram (Watson et al. 2003). Caldas et al. (2004) reviewed the effects of general anaesthesia, surgery and hospitalisation on children's cognitive, academic, emotional and socio-behavioural development and suggested including various age groups in studies for comparison purposes so that more efficient interventional programs can be developed (Caldas et al. 2004).

4.4.2 Surgical specialties

The surgical specialties included in this study were general surgery, ENT and urology surgery. In the study planning process, participating sites were visited and discussions with relevant senior doctors, nurses and administrative staff lead to decisions regarding the inclusion of these three specialties. All three of the participating hospitals agreed that these specialties were the most comparable in terms of their admission procedures, peri-operative care and overall length of stay. More complex surgeries such as neurology and cardiac had quite different admission procedures, pre-operative work-up, i.e. tests (invasive and non-invasive) and postoperative care with a large proportion of children being admitted to intensive care units. Inclusion of these more complex surgeries would have added a

number of confounding variables that could potentially influence the overall outcome of PB and postoperative pain.

Children admitted for both inpatient and day case surgery were included in the study to explore the effect that staying one night or more in hospital would have on PB. Parents level of participation in their child's care and their (and their child, if > 8 years) satisfaction with pain management were areas of interest in the inpatient population as well as how these factors were associated with PB following discharge.

Initially, only children who were admitted for first time surgery were included in the study but after two months of recruiting participants, a number of parents whose children were being admitted for their second or subsequent surgery expressed a desire to participate and an amendment was submitted to the research ethics committee and approved to extend the inclusion criteria to children (and their parents) who had undergone previous surgery.

4.4.3 Exclusion criteria

Children were excluded from the study for the following reasons:

- Children (and their parents) were excluded if they were admitted for emergency / unplanned surgery. Admissions for emergency surgery do not follow the same pre-operative procedures / preparation that planned surgeries do and one of the main objectives of this study was to describe pre-operative preparation and any associations that this might have with post-discharge PB. Emergency surgeries would also not allow for baseline psychological measures (child and parent) to be collected, which were to be described in association with peri-operative factors and PB post-discharge.
- Children were excluded from the study if they had special needs or a disability severe enough that their parent could not describe their behaviour using the Post-Hospital Behaviour Questionnaire (PHBQ) (primary outcome for this study).
- Children with an American Society of Anaesthesiologists (ASA) status of ≥ 3 were not included in the study as their underlying health status would add potentially confounding variables to the study. These children would require different medical treatment peri-operatively making them less comparable to healthier children.

According to the American Society of Anaesthesiologists, ASA status is defined as follows:

ASA 1 – A normal healthy patient

ASA 2 – A patient with mild systemic disease

ASA 3 – A patient with severe systemic disease

ASA 4 – A patient with severe systemic disease that is a constant threat to life

ASA 5 – A moribund patient who is not expected to survive without the operation

ASA 6 – A patient declared brain-dead whose organs are being removed for donor purposes (American Society of Anesthesiologists 2010).

- Families were also excluded from the study if they could not communicate in English or if an interpreter was not available over the duration of the study period to assist them. All the measures used in this study are validated for use in English.

4.5 Setting

The three hospitals that participated in this study had different pre-operative preparation programmes, admission and discharge procedures. Table 4.1 provides a summary of the different services provided by each of the hospitals at the time of data collection.

4.5.1 Participating hospitals

Forty five (30 inpatients, 15 day case) children who participated in the study were admitted to Hospital 1 and were recruited between November 2006 and March 2008. It is a national centre of excellence in the provision of children's healthcare that offers mainly tertiary care to children.

Twenty nine (6 inpatients, 23 day case) children were admitted to Hospital 2 and were recruited between March and December 2007. It is a general teaching hospital that offers specialist services in paediatric and neonatal surgery. Study participants were recruited from the general and urology specialties only.

Fifty seven (24 inpatients, 30 day case) children were admitted to Hospital 3 and were recruited between mid-April 2007 to March 2008. This hospital is a general hospital with a specialist paediatric surgical centre.

Table 4.1 Pre-operative preparation, admission and discharge procedures at participating sites

	Pre-operative preparation				Admission procedures		Discharge procedures	
Hospital	**PEIR**	**TSA**	**PS**	**IP**	**PS**	**STA/ATA/NTA**	**IP**	**TF**
Hospital 1:								
GS	✓	✓	✓*	✓	✓*	✓✓✓	✓	✓*
URO	✓	✓		✓	✓*	✓✓✓	✓	✓*
ENT	✓†				✓*	✓✓✓	✓	✓*
Hospital 2								
GS & URO		✓+	✓+	✓	✓*	✓✓✓	✓	
Hospital 3:								
ENT	✓	✓		✓	✓*	✓✓✓	✓	
GS & URO					✓*	✓✓✓	✓	

PEIR physical examination investigations and referrals, TSA tour of surgical areas, PS seen by play specialist, IP written information provided to families, STA surgical team assessment, ATA anaesthetic team assessment, NTA nursing team assessment, TF telephonic follow-up, GS general surgery, ENT ear nose and throat surgery, URO urology surgery, * only provided to children/families identified by ward staff as being in need, † telephonic assessment only, + offered to all families but <50% uptake

4.5.2 Pre-operative preparation procedures

Hospital 2 was the only hospital that did not offer a pre-admission clinic visit which included a physical examination, investigations and referrals. A formal pre-operative preparation programme run by play specialists was in operation at this hospital at the time of data collection with the main focus of adequately preparing children and their families. Hospitals 1 and 3 incorporated any formal preparation, including a tour of the surgical areas and exposure to surgery/anaesthetic related equipment, into a pre-admission clinic visit. ENT patients at Hospital 1 and general surgery and urology patients at Hospital 3 were contacted by telephone or not at all prior to admission to surgery. Most children and their families were offered written information about the proposed surgery in addition to pre-admission clinic attendance and/or formal pre-operative preparation.

4.5.3 Admission procedures

The admission procedures were similar across all of the participating sites. Children and their families were asked to arrive on the ward between 7h00 and 7h30 for morning surgery

and from 10h45 for afternoon surgery. All hospitals reported that play specialists were available on an ad-hoc basis prior to surgery and spent time with children that the nursing staff had identified as being most in need. All children were assessed by nursing teams, surgical and anaesthetic teams between admission and being taken to theatre.

4.5.4 Discharge procedures

All children and their families were offered written information or referred to the hospital website for surgery-specific information prior to discharge. Hospital 1 confirmed that parents were contacted at home by telephone if the family had been identified as being in need of follow-up by telephone by the ward staff. Hospitals 2 and 3 did not contact families by telephone post-discharge but encouraged families to contact the ward staff if they had any surgery-related concerns.

4.6 Measures

4.6.1 Primary outcome – child problematic behaviour

The primary outcome in this study was PB in children following discharge from hospital after surgery. Vernon's post-hospital behaviour questionnaire (PHBQ) was chosen to measure child PB (Vernon et al. 1993). The PHBQ is the most commonly used tool for assessing children's post-hospital behaviour and originally consisted of 28 behaviour items developed by Vernon et al (1966) following a review of the child PB literature between 1945 and 1959. One item was removed (quarrelling with brothers and sisters), as not all children have siblings. The tool consists of a list of 27 possible PB that children could exhibit, each given an equal weighting. Children serve as their own controls, i.e. each child's behaviour post-hospital / post-surgery is compared to his/her behaviour prior to hospital / surgery. Children are rated by parents as exhibiting the PB less than before surgery, the same as before surgery or more than before surgery. In the initial study in which data were collected using the PHBQ from a heterogeneous sample (387 children between the ages of 1 month and 16 years admitted to hospital for a number of different reasons, e.g. orthopaedic disorders, miscellaneous congenital defects, cardiac disorders, neurological disorders, hernias, traumatic lesions), factor analysis revealed six sub-scales: general anxiety and regression, separation anxiety, anxiety about sleep, eating disturbance, aggression toward authority and apathy-withdrawal (Vernon et al. 1993). Results of a

univariate and multivariate analyses of variance of the total and subscale scores with child age, parent occupational status, degree of pain, duration of hospitalisation and prior hospitalisation revealed significantly increased scores for separation anxiety in children six months to three years and eleven months old ($p<0.001$) and higher anxiety about sleep, aggression toward authority and apathy-withdrawal scores in children hospitalised for two to three weeks (versus those hospitalised for shorter or longer periods) ($p<0.01$) (Vernon et al. 1993). Clinic patients appeared to benefit from the experience in the area of general anxiety and regression compared to multi-bed and private patients ($p<0.001$) although it is not clear from the published report how the care provided to these patients differed. No significant differences were found for child gender, prior hospitalisation, degree of pain (estimates made from admission diagnoses only) and birth order (Vernon et al. 1993). The PHBQ showed excellent test-retest reliability over a one-month period ($r=0.65$) and total scores were also moderately correlated with ratings of PB following interviews conducted by an experienced child psychiatrist with parents of children who had tonsillectomies ($r=0.47$) (Vernon et al. 1993). The PHBQ has been validated in a Swedish paediatric population (Karling et al. 2006).

The PHBQ has been used in many studies conducted over the last four decades: two meta-analyses were published in 1993 (Thompson et al. 1993;Vernon et al. 1993) that included studies using variations of the PHBQ to describe changes in child behaviour after hospitalisation for any condition, with and without experimental interventions and in more recent years, key researchers in the field of child PB following hospitalisation for surgery have also used the PHBQ as their primary outcome measure (Kain et al. 1996c;Karling et al. 2007;Kotiniemi et al. 1997;Stargatt et al. 2006).

Two versions of the PHBQ exist. Using the original, comparative version, parents consider each behaviour listed on the questionnaire and compare their child's post-hospital behaviour with their pre-hospital behaviour. A five-point response scale ranges from the behaviour occurring "much less" than before surgery to "much more" than before surgery. The "absolute" version of the PHBQ is a modification of the original version in which parents rate their child's behaviour both before and after hospitalisation, with a comparison made of these separate ratings to assess behavioural change. The original version is simpler to administer, has a greater capacity to detect subtle changes in behaviour, and is

more indicative of psychological upset (Vernon et al. 1993). The original version was used in the current study.

A number of scoring methods are commonly used for the PHBQ:

1. Behaviour Change Score: An overall change in behaviour can be calculated by summing the scores of the 27 PB items. For this method, the parent ratings are treated as an ordinal scale: (1) “much less than before”, (2) “less than before”, (3) “same as before”, (4) “more than before” and (5) “much more than before”. Scores are calculated by summing scores at face-value to determine overall change in behaviour, i.e. total score range 27 to 135, with 27-80 representing “fewer PB”, 81 representing “no change” (overall) in behaviour and 82-135 representing “more PB”.
2. More PB: For this method, the ratings of less frequent PB or no change in PB (i.e., answers 1 to 3) are given a value = 0. The ratings of more PB (i.e., answers 4 to 5) are given a value = 1. The total score for the 27 items is computed (range 0 to 27), with higher scores indicating more PB.
3. Fewer PB: For this method, the ratings of less frequent PB (i.e., answers 1 to 2) are given a value = 1. The ratings of no change or more PB (i.e., answers 3 to 5) are given a value = 0. The total score for the 27 items is computed (range 0 to 27), with higher scores indicating fewer PB.

4.6.2 Secondary outcomes

4.6.2.1 Child pain at home

Postoperative pain at home was measured using the Faces Legs Activity Cry and Consolability (FLACC) scale, the Wong-Baker FACES pain scale, and a 0-10 numeric rating scale (NRS), depending on the age of the child (Hockenberry et al. 2003). These pain scales were chosen as they were used in the current hospital setting therefore parents and children (>5 years) were familiar with their use and research has shown that parents and children could use them accurately (Hockenberry et al. 2003;Merkel et al. 1997;Wong et al. 1988).

The FLACC has shown high inter-rater reliability and validity and provides a simple framework for quantifying pain behaviours in children who may not be able to verbalise the presence or severity of pain (Merkel et al. 1997). The FLACC consists of five categories: Face (F), Legs (L), Activity (A), Cry (C) and Consolability (C). Each category is scored from 0-2 yielding a possible total score of 0-10 with higher scores indicating higher pain levels. Parents were advised to use the FLACC for preschool children in the current study (2-4 years) as these children would not necessarily be able to verbalise their pain (presence of pain or intensity).

The Wong-Baker FACES pain scale consists of six cartoon-type faces. A smiling face represents no pain (score=0) and a tearful face represents the worst pain (score=5) with faces between these varying in degrees of facial grimaces and representing levels of pain from 2 to 4. This scale has been tested for validity and reliability (Merkel et al. 1997;Wong et al. 1988). For use in the current study, scores assigned to each face were in increments of 2, i.e. 0, 2, 4, 6, 8 and 10 yielding a possible total score of 0-10 with higher scores indicating higher pain intensity levels. Parents were advised to ask the older children in the current study (5-12 years) to rate their own pain using the Wong-Baker FACES pain scale.

In addition to the FLACC and the Wong-Baker FACES pain scale, parents were asked to rate their child's pain (all ages in the current study, i.e. 2-12 years) on a 0-10 NRS. The use of a NRS allowed parents to rate their child's pain intensity verbally (by telephone) or in questionnaire format. Child pain at home was recorded on day 2 post-discharge from hospital and again at the end of week 1, 2 and 4 either in questionnaire format or by telephone.

4.6.2.2 Other child postoperative symptoms and family's return to work/school

In addition to children's pain, open-ended questions asked parents to report any other postoperative symptoms, e.g. nausea and vomiting, that their child may have suffered from and details of parents' actions to manage pain and other symptoms. In order to describe how children's postoperative pain/other symptoms and/or PB affected family functioning, parents were given forced choice questions (yes/no) regarding whether or not they had (i)

taken their child to the general practitioner (GP) or for any other medical consultation as a result of the child's surgery, (ii) whether or not the parent had taken any additional time off work or (iii) the child any additional time off school.

4.6.2.3 Parent pre-operative anxiety

Parents' state anxiety prior to their child's surgery was measured using the State Trait Anxiety Inventory (STAI) (Spielberger 1983). This is the most widely used self-report anxiety instrument for adults. It consists of two separate 20-item scales to measure state anxiety and trait anxiety. Items are scored 1-4 and total scores range from 20-80 on each scale. Mean scores for state anxiety under stressful conditions are reported to be 43.01 for males and 43.69 for females (Spielberger 1983). The STAI has good test-retest reliability and construct and concurrent validity. Parent anxiety prior to their child's surgery has been reported as a risk factor for child PB following discharge from hospital (Carson et al. 1991;Kain et al. 1996c;Stargatt et al. 2006).

4.6.2.4 Child pre-operative anxiety

Child pre-operative anxiety was measured using the modified Yale Pre-operative Anxiety Scale (mYPAS) (Kain et al. 1997). The mYPAS is a 27-item observational measure of children's pre-operative anxiety, with five domains: activity, emotional expressivity, arousal, vocalisation, and use of parents. Total scores range from 0-100 with higher scores indicating higher levels of anxiety and a score of > 30 indicative of high anxiety. The mYPAS has good to excellent reliability and validity, it has been validated for use in children 2-12 years of age and can be used to assess the effectiveness of anxiety reduction interventions for children scheduled for surgery (Kain et al. 1997). Two researchers observed child pre-operative anxiety over the course of the data collection period and a substantial agreement in mYPAS scores was achieved, kappa = 0.76 (substantial agreement if $0.61 \leq$ kappa ≤ 0.80) (Petrie et al. 2005).

4.6.3 Potential confounding / influencing variables

A confounding variable is an explanatory variable that is related to the dependent/outcome variable and to one or more of the other explanatory variables and is best adjusted for in a multivariable regression model (Petrie et al. 2005).A number of variables were identified

from a systematic literature review (Chapter 2) and a theoretical framework (Chapter 3) as potential confounding/influencing variables on child PB, postoperative pain and child and parent pre-operative anxiety.

4.6.3.1 Parent information needs and satisfaction with information and preparation (PISP)

The PISP questionnaire was developed for the current study. The purpose of the PISP was to gather information about how parents felt regarding the information and preparation that they and their child received prior to the child's admission to hospital for surgery. The PISP includes 12-items that ask parents to describe their views on the pre-operative information and preparation they and their child received. Types of questions include 0-10 NRS for levels of being prepared for the child's admission to hospital, for the child's care at home post-discharge and for satisfaction levels regarding information received. Other questions included forced choice answers regarding when information was given/received and how this information and / or preparation was conveyed. The PISP also includes the 6-item Amsterdam Pre-operative Anxiety and Information Scale (APAIS), which showed good internal consistency, test-retest reliability, discriminate validity and sensitivity (Cassady et al. 1999;Miller et al. 1999;Spencer et al. 2005). The APAIS is a six-item self-report measure of parent pre-operative anxiety and need for information regarding their child's anaesthesia. Parents are asked to rate their level of agreement with the six items on a five-point likert scale with total scores ranging from 6 to 30 and higher scores indicating higher levels of anxiety/need for information. Two subscales can be calculated: APAIS anxiety scale (4 items, score range: 4 to 20) and APAIS need for information scale (2 items, score range: 2 to 10). APAIS total and subscale scores have been correlated to parents' STAI state anxiety scores and remained correlated after parents were given information regarding their child's anaesthesia (Miller et al. 1999).

4.6.3.2 Parent participation in the care of their hospitalised child

The Index of Parent Participation (IPP) was given to parents whose child had spent at least one night in hospital and was used to measure the level of activities that parents performed for their children while hospitalised. The IPP is a 36-item questionnaire with established construct validity and reliability that describes typical parenting behaviours in which

parents can engage during their children's hospitalisation (e.g. bathing the child) (Melnyk 1994). Parents are asked to tick the activities that they did for their child and scores are calculated as a percentage of total activities performed with higher scores indicating higher levels of parent participation. The IPP was developed and pilot-tested following a systematic review of the literature and interviews with parents to determine typical parent behaviours during their child's hospitalisation (Melnyk 1995). Favourable outcomes have been reported in parent mood states (stress and depression) and child post-hospital behaviour when parents engaged more in the care of their hospitalised children (Melnyk et al. 2004).

4.6.3.3 Parent and child satisfaction with in-hospital pain management

Parents whose child had spent at least one night in hospital were also asked to report on the information that they had received regarding their child's postoperative pain and their satisfaction with pain management. This was measured using an adapted version of the Child/Parent Total Quality Pain Management questionnaire (A-TQPM) (Foster et al. 2002). Adaptation of the questionnaire consisted of the removal of two sections of questions from the original TQPM: questions regarding parent observations of their child's response to pain medication and the length of time the child was in pain. These questions were not objectives in the current study. A child version of the A-TQPM was given to children eight years and older to complete about the information that they received regarding their own postoperative pain and their satisfaction with pain management. The Adult/Child TQPM is validated for use in children 8-12 years of age and has established construct validity and reliability (Foster et al. 2002). The purpose of the A-TQPM was to describe if parents and children were given any information regarding the child's postoperative pain management, when this information was given, how it was conveyed and how pain management could be improved. NRS and Wong-Baker FACES pain scales were included for parents and children respectively to rate the child's worst pain and expected pain while in hospital. A final open-ended question provided the opportunity for parents and children to state how they thought pain management could be improved.

4.6.3.4 Parent state and trait anxiety (STAI)

Details of this measure have been described above (secondary outcomes).

4.6.3.5 Parent coping style

The Monitor Blunter Style Scale (MBSS) identifies coping styles through four scenarios of stressful situations (i.e. you are on an aeroplane that is experiencing severe turbulence) (Miller 1987). A list of 8 possible reactions to the situation is presented and participants are asked to check each behaviour in which they would engage in that situation (i.e., look for exits or watch the in-flight movie). Total scores range from -16 to 16 and are calculated by subtracting the number of blunting items marked by parents from the number of monitoring items marked by parents (possible 16 blunting items and 16 monitoring items). Subjects are divided into high or low monitors on the basis of whether they score above or below the mean on the monitoring subscale (score range 0-16) and high and low blunters on the basis of whether they score above or below the mean on the blunting subscale (score range 0-16) (Miller 1987). The MBSS was developed for patients undergoing medical procedures and has excellent validity and reliability (Miller 1987). The MBSS has been shown to influence parents' pre-operative anxiety (Kain et al. 2000;McCann et al. 2001).

4.6.3.6 Child temperament

Child temperament was measured using the Emotionality, Activity, Sociability, and Impulsivity Instrument of Child Temperament (EASI) (Buss et al. 1984). The EASI scale assesses child temperament using 20 items in four behavioural categories: Emotionality, Activity, Sociability, and Impulsivity. Total category scores range from 5 to 25 (total score range 20 to 100), with higher scores indicating higher temperament scores in each of the five behavioural categories. The EASI has good reliability and validity and has been shown to predict increased peri-operative anxiety and specific problem behaviour responses in PHBQ categories in American children (Buss et al. 1984;Kain et al. 1996c;McCann et al. 2001).

4.6.3.7 Child pre-operative adjustment

The Strengths and Difficulties Questionnaire (SDQ) is a brief, well validated and reliable 25 item questionnaire (Goodman et al. 1998;Goodman 2001). The SDQ was used to control for pre-operative adjustment by yielding a total difficulties score, and sub-scale scores for emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour. The SDQ focuses on strengths as well as difficulties and scores can also be classified as normal, borderline and abnormal. Higher scores indicate more difficulties and lower scores more strengths. It is recommended by the Department of Health and UK norms are available. The SDQ shows significant differences between children rated as being in good or poor health (Calam et al. 2005).

4.6.3.8 Parent and child thoughts and feelings associated with pain experience

The Pain Catastrophizing Scale-Parent (PCS-P) and Pain Catastrophizing Scale-Child (PCS-C) are 13-item validated and reliable questionnaires that ask the parent/child (over 8 years) to rate the extent to which they experience the 13 thoughts and feelings when their child/they are in pain on a 5-point scale (0=not at all to 4=extremely) (Crombez et al. 2003;Goubert et al. 2006). The PCS yields a score in the rage of 0-52 with subscale scores for rumination, magnification and helplessness. Higher scores indicate more catastrophic thinking about pain. Parents' catastrophic thinking about their child's pain has had a significant contribution in explaining child illness-related parent stress, depression and anxiety and children's chronic pain-related disability and school attendance (Goubert et al. 2006). Children's catastrophic thinking about their own pain has been shown to predict chronic / recurrent pain intensity and pain-related disability (Crombez et al. 2003). The PCS-P and PSC-C were used in the current study to determine if/how parents' and children's catastrophic thinking about pain was related to parent and child pre-operative anxiety; satisfaction with information, preparation and in-hospital pain management; pain at home, return to work/school and PB.

4.6.3.9 Parent beliefs about their hospitalised child's behavioural response and their role during the child's hospitalisation

The Parental Beliefs Scale (PBS) is a validated and reliable 20-item questionnaire with subscales for parent beliefs about child behaviours and parent beliefs about their role in their child's care (Melnyk 1995). Items in the PBS operationalize parent beliefs about their hospitalized child (i.e. "I know what changes to expect in my child while he/she is in the hospital") and their role during their child's hospitalisation (i.e. "I am clear about the things that I can do to best help my child deal with being in the hospital"). Parents indicate agreement with each item on a 5-point scale (1=strongly disagree to 5=strongly agree) with higher scores indicating more positive beliefs. Positive correlations have been found between parent beliefs and their participation in their child's hospitalised care (Melnyk 1995). Stronger parent beliefs regarding their child's response to hospitalization and how they could enhance their child's adjustment have been reported following an intervention to increase parent knowledge of child behaviour and emotions and instructions regarding parent participation in their child's physical and emotional care (Melnyk et al. 2004).

4.6.3.10 Demographic and clinical questionnaire

A demographic and clinical questionnaire (DCQ) included questions regarding the family dynamics, i.e. single-parent home, education level of parent, employment status, number of children in the home, birth order of the child in the study and family's index of multiple deprivation (IMD). IMD is based on a number of indicators categorised into seven domains: income; employment; health deprivation and disability; education, skills and training; barriers to housing and services; crime; and living environment (Index of Multiple Deprivation 2007). Questions were also asked about the parent and child's previous surgeries and recent pain and anxiety during their previous medical / surgical encounter. These factors were explored in association with child / parent pre-operative anxiety, satisfaction with preparation for surgery, pain at home and any PB.

Table 4.2 includes a breakdown of all the measures and the time-points at which they were used.

Table 4.2 Measures used in study

Parent/Child Variable	Completed by:	About:	Validated measure used	When completed
Demographic & clinical details	Parent	Parent & Child	Demographic & Clinical Questionnaire (DCQ) *	5-10 days prior to surgery
Parental coping style	Parent	Parent	Monitor Blunting Style Scale (MBSS)	
Child temperament	Parent	Child	Emotionality, Activity, Sociability & Impulsivity (EASI)	
Child pre-operative adjustment	Parent	Child	Strengths & Difficulties Questionnaire (SDQ)	
Child & parent thoughts & feelings about pain	Parent & Child (>8)	Parent & Child	Pain Catastrophizing Scale (PCS-P & PCS-C)	
Parent state & trait anxiety	Parent	Parent	State & Trait Anxiety Inventory (STAI)	
Parent beliefs about child behaviour and parent role	Parent	Parent	Parent Beliefs Scale (PBS)	
Child anxiety	Child	Researcher/s	modified Yale Pre-operative Anxiety Scale (mYPAS)	Child observed prior to surgery
Parent state anxiety	Parent	Parent	State & Trait Anxiety Instrument (STAI) – state anxiety only	Prior to the child's surgery (same time as mYPAS)
Parent information needs & satisfaction with preparation	Parent	Parent/child	Parent information and satisfaction with preparation (PISP)* Including	Once child taken to theatre

			Amsterdam Pre-operative Anxiety and Information Scale (APAIS)	
Level of parent participation in child's hospitalised care	Parent	Parent	Index of Parent Participation (IPP)	Completed on Day 2 post discharge (only if child was an inpatient)
Parent & child satisfaction with child pain management	Parent & Child (>8yrs)	Parent & Child	Child/Parent Total Quality Pain Management (A-TQPM)	
Child pain, postoperative symptoms and family's return to work/school	Parent (self-report by child ≥ 5)	Child	0-10 pain NRS, Wong-Baker FACES pain scale, FLACC	Day 2, week 1, 2 and 4 post-discharge
Child post-hospital behaviour	Parent	Child	Child Post-Hospital Behaviour Questionnaire (PHBQ)	

* Measures created for current study

4.7 Recruitment and data collection procedures

The researcher was in contact with parents and children that participated in the study at least seven times over the course of the study: twice before surgery, on the day of surgery and at four follow-up time points after discharge. The inpatient population were often contacted while still in hospital to confirm the date of discharge in order for the correct follow-up days to be established.

4.7.1 Recruitment, consent and participation

All children, 2 to 12 years, scheduled for planned surgery (ENT, general or urology) were identified from the relevant surgery lists at each site. Information about the study and an invitation to participate was sent to families with their appointment letters for surgery. The invitation to participate included a return slip to be mailed back to the researcher if the

parents did not wish to be contacted further. Eligible families, who had been sent information about the study, were contacted by telephone one to two weeks after their appointment letters had been sent to discuss the study in more detail and to answer any questions the parents / children may have had. The researcher explained details of the study to the parents providing information about what participation would involve, why the study was being conducted, details regarding relevant Research Ethics Committee and Research and Development approvals and offered to answer any questions or to clarify any aspects of the study (procedure, content or purpose) that were unclear. If the parents (and children) agreed to participate parents were given the choice to meet the researcher at their child's pre-admission clinic visit (if booked to attend and if the clinic visit was a week or more prior to the date of surgery) where consent/assent forms and a baseline questionnaire set (BQS) were given to the parents. If parents preferred, the consent/assent forms and BQS were sent by post or email, for completion at least one-week prior to surgery. Signed consent/assent forms and completed BQS were collected from the parents at pre-admission clinic, returned to the researcher by post, or handed to the researcher on the day of surgery. All parents were contacted by telephone prior to admission to remind them to complete the consent/assent forms and BQS, to confirm their participation in the study and to address any study-related queries they might have had. The BQS included:

1. Demographic and clinical details (DCQ) for both the child and parent
2. Parent coping style (MBSS)
3. Parent anxiety (STAI)
4. Thoughts and feelings about pain (PCS-P and PCS-C if child > 8 years)
5. Child temperament (EASI)
6. Child pre-operative adjustment (SDQ)
7. Parent beliefs (PBS)

4.7.2 The day of surgery

Children and their parents were met by the researcher on the day of surgery shortly after admission. Children who had spent the night prior to surgery in hospital were met for the first time on the day of their surgery. Children's pre-operative anxiety was measured using the mYPAS and parents were asked to complete the STAI (state anxiety only). The parents

were also given the PISP to complete regarding their information needs and satisfaction with preparation for the child's surgery.

4.7.3 Post-discharge follow-up

The follow-up questionnaires included questions about child pain, postoperative symptoms, family's return to work/school and the PHBQ. Options regarding completion of the follow-up questionnaires were discussed with parents on the day of surgery; parents could choose to complete the questionnaires themselves with telephonic reminders at the four follow-up time-points or they could complete the questionnaires by telephone. Negligible differences have been found between PHBQ scores when questionnaires were completed during interviews with parents, when parents completed the questionnaires in hospital and when parents received the questionnaires in the post ($p>0.20$) (Vernon et al. 1966). For the parents that chose to complete the questionnaires themselves, four sets of follow-up questionnaires were given and for those who chose to complete the questionnaires by telephone a sample of the questionnaires were given so that they had a visual guide to follow. Time was spent with the parents going through each questionnaire and clarifying any issues raised, i.e. follow-up time points were calculated after the day of discharge and not the day of surgery, if the child was to spend one night or more in hospital. Parents were also given a sample of the pain assessment tools to be used on the follow-up days (FLACC for children < 5 years, Wong-Baker FACES pain scale for children ≥ 5 years and the 0-10 NRS for parents) and clear instructions regarding their use established. The children ≥ 5 years were shown the Wong-Baker FACES pain scale and were given the opportunity to ask questions regarding its use.

If the parents had been told to expect that the child might spend one or more nights in hospital, an additional set of questionnaires was given to them including the IPP and the A-TQPM. Parents were instructed to complete these questionnaires on day 2 after discharge, with the first set of follow-up questionnaires.

Dates for follow-up of each parent-child dyad were day 2 post-discharge and again at the end of week 1, week 2 and week 4. Dates relative to each parent-child dyad were written in

the study diary as well as reminders to check discharge days for children who were likely to spend at least one night in hospital.

Once the child had been discharged from hospital, additional information was recorded directly from their hospital notes. This information included the time of surgery; how long the child had to wait between admission and being taken to theatre; details of premedication or analgesia given pre-surgery and the number of nights the child spent in hospital.

At every stage during recruitment and data collection, the researcher confirmed that the parents and children were happy to participate and they were reminded that their participation was voluntary and that withdrawal at any stage would not jeopardise their child's treatment or future care in any way.

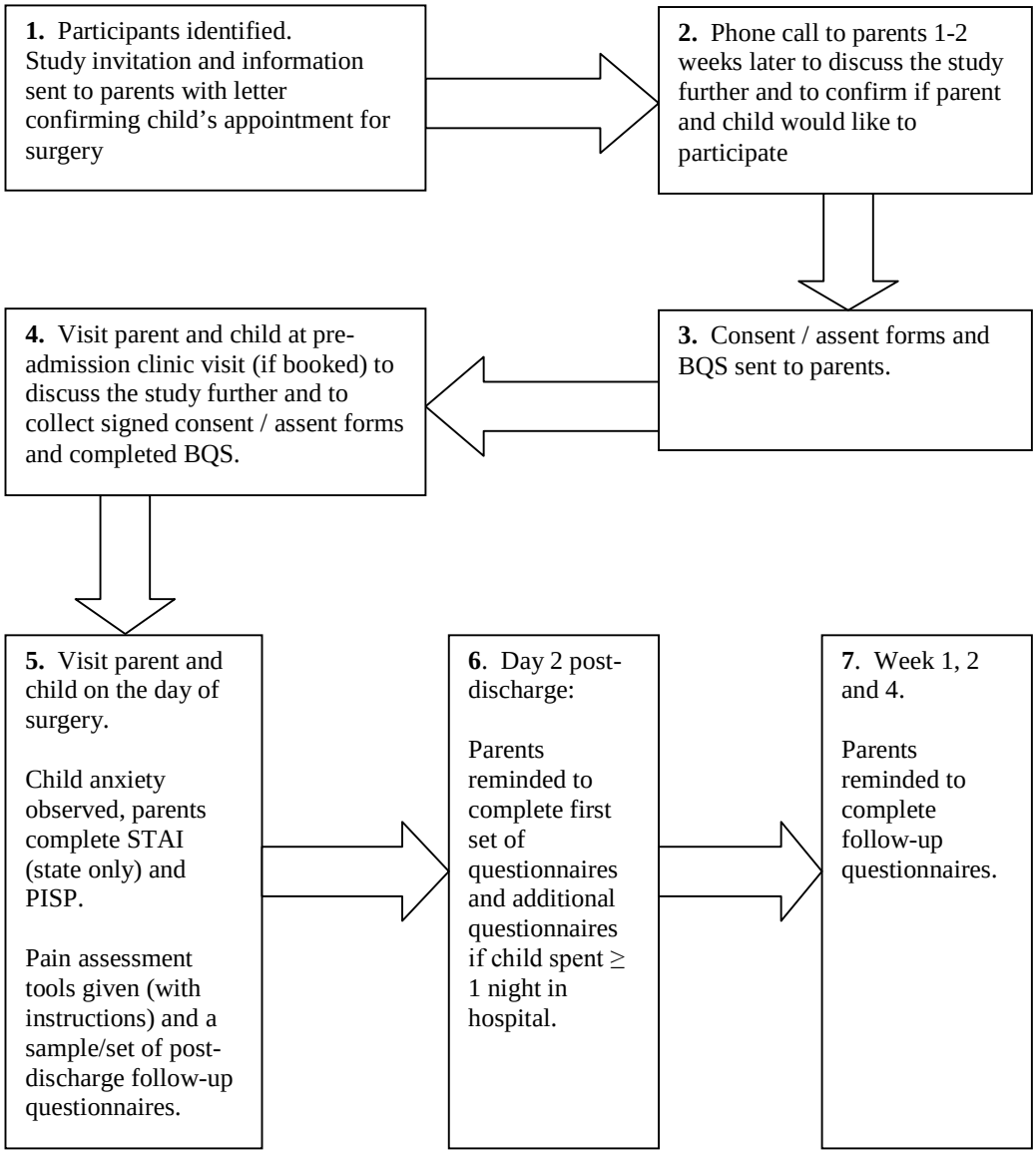


Figure 4.1 Flow chart of data collection process

4.8 Data analysis

Quantitative data analyses were performed on over 2,700 records consisting largely of numerical data received throughout the data collection period. Data analyses were performed using version 15.0 of the Statistical Package for the Social Sciences (SPSS Inc. Chicago, Illinois). Comparisons of basic demographic characteristics were made between the sample and those eligible but not recruited, and between completers and non-completers, to evaluate representativeness and possible sources of bias in the sample. The sample means and standard deviations were used to construct the interval within which

95% of the values would be expected to lie if the data were normally distributed. The interval was calculated: mean ± 1.96 standard deviation and should exclude approximately 2.5% of the sample values at either side in a normal distribution. Wherever this was not the case or where the interval had unfeasible limits, e.g. age of child -2, data were considered non-normal (Petrie et al. 2005). Most of the data in this study did not fit a normal distribution and were not compatible with normality after transforming data (logging positively skewed data and squaring negatively skewed data). Therefore non-parametric statistics were used throughout the analysis as they make no assumptions about the underlying distribution of the data, as parametric statistics do, which would result in misleading conclusions (Petrie et al. 2005).

4.8.1 Problematic behaviours: Descriptive and exploratory statistics

Children's degree of post-hospital PB as measured by the PHBQ, were presented for each of the 4 follow-up time-points under three categories: more PB; fewer PB; and overall change. Percentages of children that exhibited PB (less or more) for each of the six PHBQ subscales were also presented. Similarly, the levels of postoperative symptoms, pre-operative preparation provision and uptake, parental anxiety (both pre-admission and on the day of surgery), child pre-operative, parent views on preparation, participation and pain care (for inpatient sub-group only) were described and presented. Data were presented as means ± standard deviations if normally distributed and medians with inter-quartile ranges for non-normally distributed data.

Within-parent changes in parent anxiety at baseline and the day of surgery were calculated. Correlations and associations were tested between child PB and child/parent demographics, baseline psychological factors, pre-operative preparation provision and uptake, in-hospital factors, pain and other postoperative symptoms at home and the family's return to work/school. Correlations / associations were also tested between potential influencing variables and secondary outcomes: parent and child pre-operative anxiety, pre-operative information needs and satisfaction with preparation, pain at home. Non-parametric tests used were the Mann-Whitney and the Kruskal-Wallis tests for numerical data and the chi-squared / Fisher's exact tests for categorical data. Spearman's correlation coefficient was used for correlations tests.

4.8.2 Problematic behaviours: Multiple regression analyses

PB was dichotomised as PB (≥ 1 of the 27 PB items on the PHBQ) versus no PB. Stepwise multiple binary logistic regression analyses were performed to explore the relationships between children's PB (total and subscale scores) and potential predictor variables. These variables were grouped into (i) parent factors (demographic factors, baseline and pre-operative psychological factors, previous exposure to hospitalisation for surgery (self/children) and information/preparation received), (ii) child factors (demographic factors, baseline and pre-operative psychological factors, previous exposure to hospitalisation for surgery and information/preparation received), (iii) in-hospital factors and (iv) the family's home experience factors (child pain and family's return to work/school). Regression analyses were performed in two steps: Step 1 consisted of models constructed for each of the four groups of variables, i.e. parent factors, child factors, in-hospital factors and home factors and Step 2 consisted of a final model made up of the best predictor/s from each of the four groups in Step 1. Greater detail regarding the building of regression models is provided in Chapter six – Results: logistic regression (section 6.2).

The regression analyses were exploratory in nature and designed to generate hypotheses and areas for future more detailed and direct investigation within randomised controlled trials of different pre-operative preparation types aimed at preparing the child and parents for admission to hospital for surgery and for the child's post-discharge care at home.

4.9 Sample size estimation

A two-step approach to the binary logistic regression analyses was chosen due to the large number of possible predictor variables identified from this study. Sample size estimation was calculated from the assumption that at least 2 to 3 variables per factor group (parent, child, in-hospital and home factors) could be predictive of PB (total or subscale scores). Therefore a total of 8 to 12 (2 to 3 multiplied by 4 factor groups) variables was considered as a likely number of possible predictors. Newton et al. (1999) propose a rule of thumb for testing a multiple correlation, applying the formula $N \geq 50 + 8k$, where k is the number of independent variables. Therefore with 12 likely predictor variables, $N \geq 50 + 8(12) = 146$. This formula assumes an alpha of .05, a power of .8 and a medium effect size (Newton et

al. 1999).Taking into account that some parents and children (±15%) would be lost to follow-up or withdraw from the study following recruitment a conservative target sample size of 170 was chosen.

4.10 Ethical considerations

The main ethical considerations in this study were the participation of children less than 18 years of age and parents who were in a vulnerable state when their child was about to have surgery.

The UK Medical Research Council's Ethics Guide: Medical Research Involving Children (2007) highlights five important points to be considered when conducting research with children:

1. *Risk assessment: The foreseeable risks should be kept as low as possible and the potential benefits from the development of treatments and furthering of knowledge must outweigh any foreseeable risks.*

Risks to children and/or their parents were considered minimal. According to the MRC minimal risk (the least possible) includes procedures such as questioning, observing, and measuring children, provided that procedures are carried out in a sensitive way, respecting the child's autonomy, and that consent has been given (The UK Medical Research Council 2007). There was a possibility that children and/or their parents would become upset due to their participation in the research study. Following informed consent, a letter was sent to the family's GP informing him/her of the family's consent to participate in the study including written information about the study and contact details of the research team should further information be required.

There were no direct anticipated benefits to participants other than the opportunity to share their experience and potentially benefit others in future. Knowledge gain from the results of this study will benefit children hospitalised for surgery in the future by providing researchers and clinicians with a better understanding of the prevalence and variability of post-hospital PB, postoperative symptoms and the associated factors.

2. *Consent: The voluntary agreement of an adult or competent child, based on adequate knowledge and understanding of relevant information, to participate in the research.*

Informed, written consent was obtained from the parents / legal guardians of all children eligible to participate. Age-appropriate information sheets were given to children of reading age explaining why the research was being carried out and what it would involve. Careful consideration was given to the opinions of those children who are capable of assessing the information provided. If the child was not willing to participate this took precedence over the legal consent given by the parent. The child was asked to sign an assent form to record the outcome of the discussion. A time-frame of at least one week was given for families to decide whether or not they would like to participate and they were assured that participation was voluntary and that a decision to withdraw from the study (at any stage) would not jeopardise their child's future care in any way. At each of the contact time-points before, during and after the child's admission to hospital for surgery, the researcher confirmed that both the parent and the child were still happy to participate in the study and opportunities were given for any queries to be raised and dealt with. Examples of the information sheets for parents and children and consent/assent forms are provided in the Appendices.

3. *Confidentiality: Medical professionals have a duty of confidentiality to all patients including children.*

All parents and their children that provided consent/assent to participate in the study were assigned pseudonyms in the form of study identification numbers (representing individuals and study site). Study IDs were used to represent participant details on all participant records and only the designated researchers had access to actual participant details, which were used for follow-up purposes only. Participants were assured anonymity and no personal identifiable data was stored in any electronic form nor will they be published. The research team had access to participant data for the purpose of data evaluation and analysis.

4. *Children's safety in relation to researchers: Any individual working directly with children will undergo security screening, including criminal records review.*

Prior to data collection, researchers were subject to Criminal Records Bureau checks (2010). Researcher qualifications, research experience and occupational health status were also reviewed by each of the participating site's Research and Development and Human Resource departments. The normal NHS complaints procedures were available to participants. Details of who direct complaints could be addressed to, were included in the participant information sheets.

5. *Ethics committee review: According to guidance from The Council of Europe Protocol to the Convention on Human Rights and Biomedicine on Biomedical Research, every research project must be submitted for independent examination of its scientific merit, including assessment of the importance of the aim of research and ethical acceptability to an ethics committee (2004).*

The study protocol was reviewed by The National Research Ethics Service (NRES) in October 2006, formerly known as Central Office for Research Ethics Committee (COREC), who granted clearance for participant recruitment and data collection to commence in November 2006. The NRES is part of the National Patient Safety Agency and is comprised of NHS Research Ethics Committees (REC) in England, volunteer members and chairs, REC co-ordinators, local managers and the NRES National Patient Safety Agency division (2009). The aim of the NRES is to protect the rights, safety, dignity and well-being of research participants and to promote ethical research that could potentially benefit participants, science and society. Parent and age-appropriate child study information sheets were reviewed and cleared for distribution by the NRES.

The study protocol was also reviewed and approved by the Research and Development (R&D) department at each of the participating sites. The R&D departments ensure that quality clinical research is carried out within their respective hospitals and that all study protocols are peer reviewed prior to approval. They are also responsible for ensuring that researchers are experienced and appropriately trained in dealing with patient-related data.

Please see Appendices for copies of approval letters from the NRES (COREC at the time of study approval) and confirmation of R&D sponsorship. Also included in the Appendices

are copies of parent and child information sheets, consent/assent forms and all questionnaires.

4.11 Conclusion

This chapter detailed the study objectives and how these were best addressed by the study design, the participants, setting, variables of interest, and analyses. Children, 2 to 12 years of age, and their parents, scheduled for day case or inpatient ENT, urology and general surgery under general anaesthetic were identified and approached to participate in this descriptive prospective repeated measures study. Child PB at home post-discharge was identified as the primary outcome of this study. Secondary outcomes included postoperative pain and other symptoms at home, and child and parent pre-operative anxiety. Potential influencing/confounding variables included parent information needs and satisfaction with preparation for their child's surgery, parent and child baseline psychological measures, demographic details and previous surgical and/or pain experience. Data collection took place over 4 to 6 weeks from recruitment to follow-up four weeks after the child's discharge from hospital. Binary multiple logistic regression analyses were chosen as the best approach to address the primary study objective and an appropriate sample size estimation was calculated. Prior to commencement of data collection, the study protocol was subject to review by the Nation Research Ethics Service and the Research and Development departments at the participating hospital sites.

Chapter five provides details of descriptive statistics and exploratory analyses. The study participants will be described and the results of each individual questionnaire presented including all significant associations / correlations for the primary and secondary outcomes.

Chapter 5

Results: Exploratory and Descriptive

5.1 Introduction

Chapter four detailed the specific study objectives and how these were best addressed by the study design, the participants, setting, variables of interest, and analyses. A number of measures that were used to quantify child PB and secondary outcomes of the study were described as well as the potential influencing / predicting variables. Details and rationale were provided of data collection procedures. This chapter provides details of descriptive statistics and exploratory analysis. The study participants are described and demographic details have been compared to participants who failed to complete the study, i.e. withdrawals or loss to follow-up. The results of each individual questionnaire are described and only significant associations / correlations (at $p<.05$ significance level) for the primary and secondary outcomes are presented. For measures that were normally distributed, results are presented as mean ± standard deviation and for those that were not normally distributed results are presented as median and inter-quartile range.

5.2 Study participants

Data were received from 131 children (68.7% male, 31.3% female) 2 to 12 years of age (median 5: 3, 7) and one of their parents, scheduled for ENT (29.8%), general (35.9%) and urology (34.4%) surgery. Children were admitted for day case (54.2%) or inpatient (45.8%) surgery at three London-based hospitals (34.4% hospital 1, 22.1% hospital 2 and 43.5% hospital 3) between January 2007 and March 2008. Participant recruitment and data collection at the three participating hospitals were as follows:

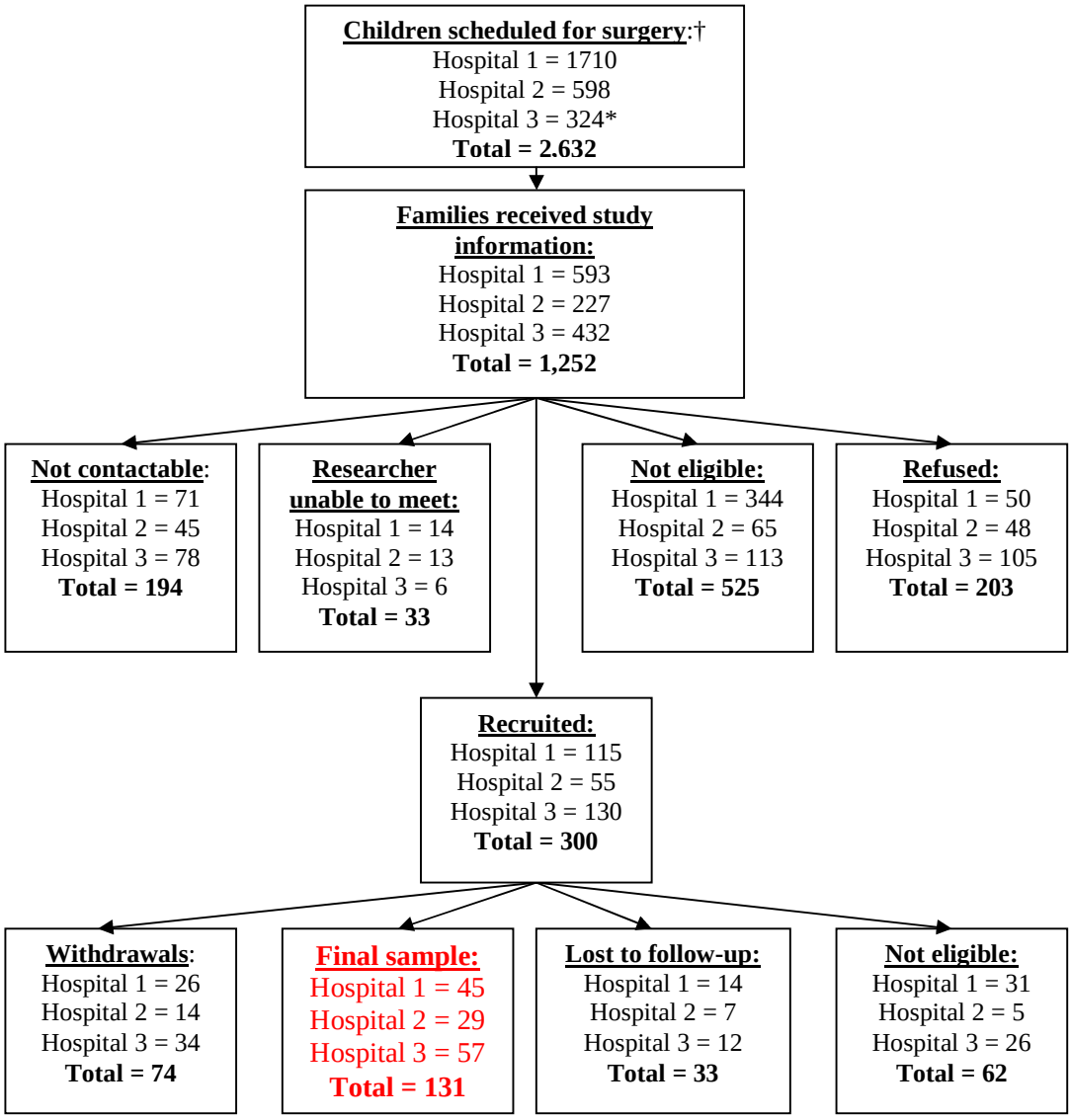
Hospital 1: November 2006 to March 2008

Hospital 2: March 2007 to December 2007

Hospital 3: mid-April 2007 to March 2008

Figure 5.1 illustrates a breakdown of the number of children who had surgery during the data collection period, those who received information about the study,

withdrawals/exclusions and finally who participated in the study. It was not always possible to screen families for eligibility prior to sending out information, which resulted in a large number of families who received information and who were contacted for telephonic screening and (if eligible) invitation to participate. Study information was not sent to families when the administrative staff who assisted with the research study, were ill, on annual leave or during periods where time constraints did not allow for information to be included with the appointment letters or accurate details to be kept of who had received the information.



† Number of children 2-12 yrs, scheduled for ENT, urology and general surgery
* Hospital 3: number of children scheduled less than number of families that received information as families whose children were scheduled for investigative procedures under general anaesthetic were also sent information

Figure 5.1 Flow chart of children included in the study

A breakdown of the number of questionnaires/measures received from the parent-child dyads included in the analysis is presented in Table 5.1.

Table 5.1 Completed questionnaires/measures

Questionnaire / measure	N
Baseline questionnaire set	
Parent demographics	131
Child demographics	131
MBSS	124
EASI	127
SDQ	125
PCS-P	125
PCS-C	29
STAI-State	121
STAI-Trait	125
PBS	125
Day of surgery	
mYPAS	118
STAI-State	115
PISP	124
Peri-operative details	131
Post-discharge follow-up questionnaires	
Symptoms and return to work/school	
Day 2	129
Week 1	115
Week 2	119
Week 4	113
PHBQ	
Day 2	117
Week 1	116
Week 2	119
Week 4	110
Inpatient group questionnaires	
IPP	55
Child A-TQPM	10
Parent A-TQPM	49

MBSS Monitor-Blunter Style Scale, EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire, PCS Pain Catastrophising Scale, P parent, C child, STAI State Trait Anxiety Inventory, PBS Parent Beliefs Scale, mYPAS modified Yale Pre-operative Anxiety Scale, PISP parent information needs and satisfaction with preparation, PHBQ Post-Hospital Behaviour Questionnaire, IPP Index of Parent Participation, A-TQPM Adapted Total Quality Pain Management,

5.2.1 Refusals, withdrawals, non-eligible participants and participants lost to follow-up

Only the child's surname and hospital allocation were available for children whose families received study information but were not contactable (N=194), those who the researcher was unable to see (N=33), those not eligible after initial screening (N=525) and whose parents refused to participate (N=203). Therefore no comparisons can be made between these children and those recruited. From the 300 children recruited, only child gender and age were available for those who withdrew prior to surgery (N=74) and those who were no longer eligible (N=62). A significant majority of the children in both of these groups were older (5-12 vs. 2-4 years) (see Tables 5.2 and 5.3).

Table 5.2 Child age-group differences between participants in final sample and those that withdrew following recruitment

Comparison variable	Final sample (N=131)	Withdrawals after recruitment (N=74)	p-value
Child age-group			
2-4 years	44.3%	11.5%	P<.001
5-12 years	55.7%	88.5%	

Reasons for families withdrawing prior to surgery consisted of: no contact between the family and the researcher (2.7%), families not having enough time to participate (34.7%), families no longer interested in participating (49.3%) and families too stressed to participate (13.3%).

Table 5.3 Child age-group differences between participants in final sample and those no longer eligible following recruitment

Comparison variable	Final sample (N=131)	Not eligible after recruitment (N=62)	p-value
Child age-group			
2-4 years	44.3%	10.2%	P<.001
5-12 years	55.7%	89.8%	

Following recruitment, a number of families were identified as no longer eligible for participation and reasons included: children > 12 years old (3.2%), children with developmental delay (14.5%), children who were to be admitted to intensive care following their surgery (3.2%), families who were unable to communicate adequately in English and who could not complete all the questionnaires (14.5%) and children no longer having surgery (62.8%).

Thirty three families were lost to follow-up and did not return any of the post-hospital questionnaires. Demographic variables, baseline and pre-operative psychological variables were available for comparison between the final sample (N=131) and those lost to follow-up (N=33) as baseline questionnaire sets and pre-operative anxiety measures were completed for these children. There were significantly more single-parents in the group that did not return any post-hospital questionnaires compared to those that did. Children in the lost to follow up group had significantly lower temperament sociability, higher emotional symptoms and peer problems. Parents also had significantly higher baseline state and trait anxiety and higher catastrophic thoughts regarding their child's possible postoperative pain. Significant differences are presented in Table 5.4.

Table 5.4 Comparison of baseline psychological variables between participants in final sample and those lost to follow-up

Comparison variable	Final sample (N=131)	Sample lost to follow-up (N=33)	p-value
Parent marital status			
Single-parent	22.4%	40.6%	p=.036
Living with partner	77.6%	59.4%	
Child EASI			
Sociability	17.73 ± 2.9	16.31 ± 2.8	p=.016
Child SDQ total score	9 (5, 14.5)	12 (8, 18.5)	p=.015
Emotional symptoms	2 (1, 3)	3 (1.5, 5.5)	p=.008
Peer problems	1 (0, 3)	3 (1, 4.5)	p=.008
Parent PCS total score	23.91 ± 11.5	37.04 ± 12.2	p<.001
Magnification	4.2 ± 2.9	7.7 ± 3.7	p<.001
Helplessness	8.61 ± 6	14.48 ± 6	p<.001
Rumination	11.1 ± 3.7	14.85 ± 4	p<.001

Parent baseline STAI			
State anxiety	37 (26.8, 48)	48 (37, 52)	p=.001
Trait anxiety	37 (30, 46.5)	44 (40, 50.5)	p=.008

EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire, PCS Pain Catastrophising Scale, STAI State Trait Anxiety Inventory

5.2.2 Demographic, clinical and baseline psychological factors

Only one parent per child was invited to participate in the research and this was usually the parent who planned to remain with the child on the day of surgery and during their hospital stay (for the inpatient group). In most cases this was also the parent who spent more time with the child at home and who would complete the follow-up questionnaires. Table 5.5 provides details of parent demographics.

Table 5.5 Parent demographics

Participating parent	%
Mother	90.8
Father	8.4
Other (foster mother)	0.8
Age of parent	
20-25	4
26-30	8.7
31-35	21.4
36-40	31.7
>40	34.1
Marital status	
Married/in-house partner	77.6
Single/divorced/separated	22.4
Ethnicity	
White British	62
Black British	10.9
Asian British	3.9
Other	23.3
Education level	
Primary school	0.9
Secondary school	40.7
Graduate	37.2

Post-graduate	21.2
Occupation*	
Managers and senior officials	9.1
Professional occupations	14.9
Associate professional and technical occupations	8.3
Administrative and secretarial occupations	12.4
Skilled trades occupations	1.7
Personal service occupations	10.7
Sales and customer service occupations	3.3
Elementary occupations	2.5
Unemployed/stay-at-home parent/retired	33.9
Student	3.3

*Parents' occupations were categorised according to the Office for National statistics – standard occupation classification (2000)

Child demographic and clinical characteristics are shown in Table 5.6 by comparison between the inpatient and day case population.

Table 5.6 Child demographic and clinical characteristics

Variable	**Inpatients (N = 60)**	**Day case patients (N = 71)**
Boys n (%)	40 (66.7%)	50 (70.4%)
Girls n (%)	20 (33.3%)	21 (29.6%)
Age group		
2-4 years	31 (51.7%)	27 (38%)
5-12 years	29 (48.3%)	44 (62%)
Number of siblings (median: IQR)	1: 1, 2	1: 1, 2
Attending school		
Yes	44 (73.3%)	48 (71.6%)
No	16 (26.7%)	19 (28.4%)
Hospital		
1	30 (50%)	15 (21.1%)
2	6 (10%)	23 (32.4%)
3	24 (40%)	33 (46.5%)
Specialty		
ENT	27 (45%)	12 (16.9%)
General	19 (31.7%)	28 (39.4%)
Urology	14 (23.3%)	31 (43.7%)

Prior surgery		
Yes	24 (45.3%)	24 (36.9%)
No	29 (54.7%)	41 (63.1%)
Recent prior pain experience*		
Yes	29 (53.7%)	24 (43.6%)
No	25 (46.3%)	31 (56.4%)
Premedication given		
Yes	11 (19.6%)	12 (17.9%)
No	45 (80.4%)	55 (82.1%)
Induction type		
Inhalation	30 (55.6%)	36 (53.7%)
Intravenous	24 (44.4%)	31 (46.3%)

ENT Ear Nose and Throat, * Pain experienced during last medical procedure e.g. GP visit, pre-surgery examination/check-up by consultant, routine immunizations, venipuncture and blood tests

5.2.2.1 Parent and child's previous medical/surgical encounters

Details of both parents' and their child's previous medical/surgical experiences were recorded (Table 5.7). Parents were asked about their child's most recent medical procedure and asked to rate their child's anxiety and pain intensity (if any) on a 0-10 numeric rating scale (NRS). Medical procedures included a variety of consultations e.g. GP visit, pre-surgery examination/check-up by consultant, routine immunizations, venipuncture and blood tests. Parents' anxiety and pain referred to the parents' last hospitalisation for surgery. Two questions (baseline questionnaire set, page 2, questions 7 and 10 – see Appendix) that asked the parents to provide information about the child's medical/surgical conditions have been excluded from any analysis, as the type of answers provided varied so greatly. It is possible that it was not clear exactly what information was required.

Table 5.7 Parent and child's previous surgical experiences

Parent's admission to hospital for surgery (Y/N) (%)	74.8/25.2
Number of previous surgeries (N) (%)	1-2 (53.2)
	3-5 (39.4)
	>5 (7.4)
Anxiety during last hospitalisation for surgery (median; IQR)	5; 2.75, 8
Worst pain (median; IQR)	5.5; 3, 7.5
Has this/other child had surgery before (Y/N) (%)	45.7/54.3

Accompanied this/other child for surgery (Y/N) (%)	91.7/8.3
Child had previous surgery (Y/N) (%)	40.7 / 59.3
Number of previous surgeries (median; IQR)	2; 1, 3
Child's anxiety during last medical procedure (median; IQR)	4; 1, 7
Child recent prior pain experience* (Y/N) (%)	48.6 / 51.4
Pain during procedure (median; IQR)	4; 1.5, 7

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests

5.2.2.2 Parent and child's baseline psychological measurements

Parents were asked to complete four baseline psychological measures about themselves. These included a measure of their coping style (MBSS), their general anxiety (STAI state and trait), their thoughts and feelings about the pain that their child would experience (PCS-P) and their beliefs about their participation in their child's hospitalised care (PBS).

Parents completed two baseline psychological measures about their child, one related to child temperament (EASI) and the other to their child's pre-operative adjustment (SDQ). Children over the age of eight were invited to complete a measure concerning their thoughts and feelings about any pain they would experience (PCS-C).

Summary statistics for each of the measures and their subscales, where applicable, are provided in Tables 5.8 and 5.9.

Table 5.8 Parent baseline psychological measures

Measure (Range)	Mean ± SD	Median	IQR
MBSS (-16 - 16)	5.13 ± 3.46		
Total monitoring (0-16)	7.8 ± 3.2		
Total blunting (0-16)	2.67 ± 1.95		
STAI			
State (20-80)		37	26, 49.5
Trait (20-80)		37	30, 46.5
PCS (0-52)	23.91 ± 11.49		
Magnification (0-12)	4.2 ± 2.9		
Helplessness (0-24)	8.61 ± 6		
Rumination (0-16)	11.1 ± 3.66		

PBS (20-100)	74.2 ± 11.84
Child behaviour (8-40)	27.16 ± 6.31
Parent role (12-60)	47.04 ± 6.79

MBSS Monitor-Blunter Style Scale, STAI State Trait Anxiety Inventory, PCS Pain Catastrophising Scale, PBS Parent Beliefs Scale

Table 5.9 Child baseline psychological measures

Measure (Range)	Mean ± SD	Median	IQR
EASI (20-100)	60.71 ± 9.62		
Emotionality (5-25)	12.36 ± 4.04		
Activity (5-25)	16.41 ± 4.43		
Sociability (5-25)	17.73 ± 2.92		
Impulsivity (5-25)	14.2 ± 4.04		
SDQ (0-40)		9	5, 14.5
Emotional symptoms (0-10)		2	1, 3
Conduct problems (0-10)		1	0, 2.75
Hyperactivity (0-10)		4	2, 6.1
Peer problems (0-10)		1	0, 3
Pro-social (0-10)		8	6.46, 9
PCS (0-52)	26.41±10.44		
Magnification (0-12)	5.14 ± 3.08		
Helplessness (0-24)	10.74 ± 5.82		
Rumination (0-16)	10.55 ± 3.46		

EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strength and Difficulties Questionnaire, PCS Pain Catastrophising Scale

5.2.2.3 In-hospital factors

The child's notes were reviewed once the child had been discharged from hospital. An attempt was made to collect as much data as possible on the child's analgesia prescribed and given and on pain assessment and management. Unfortunately, due to inconsistency in reporting (or lack thereof) between hospitals and between specialties within the same hospital, these data were often not reported or filed elsewhere and therefore not retrieved. Too much of these data were missing for any analysis to be performed. Therefore, the only information collected from the child's notes that was used in the analysis consisted of: the length of time between the child's admission to hospital and his/her surgery, length of hospital stay, premedication prescribed (Y/N) and type of induction

(intravenous/inhalation). The median length of time that a child waited for surgery was 225 minutes (3hours and 45min). The shortest wait for surgery was 45 min (1 child) and 5 children were admitted to hospital the night before their surgery, therefore waiting for periods greater than 12 hours. 18.7% of the children were prescribed premedication (data missing from 8 children) and of those that were, 2 were given Atropine and 21 Midazolam. The type of induction was only retrieved from 121 child notes (10 missing); 49.6% were given intravenous anaesthetic induction and 50.4% inhalation induction. 54.2% children were admitted for day case surgery and 45.8% spent at least one night in hospital.

A list of surgeries that children were admitted to hospital for is presented in Table 5.10.

Table 5.10 List of surgeries that children were admitted for

Surgery	**N**
ENT	
Tonsillectomy with/without adenoidectomy/grommets	20
Adenoidectomy / grommets / both	10
Bone anchored hearing aid / cochlear implant	3
Excision brachial fistula	1
Meatoplasty	1
Removal of intercranial dermoid cyst	1
Removal of stone in salivary gland	1
Repositioning of salivary glands	1
Tympanoplasty and right mastoid exploration	1
General	
Hernia repair	21
Excision of lump/mole/cyst	5
Nissen Fundoplication	4
Rectal biopsies	3
Oesophageal dilatation and biopsies	3
PEG insertion	3
Anal dilatation	1
Distal colectomy	1
Duodenal biopsy	1
Excision of accessory digit	1
Removal of spleen and gall bladder	1
Repair of ingrown toenail	1

Reversal of colostomy	1
Urology	
Circumcision	13
Orchidopexy	11
Urethral / ureteric procedure	5
Ligation patent processus vaginalis	5
Hypospadias repair	3
Kelly procedure	2
First stage Fowler-Stephens	1
Partial nephrectomy	1
Removal of renal obstruction	1
Repair of hydrocele	1

ENT, ear nose and throat, PEG percutaneous endoscopic gastrostomy

5.3 Behaviour changes

The PHBQ consists of a list of 27 PB exhibited by children. Parents were asked to rate their child from 1 to 5 for each item: 1 to 2 indicating that the child exhibited the listed behaviour much less and less than before surgery, 3 indicating no change from before surgery or if the behaviour was not applicable to the child and 4 to 5 indicating that the child exhibited the behaviour more and much more than before surgery. Three scores were calculated for changes in child behaviour at the four follow-up time-points (day 2, end of week 1, 2 and 4): more PB (versus no change/fewer PB), fewer PB (versus no change/more) and overall change, i.e. more or fewer PB or no change.

5.3.1 The incidence of children who exhibited problematic behaviours

In order to determine how many of the possible 27 PB a child exhibited, scores for each item were transformed as follows: scores 1 to 3 = 0 and scores 4 to 5 =1, the resultant score range being 0-27. Table 5.11 provides a breakdown of the medians and inter-quartile ranges (IQR) for each of the four follow-up time-points.

Table 5.11 Child problematic behaviours

PHBQ (Range)	Median	IQR
PB (0-27)		
Day 2	2	0, 6
Week 1	1.5	0, 4
Week 2	0	0, 2
Week 4	0	0, 2

PHBQ Post-Hospital Behaviour Questionnaire, PB problematic behaviour

73.3% children exhibited PB in at least one of the 27 items on day 2 post discharge from hospital. 58.6% at the end of week 1, 42.9% at the end of week 2 and by the end of week 4 PB were reported in 31.8% children. There was a significant decrease in PB over time ($p<.001$). Table 5.12 provides a breakdown of the frequency of reported PB items at each of the four follow-up time points, rank ordered (descending %) for week 2.

Table 5.12 Frequency of problematic behaviour change items

Behaviour statement (subscale)	D2 (n=117) %	Wk1 (n=116) %	Wk2 (n=119) %	Wk4 (n=110) %
* Does your child…				
have temper tantrums? (AA)	12.8	18.1	15.1	11.8
make a fuss about eating? (EA)	23.9	17.2	13.4	10
get upset when you leave him for a few minutes? (SA)	28.2	15.5	13.4	8.2
spend time trying to get or hold your attention? (SA)	25.6	19.8	13.4	10
get upset when someone mentions doctors/hospitals? (SA)	17.1	12.9	11.8	12.7
have bad dreams at night or wake up and cry? (SA)	18.8	14.7	10.9	9.1
have trouble getting to sleep at night? (SL)	9.4	13.8	10.9	7.3
make a fuss about going to bed at night? (SL)	12	14.7	10.9	8.2
tend to disobey you? (AA)	10.3	13.8	10.1	7.3
follow you everywhere around the house? (SA)	12	18.1	9.2	7.3
Is your child afraid of the dark? (SL)	6.8	12.1	9.2	5.5
have a poor appetite? (EA)	24.8	17.2	9.2	10
have irregular bowel movements? (GA)	17.9	12.1	8.4	6.4
have difficulty making up his mind? (GA)	7.7	11.2	7.6	2.7
Is it difficult to get your child to talk to you? (AW)	11.1	6.9	7.6	1.8
need a lot of help doing things? (AW)	28.2	12.9	6.7	4.5
seem to avoid/afraid of new things? (GA)	5.1	6.9	5	4.5

break toys or other objects? (AW)	0.9	2.6	5	2.7
wet the bed at night? (AW)	5.1	4.3	4.2	3.6
bite his fingernails? (GA)	6.8	5.2	4.2	2.7
Is it difficult to get your child interested in doing things? (AW)	11.1	6	4.2	1.8
spend time just sitting/lying doing nothing? (EA)	39.7	18.1	2.5	2.7
seem to be shy around strangers? (AW)	15.4	9.5	2.5	4.5
uninterested in what goes on around him? (GA)	10.3	4.3	1.7	0.9
suck his fingers or thumbs? (GA)	4.3	1.7	1.7	0.9
need a pacifier? (GA)	6	1.7	0.8	1.8
seem to be afraid of leaving the house with you? (GA)	6	4.3	0.8	0

GA general anxiety and regression, SA separation anxiety, EA eating disturbance, AA aggression toward authority, AW apathy/withdrawal, SL anxiety about sleep, * statements rank ordered on frequency at week 2

Figure 5.2 represents the children (%) with PB based on the 6 subscales of the PHBQ over the four follow-up time-points.

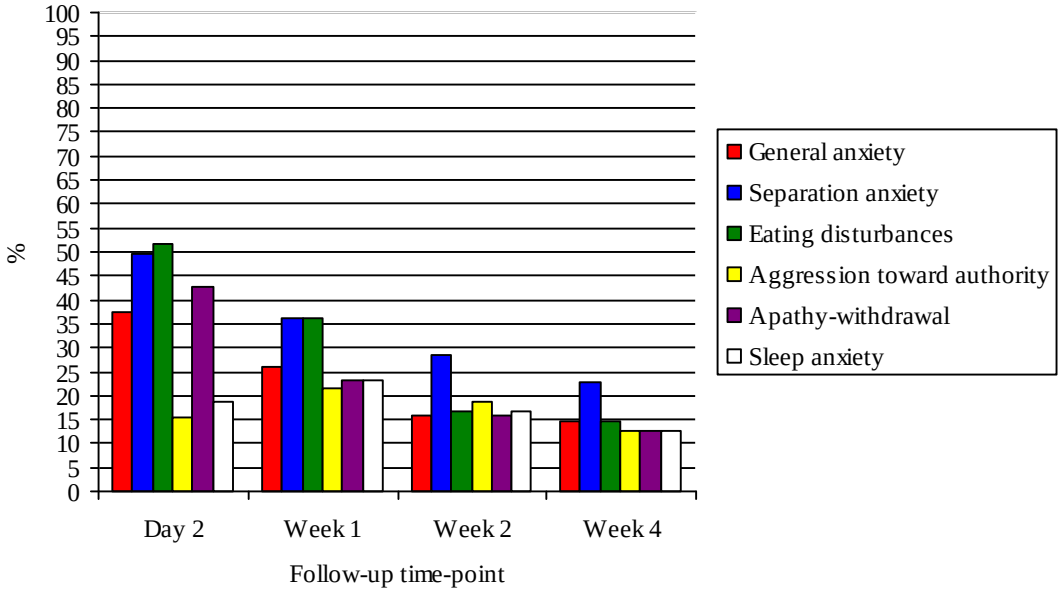


Figure 5.2 PB exhibited post-discharge based on subscales of the PHBQ

5.3.2 The incidence of children who exhibited fewer problematic behaviours

Over 25% children exhibited fewer PB compared to pre-operative behaviour in at least one of the 27 items at all four follow-up time-points: 39.7% on day 2, 31.9% at the end of week 1 and week 2 and 25.5% at the end of week 4. Table 5.13 provides a breakdown of the

frequency of reported PB items that children exhibited less at each of the four follow-up time points, rank ordered for week 2.

Table 5.13 Frequency of fewer problematic behaviour change items

Behaviour statement (subscale)	D2 (n=117) %	Wk1 (n=116) %	Wk2 (n=119) %	Wk4 (n=110) %
*Does your child…				
spend time just sitting/lying doing nothing? (EA)	10.3	12.1	14.3	12.7
make a fuss about eating? (EA)	12	9.5	13.4	13.6
wet the bed at night? (AW)	9.4	12.1	13.4	11.8
get upset when someone mentions doctors/hospitals? (SA)	6	12.1	13.4	11.8
need a pacifier? (GA)	15.4	14.7	12.6	10
uninterested in what goes on around him? (GA)	7.7	12.1	12.6	13.6
Is it difficult to get your child to talk to you? (AW)	10.3	12.1	12.6	11.8
seem to be shy around strangers? (AW)	6	5.2	12.6	10
Is it difficult to get your child interested in doing things? (AW)	8.5	11.2	11.8	10.9
seem to be afraid of leaving the house with you? (GA)	12.8	11.2	10.9	10
seem to avoid/afraid of new things? (GA)	9.4	9.5	10.9	10.9
have a poor appetite? (EA)	8.5	8.6	10.9	12.7
bite his fingernails? (GA)	12.8	13.8	10.1	9.1
get upset when you leave him for a few minutes? (SA)	7.7	11.2	10.1	10
need a lot of help doing things? (AW)	6.8	5.2	10.1	10
suck his fingers or thumbs? (GA)	11.1	11.2	10.1	9.1
make a fuss about going to bed at night? (SL)	10.3	8.6	9.2	11.8
have difficulty making up his mind? (GA)	6.8	6.9	9.2	10.9
follow you everywhere around the house? (SA)	9.4	8.6	9.2	9.1
spend time trying to get or hold your attention? (SA)	5.1	6	9.2	7.3
have bad dreams at night or wake up and cry? (SA)	8.5	10.3	9.2	10.9
have temper tantrums? (AA)	9.4	6	8.4	6.4
tend to disobey you? (AA)	8.5	8.6	8.4	6.4
break toys or other objects? (AW)	10.3	10.3	8.4	6.4
have irregular bowel movements? (GA)	7.7	8.6	7.6	10
have trouble getting to sleep at night? (SL)	9.4	7.8	7.6	10
Is your child afraid of the dark? (SL)	8.5	6	5.9	7.3

GA general anxiety, SA separation anxiety, EA eating disturbances, AA aggression to authority, AW apathy/withdrawal, SL sleep disturbances
* statements rank ordered on frequency at week 2

Figure 5.3 represents PB exhibited less than before surgery based on the 6 subscales of the PHBQ.

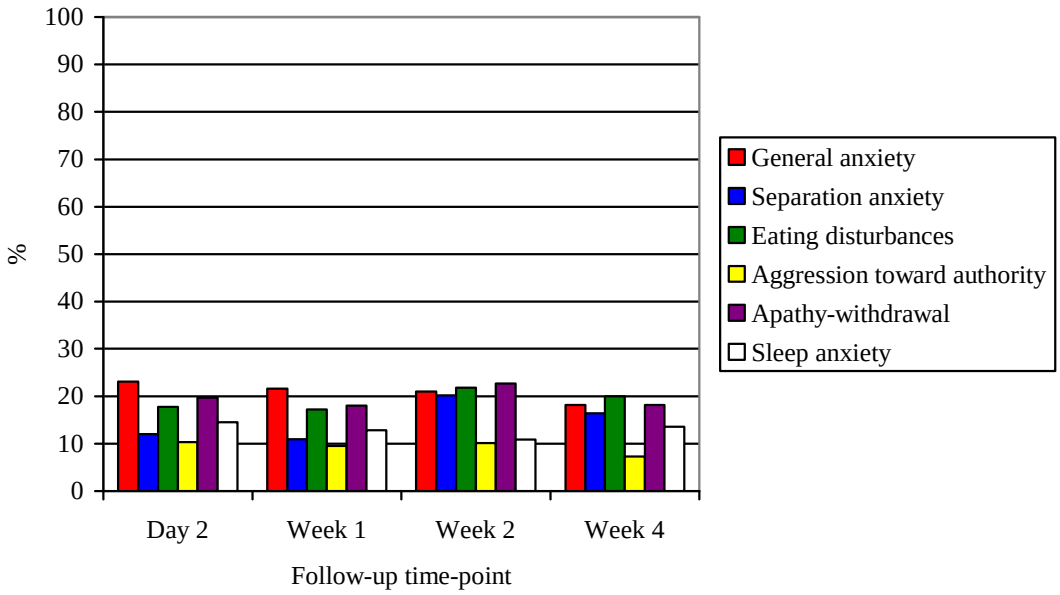


Figure 5.3 PB exhibited less post-discharge based on the subscales of the PHBQ

5.3.3 Overall change in behaviour

For the overall change in behaviour, items 1-27 were scored at face value with a resultant total score ranging from 27 to 135. Scores 27 – 80 indicated that overall children exhibited PB less than before surgery, a score of 81 indicated no overall change in behaviour and scores 81 – 135 indicated overall PB.

On day 2 post-discharge, 17.9% of the children exhibited fewer PB than before surgery. This increased slightly to 18.1% at the end of week 1 and 20.2% at the end of week 2. By week 4 17.3% of the children still exhibited fewer PB. A score of 81 was reported for 23.1% of the children on day 2, 32.8% at the end of week 1, 48.7% at the end of week 2 and 57.3% at the end of week 4. Overall PB was reported in 59% on day 2, 49.1% at the end of week 1, 31.1% at the end of week 2 and 25.4% at the end of week 4.

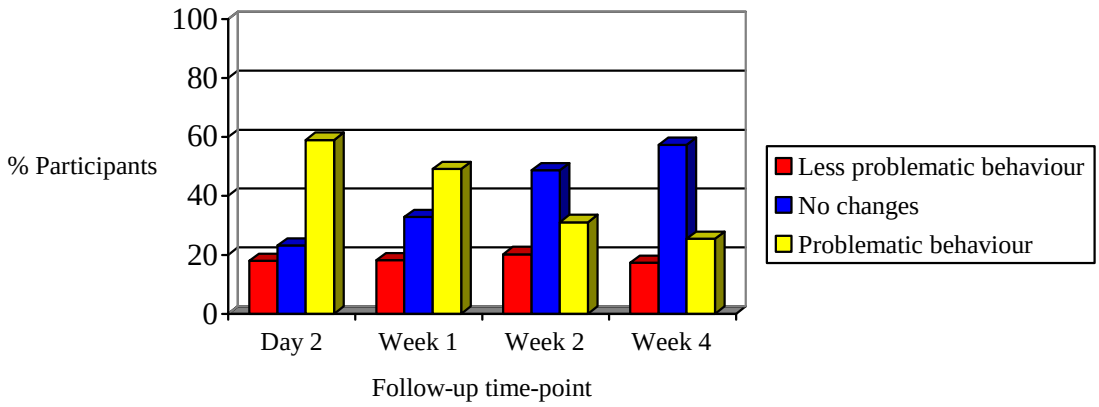


Figure 5.4 Overall changes in behaviour

5.3.4 Significant correlations / associations with problematic behaviours

PB total scores and subscale scores were tested for correlations / associations with demographic and clinical factors, baseline and pre-operative psychological measures, in-hospital factors, parent information needs and satisfaction with preparation scores, levels of parent participation and satisfaction with pain management (for inpatient group only), post-discharge pain scores and return to work/school.

5.3.4.1 Demographic and clinical factors

On day 2 post-discharge children higher in birth order (rho=-.214, p=.036, N=96) and children whose parents were more educated (graduates / post-graduates vs. school education) (median score 3 vs. 2, p=.036, N=103) exhibited more PB (total scores). Factors associated with behaviour changes in any of the six subscales but not with the PB total scores were: younger child age (2-4 vs. 5-12 years) (separation anxiety: median score 1 vs. 0, p=.001, N=117), children without prior surgical experience (separation anxiety: 1 vs. 0, p=.025, N=105), children whose families had a higher deprivation index (aggression toward authority: rho=-.271, p=.005 and anxiety about sleep: rho=-251, p=.009, N=107) and lower parent anxiety during parent's last hospitalisation for surgery (general anxiety: rho=-.299, p=.005 and apathy-withdrawal: rho=-.214, p=.049, N=85).

At the end of week 1, factors associated with PB total scores and/or subscales were: younger child age (total score: median 2.5 vs. 0, p=.003 and separation anxiety: 1 vs. 0, p<.001, N=115), children who had had a recent prior pain experience (total score: median 2 vs. 0, p=.005, N=95), children higher in birth order (total score: rho=-.238, p=.020, eating disturbance: rho=-.208, p=.042 and anxiety about sleep: rho=-.273, p=.007, N=96), number of children the parent had (total score: rho=-.188, p=.05, separation anxiety: rho=-.241, p=.012 and anxiety about sleep: rho=-.210, p=.029, N=109), children whose parents were more educated (total score: median 2 vs. 0, p=.005, N=100), children whose families had a higher deprivation index (general anxiety: rho=-.202, p=.038 and apathy-withdrawal: rho=-.264, p=.006, N=105) and lower parent anxiety during the parent's last hospitalisation for surgery (general anxiety: rho=-.311, p=.004, N=83).

Factors associated with PB total scores at the end of week 2 were younger child age (median 1 vs. 0, p=.023, N=118), children who had had a recent prior pain experience (median 1 vs. 0, p=.03, N=98) and children whose parents who were more educated (median 1 vs. 0, p=.037, N=103). Children whose families had a higher deprivation index had more general anxiety (rho=-.255, p=.008) and more apathy-withdrawal (rho=-.252, p=.009) (N=108).

By the end of week 4, no child or parent demographic or clinical factors were associated / correlated with PB.

5.3.4.2 Baseline and pre-operative psychological measures

On day 2 and at the end of week 1, 2 and 4 post-discharge parent baseline state and trait anxiety, child temperament factors, parent beliefs about child behaviour and parent role and parent pain catastrophising were significantly correlated with PB total scores. Parent coping style was significantly correlated to the subscales apathy-withdrawal and anxiety about sleep at the end of week 1. Child pain catastrophising was significantly correlated to eating disturbance on day 2 post-discharge and again at the end of week 2 and 4 but not at the end of week 1. Child pre-operative anxiety was only correlated to the eating disturbance subscale at the end of week 1. Table 5.14 provides details of significant correlations (Spearman's rho).

Table 5.14 Negative behaviour changes and significant baseline and pre-operative psychological correlates

	Child EASI total	Child EASI – E	Child EASI-A	Child EASI-S	Child EASI-I	Child SDQ total	Child SDQ-ES	Child SDQ-CP	Child SDQ-PP	Child SDQ-H	Child PCS total	Child PCS-R	Child PCS-H
Day 2 PB total	NS	.213 (N=113)	NS	NS	NS	NS	.203 (N=111)	NS	NS	NS	NS	NS	NS
GA	NS	NS	-.219 (N=114)	-.218 (N=114)	NS	NS	.294* (N=111)	NS	NS	NS	NS	NS	NS
SA	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
SL	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
EA	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	-.412 (N=26)	NS
AA	NS	NS	NS	-.201 (N=114)	NS	NS	NS	.203 (N=111)	NS	NS	NS	NS	NS
AW	NS	.233 (N=113)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Week 1 PB total	NS	.217 (N=113)	NS	-.337** (N=113)	NS	.208 (N=111)	.223 (N=111)	NS	.218 (N=111)	NS	NS	NS	NS
GA	NS	NS	NS	-.239 (N=113)	NS	NS	NS	NS	NS	NS	NS	NS	NS
SA	NS	NS	NS	-.209 (N=113)	.204 (N=113)	.198 (N=111)	NS	NS	.211 (N=111)	NS	NS	NS	NS
SL	NS	.269* (N=113)	NS	-.277* (N=113)	NS	.236 (N=111)	.231 (N=111)	.197 (N=111)	.206 (N=111)	NS	NS	NS	NS
EA	NS	NS	NS	NS	NS	.197 (N=111)	.266* (N=111)	NS	NS	NS	NS	NS	NS
AA	NS	NS	NS	-.273* (N=113)	NS	NS	NS	.217 (N=111)	NS	NS	NS	NS	NS
AW	NS	.308** (N=113)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS

	Child EASI total	Child EASI – E	Child EASI-A	Child EASI-S	Child EASI-I	Child SDQ total	Child SDQ-ES	Child SDQ-CP	Child SDQ-PP	Child SDQ-H	Child PCS total	Child PCS-R	Child PCS-H
Week 2 PB total	NS	NS	NS	-.200 (N=116)	.190 (N=116)	.250* (N=114)	.191 (N=114)	.251* (N=114)	.202 (N=114)	NS	NS	NS	NS
GA	NS	NS	NS	-.206 (N=116)	NS	.252* (N=114)	.193 (N=114)	.219 (N=114)	.234 (N=114)	NS	NS	NS	NS
SA	NS	NS	NS	-.236 (N=116)	.235 (N=116)	.253** (N=114)	.208 (N=114)	.231 (N=114)	.218 (N=114)	NS	NS	NS	NS
SL	NS	NS	NS	-.227 (N=116)	NS	.246* (N=114)	.208 (N=114)	.221 (N=114)	NS	NS	NS	NS	NS
EA	NS	NS	NS	NS	NS	.193 (N=114)	.199 (N=114)	NS	NS	NS	.441 (N=25)	NS	.490 (N=25)
AA	NS	NS	NS	-.269* (N=116)	NS	.197 (N=114)	NS	.231 (N=114)	NS	NS	NS	NS	NS
AW	NS	.201 (N=116)	NS	NS	NS	.193 (N=114)	NS	.235 (N=114)	.204 (N=114)	NS	NS	NS	NS
Week 4 PB total	NS	NS	NS	-.214 (N=107)	NS	.279* (N=105)	NS	.274* (N=105)	.254* (N=105)	NS	NS	NS	NS
GA	NS	NS	NS	NS	NS	.232 (N=105)	NS	.238 (N=105)	.208 (N=105)	NS	NS	NS	NS
SA	NS	NS	.195 (N=107)	-.280* (N=107)	NS	.252* (N=105)	NS	.223 (N=105)	.226 (N=105)	.196 (N=105)	NS	NS	NS
SL	NS	NS	NS	NS	NS	.240 (N=105)	NS	.249* (N=105)	.308** (N=105)	NS	NS	NS	NS
EA	NS	NS	NS	NS	NS	.267* (N=105)	.255* (N=105)	.231 (N=105)	.231 (N=105)	NS	.454 (N=22)	NS	.466 (N=22)
AA	NS	NS	NS	-.264* (N=107)	NS	.286* (N=105)	.248 (N=105)	.288* (N=105)	.292* (N=105)	NS	NS	NS	NS
AW	.234 (N=107)	.300* (N=107)	NS	NS	.225 (N=107)	.356** (N=105)	NS	.414** (N=105)	.262* (N=105)	.287* (N=105)	NS	NS	NS

	STAI-state (baseline)	STAI-trait	Parent PBS total	Parent PBS-PR	Parent PBS-CB	Parent MBSS total	Parent MBSS-B	Parent PCS total	Parent PCS-M	Parent PCS-H	Parent PCS-R	STAI-sate (presurg)	Child mYPAS
Day 2 PB total	NS	.209 (N=111)	-.206 (N=112)	-.200 (N=112)	NS	NS	NS	NS	NS	NS	NS	NS	NS
GA	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
SA	NS	.200 (N=111)	-.254* (N=112)	-.197 (N=112)	-.273* (N=112)	NS	NS	.194 (N=112)	NS	.187 (N=112)	NS	NS	NS
SL	.201 (N=108)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
EA	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
AA	.249* (N=108)	NS	-.194 (N=112)	NS	-.193 (N=112)	NS	NS	NS	NS	NS	NS	NS	NS
AW	NS	.208 (N=111)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Week 1 PB total	.314** (N=107)	.306** (N=111)	NS	NS	NS	NS	NS	NS	.191 (N=112)	NS	NS	NS	NS
GA	.234 (N=107)	.228 (N=111)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
SA	.340** (N=107)	.267* (N=111)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
SL	.332** (N=107)	.314** (N=111)	-.187 (N=111)	-.226 (N=111)	NS	NS	NS	.275* (N=112)	.252* (N=112)	.231 (N=112)	.230 (N=112)	.237 (N=100)	NS
EA	NS	NS	-.200 (N=111)	-.257* (N=111)	NS	.252* (N=109)	NS	NS	NS	NS	NS	NS	.275* (N=102)
AA	.229 (N=107)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	.246 (N=100)	NS
AW	.245 (N=107)	.280* (N=111)	-.187 (N=111)	NS	-.193 (N=111)	NS	-.192 (N=109)	.317** (N=112)	.252* (N=112)	.283* (N=112)	.218 (N=112)	NS	NS

STAI-state (baseline)	STAI-trait	Parent PBS total	Parent PBS-PR	Parent PBS-CB	Parent MBSS total	Parent MBSS-B	Parent PCS total	Parent PCS-M	Parent PCS-H	Parent PCS-R	STAI-sate (presurg)	Child mYPAS	STAI-state (baseline)
Week 2 PB total	.350** (N=110)	.276* (N=114)	NS	-.215 (N=114)	NS	NS	NS	.238 (N=114)	.279* (N=114)	.213 (N=114)	NS	NS	NS
GA	.267* (110)	.257* (N=114)	NS	-.236 (N=114)	-.218 (N=114)	NS	NS	NS	NS	NS	NS	NS	NS
SA	.387** (N=110)	.303** (N=114)	NS	NS	NS	NS	NS	.220 (N=114)	.252* (N=114)	.222 (N=114)	NS	NS	NS
SL	.271* (N=110)	.201 (N=114)	NS	NS	NS	NS	NS	.220 (N=114)	.220 (N=114)	.215 (N=114)	NS	NS	NS
EA	.211 (N=110)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
AA	.248* (N=110)	.230 (N=114)	NS	NS	NS	NS	NS	NS	NS	NS	NS	.212 (N=103)	NS
AW	.270* (N=110)	.291* (N=114)	NS	-.186 (N=114)	NS	NS	NS	.191 (N=114)	.249* (N=114)	.208 (N=114)	NS	NS	NS
Week 4 PB total	.423** (N=101)	.466** (N=105)	-.232 (N=106)	-.276* (N=106)	NS	NS	NS	.264* (N=105)	.298* (N=105)	.227 (N=105)	.200 (N=105)	.318* (N=96)	NS
GA	.237 (N=101)	.289* (N=105)	-.196 (N=106)	-.226 (N=106)	NS	NS	NS	NS	NS	NS	NS	.210 (N=96)	NS
SA	.342** (N=101)	.396** (N=105)	-.194 (N=106)	-.218 (N=106)	NS	NS	NS	NS	.206 (N=105)	NS	NS	.314* (N=96)	NS
SL	.286* (N=101)	.342** (N=105)	-.236 (N=106)	-.279* (N=106)	NS	NS	NS	.224 (N=105)	.280* (N=105)	.232 (N=105)	NS	NS	NS
EA	.301* (N=101)	.271* (N=105)	-.221 (N=106)	-.230 (N=106)	NS	NS	NS	NS	.203 (N=105)	NS	NS	.266* (N=96)	NS
AA	.223 (N=101)	.352** (N=105)	NS	-.204 (N=106)	NS	NS	NS	NS	NS	NS	NS	.202 (N=96)	NS
AW	.326** (N=101)	.318** (N=105)	-.248* (N=106)	-.257* (N=106)	NS	NS	NS	.252* (N=105)	.280* (N=105)	.253* (N=105)	NS	NS	NS

GA general anxiety and regression, SA separation anxiety, SL anxiety about sleep, EA eating disturbance, AA aggression toward authority, AW apathy-withdrawal, EASI Emotionality Activity Sociability Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire, ES emotional symptoms, CP conduct problems, PP peer problems, H hyperactivity, PCS Pain Catastrophising Scale, M magnification, R rumination, H helplessness, STAI State Trait Anxiety Inventory, PBS Parent Beliefs Scale, PR parent role, CB child behaviour, MBSS Monitor Blunter Style Scale, B blunter, mYPAS modified Yale Pre-operative Anxiety Scale,
All Spearman's correlation co-efficient (rho), all values significant at $p<.05$,
* $p\leq .01$ ** $p\leq .001$

5.3.4.3 In-hospital factors

Children who had spent at least one night in hospital had more PB on day 2 post-discharge (eating disturbance: median 1 vs. 0, N=116, p=.028) and again at the end of week 1 (PB total score: median 3 vs. 0, p=,003, separation anxiety: 0.5 vs. 0, p=.004 and eating disturbance: 0.5 vs. 0, p=.003, N=115) and week 2 (PB total score: 1 vs. 0, p=.009, N=118). Children who were not given premedication prior to surgery had more PB on day 2 (PB total score: median 3 vs.1, p=.048, N=109) and children who had inhalation inductions of anaesthesia versus intravenous inductions had more PB at the end of week 1 (PB total score: median 2 vs. 0, p=.032, N=108).

5.3.4.4 Parent information needs and satisfaction with preparation

Parents' levels of preparation for their child's admission to hospital / care at home, satisfaction levels regarding information received / preparation and anxiety regarding their child's anaesthetic were significantly correlated to PB (total scores and/or subscales) on day 2, week 1, 2 and 4 and details are presented in Table 5.15. Other factors significantly associated with PB at the end of week 1 were: parents who answered "no" when asked if they felt prepared to look after their child at home (separation anxiety: median 0.5 vs. 0, p=.049, N=106) and children who received an information leaflet and had a discussion with a doctor or nurse regarding their admission to hospital for surgery (versus information leaflet only, discussion only, or video) (separation anxiety: median 2 vs. 0, p=.017, N=106); at the end of week 2: children who attended a pre-admission clinic (PB total score: median 1 vs. 0, p=.018, N=110) and parents who did additional information searching on their own (PB total score: median 1 vs. 0, p=.044, N=112); and week 4: parents who answered "no" when asked if they felt prepared to look after their child at home (PB total score: median 2 vs. 0, p=.02, N=101).

Table 5.15 PB and significant correlates with parent information needs and satisfaction

	Preparation: Care at home	Satisfaction: Parent information	APAIS total score	APAIS need for information	APAIS anxiety
Day 2 PB total	-.410** (N=107)	NS	.219 (N=109)	NS	.225 (N=109)
GA	-.285* (N=107)	NS	NS	NS	
SA	-.371** (N=107)	NS	.196 (N=109)	NS	.190 (N=109)
SL	NS	NS	NS	.267* (N=110)	NS
EA	-.339** (N=107)	NS	NS	NS	.188 (N=109)
AA	-.202 (N=107)	.199 (N=105)	NS	NS	NS
AW	-.221 (N=107)	NS	NS	NS	NS
Week 1 PB total	-.313** (N=106)	NS	.199 (N=109)	NS	NS
SA	-.253* (N=106)	NS	NS	NS	NS
SL	NS	NS	.271* (N=109)	NS	.243 (N=109)
EA	-.304 (N=106)	NS	NS	NS	NS
AA	-.210 (N=106)	NS	NS	NS	NS
AW	NS	NS	NS	NS	.210 (N=109)
Week 2 PB total	-.309** (N=108)	NS	NS	NS	NS
GA	-.248* (N=108)	NS	NS	NS	NS
SA	-.304** (N=108)	NS	NS	NS	NS
EA	-.272* (N=108)	NS	NS	NS	NS
AA	-.258* (N=108)	NS	NS	NS	NS
AW	-.196 (N=108)	NS	NS	NS	NS
Week 4 PB total	-.380** (N=101)	NS	NS	NS	.192 (N=104)
GA	-.207 (N=101)	NS	NS	NS	NS
SA	-.346** (N=101)	NS	NS	NS	NS
SL	-.236 (N=101)	NS	NS	NS	NS
EA	-.230 (N=101)	NS	.196 (N=104)	NS	NS
AA	-.206 (N=101)	NS	NS	NS	NS
AW	NS	NS	.193 (N=104)	NS	NS

GA general anxiety and regression, SA separation anxiety, SL anxiety about sleep, EA eating disturbance, AA aggression toward authority, AW apathy-withdrawal, APAIS Amsterdam Pre-operative Anxiety and

Information Scale, All Spearman's correlation co-efficient (rho), all values significant at p<.05,
* p≤ .01 ** p≤ .001

5.3.4.5 Inpatient factors

Forty five.8% of the children spent one or more nights in hospital. For this sub-group, levels of parent participation in the child's care and parent and child (>8 years) satisfaction with pain management were measured. Significant correlations with PB are detailed in Table 5.16. Children (> 8yrs) who said that they were "very unhappy" with the way the doctors and nurses took away their pain after surgery had significantly more eating disturbances (median 2) than children who were "happy" (median 1) and "very happy" (median 0) (p=.016, N=8).

5.3.4.6 Pain and return to work/school

Children's pain intensity at home was significantly correlated to their parents' reports of PB at home (see Table 5.16 for details).

At the end of week 1 parents took additional time off work if their child had eating disturbances (median 1 vs. 0, p=.029, N=94). At the end of week 2 parents whose children had more PB took their child to the GP (PB total score: median 6 vs. 0, p=.001, general anxiety and regression: 0.5 vs. 0, p=.001 and separation anxiety: 2.5 vs. 0, p<.001, N=116) and took additional time off work (PB total score: median 2 vs. 0, p=.009 and separation anxiety: 1 vs. 0, p=.003, N=99).

Table 5.16 PB and pain: in-hospital and at home

	CR in-hospital moving pain	CR in-hospital resting pain	CR in-hospital expected pain	PR satisfaction with in-hospital pain management	Pain at home: day 2	Pain at home: week 1	Pain at home week 2	Pain at home week 4
Day 2 PB total	NS	NS	NS	NS	.333** (N=111)			
GA	NS	NS	NS	NS	.234 (N=111)			
SA	NS	NS	NS	NS	.311** (N=111)			
SL	NS	NS	NS	NS	.214 (N=111)			
EA	NS	NS	NS	NS	.253* (N=111)			
AA	NS	NS	NS	NS	NS			
AW	NS	NS	NS	NS	.229 (N=111)			
Week 1 PB total	NS	NS	NS	NS	.212 (N=108)	.332** (N=111)		
GA	NS	NS	NS	NS	.224 (N=108)	.322** (N=111)		
SA	NS	NS	-.719 (N=8)	NS	NS	.226 (N=111)		
SL	NS	NS	NS	NS	NS	NS		
EA	NS	NS	NS	-.327 (N=39)	.299* (N=108)	.404** (N=111)		
AA	.757 (N=8)	NS	NS	-.322 (N=39)	NS	NS		
AW	NS	NS	NS	NS	.211 (N=108)	NS		
Week 2 PB total	.727 (N=9)	.917** (N=9)	NS	-.347 (N=41)	NS	NS	.234 (N=112)	
GA	NS	NS	NS	NS	NS	.215 (N=110)	.303** (N=112)	

	CR in-hospital moving pain	CR in-hospital resting pain	CR in-hospital expected pain	PR satisfaction with in-hospital pain management	Pain at home: day 2	Pain at home: week 1	Pain at home week 2	Pain at home week 4
SA	.786 (N=9)	.722 (N=9)	NS	NS	NS	NS	NS	
SL	NS	NS	NS	-.363 (N=41)	NS	NS	NS	
EA	NS	.709 (N=9)	NS	NS	.323** (N=109)	NS	.321** (N=112)	
AA	.792 (N=9)	.709 (N=9)	NS	NS	NS	NS	NS	
AW	.720 (N=9)	.701 (N=9)	NS	NS	NS	NS	.209 (N=112)	
Week 4 PB total	NS	NS	NS	NS	NS	NS	.205 (N=105)	.238 (N=104)
GA	NS	NS	NS	NS	NS	NS	.229 (N=105)	.208 (N=104)
SA	NS	NS	NS	NS	NS	NS	NS	NS
SL	NS	NS	NS	NS	NS	NS	NS	NS
EA	NS	.872 (N=7)	NS	NS	.204 (N=104)	NS	.254* (N=105)	.300* (N=104)
AA	NS	.877* (N=7)	NS	NS	NS	NS	NS	NS
AW	NS	NS	NS	NS	NS	NS	.199 (N=105)	NS

GA general anxiety and regression, SA separation anxiety, SL anxiety about sleep, EA eating disturbance, AA aggression toward authority, AW apathy-withdrawal, CR child report, PR parent report

All Spearman's correlation co-efficient (rho), all values significant at $p<.05$,

* $p\leq .01$ ** $p\leq .001$

5.3.5 Summary

The incidence of PB decreased significantly over the four follow-up time-points. Seventy three.3% of the children exhibited at least one PB on day 2 post-discharge from hospital, 58.6% at the end of week 1, 42.9% at the end of week 2 and 31.8% at the end of week 4. The number of PB that children exhibited at each of the four time-points was generally low: median 2 on day 2 (range reported 0-19, possible range 0-27), median 1.5 at the end of week 1 (range reported 0-24) and median 0 at the end of weeks 2 and 4 (range reported 0-15 and 0-16 respectively).

More than a quarter of children exhibited fewer PB than before surgery at each of the four follow-up time-points but the incidence was less than those that exhibited PB: 39.7% on day 2, 31.9% at the end of weeks 1 and 2 and 25.5% at the end of week 4.

Parent factors that were significantly associated/correlated with PB (total scores or subscale scores) at more than one follow-up time-point were: parents' level of education (graduate/post-graduate versus primary/secondary school) (day 2, week 1 and 2), parents with a higher deprivation index (day 2, week 1 and 2), parents with lower self-report anxiety during the parents' previous hospitalisation for surgery (day 2, week 1 and 2), parent baseline state and trait anxiety (day 2, week 1, 2 and 4), parent pre-operative anxiety (week 1, 2 and 4), parents' anxiety regarding their child's anaesthesia (day 2, week 1 and 4) and parents who felt less prepared for their child's care at home (day 2, week 1, 2 and 4).

Child factors significantly associated/correlated with PB (total scores or subscale scores) at more than one follow-up time-point were: children higher in birth order (day 2 and week 1), younger children (2-4 vs. 5-12 yrs) (day 2, week 1 and 2), children with higher temperament emotionality (day 2, week 1, 2 and 4), higher temperament impulsivity (week 1, 2 and 4), lower temperament activity (day 2 and week 4), lower temperament sociability (day 2, week 1, 2 and 4), and more pre-operative behavioural difficulties (emotional symptoms, conduct problems and peer problems) (day 2, week 1, 2 and 4).

Children who spent at least one night in hospital was the only in-hospital factor for the

whole population (N=131) significantly associated with PB at more than one follow-up time-point (day 2, week 1 and 2). For the inpatient group only (N=60) additional factors were significantly correlated to PB: child-reports (N=9) of their in-hospital postoperative pain while resting (week 2 and 4) and while moving (week 1 and 2) and parent-reports (N=39) of their satisfaction with their child's in-hospital postoperative pain management (week 1 and 2).

Child pain intensity at home on day 2 post-discharge from hospital was significantly correlated to their PB at all four follow-up time-points, while pain at the end of week 1 significantly correlated with PB at the end of week 1 and 2 and pain at the end of week 2 significantly correlated with PB at the end of week 2 and 4.

5.4 Post-discharge symptoms

5.4.1 Pain

At each of the four follow-up time-points (day 2, week 1, 2 and 4), parents were asked to record the worst postoperative pain their child had reported using the Wong Baker FACES Pain Scale (≥5 years) or the FLACC (<5 years). Parents were also asked to rate their child's postoperative pain on a 0-10 NRS (Table 5.17). On day 2, 93.4% children were reported to be in some pain (≥1, 0-10 NRS), 28.1% had moderate pain (4-6, 0-10 NRS) and 36.4% severe pain (≥7, 0-10 NRS) (range 1-10). 75.9% were in some pain at the end of week 1 (20.5% moderate pain, 15.2% severe pain, range 1-10), 55.8% at the end of week 2 (14.2% moderate, 8.8% severe, range 1-10) and by the end of week 4 25.2% were still experiencing some pain (3.7% moderate, range 1-5).

Table 5.17 Child postoperative pain

Pain scale (0-10)	Day 2 (median; IQR) (N)	Week 1	Week 2	Week 4
Wong Baker Faces (≥5 yrs)	6; 2, 8 (57)	2; 1.8, 4.3 (46)	1.5; 0, 2 (46)	0; 0, 0.5 (45)
FLACC (≤4 years)	2; 0.8, 8 (42)	1; 0, 4 (31)	0; 0, 1 (35)	0; 0, 0.3 (34)
NRS (all ages)	5; 2.5, 7.5 (121)	2; 1, 5 (112)	1; 0, 3 (113)	0; 0, 1 (107)

FLACC Faces Legs Activity Cry and Consolability

Pain scores were highly correlated between the Wong Baker FACES Pain Scale and NRS (≥5 years) at all time-points (rho=.853, .943, .898, .876 respectively, p<.001) and between the FLACC and NRS (≤4 years) (rho=.732, .844, .670, p<.001 and .473, p=.006). For all further analyses, only the NRS was used as a measure of postoperative pain.

Parents reported higher pain levels for children who had spent at least one night in hospital (versus day case children) at the end of week 1 (median score 3 vs. 2, p=.007, N=112) and week 2 (median score 1 vs. 0, p=.001, N=113). Parents who answered "no" when asked if they felt prepared to look after their child at home reported higher child pain scores at the end of week 4 (median score 1 vs. 0, p=.014, N=98). Table 5.18 provides details of all factors that were significantly correlated to parent reports of their child's pain at each of the four time-points.

In order to determine how the child's surgery had affected families' return to work/school, parents were asked if they had taken any additional unplanned time off work to care for their child as a result of the child's surgery and if the child had taken any additional time off school. Responses showed that of working parents 59% had taken additional time off work on day 2, 35.8% at the end of week 1, 18% at the end of week 2 and 9.5% at the end of week 4. Parents' who took additional time off work at the end of week 1 and 2 reported higher child pain scores at these time-points (median score 4 vs. 2, p=.002, N=94; 4 vs. 0, p<0.0001, N=95 respectively). The percentage children taking additional time off school as a result of their surgery were 74.5% on day 2, 55.6% at the end of week 1, 24.2% at the end of week 2 and 12.6% at the end of week 4. Higher pain scores were reported for these children at the end of week 1 (median score 3 vs. 1, p<.001, N=97) and week 2 (median score 4 vs. 0, p=.001, N=95).

Table 5.18 Parent reports of child pain at home and significant correlates

	Pain Day 2	Pain Week 1	Pain Week 2	Pain Week 4	STAI-state (baseline)	STAI-trait	IMD	Parent PAH	Preparation: admission	Preparation: home care
Pain Day 2		.519** (N=106)	.385** (N=106)	NS	NS	NS	NS	-.223 (N=87)	NS	-.304** (N=113)
Pain Week 1			.691** (N=108)	.201 (N=102)	.272* (N=104)	.208 (N=108)	-.235 (N=103)	NS	-.297* (N=107)	-.384** (N=104)
Pain Week 2				.378** (N=107)	.385** (N=105)	.251* (N=109)	-.244 (N=103)	NS	-.256* (N=107)	-.251* (N=104)
Pain Week 4					.262* (N=100)	NS	-.217 (N=99)	NS	NS	NS

	Satisfaction parent information	Satisfaction: child information	APAIS anxiety	STAI-state (pre-operative)	IPP	PR in-hospital resting pain	PR in-hospital moving pain	PR in-hospital expected pain	CR in-hospital resting pain
Pain Day 2	-.218 (N=109)	NS	NS	NS	.326 (N=49)	.653** (N=43)	.651** (N=42)	NS	.994** (N=8)
Pain Week 1	-.301* (N=102)	-.235 (N=92)	NS	.286* (N=98)	NS	NS	NS	NS	NS
Pain Week 2	NS	-.232 (N=92)	.209 (N=108)	.332** (N=99)	NS	NS	NS	NS	NS
Pain Week 4	NS	NS	NS	NS	NS	NS	NS	.375 (N=34)	NS

	SDQ-total score	SDQ-ES	SDQ-CP	SDQ-PS	EASI-total	EASI-A	EASI-S
Pain Day 2	NS	NS	-.201 (N=116)	.205 (N=116)	NS	NS	NS
Pain Week 1	NS	.258* (N=108)	NS	NS	NS	NS	NS
Pain Week 2	NS	NS	NS	NS	-.193 (N=111)	-.202 (N=111)	NS
Pain Week 4	NS	NS	NS	NS	NS	NS	.210 (N=106)

STAI State Trait Anxiety Inventory, IMD Index of Multiple Deprivation, PAH previous anxiety during hospitalisation for surgery, APAIS Amsterdam Pre-operative

Anxiety and Information Scale, IPP Index of Parent Participation, PR parent report, CR child report, SDQ Strengths and Difficulties Questionnaire, ES emotional symptoms, CP conduct problems, PS pro-social, EASI Emotionality Activity Sociability and Impulsivity Instrument,
All Spearman's correlation co-efficient (rho), all values significant at $p<.05$, * $p<.01$ **$p<.001$

5.4.2 Other symptoms

Other symptoms reported by parents were nausea, vomiting and discomfort. Parents who reported postoperative symptoms, including pain, responded to their children by providing medication, physical comfort, distraction and reassurance. Table 5.19 provides a breakdown of the various child symptoms reported and actions taken by parents at the four follow-up time-points.

Table 5.19 Child postoperative symptoms and parent management

	Day 2	Week 1	Week 2	Week 4
Symptoms reported by parents (Y/N) (%):	72.9/27.1	54.8/45.2	34.5/65.5	15/85
Pain*	67.4	47.8	29.4	10.6
Nausea	7	2.6	1.7	0
Vomiting	7	1.7	1.7	0.9
Discomfort	5.4	8.7	5	2.7
Other	8.5	7	7.6	3.5
Of the parents who reported symptoms, their management included (%):				
Medication	81	73.2	55.8	46.7
Physical comfort	41.3	29.2	22	33.3
Distraction	9.3	6.2	4.9	0
Reassurance	29.3	31.8	34.1	47.1

* Written symptom: pain in addition to pain intensity rating on 0-10 NRS

Parents were asked if there was any need for them to take their child back to the hospital, to their GP or clinic as a result of the surgery and if so why. Eight (6.2%) parents took their child back between discharge and day 2 post-surgery; 13 (11.3%) between day 2 and the end of week 1; 7 (5.9%) by the end of week 2 and 5 (4.4%) by the end of week 4. Reasons for seeking medical advice are listed in Table 5.20.

Table 5.20 Child reasons for attending hospital, clinic or GP

	Day 2 N=8	Week 1 N=13	Week 2 N=7	Week 4 N=5
Pain (%)	14.3	23.1	28.6	0
Trouble sleeping	0	0	14.3	20
Trouble with elimination	14.3	0	14.3	40
Wound care	57.3	61.5	14.3	40
Check-up	14.3	7.7	28.6	0
No reason given	0	7.7	0	0

Parents taking their child to the GP (yes/no) was significantly associated with pain scores at the end of week 2 (median score 5 vs. 1, p=.02, N=111) even though only 2 of these 7 (28.6%) parents said that they took their child to the GP because of pain.

5.4.3 Summary

Most parents (93.4%) reported some pain in their children on day 2 post-discharge from hospital (median 5, range reported 0-10, 0-10 NRS), 75.9% at the end of week 1 (median 2, range reported 0-10), 55.8% at the end of week 2 (median 1, range reported 0-10) and 25.2% at the end of week 4 (median 0, range reported 0-5). Parent factors that were significantly associated/correlated with child pain intensity scores at more than one follow-up time-point were: parent baseline state anxiety (week 1 and 2), parent baseline trait anxiety (week 2 and 4), parent pre-operative anxiety (week 1, 2 and 4), parents who felt less prepared for their child's admission (week 1 and 2), parents who felt less prepared for their child's care at home (day 2, week 1 and 2) and parents less satisfied with the information that they and their child had received regarding the child's admission (day 2, week 1 and 2). Child factors significantly associated/correlated with child pain intensity scores at more than one follow-up time-point were: pre-operative behaviour difficulties (day 2 and week 1) and child temperament factors (week 2 and 4). The only in-hospital factor significantly associated with child pain-intensity was children who had spent at least one night in hospital (week 1 and 2).

Other symptoms reported by parents were nausea, vomiting and discomfort. Parents responded to their children's pain and other symptoms by offering medicine, physical

comfort, distraction and reassurance. At least five children were taken to see the GP at each of the 4 follow-up time-points as a result of the child's surgery and the most frequently reported reasons included wound care (day 2 and week 1), wound care and pain (week 2) and wound care and problems with elimination (week 4).

Of the parents that were employed, at least 9% took additional time off work as a result of their child's surgery at each of the 4 follow-up time-points. Over 12% of school-going children took additional time off school as a result of their surgery. Parents who took additional time off work and whose children took additional time off school reported higher pain intensity for their children at the end of week 1 and 2.

5.5 Pre-operative anxiety

Child and parent pre-operative anxiety were measured shortly after admission to the pre-operative ward on the day of surgery. Parents completed the STAI-state self-report measure and children's anxiety was measured with the mYPAS observational scale. Child and parent anxiety were significantly correlated (rho=.251, p=.009, N=107).

Table 5.21 Child and parent pre-operative anxiety

Measure (Range)	Median	IQR
mYPAS (0-100)	23.33	23.33, 33.33
STAI-state 2 (20-80)	41	33, 55

mYPAS modified Yale Pre-operative Anxiety Scale, STAI State Trait Anxiety Inventory

The child's level of anxiety during their previous medical procedure, as reported by the parents on a 0-10 NRS was significantly correlated to their pre-operative anxiety (rho=.296, p=.003, N=99). Children whose parents had said "yes" when asked if their child had experienced pain during their last medical procedure were more anxious than children who had not experienced pain (median score 28.3 vs. 23.3, p=.036, N=98). No other baseline characteristics (demographic/psychological factors) were correlated to child pre-operative anxiety. Children who had not attended a pre-admission clinic and who had not received information about their surgery were no more or less anxious than children who had.

Parents were more anxious if they reported that their child had experienced pain during their last medical procedure (median score 44 vs. 37, p=.028, N=94) and if their children were between the ages of 2-4 (versus 5-12) (median score 43 vs. 40, p=.044, N=115). Single parents (median score 49.5 vs. 39, p=.017, N=109) and those who were stay at home parents at the time of their child's surgery (46.5 vs. 40, p=.033, N=106) were significantly more anxious than married/partnered parents and those who were employed. Parent anxiety was significantly correlated to parent rating of their child's anxiety during the child's previous medical procedure (rho=.273, p=.008, N=94), child pre-operative anxiety (rho=.251, p=.009, N=107) and parents' anxiety regarding their child's anaesthetic (APAIS anxiety) (rho=.583, p<.001, N=110). Other significant correlates to parent pre-operative anxiety are presented in Tables 5.24a and 5.24b.

5.5.1 Summary

Parents' median anxiety score was 41 (IQR: 33, 55), which is only slightly below Spielberger's reported mean scores for state anxiety under stressful conditions (males: 43.01 and females: 43.69) (Spielberger 1983). Children's median anxiety was low at 23.33 (IQR: 23.33, 33.33), as a score of > 30 is indicative of high anxiety (Kain et al. 1997). Child and parent pre-operative anxiety were significantly correlated. Both the parents' and children's pre-operative anxiety were significantly correlated/associated with children who had been more anxious and who had experienced pain in a recent prior medical encounter (e.g. GP/consultant visit, immunizations, venipuncture). Parents were also more anxious if they had been anxious and experienced more pain during their own previous admission to hospital for surgery. Other factors significantly correlated to parents' pre-operative anxiety were parents with younger children (2-4 vs. 5-12 yrs), single parents, those not employed, parents' anxiety and need for information regarding their child's anaesthesia, parent baseline state and trait anxiety, those with higher catastrophic thoughts about their child's possible pain, those that felt less prepared for their child's admission and care at home, those less satisfied with the information their child had received and parents whose children had pre-operative behavioural difficulties (emotional symptoms, conduct problems and peer problems).

5.6 Parent information needs and satisfaction with preparation

During the pre-operative period parents were asked to complete the parent information needs and satisfaction with preparation (PISP) questionnaire. Most parents chose to complete this questionnaire once their child had been taken to surgery or once their child had been reunited with them following surgery. One hundred and twenty four PISP questionnaires were returned by parents. Questions 1 to 3 referred to the period between being told their child was to have surgery and the date of surgery. Answers to these three questions are described with the other peri-operative details taken from the child's surgical notes (details below). Parents reported that 48.4% children attended a pre-admission clinic. Reasons for attendance included: checking that the child was fit for surgery / clerking only (N=14); for the child to meet the staff, have a tour of the ward/hospital and to be told what would happen on the day of surgery only (N=6); to meet with a play specialist and receive preparation for admission only (N=2); to check that the child was fit for surgery / clerking and to have a tour of the ward/hospital (N=21); to check that the child was fit for surgery / clerking and to see a play specialist (N=1); for the child to have a tour of the ward / hospital and see a play specialist (N=3); or to do all three (N=9). 93.5% parents said that they received information about their child's surgery in the form of an information leaflet only (N=65), a discussion with a nurse or doctor only (N=21); an information leaflet and a discussion with a nurse or doctor (N=26); or an information leaflet and a video (N=1). Thirty one.5% of the parents did additional information seeking on their own, 76.9% of which used the internet (including hospital information sites). Other forms of information included phoning the ward to speak to staff regarding their queries; speaking to friends, work colleagues or family members in the health profession; reading medical books/journals and speaking to school professionals and other parents who had experience with children who had the same/similar procedure. Half of the children (50%) reportedly received information about their surgery (apart from pre-admission clinic), which included an information leaflet only (N=28), a video only (N=1); a discussion with a nurse or doctor (N=15); or an information leaflet and a discussion with a nurse or doctor (N=4). Ten parents reported that their children received 'other' forms of information about their surgery. Free text answers revealed that these parents had all prepared their children themselves: 2 parents read a story to their child about going to hospital for surgery, 1 parent dressed up as a doctor and played "doctors and patients" with their

child and all their child's toys, 1 parent used a leaflet that they had been given to prepare the child and 6 gave detailed explanations of what the child should expect. Demographic details confirmed that only two of these parents were health professionals (a senior midwife and a surgical registrar). One of the parents had personal experience of having the same procedure done so was able to answer any queries her child had.

Parents rated their levels of being prepared for their child's admission and discharge and their satisfaction with preparation on 0-10 NRS. The PISP also included the 6-item Amsterdam Preoperative Anxiety and Information Scale (APAIS), which has subscales for parent anxiety and need for information regarding their child's anaesthesia. Descriptive statistics for the NRS and APAIS are summarized in Table 5.22. Parents were invited to provide free text comments on how they think parents and children should be prepared for admission to hospital for surgery. Three parents suggested pictorial books for children about going to hospital or an album with a sequence of photos of the whole process from packing a bag at home to recovering from the operation. Four parents thought that more information about the surgery should be provided, including "benefits", "possible problems" and "side-effects". Parents requested more information: "as much information as possible" (parent 1034), "more leaflets specific to the surgery" (parent3002). Other suggestions included: "the appointment should not be cancelled" (parent 3010), "we had short notice and didn't know who would be performing the surgery" (parent 3012). The mother of a little boy who had not been prepared for surgery and who had not been given any information wrote: "You should be aware that your research questionnaire, in the absence of any other information from the hospital, had the effect of alarming him because of the talk of pain" (parent 3009).

Table 5.22 Parents' satisfaction with information and preparation and APAIS scores

Measure (Range)	(Y/N)(%)	Median	IQR
Parents' preparation for child's admission (0-10)		8	7, 10
Prepared to take care of child at home (Y/N)	86.7/13.3		
Parents' preparation for child's home care (0-10)		9	7, 10
Satisfaction with information that parents received (0-10)		8	7, 9
Satisfaction with information that child received (0-10)		8	5, 9
APAIS total (6-30)		21	18, 25
APAIS anxiety (4-20)		13	10, 16

APAIS need for information (2-10)	8	8, 9

APAIS Amsterdam Pre-operative Anxiety and Information Scale

Parents felt more prepared for their child's admission to hospital if their child had had surgery before (median score 9 vs. 8, p=.014, N=110) and if the parent answered "yes" to feeling prepared to look after their children at home (median score 9 vs. 5.5, p<.001, N=120). Parents whose child's surgery had previously been cancelled reported higher levels of being prepared to look after their child at home (median score 10 vs. 9, p=.026, N=115) and reported higher satisfaction levels with the information that they had received regarding their child's admission to hospital (median score 9 vs. 8, p=.018, N=112). Parents who had received information about their child's admission to hospital for surgery reported higher satisfaction levels regarding the information that their child received (median score 8 vs. 6, p=.008, N=105). With regards to the type of information received, parents reported higher satisfaction levels for information that their child had received if their child had a discussion with a doctor/nurse only (median=10); received an information leaflet and had a discussion with a doctor/nurse (median=9); followed by an information leaflet only (median=8) (p=.035, N=43). Parents whose children had attended a pre-admission clinic and who were single had higher APAIS anxiety scores (median score 14.5 vs. 12, p=.02, N=121 and median score 16 vs. 12, p=.003, N=118 respectively). Parents' levels of preparation and satisfaction and APAIS scores were significantly correlated (Spearman's correlation co-efficient) to a number of demographic and baseline psychological factors and these are detailed in Tables 5.23, 5.24a and 5.24b.

Table 5.23 Parents' levels of preparation and satisfaction and significant correlates

	Preparation: admission	Preparation: Home care	Satisfaction: Parent information	Satisfaction: Child information	STAI-State (baseline)	STAI-Trait	PBS-total score	PBS-CB	PBS-PR	SDQ-ES
Preparation: admission		.591** (N=120)	.517** (N=117)	.396** (N=105)	-.336** (N=113)	-.324** (N=117)	.242* (N=118)	.217 (N=118)	.244* (N=118)	NS
Preparation: Home care			.437** (N=114)	.371** (N=103)	-.214 (N=110)	-.284* (N=114)	.192 (N=115)	.187 (N=115)	.028 (N=115)	-.228 (N=114)
Satisfaction: Parent information				.680** (N=103)	NS	-.194 (N=111)	NS	NS	NS	NS

STAI State Trait Anxiety Inventory, PBS Parent Beliefs Scale, CB child behaviour, PR parent role, SDQ-ES Strengths and Difficulties Questionnaire Emotional Symptoms, NS not significant

All Spearman's correlation co-efficient (rho), all values significant at p<.05

* p<.01 **p<.001

Table 5.24a Parent APAIS scores, pre-operative anxiety and significant parent correlates

	Parent PAH	Parent WPH	PBS Total	PBS CB	STAI-State (baseline)	STAI-Trait	Parent PCS total	Parent PCS-M	Parent PCS-H	Parent PCS-R	Preparation: Admission	Preparation: Home care	Satisfaction: Child information
APAIS total	.400** (N=88)	.344** (N=86)	-.225 (N=118)	-.275 (N=188)	.352** (N=113)	.325** (N=117)	.406** (N=118)	.332** (N=118)	.373** (N=118)	.344** (N=118)	NS	NS	NS
APAIS anxiety	NS	NS	-.264* (N=118)	-.311** (N=118)	.374** (N=113)	.382** (N=117)	.430** (N=118)	.355** (N=118)	.405** (N=118)	.349** (N=118)	NS	NS	NS
APAIS need for information	NS	NS	NS	NS	NS	NS	NS	NS	NS	.189 (N=118)	NS	NS	NS
STAI-state (pre-operative)	.276* (N=86)	.339* (N=84)	NS	NS	.507** (N=106)	.505** (N=109)	.435** (N=109)	.405** (N=109)	.389** (N=109)	.384** (N=109)	-.269* (N=110)	-.232 (N=107)	-.244 (N=94)

APAIS Amsterdam Pre-operative Anxiety and Information Scale, PAH previous anxiety during hospitalisation for surgery, WPH worst pain during hospitalisation for surgery, PBS Parent Beliefs Scale, CB child behaviour, STAI State Trait Anxiety Inventory, PCS Pain Catastrophising Scale, M magnification, H helplessness, R rumination,

All Spearman's correlation co-efficient (rho), all values significant at p<.05
* p<.01 **p<.001

Table 5.24b Parent APAIS scores, pre-operative anxiety and significant child correlates

	Child EASI total	Child EASI-E	Child EASI-A	Child EASI-S	Child EASI-I	Child SDQ total	Child SDQ-ES	Child SDQ-CP	Child SDQ-H	Child SDQ-PP	Child SDQ-PS
APAIS total	.280* (N=120)	.325** (N=120)	.197 (N=120)	NS	.253* (N=120)	.326** (N=117)	.187 (N=117)	.203 (N=117)	.296** (N=117)	.206 (N=117)	-.197 (N=117)
APAIS Anxiety	.247* (N=120)	.330** (N=120)	NS	.202 (N=120)	.229 (N=120)	.321** (N=117)	.204 (N=117)	.216 (N=117)	.251* (N=117)	.237* (N=117)	-.195 (N=117)
APAIS need for information	.217 (N=120)	NS	NS	NS	.185 (N=120)	.193 (N=117)	NS	NS	.257* (N=117)	NS	NS
STAI-state (pre-operative)	NS	NS	NS	NS	NS	.299* (N=109)	.281* (N=109)	.231 (N=109)	NS	.207 (N=109)	NS

APAIS Amsterdam Pre-operative Anxiety and Information Scale, EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire, ES emotional symptoms, CP conduct problems, H hyperactivity, PP peer problems, PS pro-social

All Spearman's correlation co-efficient (rho), all values significant at $p<.05$

* $p<.01$ ** $p<.001$

5.6.1 Summary

Less than half the children in this study attended a pre-admission clinic and only 32% received formal preparation for surgery in the form of meeting staff, a tour of the wards and theatre areas and/or to see a play specialist. Only 50% children received any information regarding their admission to hospital for surgery (apart from pre-admission clinic attendance) and 10 of these children (7.6% of total) had been prepared by their parents. Most of the parents (93.5%) reported receiving some information regarding their child's surgery but 31.5% sought additional information and suggestions were made for more information to be provided to families. Median scores for parents' preparation for their child's admission to hospital and care at home were high (medians 8 and 9 respectively, 0-10 NRS) and parents were reportedly satisfied with the information that both they and their child had received (median scores 8, 0-10 NRS). Parents' reported level of preparation for their child's admission was significantly ($p<.05$) associated with parents' own experience of hospitalisation for surgery (yes versus no) and parents' preparation for their child's care at home was higher if their child's surgery had previously been cancelled. Preparation levels (admission and home) were significantly correlated with parents' lower baseline state and trait anxiety, higher beliefs regarding their role in their child's care and their child's behaviour and higher satisfaction levels regarding information received. Parents' preparation for their child's home care was also significantly correlated to children with less emotional behavioural problems (as measured by SDQ).

Parents self-reported anxiety and need for information regarding their child's anaesthesia was high (median 21, score range 6-30 APAIS) and significantly associated / correlated with children who had attended a pre-admission clinic, parents who were single, parents' anxiety and pain during the parents' previous hospitalisation for surgery, parent baseline state and trait anxiety, catastrophic thoughts about their child's possible pain, higher child temperament factors (emotionality, activity and impulsivity) and pre-operative behavioural difficulties (emotional symptoms, conduct problems, hyperactivity, peer problems and pro-social behaviour).

5.7 Inpatient subgroup

45.8% (N=60) children spent one night or more in hospital. This subset of participants was asked to complete two additional questionnaires on day 2 post-discharge from hospital. The level that parents were able to or chose to participate in their child's care as well as the parents' and children's (> 8 years) views on pain management while in hospital were of interest.

5.7.1 Parent participation in their child's hospitalised care

Parents were provided with a list of 36 activities and asked to indicate whether they performed that activity for their child e.g. fed child, helped with elimination, bathed/sponged child. 55 parents completed the index of parent participation (IPP). The median IPP score was 66.67 (percentage activities performed) (IQR: 55.56, 75).

Parents who had not had surgery themselves had higher levels of participation in their child's care (median score 72.2 vs. 63.9, p=.047, N=54). Parents also participated more in their child's care if the child was female (median score 72.2 vs. 62.5, p=.022, N=55) and the longer the child stayed in hospital i.e. participation greatest in children who stayed 6 to 10 nights (median=75), followed by 2 to 5 nights (median=66.7) and then only 1 night (median=63.9) (p=.049, N=55). Participation by parents was significantly correlated to the parents' level of preparation for their child's admission to hospital and negatively correlated to child baseline temperament scores (Table 5.25).

Table 5.25 Parents' level of participation in their child's care and significant correlates

Parent/child factors (range)	Spearman's correlation co-efficient	N
Parents' level of preparation for their child's admission (0-10)	0.320	54
Child EASI total score (20-100)	0.449**	54
Emotionality (5-25)	-0.380*	
Activity (5-25)	0.362*	
Impulsivity (5-25)	-0.364*	

Child SDQ total (0-40)	-0.341	53
Hyperactivity (0-10)	-0.415*	

EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire,
All Spearman's correlation co-efficient (rho), all values significant at p<.05,
* p≤ .01 ** p≤ .001

5.7.2 Quality pain management

Children > 8 years were invited to complete the A-TQPM. Of the 11 children older than 8 years in the inpatient group, completed questionnaires were received from 10 (90.9%). 49 parents (81.67% of inpatient group parents) completed the parent version of the A-TQPM. The first four questions addressed whether or not parents/children were given information about ways to manage pain and if so, when and how it was received. Eight children confirmed that they were given information about ways to manage their pain (7 both before and after surgery and 1 after surgery only). This information was conveyed in person by doctors or nurses (for 6 children) and by written information (for 2 children). Only 1 child found this information difficult to understand.

85.7% parents confirmed that they had received information about how to manage their child's pain, 10.8% prior to their child's surgery, 40.5% after surgery and 48.6% on both occasions. This information was received by talking with hospital staff (85.4%) and through written information (12.2%). Only one parent found this information difficult to understand. Four parents said that this information was received through 'other' means: 2 parents wrote that they had to ask for this information and 2 parents did not elaborate on what 'other' means were.

With regard to pain intensity, parents and children were asked to rate the most pain that they thought the child had experienced after surgery when lying quietly and resting, while moving around in bed or up out of bed and how much pain they thought the child would have had (expected pain). The parents rated their child's pain on a 0-10 NRS and the children rated their own pain using the Wong-Baker FACES Pain Scale (Table 5.26)

Table 5.26 Inpatient pain scores and parent satisfaction with pain management

Variable	Parent (N=49) (Median; IQR)	Child (if > 8 years old) (N=10)	Spearman's correlation
Mean pain score			
Resting	6; 4, 8	7; 3.5, 10	0.890 (p=.001)
Moving	6.5; 5, 8	5.5; 3.5, 8.5	0.784 (p=.021)
Expected pain score	6; 3, 9	8; 4, 10	0.671 (NS)
Parent satisfaction	8; 6, 10		

Parents' rating of their child's pain at rest and when moving were significantly correlated (rho=.840, p<.001) as were the children's ratings of their own pain (rho=.761, p=.01). However, neither the parents' nor the children's expected pain scores were significantly correlated to their actual ratings of pain.

Overall, parents were satisfied with their child's pain management (median rating 8; IQR: 6, 10 on a 0-10 scale). The children were given forced-choice questions regarding their satisfaction with pain management. Three children were 'very happy' with their pain management, 5 were 'happy' and 2 were 'unhappy'. Table 5.27 provides a breakdown of how parents and children thought the child's pain management could be improved (forced-choice questions).

Table 5.27 Inpatient suggestions of how to improve pain management

Suggestion:	Parents (n=49) %	Child (n=10) %
Provide more information about analgesia	22.4	10
Administer more or better analgesia	14.3	40
Faster administration of analgesia	34.7	30
Staff should listen to what parents/children would want for pain management	26.5	30
Everything was fine – no improvement suggestions	49	50

Parents who had experience with one of their children having had surgery before gave their child higher pain scores while lying down (median score 6.5 vs. 5, p=.019, N=36) and while moving (median score 8 vs. 5, p=.019, N=35). Parents gave higher ratings for their

child's expected postoperative pain if the parents were single (median score 8.5 vs. 6, p=.04, N=47), if the parents had not had an operation themselves (8 vs. 6, p=.036, N=48) and parents whose children had attended a pre-admission clinic (8 vs. 5, p=.015, N=47).

Factors correlated to parents' reports of their child's pain while resting were: parents who felt less prepared for their child's home care (rho=-.342, p=.019, N=45), parents less satisfied with the information parents had received (rho=-.302, p=.043, N=45), parent anxiety during previous hospitalisation for surgery (rho=.403, p=.02, N=33), parents with lower baseline state anxiety (rho=-.369, p=.011, N=47) and children with less pre-operative behaviour difficulties (SDQ) (rho=-.295, p=.047, N=46). Parents' reports of their child's expected pain in hospital was correlated to the parents' worst pain during their previous hospitalisation for surgery (rho=.354, N=33, p=.043). Parents' satisfaction with their child's in-hospital pain management was correlated to children with less pre-operative behaviour difficulties (rho=-.356, p=.015, N=46) and parents with less catastrophic thinking about their child's pain (rho=-.390, p=.006, N=48).

Children's self-reported pain while resting was significantly negatively correlated to their parents' satisfaction with information that they and their parent had received regarding the child's admission to hospital (rho=-.659, p=.035, N=10 and rho=-.814, p=.008, N=9 respectively), parents with lower beliefs about the parent role/child behaviour (rho=-.743, p=.014, N=10) and parents with higher catastrophic thinking about their child's pain (helplessness subscale) (rho=.682, p=.03, N=10). Child self-reports of pain while moving correlated to their pre-operative behavioural difficulties (emotional symptoms) (rho=.813, p=.004, N=10) and self-reports of expected pain correlated to parent reports of child pain during a previous medical procedure (rho=.850, p=.015, N=7), children with lower pre-operative behavioural difficulties (peer problems) (rho=-.638, p=.047, N=10) and parents with lower baseline trait anxiety (rho=-.833, p=.003, N=10).

In answer to an open-ended question asking children/parents to provide suggestions of how pain management could be improved, responses were written by 1 child and 14 parents. These responses provided suggestions for improving the assessment of pain: "More regular

pain assessment" (parent 1001), "Talk to children and enquire about their pain needs and the effect of analgesia" (parent 2004). Two parents used the phrase "better understanding" of children's pain needs (parents 2002, 3046). Parents also commented on the administration of analgesia: "Better communication between doctors prescribing the pain relief and nurses carrying out the orders" (parent 3101) and the type/route of analgesia given: "Use suppositories for our child - was very sick and not keeping in oral pain killers. Was ok with suppositories for pain relief" (parent 3048) and "Gave morphine which the patient didn't like – need to listen to the patient" (parent 1069). One mother had discussed how her child's patient-controlled analgesia (PCA) pump had run out of morphine over night and the staff on duty had not been able to refill and start the pump again. Her suggestion was: "Ensure that night staff have enough medication so analgesia can be prepared over a 24hr period. Ensure that policy exists so that pump is prepared before it runs out". Her child was the only child to write a suggestion for the improvement of pain management and it echoed his mother's comments: "I think that some pain relief should be waiting so that when the pump runs out they can hook up a new one" (parent and child, 12years, 1054). More information about pain was suggested by two parents: "More information when going home regarding pain management" (parent 1003) and "Information on possible side-effects beforehand" (parent 1025). One parent used the opportunity to express a concern that she had over a nurse's knowledge of dosage: "One nurse told me that 5ml of medicine was equivalent to 1 tablespoon - a bit worrying" (parent 3019). Another parent's concern regarding too much analgesia was evidenced by her comment: "Tell older children that if they take a lot of a certain pain killer, it could make them feel or even be sick" (parent 3011). Finally, one parent suggested more general information be given about the child's surgery: "I would suggest that parents be given ideas about the technique of the operation, kinds of equipment used to do the operation. I was interested to know that" (parent 3029).

5.7.3 Summary

Nearly half (45.8%) of the children in this study spent at least one night in hospital. Parents' level of participation in their child's care was high (median 66.7, 0-100 IPP) and significantly associated/correlated with parents previous surgical experience (no), female children, children who spent more nights in hospital, parents who felt more prepared for

their child's admission, children with lower temperament emotionality and impulsivity, higher temperament activity and less pre-operative behavioural difficulties (hyperactivity).

Most of the children and parents reported receiving information regarding the child's postoperative pain management (80% children, 85.7% parents). Only 1 child and 1 parent expressed difficulty in understanding this information. Parents' and children's reports of pain while resting (median 6, 0-10 Wong Baker FACES pain scale and 7, 0-10 NRS respectively) and pain while moving (median 6.5, 0-10 Wong Baker FACES pain scale and 5.5, 0-10 NRS respectively) were significantly correlated. Parents' reports of their child's pain while resting were significantly associated/correlated with parents' experience of another child's surgery (yes), parents' anxiety during their own previous admission to hospital for surgery, lower baseline state anxiety, children with less pre-operative behavioural difficulties, parents who felt less prepared for their child's home care and parents less satisfied with the information that they had received regarding their child's admission. Parents' reports of their child's pain while moving was also significantly associated with parents' experience of another child's surgery (yes). Parents reported higher expected pain for their child if the parents were single, had not had surgery themselves, if their child had attended a pre-admission clinic and parents' who reported higher pain levels during their own previous admission to hospital for surgery.

Children's reports of their pain while resting was significantly correlated to lower parent beliefs regarding the child's behaviour / parent role and parents with lower catastrophic thoughts regarding the child's possible pain. Children with more pre-operative behavioural difficulties reported higher pain while moving and lower expected pain. Children's expected pain was also significantly correlated to their parents' reports of the child's pain during a recent prior medical encounter and parents with lower baseline trait anxiety.

Parents reported high levels of satisfaction with their child's pain management (median 8, 0-10 NRS). Parents were more satisfied with their child's pain management if the child had less pre-operative behavioural difficulties and if the parents had lower catastrophic thoughts about their child's possible pain. Eight children (of 10 who completed the questionnaire) reported that they were happy or very happy with their pain management.

Suggestions by parents to improve children's in-hospital pain management consisted of improving pain assessment, suggestions regarding the administration (type/route) of analgesia and more information regarding analgesia.

5.8 Conclusion

This chapter provided a full description of the study participants: descriptions of their demographic variables, previous experience with surgery and/or pain, baseline psychological variables and how these compared with children whose families withdrew between recruitment to the study and the day of surgery and those that failed to complete the study.

The primary outcome, PB, was described and presented in terms of the incidence, types of PB, change in PB over time and significant associations / correlations with all other child and parent variables (descriptive variables and secondary outcomes).

A number of secondary outcomes were presented: pain and other symptoms at home, child and parent pre-operative anxiety, parent information needs, satisfaction with preparation, anxiety and need for information regarding their child's anaesthesia, level of participation in the child's inpatient care and satisfaction with inpatient pain management. Means (± standard deviations) / medians (inter-quartile ranges) were presented for normally distributed data and non-normally distributed data respectively and any significant associations / correlations with demographic variables, baseline psychological variables, anxiety, preparation and satisfaction variables, in-hospital variables, pain and other symptoms at home were presented.

Chapter 6 presents the findings of a number of binary multivariable logistic regression models to determine which factors best predict child PB (total scores and subscale scores) at each of the four follow-up time-points.

Chapter 6
Results: Binary Logistic Regression

6.1 Introduction

Chapter five provided details of descriptive statistics and exploratory analyses. The study participants were described and the results from each questionnaire completed by parents (and children > 8 years) and any significant associations / correlations with primary and/or secondary outcomes were detailed. This chapter presents the findings from binary logistic regression analyses to determine the factors that best predicted PB (total and subscale scores) at each of the four follow-up time-points.

The results of binary logistic regression models are presented in the order of the follow-up time-points. Findings from regression models related only to the inpatient population are presented after the findings from regression models related to the entire sample. Study objective 10 (Chapter 4, section 4.2) is addressed in this chapter: To determine which parent factors, child factors, in-hospital and home factors are potentially predictive of child post-hospital PB.

6.2 Binary logistic regression models

Stepwise multiple binary logistic regression analysis was performed to identify the factors that predicted parents' reports of their child's PB (total scores and subscales) on day 2 and at the end of week 1, 2 and 4 post-discharge from hospital. Due to the large number of possible variables that could be related to PB (total scores and subscales), regression analyses were performed in two steps. In Step 1 models were constructed for each of the following sub-groups of factors: (i) parent factors (demographic factors, baseline and pre-operative psychological factors, previous exposure to hospitalisation for surgery (self/children) and information/preparation received), (ii) child factors (demographic factors, baseline and pre-operative psychological factors, previous exposure to

hospitalisation for surgery and information/preparation received), (iii) in-hospital factors, and (iv) the family's home experience factors (child pain and family's return to work/school). In Step 2 a final model was constructed that combined the variables that best predicted PB from each of the sub-groups in Step 1 to identify the overall best potential predictor/s of PB (total scores and subscales) at each of the four time-points. Entry and removal of variables into the stepwise regression models were set at $p=0.05$ and $p=0.1$ respectively. This meant that some of the final models contained variables where $0.05<p<0.1$.

Missing data were dealt with via listwise deletion of variables on a model-by-model basis. This meant that models were based on differing numbers as the listwise approach omits variables with missing values. Therefore, it is likely that the number of cases included in the models decreased as more variables with any missing values are added. Variables from questionnaires that were only completed by children >8 years e.g. Child Pain Catastrophising Scale and by parents whose children had spent ≥ one night in hospital were not included in the regression models due to the reduced number of cases (children eligible to complete questionnaires, N=32, children who spent ≥ 1 night in hospital, N=60) as this would have considerably reduced the total number of cases included in the models. Child-completed questionnaires were explored in terms of significant associations / correlations to PB (total and subscale scores) in Chapter 5 (Tables 5.14 and 5.16). Questionnaires completed by parents whose children had spent ≥ 1 night in hospital were added to in-hospital factor models for PB (total and subscale scores) and are discussed at the end of this chapter (section 6.7). Variables from questions that followed stem questions were also excluded from the models due to the large number of missing (not applicable) values (e.g. did parents accompany another child for surgery (yes/no) was not included as it followed the question: have any of your other children had surgery before (yes/no)). Variables theorised or shown in prior research to be associated with the outcome were included in Step 1 (PB total scores and subscale scores) even if statistically significant correlations / associations were not found (Chapter 5). Backwards stepwise regression was selected first when building the regression models as it is more likely to reveal a suppressor effect than forward stepwise regression (Katz 2006). Where models showed a lack-of-fit, forward stepwise regression was performed to see if a better fit model could be constructed. Variables were tested for multicollinearity before constructing the models.

Multicollinearity occurs when two or more variables are so closely related to each other (variables correlated at >.8) that the regression model may not reliably determine each variable's independent contribution (Katz 2006). Where possible predictors included total scores and subscale scores, e.g. Parent Beliefs Scale, total scores were not entered into the model as they were highly correlated (r >.8) to the individual subscales. No other multicollinear variables (r>.8) were identified.

The Hosmer-Lemeshow goodness-of-fit test and the -2log-likelihood/deviance was used to assess the adequacy of the models. The former test compares the estimated to the observed likelihood of outcome for groups of subjects (Katz 2006) and the latter measures the extent to which the final model deviates from the model containing all possible predictors with smaller values indicating a model with a better fit (Petrie et al. 2005). The models with the best goodness-of-fit are presented below.

At the end of this chapter, tables 6.47 to 6.49 present all the parent factors, child factors, in-hospital and home factors that were potentially predictive of PB total scores and subscale scores in final models from Step 2 of the binary logistic regression analyses over the four time-points.

6.3 Problematic behaviours: Day 2

6.3.1 Total score: Step 1

Tables 6.1 to 6.4 present the models with the best goodness-of-fit for the parent factor, child factor, in-hospital factor and home factor variables that predicted PB total scores on day 2 post-discharge from hospital.

Table 6.1 Parent factor predictors for PB on day 2

N=92	Odds ratio	95% CI	P-value
Parents who felt less prepared for their child's home care (0-10 NRS)	0.502	0.314 – 0.801	0.004
Parents with higher anxiety regarding their child's anaesthesia (4-20 APAIS)	1.202	1.042 – 1.388	0.012
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	4.529	1.394 – 14.710	0.012
Parents who did no additional information searching	0.253	0.074 – 0.863	0.028

NRS numeric rating scale, APAIS Amsterdam Pre-operative Anxiety and Information Scale

Table 6.2 Child factor predictors for PB on day 2

N=103	Odds ratio	95% CI	P-value
Children with higher temperament emotionality (5-25 EASI)	1.247	1.082 – 1.437	0.002
Children with lower temperament impulsivity (5-25 EASI)	0.838	0.733 – 0.958	0.009

EASI Emotionality Activity Sociability and Impulsivity Instrument

Table 6.3 In-hospital factor predictors for PB on day 2

N=103	Odds ratio	95% CI	P-value
Children who spent ≥ 1 night in hospital	3.537	1.258 – 9.946	0.017
Children not given premedication	0.398	0.135 – 1.175	0.095

Table 6.4 Home factor predictors of PB on day 2

N=78	Odds ratio	95% CI	P-value
Child pain intensity on day 2 (0-10 NRS)	1.207	1.016 – 1.434	0.033

NRS numeric rating scale

6.3.2 Total score: Step 2

These factors were combined in a final model to identify those factors that best predicted PB on day 2 (Step 2). A six-factor model provided the best fit for potential predictors of children's PB (total score) on day 2 (Table 6.5).

Parents who felt less prepared to look after their child at home, parents who were more anxious about their child's anaesthesia, who did not do any additional information searching, who had a graduate / post-graduate qualification, whose children spent ≥ 1 night in hospital and whose children had lower temperament impulsivity were more likely to report PB in their child on day 2 post-discharge from hospital.

Table 6.5 Overall predictors for PB on day 2

N=86	Odds ratio	95% CI	P-value
Parents who felt less prepared for their child's home care (0-10 NRS)	0.503	0.286 – 0.885	0.017
Parents with higher anxiety regarding their child's anaesthesia (4-20 APAIS)	1.297	1.048 – 1.605	0.017
Parents who did no additional information searching	0.146	0.026 – 0.806	0.027
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	7.896	1.648 – 37.842	0.010
Children who spent ≥ 1 night in hospital	15.054	2.435 – 93.048	0.004
Children with lower temperament impulsivity (5-25 EASI)	0.777	0.623 – 0.970	0.026

NRS numeric rating scale, APAIS Amsterdam Pre-operative Anxiety and Information Scale, EASI Emotionality Activity Sociability and Impulsivity Instrument

6.3.3 Subscale scores

Step 1 and Step 2 were carried out for each of the six subscales scores of PB on day 2 post-discharge from hospital. Tables 6.6 to 6.11 present the final models (Step 2) that best predicted PB in each of the subscales.

Table 6.6 Overall predictors for general anxiety and regression (GA) on day 2

N=80	Odds ratio	95% CI	P-value
Children with lower temperament sociability (5-25 EASI)	0.740	0.590 – 0.928	0.009
Children with higher temperament emotionality (5-25 EASI)	1.192	1.016 – 1.399	0.031
Children fewer behavioural difficulties: hyperactivity (0-10 SDQ)	0.710	0.549 – 0.918	0.009
Child pain intensity on day 2 (0-10 NRS)	1.295	1.047 – 1.602	0.017
Children not given premedication	0.174	0.036 – 0.833	0.029

EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire, NRS numeric rating scale

Table 6.7 Overall predictors for separation anxiety (SA) on day 2

N=91	Odds ratio	95% CI	P-value
Parent baseline trait anxiety (20-80 STAI)	1.130	1.058 – 1.207	0.000
Younger children (2-4 vs. 5-12 yrs)	0.145	0.040 – 0.518	0.003
Child pain intensity on day 2 (0-10 NRS)	1.339	1.084 – 1.654	0.007
Children with lower temperament activity (5-25 EASI)	0.822	0.711 – 0.950	0.008
Children not given premedication	0.125	0.025 – 0.621	0.011

STAI State Trait Anxiety Inventory, NRS numeric rating scale, EASI Emotionality Activity Sociability and Impulsivity Instrument

Table 6.8 Overall predictors for eating disturbances (EA) on day 2

N=57	Odds ratio	95% CI	P-value
Parents who did no additional information searching	0.035	0.003 – 0.361	0.005
Parents who felt less prepared for their child's home care (0-10 NRS)	0.534	0.319 – 0.895	0.017
Parents' previous pain experience (0-10 NRS)*	1.304	1.020 – 1.668	0.034
Children who spent ≥ 1 night in hospital	7.437	1.162 – 47.574	0.034

NRS numeric rating scale, *Parent self-report pain intensity during previous hospitalisation for surgery

Table 6.9 Overall predictors for aggression toward authority (AA) on day 2

N=81	Odds ratio	95% CI	P-value
Parents who did not feel prepared for their child's admission	0.510	0.328 – 0.792	0.003
Parents who were more satisfied with parent information (0-10 NRS)	3.064	1.345 – 6.980	0.008
Children higher in birth order	0.372	0.135 – 1.022	0.055

NRS numeric rating scale

Table 6.10 Overall predictors for apathy-withdrawal (AW) on day 2

N=94	Odds ratio	95% CI	P-value
Children with higher temperament emotionality (5-25 EASI)	1.241	1.083 – 1.421	0.002
Children with fewer behavioural difficulties: hyperactivity (0-10 SDQ)	0.815	0.672 – 0.990	0.039
Parents who did no additional information searching	0.327	0.110 – 0.968	0.043

EASI Emotionality Activity Sociability and Impulsivity Instrument, SDQ Strengths and Difficulties Questionnaire

Table 6.11 Overall predictors for anxiety about sleep (SL) on day 2

N=90	Odds ratio	95% CI	P-value
Parents who felt less prepared for their child's home care (0-10 NRS)	0.739	0.573 – 0.954	0.020
Families with a higher deprivation index (1-32,482 IMD)	1.051	1.001 – 1.103	0.047

NRS numeric rating scale, IMD index of multiple deprivation

6.3.4 Summary

Twenty one variables (11 parent factors, 7 child factors, 2 in-hospital factors and 1 home factor) predicted PB (total score and/or subscale scores) on day 2 post-discharge from hospital. Seven of these factors were potential predictors in more than one model: parents who felt less prepared for their child's home care (PB total score, eating disturbances, anxiety about sleep), parents who did not do any additional information searching (PB total score, eating disturbances, apathy-withdrawal), children with higher temperament emotionality (general anxiety and regression, apathy-withdrawal), fewer child behavioural difficulties: hyperactivity (general anxiety and regression, apathy-withdrawal), children not given premedication (general anxiety and regression, separation anxiety), children who spent ≥ 1 night in hospital (PB total score, eating disturbances) and child pain intensity on day 2 (general anxiety and regression, separation anxiety).

6.4 Problematic behaviours: Week 1

6.4.1 Total score: Step 1

Tables 6.12 to 6.15 present the models with the best goodness-of-fit for the parent factor, child factor, in-hospital factor and home factor variables that predicted PB total scores at the end of week 1 post-discharge from hospital.

Table 6.12 Parent factor predictors for PB at the end of week 1

N=89	Odds ratio	95% CI	P-value
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	3.881	1.541 – 9.770	0.004
Parent baseline trait anxiety (20-80 STAI)	1.050	1.003 – 1.099	0.038

STAI State Trait Anxiety Inventory

Table 6.13 Child factor predictors for PB at the end of week 1

N=76	Odds ratio	95% CI	P-value
Younger children (2-4 vs. 5-12 yrs)	0.108	0.029 – 0.402	0.001
Children with a recent prior pain experience (Y/N)*	4.287	1.384 – 13.285	0.012
Children who did not attend a pre-admission clinic	0.207	0.059 – 0.722	0.013

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests

Table 6.14 In-hospital factor predictors for PB at the end of week 1

N=102	Odds ratio	95% CI	P-value
Children who spent ≥ 1 night in hospital	2.125	0.925 – 4.882	0.076
Children who had an inhalation induction of anaesthesia (vs. intravenous)	0.498	0.221 – 1.119	0.091

Table 6.15 Home factor predictors of PB at the end of week 1

N=69	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 1 (0-10 NRS)	1.302	1.049 – 1.618	0.017

NRS numeric rating scale

6.4.2 Total score: Step 2

These factors were combined in a final model to identify which of these factors best predicted PB at the end of week 1 (Step 2). A four-factor model provided the best fit for potential predictors of children's PB (total score) at the end of week 1 (Table 6.16).

Parents of younger children, those whose children did not attend a pre-admission clinic, who reported higher pain intensity in their children at the end of week 1 and who had a graduate / post-graduate qualification were more likely to report PB in their child at the end of week 1 post-discharge from hospital.

Table 6.16 Overall predictors for PB at the end of week 1

N=86	Odds ratio	95% CI	P-value
Younger children (2-4 vs. 5-12 yrs)	0.114	0.027 – 0.493	0.004
Children who did not attend a pre-admission clinic	0.163	0.039 – 0.674	0.012
Child pain intensity at the end of week 1 (0-10 NRS)	1.369	1.046 – 1.790	0.022
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	7.155	1.931 – 26.503	0.03

NRS numeric rating scale

6.4.3 Subscale scores

Step 1 and Step 2 were carried out for each of the six subscales scores of PB at the end of week 1 post-discharge from hospital. Tables 6.17 to 6.22 present the final models (Step 2) that best predicted PB in each of the subscales.

Table 6.17 Overall predictors for general anxiety and regression at the end of week 1

N=65	Odds ratio	95% CI	P-value
Younger children (2-4 vs. 5-12 yrs)	0.004	0.000 – 0.137	0.002
Parents with lower self-report anxiety during previous admission for parent's surgery (0-10 NRS)	0.413	0.228 – 0.751	0.004
Parents with lower blunter coping style (0-16 MBSS)	0.433	0.219 – 0.856	0.016
Children who had an inhalation induction of anaesthesia (vs. intravenous)	0.056	0.004 – 0.846	0.037
Children who did not attend a pre-admission clinic	0.090	0.006 – 0.445	0.089

NRS numeric rating scale, MBSS Monitor-Blunter Style Scale

Table 6.18 Overall predictors for separation anxiety at the end of week 1

N=71	Odds ratio	95% CI	P-value
Younger children (2-4 vs. 5-12 yrs)	0.081	0.018 – 0.375	0.001
Children who had an inhalation induction of anaesthesia (vs. intravenous)	0.103	0.022 – 0.474	0.003
Parents with lower blunter coping style (0-16 MBSS)	0.598	0.407 – 0.880	0.009
Parents with higher beliefs regarding their child's behaviour (8-40 PBS)	1.132	1.007 – 1.274	0.038
Parent baseline state anxiety (20-80 STAI)	1.062	0.997 – 1.131	0.062

MBSS Monitor-Blunter Style Scale, PBS Parent Belief Scale, STAI State Trait Anxiety Inventory

Table 6.19 Overall predictors for eating disturbances at the end of week 1

N=100	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 1 (0-10 NRS)	1.387	1.134 – 1.697	0.001
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.912	0.845 – 0.984	0.018
Parents with higher monitor coping style (0-16 MBSS)	1.217	1.032 – 1.436	0.019
Children who spent ≥ 1 night in hospital	2.825	1.046 – 7.628	0.041

NRS numeric rating scale, PBS Parent Beliefs Scale, MBSS Monitor-Blunter Style Scale

Table 6.20 Overall predictors for aggression toward authority at the end of week 1

N=91	Odds ratio	95% CI	P-value
Parents with higher thoughts of magnification regarding their child's pain (0-12 PCS)	1.799	1.161 – 2.788	0.009
Parents with lower thoughts of helplessness regarding their child's pain (0-24 PCS)	0.767	0.617 – 0.953	0.017
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.804	1.128 – 2.885	0.014
Parents who felt less prepared for their child's home care (0-10 NRS)	0.671	0.484 – 0.932	0.017
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.845	0.731 – 0.977	0.022
Parents with higher beliefs regarding their child's behaviour (8-40 PBS)	1.217	1.007 – 1.471	0.042

PCS Pain Catastrophizing Scale, SDQ Strengths and Difficulties Questionnaire, NRS numeric rating scale, PBS Parent Beliefs Scale

Table 6.21 Overall predictors for apathy-withdrawal at the end of week 1

N=77	Odds ratio	95% CI	P-value
Child pain intensity on day 2 (0-10 NRS)	1.373	1.069 – 1.763	0.013
Parents with lower blunter coping style (0-16 MBSS)	0.603	0.399 – 0.910	0.016
Children with higher temperament emotionality (5-25 EASI)	1.200	1.017 – 1.416	0.030

NRS numeric rating scale, MBSS Monitor-Blunter Style Scale, EASI Emotionality Activity Sociability and Impulsivity Instrument

Table 6.22 Overall predictors for anxiety about sleep at the end of week 1

N=88	Odds ratio	95% CI	P-value
Parent baseline state anxiety (20-80 STAI)	1.086	1.036 – 1.138	0.001
Children higher in birth order	0.399	0.183 – 0.871	0.021

STAI State Trait Anxiety Inventory

6.4.4 Summary

Eighteen variables (9 parent factors, 5 child factors, 2 in-hospital factors and 2 home factors) predicted PB (total score and/or subscale scores) at the end of week 1 post-discharge from hospital. Seven of these factors were potential predictors in more than one model: parents with lower blunter coping style (separation anxiety, apathy-withdrawal), parents with higher beliefs regarding their child's behaviour (general anxiety and regression, aggression toward authority), parents with lower beliefs regarding their role in their child's care (eating disturbance, aggression toward authority), children who did not attend a pre-admission clinic (PB total scores, general anxiety and regression), younger children (PB total scores, general anxiety and regression, separation anxiety), children who had inhalation induction of anaesthesia (general anxiety and regression, separation anxiety) and child pain intensity at the end of week 1 (PB total scores and eating disturbances).

Parent factors that predicted PB (total or subscale scores) on day 2 and at the end of week 1 were: higher education level, parents who felt less prepared for their child's home care and parents with lower blunter coping styles. Child factors were higher temperament emotionality and younger children. In-hospital and home factors that predicted PB (total or subscale scores) at both time-points were: children who spent ≥ 1 night in hospital and pain

at home: pain on day 2 predicted PB (total or subscale scores) at both time-points and pain at the end of week 1 predicted PB (total and subscale scores) at the end of week 1.

6.5 Problematic behaviours: Week 2

6.5.1 Total score: Step 1

Tables 6.23 to 6.26 present the models with the best goodness-of-fit for the parent factor, child factor, in-hospital factor and home factor variables that predicted PB total scores at the end of week 2 post-discharge from hospital.

Table 6.23 Parent factor predictors for PB at the end of week 2

N=88	Odds ratio	95% CI	P-value
Parent baseline state anxiety (20-80 STAI)	1.049	1.012 – 1.088	0.009
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	2.701	1.003 – 7.273	0.049
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.939	0.873 – 1.010	0.091

STAI State Trait Anxiety Inventory, PBS Parent Beliefs Scale

Table 6.24 Child factor predictors for PB at the end of week 2

N=88	Odds ratio	95% CI	P-value
Child pre-operative anxiety (0-100 mYPAS)	1.076	1.022 – 1.133	0.005
Children with a recent prior pain experience*	2.885	1.090 – 7.632	0.033
Children with lower temperament sociability (5-25 EASI)	0.821	0.679 – 0.994	0.044
Younger children (2-4 vs. 5-12 yrs)	0.376	0.139 – 1.016	0.054

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests, mYPAS modified Yale Pre-operative Anxiety Scale, EASI Emotionality Activity Sociability and Impulsivity Instrument

Table 6.25 In-hospital factor predictors for PB at the end of week 2

N=105	Odds ratio	95% CI	P-value
Children who spent ≥ 1 night in hospital	2.836	1.250 – 6.432	0.013
Children not given premedication	0.360	0.116 – 1.120	0.078

Table 6.26 Home factor predictors of PB at the end of week 2

N=81	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 2 (0-10 NRS)	1.285	1.026 – 1.608	0.029
Children who had been taken to the GP due to their surgery in the second postoperative week	6.814	0.837 – 55.456	0.073

NRS numeric rating scale

6.5.2 Total score: Step 2

These factors were combined in a final model to identify which of these factors best predicted PB at the end of week 2 (Step 2). A four-factor model provided the best fit for potential predictors of children's PB (total score) at the end of week 2 (Table 6.27).

Parents with higher baseline state anxiety, whose children had lower temperament sociability, whose children had had a recent pain experience during their last medical encounter prior to admission for surgery and who had higher pre-operative anxiety were more likely to report PB (total or subscale scores) in their children at the end of week 2.

Table 6.27 Overall predictors for PB at the end of week 2

N=61	Odds ratio	95% CI	P-value
Children with lower temperament sociability (5-25 EASI)	0.631	0.469 – 0.848	0.002
Children with a recent prior pain experience*	8.208	1.890 – 35.646	0.005
Parent baseline state anxiety (20-80 STAI)	1.095	1.027 – 1.168	0.006
Child pre-operative anxiety (0-100 mYPAS)	1.105	1.027 – 1.189	0.007

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests, EASI Emotionality Activity Sociability and Impulsivity Instrument, STAI State Trait Anxiety Inventory, mYPAS modified Yale Pre-operative Anxiety Scale

6.5.3 Subscale scores

Step 1 and Step 2 were carried out for each of the six subscales scores of PB at the end of week 2 post-discharge from hospital. Tables 6.28 to 6.33 present the final models (Step 2) that best predicted PB in each of the subscales.

Table 6.28 Overall predictors for general anxiety and regression at the end of week 2

N=89	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 2 (0-10 NRS)	1.602	1.219 – 2.106	0.001
Children with behavioural difficulties: conduct problems (0-10 SDQ)	2.060	1.269 – 3.347	0.003
Child pre-operative anxiety (0-100 mYPAS)	0.906	0.798 – 1.029	0.128

NRS numeric rating scale, SDQ Strengths and Difficulties Questionnaire, mYPAS modified Yale Pre-operative Anxiety Scale

Table 6.29 Overall predictors for separation anxiety at the end of week 2

N=80	Odds ratio	95% CI	P-value
Child pre-operative anxiety (0-100 mYPAS)	1.090	1.028 – 1.156	0.004
Parent baseline state anxiety (20-80 STAI)	1.071	1.020 – 1.123	0.005
Younger children (2-4 vs. 5-12 yrs)	0.228	0.066 – 0.793	0.020

mYPAS modified Yale Pre-operative Anxiety Scale, STAI State Trait Anxiety Inventory

Table 6.30 Overall predictors for eating disturbances at the end of week 2

N=90	Odds ratio	95% CI	P-value
Children with higher temperament impulsivity (5-25 EASI)	1.378	1.089 – 1.745	0.008
Child pain intensity on day 2 (0-10 NRS)	1.460	1.085 – 1.964	0.012
Child pain intensity at the end of week 2 (0-10 NRS)	1.440	1.076 – 1.929	0.014

EASI Emotionality Activity Sociability and Impulsivity Instrument, NRS numeric rating scale

Table 6.31 Overall predictors for aggression toward authority at the end of week 2

N=88	Odds ratio	95% CI	P-value
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.939	1.205 – 3.121	0.006
Parents who felt less prepared for their child's home care (0-10 NRS)	0.731	0.548 – 0.975	0.033

SDQ Strengths and Difficulties Questionnaire, NRS numeric rating scale

Table 6.32 Overall predictors for apathy-withdrawal at the end of week 2

N=111	Odds ratio	95% CI	P-value
Parent baseline trait anxiety (20-80 STAI)	1.087	1.031 – 1.145	0.002

STAI State Trait Anxiety Inventory

Table 6.33 Overall predictors for anxiety about sleep at the end of week 2

N=92	Odds ratio	95% CI	P-value
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.599	1.038 – 2.462	0.033
Parents who did not receive information regarding their child's surgery	0.139	0.023 – 0.863	0.034
Parent baseline state anxiety (20-80 STAI)	1.053	1.003 – 1.105	0.037

SDQ Strengths and Difficulties Questionnaire, STAI State Trait Anxiety Inventory

6.5.4 Summary

Twelve variables (4 parent factors, 6 child factors, 2 home factors) predicted PB (total score and/or subscale scores) at the end of week 2 post-discharge from hospital. Four of these factors were potential predictors in more than one model: parent baseline state anxiety (PB total score, separation anxiety, anxiety about sleep), child pre-operative anxiety (PB total score, general anxiety and regression, separation anxiety), child behavioural difficulties: conduct problems (general anxiety and regression, aggression toward authority) and child pain intensity at the end of week 2 (eating disturbance, general anxiety and regression).

Factors that were potentially predictive of PB (total or subscale scores) on day 2 and at the end of week 1 that remained potential predictors at the end of week 2 were: parents who felt less prepared for their child's care at home, younger children and pain at home on day 2 post-discharge. The only factor that was potentially predictive of PB at the end of week 1 and again at the end of week 2, but not on day 2, was children with more pre-operative conduct problems.

6.6 Problematic behaviours: Week 4

6.6.1 Total score: Step 1

Tables 6.34 to 6.37 present the models with the best goodness-of-fit for the parent factor, child factor, in-hospital factor and home factor variables that predicted PB total scores at the end of week 4 post-discharge from hospital.

Table 6.34 Parent factor predictors for PB at the end of week 4

N=85	Odds ratio	95% CI	P-value
Parent baseline trait anxiety (20-80 STAI)	1.138	1.066 – 1.215	0.000
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	6.719	1.558 – 28.981	0.011
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.900	0.820 – 0.987	0.025

STAI State Trait Anxiety Inventory, PBS Parent Beliefs Scale

Table 6.35 Child factor predictors for PB at the end of week 4

N=84	Odds ratio	95% CI	P-value
Children with a recent prior pain experience*	3.204	1.122 – 9.147	0.030
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.454	1.036 – 2.042	0.031

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests, SDQ Strengths and Difficulties Questionnaire

Table 6.36 In-hospital factor predictors for PB at the end of week 4

N=96	Odds ratio	95% CI	P-value
Children not given premedication	0.208	0.044 – 0.984	0.048
Children who spent ≥ 1 night in hospital	2.016	0.813 – 5.001	0.130

Table 6.37 Home factor predictors of PB at the end of week 4

N=74	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 4 (0-10 NRS)	3.233	1.612 – 6.487	0.001
Children who were taken to the GP due to their surgery in the third or fourth week after surgery	6.350	1.185 – 34.014	0.031

NRS numeric rating scale

6.6.2 Total score: Step 2

These factors were combined in a final model to identify which of these factors best predicted PB at the end of week 4 (Step 2). A three-factor model provided the best fit for potential predictors of children's PB (total score) at the end of week 4 (Table 6.38).

Parents with higher baseline trait anxiety, who were more educated and whose children had had a recent pain experience during their last medical encounter prior to admission for surgery were more likely to report PB in their children at the end of week 4.

Table 6.38 Overall predictors for PB at the end of week 4

N=62	Odds ratio	95% CI	P-value
Parent baseline trait anxiety (20-80 STAI)	1.139	1.054 – 1.231	0.001
Children with a recent prior pain experience*	4.802	1.082 – 21.319	0.039
Parents with a graduate/post-graduate qualification (vs. primary/secondary school education)	4.619	1.015 – 21.020	0.048

* GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests, STAI State Trait Anxiety Inventory

6.6.3 Subscale scores

Step 1 and Step 2 were carried out for each of the six subscales scores of PB at the end of week 4 post-discharge from hospital. Tables 6.39 to 6.44 present the final models (Step 2) that best predicted PB in each of the subscales.

Table 6.39 Overall predictors for general anxiety and regression at the end of week 4

N=90	Odds ratio	95% CI	P-value
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.957	1.145 – 3.343	0.014
Parent baseline trait anxiety (20-80 STAI)	1.087	1.012 – 1.168	0.022
Children with lower temperament activity (5-25 EASI)	0.803	0.653 – 0.988	0.038

SDQ Strengths and Difficulties Questionnaire, STAI State Trait Anxiety Inventory, EASI Emotionality Activity Sociability and Impulsivity Instrument

Table 6.40 Overall predictors for separation anxiety at the end of week 4

N=88	Odds ratio	95% CI	P-value
Parent baseline trait anxiety (20-80 STAI)	1.100	1.038 – 1.166	0.001
Parents who felt less prepared for their child's home care (0-10 NRS)	0.712	0.534 – 0.950	0.021
Children who did attend a pre-admission clinic	4.054	1.072 – 15.329	0.039

STAI State Trait Anxiety Inventory, NRS numeric rating scale

Table 6.41 Overall predictors for eating disturbances at the end of week 4

N=92	Odds ratio	95% CI	P-value
Child pain intensity at the end of week 4 (0-10 NRS)	2.520	1.376 – 4.616	0.003
Parent baseline trait anxiety (20-80 STAI)	1.090	1.022 – 1.162	0.009

NRS numeric rating scale, STAI State Trait Anxiety Inventory

Table 6.42 Overall predictors for aggression toward authority at the end of week 4

N=76	Odds ratio	95% CI	P-value
Children with behavioural difficulties: conduct problems (0-10 SDQ)	1.962	1.221 – 3.152	0.005
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.878	0.786 – 0.981	0.021

SDQ Strengths and Difficulties Questionnaire, PBS Parent Beliefs Scale

Table 6.43 Overall predictors for apathy-withdrawal at the end of week 4

N=98	Odds ratio	95% CI	P-value
Child behavioural difficulties: conduct problems (0-10 SDQ)	1.962	1.221 – 3.152	0.005
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.878	0.786 – 0.981	0.021

SDQ Strengths and Difficulties Questionnaire, PBS Parent Beliefs Scale

Table 6.44 Overall predictors for anxiety about sleep at the end of week 4

N=80	Odds ratio	95% CI	P-value
Children with behavioural difficulties: peer problems (0-10 SDQ)	1.726	1.158 – 2.573	0.007
Parents with lower beliefs regarding their role in their child's care (12-60 PBS)	0.879	0.791 – 0.977	0.017

SDQ Strengths and Difficulties Questionnaire, PBS Parent Beliefs Scale

6.6.4 Summary

Ten variables (4 parent factors, 5 child factors and 1 home factor) predicted PB (total score and/or subscale scores) at the end of week 4 post-discharge from hospital. Three of these factors were potential predictors in more than one model: lower parent beliefs regarding

their role in their child's care (aggression toward authority, apathy-withdrawal, anxiety about sleep), parent baseline trait anxiety (PB total score, general anxiety and regression, separation anxiety) and child behavioural difficulties: conduct problems (general anxiety and regression, aggression toward authority, apathy-withdrawal).

Potential predictors of PB (total and subscale scores) at the end of week 4 that were also potential predictors of PB on day 2, at the end of week 1 or at the end of week 2 were: parents with higher education (day 2, week 1 and 4), parents who felt less prepared for their child's care at home (day 2, week 1, 2 and 4), parents with lower beliefs about their role in the child's care (week 1 and 4), parent baseline trait anxiety (day 2, week 2 and 4), children with lower temperament activity (day 2 and week 4), children's preadmission clinic attendance (no attendance at week 1 and attendance at week 4), children who had had a recent pain experience during their last medical encounter prior to admission for surgery (week 2 and 4), children with more pre-operative conduct problems (week 1, 2 and 4) and pain at home (day 2, week 1, 2 and 4).

6.7 Additional predictors of problematic behaviours for the inpatient population only

In-hospital factors that pertained to the inpatient population only were factors related to parent participation in the child's in-hospital care and factors related to parent satisfaction regarding their child's inpatient pain management. These factors were added to the in-hospital factor regression models in Step 1 for PB total scores and subscale scores at each of the four follow-up time-points. Factors identified as potentially predictive in-hospital factors of PB total and subscale scores were added to the final models (Step 2) for overall potential predictors of PB (total and subscale scores).

6.7.1 Step 1

Only two models revealed inpatient factors that were potentially predictive of PB in the in-hospital factor regression models. Parents who had lower expectations of their child's in-hospital pain intensity predicted problems with separation anxiety on day 2 (Table 6.45).

Table 6.45 In-hospital factor predictors for separation anxiety on day 2

N=35	Odds ratio	95% CI	P-value
Parents with lower expectations of their child's in-hospital pain (0-10 NRS)	0.768	0.588 – 1.002	0.052

NRS numeric rating scale

Parents who participated more in their child's in-hospital care and who were less satisfied with their child's in-hospital pain management predicted PB total scores at the end of week 2 (Table 6.46).

Table 6.46 In-hospital factor predictors for PB at the end of week 2

N=34	Odds ratio	95% CI	P-value
Parents with higher levels of participation in their child's inpatient care (0-100 IPP)	1.067	1.008 – 1.129	0.026
Parents who were less satisfied with their child's inpatient pain management (0-10 NRS	0.535	0.314 – 0.910	0.021
Children with less waiting time between admission and being taken to surgery (time in minutes)	0.995	0.988 – 1.003	0.218

IPP Index of Parent Participation, NRS numeric rating scale

6.7.2 Step 2

These in-hospital potential predictors for the inpatient population were entered into the final models (Step 2) of potential predictors for separation anxiety on day 2 and PB at the end of week 3. The regression models with the best goodness of fit failed to identify these new in-hospital factors as overall potential predictors of PB.

6.7.3 Summary

Factors related to the inpatient population only were identified as in-hospital potential predictors of PB on day 2 (separation anxiety subscale) and at the end of week 2 (PB total score) but were no longer potential predictors when all other factors (parent factors, child factors and home factors) were taken into account. Therefore, factors explored in relation to the inpatient group only were not identified as additional risk factors for PB (total or subscale scores).

6.8 Conclusion

This chapter presented the results of multiple binary regression models constructed to identify parent, child, in-hospital and home factor potential predictors of PB (total and subscale scores) on day 2 and at the end of week 1, 2 and 4.

Only 2 factors were potentially predictive of PB total scores at more than 1 time-point: parents with higher education (day 2, week 1 and 4) and children who had had a recent pain experience during their last medical encounter prior to admission for surgery (week 2 and 4).

There were a number of factors that were potentially predictive of PB total scores (one time-point) and/or subscale scores. Parent factors identified were: higher anxiety regarding their child's anaesthesia, parents who felt less prepared for their child's care at home, parents who did no additional information searching, parents with higher baseline state anxiety, higher baseline trait anxiety, parents with lower blunter coping style and parents with lower beliefs regarding their role in the child's care. Child factors consisted of: lower temperament sociability, lower temperament activity, higher temperament emotionality, higher child pre-operative anxiety, younger children, pre-admission clinic attendance (no attendance at week 1 and attendance at week 4) and more pre-operative conduct problems. Children who spent ≥ 1 night in hospital and children with higher pain intensity on day 2 were the only in-hospital and home factors respectively that predicted PB total scores (one time-point) and/or subscale scores.

Finally, 13 factors were identified as potentially predictive of PB subscales at only one time-point: 7 parent factors (higher monitor coping style, parents with higher thoughts of helplessness and magnification regarding their child's postoperative pain, parents with higher self-report anxiety and pain during their last hospitalisation for surgery, parents who did not feel prepared for their child's admission, parents who received information regarding their child's admission and who were more satisfied with the information that

they received), 2 child factors (higher temperament impulsivity and more pre-operative peer problems), 2 in-hospital factors (children who received inhalation induction of anaesthesia and who did not receive premedication) and 2 home factors (pain at the end of week 2 and at the end of week 4).

Factors that related to the inpatient population only, i.e. participation in the child's hospitalised care and satisfaction regarding the child's in-hospital pain management were not potentially predictive of PB (total or subscale scores).

The next chapter will discuss the results presented in chapter five and six in the context of current literature in the field of children hospitalised for surgery. Implications for current nursing/surgical practice and future research will be presented and the study's strengths and limitations discussed.

Table 6.47 Parent factor predictors of PB total scores and subscale scores

	Day 2							Week 1							Week 2							Week 4						
Predictor variable	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**
APAIS anxiety #	●																											
Graduate/post-graduate	●							●														●						
IMD (high)							●																					
Less prepared for home care	●			●			●					●							●					●				
MBSS blunter (low)									●	●			●															
MBSS monitor (high)											●																	
No additional information searching	●			●		●																						
Not prepared for admission					●																							
PBS child behaviour (high)										●		●																
PBS parent role (low)											●	●														●	●	●
PCS helplessness (low)												●																
PCS magnification (high)												●																
Previous anxiety *									●																			
Previous pain *				●																								
Received information re surgery																					●							

Satisfied with parent information					●																								
STAI - state										●+				●	●		●				●								
STAI - trait			●																	●		●	●	●					

PB problematic behaviour, GA general anxiety and regression, SA separation anxiety, EA eating disturbances, AA aggression toward authority, AW apathy-withdrawal, SL anxiety about sleep, # Anxiety regarding child's anaesthesia, MBSS monitor-blunter style scale, PBS parent beliefs scale, PCS pain catastrophising scale, * related to parent's previous hospitalisation for surgery, STAI state-trait anxiety inventory, + $0.05<p<0.1$

Table 6.48 Child factor predictors of PB total scores and subscale scores

	Day 2							Week 1							Week 2							Week 4						
Predictor variable	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**
EASI activity (low)			●																				●					
EASI emotionality (high)		●				●							●															
EASI sociability (low)		●													●													
EASI impulsivity	● ↓																	● ↑										
Higher birth order					● +									●														
mYPAS															●	● +	●											
Pre-admission clinic attendance (Y/N)								● N	● + N															● Y				
Recent prior pain*															●							●						
SDQ conduct problems (difficulty)												●		●		●			●				●			●	●	
SDQ hyperactivity (strength)		●				●																						
SDQ peer problems (difficulty)																												●
Younger children			●					●	●	●							●											

PB problematic behaviour, GA general anxiety and regression, SA separation anxiety, EA eating disturbances, AA aggression toward authority, AW apathy-withdrawal, SL anxiety about sleep, EASI emotionality activity sociability and impulsivity scale of child temperament, mYPAS modified Yale pre-operative anxiety scale, * GP visit, pre-surgery examination by consultant, routine immunizations, venipuncture and blood tests, SDQ strengths and difficulties questionnaire, + $0.05<p<0.1$

Table 6.49 In-hospital and home factor predictors of PB total scores and subscale scores

	Day 2							Week 1							Week 2							Week 4						
Predictor variable	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**	**PB**	**GA**	**SA**	**EA**	**AA**	**AW**	**SL**
≥ 1 night in hospital	●			●							●																	
Inhalation induction									●	●																		
No pre-medication		●	●																									
Pain day 2		●	●										●					●										
Pain wk 1								●			●																	
Pain wk 2																●		●										
Pain wk 4																									●			

PB problematic behaviour, GA general anxiety and regression, SA separation anxiety, EA eating disturbances, AA aggression toward authority, AW apathy-withdrawal, SL anxiety about sleep

Chapter 7
Discussion

7.1 Introduction

Chapters 5 and 6 presented the results of descriptive and exploratory analyses and multiple binary logistic regression analyses. This chapter places the results of the current study in the wider context of prior research. The strengths and limitations of the study are discussed and emphasis is placed on the implications that the findings have for clinical practice and future research. The chapter concludes with a brief discussion of the dissemination plans and reflections on the research experience.

7.2 Discussion

The key findings from this study relate to the incidence of PB and the identified associated factors over the first month at home following the child's discharge from hospital. Other noteworthy findings relate to the incidence of pain in children after discharge and how this relates to their PB. The impact that the child's PB and pain post-discharge had on the family at home is also discussed.

7.2.1 Behaviour changes following admission to hospital for surgery

7.2.1.1 Problematic behaviours

7.2.1.1.1 Incidence

Nearly three quarters (73.3%) of the children in the current study exhibited PB in at least one of the 27 behaviour change items listed on the PHBQ on day 2 post-discharge from hospital. This incidence decreased significantly over the first month following discharge with less than half (42.9%) of the children exhibiting PB at the end of week 2 and around a third (31.8%) at the end of week 4. A lower incidence of PB within the first three days post-discharge was reported in the USA, Finland and Australia in three previous studies (Kain et al. 1999b;Kotiniemi et al. 1997;Stargatt et al. 2006) and this ranged from 16% to 67%. The incidence of PB at week 2 has previously been reported to be 12% to 54% in the

USA, Sweden and Finland (Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007;Kotiniemi et al. 1997;Lumley et al. 1993). Only one study in Australia (Stargatt et al. 2006) defined PB as changes in seven or more behaviour items listed on the PHBQ and not presence versus absence of any behaviour change. This study reported a similar incidence of seven or more PB to the current within the first three days post-discharge (24% vs. 23.3%) but almost double the incidence at the end of week 4 (16% vs. 8.2%).

One possible explanation for the differences in the incidence of PB exhibited by children post-discharge between countries may be due to cultural differences, which means that parents' assessment of what constitutes a PB might differ, e.g. some cultures may not rate children sleeping with their parents as a PB and an increase in this behaviour post-discharge from hospital may be expected in terms of the child needing more comforting rather than an increase in a problem. However, an advantage of the PHBQ is that it allows parents to assess their child's behaviour as worse, better, or the same as the child's pre-hospital behaviour without comparing the child to other children. The child serves as his/her own control so that the effect of cultural differences should be minimised. Another possible explanation might be due to different hospital practices that the children were exposed to in the various settings. Hospital environments, facilities available for children and/or their parents, standard administration of premedication, and routine separation of children from their parents prior to induction of anaesthesia are all examples of factors that could influence how the parent-child dyad appraise the stress of hospitalisation for surgery which would have an affect on their coping outcomes. This study was not powered to be able to examine the effect of all of the many factors that might influence the outcomes of interest. Nonetheless this study provides a robust estimate of the incidence and time course of post-hospital PB for British children.

7.2.1.1.2 Types of problematic behaviours

One of the strengths of the PHBQ is that it identifies specific PB exhibited by children without assigning a weighting to the behaviours. The most frequently exhibited PB over the course of the follow-up period in the current study were items listed under the subgroups of separation anxiety and eating disturbances. Apathy-withdrawal and general anxiety and regression items appeared in the top ten PB on day 2 but were replaced by items grouped

under aggression toward authority and anxiety about sleep for the remainder of the follow-up period. Therefore, children tend to exhibit less PB as time post-discharge passes and the types of PB that they exhibit also changes. The results from the current study are similar to those reported by Kain et al. (1999) who also found a higher incidence of separation anxiety and eating disturbances than other subgroup behaviours over the course of a two-week follow-up period. PB related to separation anxiety were also reported as the most frequently exhibited PB in three other studies (Kotiniemi et al. 1997;Lumley et al. 1993;Stargatt et al. 2006) but behaviours related to eating disturbances were not identified as the most prevalent PB in any of these studies. Karling et al. (2007) reported less general anxiety and regression problems than any of the other subscales. This is similar to the results in the current study, where 5 to 6 out of a possible 8 PB grouped under general anxiety and regression were in the bottom 10 PB exhibited across the follow-up period. However, Stargatt et al. (2006) reported general anxiety and regression behaviour items as the most frequently exhibited in their cohort.

The number of PB that each child exhibited at various time-points post-discharge was generally low. The median number of PB in the current study was: 2 on day 2, decreasing to 1.5 at the end of week 1 and 0 at the end of weeks 2 and 4. Median numbers of PB at the end of week 2 were similar in earlier studies (Kain et al. 1996c;Karling et al. 2007) but higher at one month (3 vs. 0) (Kotiniemi et al. 1997;Stargatt et al. 2006). The variation in frequency and type of PB found in this and the other studies suggests that the expression of PB may be individual to the child related to the interaction of temperamental, family, health and other contextual factors. It may mean that general screening for the presence of PB is important but that the support provided to children and parents may need to be individualised.

7.2.1.1.3 Factors associated with problematic behaviours identified from regression analyses

A number of variables, grouped into parent factors, child factors, in-hospital and home factors, were explored as factors that could be associated with PB within the first month following discharge from hospital. Results highlighted a number of new factors not

previously identified in other studies and confirmed factors that have previously been identified.

7.2.1.1.3.1 Factors associated with problematic behaviours within the first two weeks post-discharge

7.2.1.1.3.1.1 New factors identified from the current study

Within the first two weeks following discharge from hospital, new factors associated with PB (total scores) in children were identified as: parents who felt less prepared for their child's care at home (day 2), parents with higher anxiety specifically regarding their child's anaesthesia (day 2), parents who did not do any additional information searching prior to their child's admission (day 2), parents with a graduate / post-graduate (versus primary/secondary school) education (day 2 and week 1), and children who had a recent pain experience prior to their admission to hospital for surgery (week 2). Although not previously identified as an associated factor with PB total scores, Karling et al. (2007) identified parents' higher education as a risk factor for specific child PB, i.e. general anxiety and regression and apathy-withdrawal. Parent variables related to their preparation for their child's admission to hospital for surgery have not previously been explored in relation to their child's post-discharge behaviour.

When placed in the context of the study's theoretical framework, the association between these newly identified factors and child PB can all be described in terms of the parent/child's appraisal of the stressful event. Children who have recently experienced pain during a medical procedure may be more likely to appraise their admission to hospital for surgery as potentially harmful. Similarly, parents with a higher education level may be in a better position to adequately appraise the harmful and/or beneficial aspects of the stress, which in turn may highlight their lack of knowledge and lead them to feel more anxious about their child's anaesthesia and less prepared for their child's care once at home. Parents' lack of additional information searching may mean that they were satisfied with the information they had received and had no desire for more information or that they were unaware of where to find additional information. In either case, the amount of information they received would affect their appraisal of the stress posed upon themselves and/or their child and how they could engage in coping strategies.

7.2.1.1.3.1.2 Factors that confirm previous research

A number of factors associated with PB were identified in the current study that confirmed previous research. Younger child age (2 to 4 vs. 5 to 12 years) was associated with PB at the end of week 1. Younger child age was also identified as an associated factor with PB (total scores) within the first two weeks post-discharge in four previous studies (Karling et al. 2007;Kotiniemi et al. 1997;Stargatt et al. 2006;Tuomilehto et al. 2002). Temperament factors in the current study, i.e. lower child temperament impulsivity was associated with PB on day 2 and lower child temperament sociability was associated with PB at the end of week 2. Carson et al. (1991) identified a child's predictability, approach, adaptability and mood as temperament factors positively associated with post-hospital behaviour. In the current study, children's lack of attendance of a pre-admission clinic was associated with PB at the end of week 1. This generally involved a physical assessment of the child, provision of written information to the child and/or the parent with or without aspects of formal preparation, i.e. a tour of the surgical areas, exposure to anaesthetic and surgery related equipment and role-play/rehearsal. A number of intervention studies (Brewer et al. 2006;Margolis et al. 1998;Zahr 1998) have shown that adequate preparation of the child prior to admission to hospital for surgery has positive outcomes on child behaviour at home.

These factors all relate to the child's appraisal of the stressful event and their ability to activate coping strategies. Younger children lack the cognitive ability to adequately appraise a stressful event and lack the experience of stress exposure and learned coping skills. When younger children encounter the unfamiliar environments and people associated with admission to hospital for surgery, their appraisal of the potentially harmful aspects of the stressful event may mean that they feel more threatened. The variety of child temperament factors associated with PB highlight the individuality of the child's appraisal of the stressful event and their natural tendency to activate coping strategies. The attendance of a pre-admission clinic may or may not have included aspects of formal preparation but would have provided the child with some exposure to the hospital environment, staff and information regarding their admission to hospital for surgery. It would be expected that provision of information prior to a stressful event would initiate the

child's appraisal of the stressful event and mobilise coping strategies. Lack of any information or previous exposure would mean that the child's admission would be the first time that the child was faced with the stressors of hospitalisation which may exacerbate the appraisal of the potential harmful aspects resulting in poorer coping.

Higher child pre-operative anxiety, measured shortly after admission in the current study, was associated with PB at the end of week 2. Three descriptive studies identified higher child anxiety at separation from their parents to theatre (Kain et al. 1996c) and during induction of anaesthesia (Kain et al. 1999b;Karling et al. 2007) as factors associated with PB at 2 weeks post-discharge from hospital. Higher parent baseline state anxiety, measured within the week prior to their child's admission to hospital, was associated with PB at week 2 in the current study. Parent baseline state and trait anxiety in the current study were measured after the parent had received their child's appointment letter for surgery and in some cases written information regarding the child's admission and planned procedure. It is possible therefore that these measures were not true baseline measures. Stargatt et al. (2006) reported that higher parent state anxiety measured prior to their child's induction of anaesthesia, was associated with PB on day 3 post-discharge. Spending at least one night in hospital was associated with PB on day 2 post-discharge. Three other studies (Carson et al. 1991;Karling et al. 2007;Stargatt et al. 2006) included children admitted for both day case and inpatient surgery and two of these studies identified staying one or more nights in hospital as a factor associated with separation anxiety, general anxiety and regression, and apathy-withdrawal at the end of week 2 (Karling et al. 2007) and PB total scores on day 3 and day 30 (Stargatt et al. 2006).

In the context of the theoretical framework child and parent anxiety are considered to be immediate outcomes of coping as well as potential influencing factors for child PB (long-term coping outcome). Heightened child/parent anxiety are indicative of poor coping during the stressful event, which is either improved or worsened by additional factors that the dyad are exposed to prior to and after the child's surgery. Staying one or more nights in hospital, in this case, has been identified as a factor that provided additional stress to the dyad. A number of possible confounding factors related to the child staying over night were not explored in the current study and may have been the true cause of the association with PB. Data were not collected regarding the child's actual surgery, i.e. the complexity

and length of the surgery; the presence of intravenous lines, drains or catheters post-surgery; and factors related to any post-surgery invasive procedures all of which would potentially increase the child's stress exposure and affect coping outcomes.

Higher child pain intensity at the end of week 1 was associated with PB at the same time-point in the current study. Moderate to severe pain at home within the first two weeks post-discharge (Karling et al. 2007) and pain at home on day 0 (day of operation in day case population) (Kotiniemi et al. 1997) have previously been associated with PB at week 2 and within the first 4 weeks post-discharge respectively.

Most children experience pain following surgery. Pain and other postoperative symptoms are an important aspect of the child's postoperative recovery and are both a coping outcome and a potential influencing factor for PB. Evidence from the current study and previous research provide support for the study's theoretical framework which proposes that the child's level of pain following discharge is indicative of how well they are coping following the physiological stress of surgery. Higher pain intensity is indicative of poorer coping and the association with PB can be easily explained. A child is less likely to be mobile and to perform usual activities if pain restricts him/her from doing so, e.g. a painful limb would limit mobility and a painful throat would affect the child's ability and/or desire to eat or drink. It is also possible that negative changes in a child's usual behaviour would alert the parent to the likelihood that the child is in pain and therefore assess their child's pain as more intense.

7.2.1.1.3.2 Factors associated with problematic behaviours one month post-discharge

In the current study, three factors associated with PB were identified one month post-discharge from hospital: higher parent education (graduate/post-graduate versus primary/secondary school), higher parent baseline trait anxiety and children who had a recent pain experience prior to their admission to hospital for surgery. Two of these factors were also associated with PB within the first two weeks post-discharge, and have been discussed above. Higher parent baseline trait anxiety provides further evidence of how parent factors are just as likely to influence the parent and/or child's appraisal of the

stressful event which in turn affects chosen coping strategies and better or poorer coping outcomes by the child. No other factors associated with PB one month post-discharge were identified in the current study that confirmed previous research.

7.2.1.1.3.3 Factors associated with specific problematic behaviours

A number of factors were identified in the current study as being associated with specific PB, as measured by the PHBQ subscales, that were either new factors not previously identified in previous research (PB total or subscale scores) or that confirmed previous research.

A number of new parent factors associated with specific PB but not PB total scores appear to be contradictory, i.e. parents' higher pain but lower anxiety during their own previous admission to hospital for surgery; feeling unprepared for their child's admission to hospital but higher satisfaction levels regarding information they received; and lower parent beliefs about the parents' role in their child's care but higher beliefs about their child's expected behaviour. It would be expected that parents who experienced higher pain during their own admission to hospital for surgery would anticipate more pain in their children and thus appraise the stressful event as potentially more harmful to their children. Parents who felt less prepared for their child's admission and parents who had lower beliefs regarding the parent's role in their child's care would not be able to adequately appraise the stressful event which would affect their chosen coping strategies and ultimately their assessment of their child's coping outcomes. On the contrary, parents' lower anxiety levels during their own hospitalisation for surgery, parents who were more satisfied with the information they received and who had higher beliefs regarding what behaviour changes to expect in their children may have appraised the stressful event as less harmful to themselves and their children than it actually was. The disparity between what they expected and what actually happened would have an affect on their appraisal of the stress.

Other new parent factors identified were parents with higher catastrophic thoughts about their child's postoperative pain and parents with higher trait monitor/lower trait blunter coping styles. Higher catastrophic thoughts regarding their child's postoperative pain would result in the parents appraising the stressful event as potentially more harmful.

Parents' catastrophic thinking about their child's pain has previously explained child illness-related parent stress, depression and anxiety and children's chronic pain-related disability and school attendance (Goubert et al. 2006). The parents' trait coping strategies may have resulted in poorer outcomes due to their inability to control the environment or to minimise the stressors that they and their child were exposed to (Miller 1987).

New child factors identified as being associated with specific PB but not PB total scores were children with lower pre-operative hyperactivity behavioural disorders and children higher in birth order. Both of these factors confirm that there are a number of possible factors that result in the individuality of how the child appraises a stressful event and what coping strategies they adopt.

A number of factors associated with specific PB were identified in the current study that confirmed prior research (PB total or subscale scores). Child pre-operative behavioural difficulties, specifically conduct problems, were associated with a number of PB subgroups within the first two weeks post-discharge. This confirmed findings in a previous study (Karling et al. 2007) that found an association between increased pre-operative behavioural difficulties and aggression toward authority, general anxiety and regression, and apathy-withdrawal two weeks post-discharge. Child temperament factors (lower temperament activity, higher emotionality, lower sociability, and higher impulsivity) were associated with a number of specific PB within the first month post-discharge. Kain et al. (1996) was the only study to report child temperament (higher impulsivity) as an associated factor for general anxiety and regression. In the context of the study's theoretical framework, child pre-operative behaviour and temperament are baseline psychological factors that determine how the child would appraise the stressors imposed upon them and how they would react. The parents' appraisal of the stressful event would also be affected by their child's innate qualities as they would be experienced with how their children would usually react in times of stress. The child's attendance at a pre-admission clinic (with or without formal preparation) in the current was associated with separation anxiety at the end of week 4. This is in contrast to children who did not attend a pre-admission clinic being associated with PB (total scores) at the end of week 1 but supports findings from a study conducted by Stargatt et al. (2006) who reported an association between children who read a book

regarding their anaesthesia prior to admission to hospital and PB (total scores) on day 30. In this instance the child's clinic attendance and exposure to the hospital environment, staff and/or information regarding their admission to hospital may have heightened their awareness of the potential threats of hospitalisation for surgery, initiating their cognitive appraisal of the stress and affecting how they coped.

In-hospital factors associated with specific PB were the administration of premedication and the type of anaesthetic induction. Children not given premedication was associated with developing general anxiety and regression, and separation anxiety on day 2 post-discharge in the current study. One other study (Karling et al. 2007) identified children who were not given premedication as being an associated factor for general anxiety and regression, and aggression toward authority. Results from two intervention studies (Kain et al. 1999a;McCluskey et al. 1994) confirmed that children who were not given premedication had significantly more PB 1 to 2 weeks post-discharge than children who were given premedication. The administration of premedication may decrease the child's awareness of the stressful event which would in turn have an affect on their appraisal of the stress and their coping. Inhalation induction of anaesthesia (versus intravenous induction) was associated with general anxiety and regression, and separation anxiety at the end of week 1. Although inhalation induction of anaesthesia was not previously identified as an associated factor from regression analyses in any other study, Bal et al.'s (2006) intervention study compared inhalation induction with sevoflurane (alone and followed by a dose of propofol) to intravenous induction with propofol and reported that children who had intravenous induction had no nightmares/fear of the dark at one week after surgery whereas children in the inhalation induction groups did and significantly fewer children in the intravenous induction group wanted to sleep with their parents (Bal et al. 2006). The application of the anaesthetic mask on the child's face for inhalation of anaesthesia may exacerbate the stressful event. A number of intervention studies (Brewer et al. 2006;Kain et al. 2007a;Margolis et al. 1998;Zahr 1998) have included pre-exposure of the child to the anaesthetic mask in an attempt to adequately prepare the child for the stressors they will be exposed to during their admission to hospital for surgery. However, it is likely that more anxious children, in whom problematic behaviours are anticipated, would be selected for inhalation induction as no needles and less cooperation from the child is required.

7.2.1.2 Fewer problematic behaviours

7.2.1.2.1 Incidence

In the current study over a quarter of children (25.5% to 39.7%) exhibited fewer PB compared to pre-operative behaviour in at least one of the 27 items at all four follow-up time-points. The proportion of children who exhibited fewer problematic behaviours in the current study is higher than that reported in previous research. Two studies (Lumley et al. 1993;Schmidt 1990) reported fewer PB / improved behaviour in around one fifth (18% to 20%) of children within the first two weeks post-discharge and one study (Kotiniemi et al. 1997) reported an incidence of just under one fifth (17%) of children who exhibited fewer PB/improved behaviour one month after surgery.

These results suggest that although the incidence of children who exhibit PB post-discharge from surgery is generally higher than the incidence of children who exhibit fewer PB / improved behaviour, there is a cohort of children who may experience enhanced psychosocial development as a result of the experience of hospitalisation for surgery. This supports the Crisis theory that contends that the hospitalisation event provides either a danger or an opportunity to children who will: (i) learn adaptive new coping skills, (ii) learn mal-adaptive coping skills or (iii) emerge relatively unharmed as no new skills were required (Caplan 1961). It is the child/parent's interpretation of a situation that determines whether or not hospitalisation for surgery is a crisis and initiates coping mechanisms.

The PHBQ may not be the best tool to measure fewer PB, as it was developed by Vernon et al. (1966) following a review of the literature on child psychological upset following hospitalisation between 1945 and 1959. The 27 items listed in the PHBQ are PB, e.g. "Does your child make a fuss about going to bed at night?" and "Does your child have temper tantrums?". Therefore, although the child may exhibit these behaviours less than before surgery, they are still being rated on PB.

A number of other studies (Galland et al. 2006;Goldstein et al. 1998;Goldstein et al. 2002;Li et al. 2006;Mitchell et al. 2005) identified from the literature reported improved

behaviour following admission to hospital for surgery, using different tools to measure behaviour, e.g. the Child Behaviour Checklist (CBCL) and the Behavioural Assessment System for Children (BASC). Behaviour change in these studies was also measured at later time-points e.g. six months and one year following discharge and all of the children in these studies had been admitted to hospital for tonsillectomies with or without adenoidectomies. It is not clear whether the identification of improved behaviour in these studies is due to the sensitivity of the tools used to measure behaviour, the time-point at which the behaviour was measured or the type of surgery that the children had.

7.2.1.3 Summary

Children exhibit PB post-discharge from hospital, the incidence of which decreases as time passes. There are a wide variety of PB exhibited by individual children and although the number of PB per child is generally low, it is a dynamic process that results in children exhibiting different types of PB over the course of the first month post-discharge. There is little consensus across studies regarding the types of PB exhibited at various time-points post-discharge. Future descriptive research should focus on the dynamic process of the emergence and resolution of PB exhibited by children post-discharge so that clinicians can inform parents of what to expect at various time-points.

A number of factors associated with PB were identified within the first two weeks post-discharge. New factors identified in the current study were primarily parent factors related to their preparation for their child's surgery and care at home, parent education level and the child's previous pain experience prior to admission to hospital. At four weeks post-discharge, higher parent education level and child previous pain experience prior to admission to hospital for surgery were still associated with PB. These factors all relate to the parent and child's appraisal of the stressful event of hospitalisation for surgery. None of these factors have been previously explored and have important implications for clinical practice and further research. Clinical practice could be improved by providing parents with adequate information regarding their child's admission, surgery, hospital care, possible behavioural reactions to hospitalisation, and how the parents can participate in their child's physical and emotional care. Checking parents' satisfaction with the information provided would limit any misunderstanding and provide the parents with an

opportunity to communicate any further queries they may have. Future descriptive research that focused on parents' informational needs regarding their child's admission to hospital and care at home would help clinicians and researchers to plan appropriate information and care provided to the parents when their child is admitted to hospital for surgery. The current study confirmed that higher child and parent anxiety, younger child age, children who did not attend a pre-admission clinic and children who spent at least one night in hospital are factors associated with PB within the first two weeks. These factors relate to the parent and child's appraisal of the stressors imposed upon them and to the magnitude of the stress.

A number of factors newly identified and those that confirm previous research were associated with specific PB. New factors related to the parents' previous experience of their own hospitalisation for surgery, preparation for their child's surgery, and parent baseline psychological factors. These factors did not appear to follow any logical pattern. Contradictory factors were associated with the same PB, e.g. parents who did not feel prepared for their child's admission and parents who were more satisfied with the information they had received regarding their child's admission were both associated with the child's aggression towards authority. Factors identified that were similar to previous research but not necessarily associated with the same specific PB were child pre-operative behavioural difficulties, child temperament, exposure to aspects of hospitalisation and/or surgery by pre-admission clinic attendance, children not given premedication, and inhalation induction of anaesthesia. More descriptive research is needed to explore the factors associated with specific PB exhibited by children over various time-points post-discharge to clarify contradictory and mixed findings within and between studies before results can be generalised to all children.

Up to one fifth of children exhibited fewer PB when compared to pre-operative behaviour in the current study and three previous studies. Future research that focuses on improved behaviour in children following admission to hospital for surgery should use tools that are more sensitive to improved behaviour and/or that focus on the child's strengths as well as difficulties.

7.2.2 Postoperative symptoms and the family's return to work/school

7.2.2.1 Incidence of pain, nausea and vomiting

The vast majority of the children (93.4%) in the current study were rated by their parents to be in some pain (≥1, 0-10 NRS) on day 2 post-discharge from hospital. This incidence decreased over time with just over a quarter (25.2%) still in some pain at the end of week 4. Over half experienced moderate to severe pain (28.1% ≥4 and 36.4% ≥ 7, 0-10 NRS) on day 2 and slightly more than a fifth at the end of week 2 (14.2% ≥4 and 8.8% ≥ 7, 0-10 NRS). By the end of week 4, only 3.5% of children scored 4 or 5 (0-10 NRS). Pain scores decreased significantly ($p<.001$) from day 2 post-discharge to the end of week 1 (median scores 5 and 2 respectively), which confirms previous research that reports worst pain scores within the first three postoperative days with a significant decrease by the end of the first week (Gedaly-Duff et al. 1994;Reid et al. 1995;Tuomilehto et al. 2002). These results indicate that children's postoperative pain was not adequately managed at home. Reasons for this could be that parents were not aware of how to manage their child's pain, pharmacologically and/or non-pharmacologically, or were reluctant to give their child analgesics due to misconceptions or lack of knowledge regarding analgesic use.

Higher pain intensity was associated with PB at the end of week 1, as discussed earlier, and was also associated with eating disturbances on the same day at the end of week 1, 2 and 4. Eating-related behaviour, i.e. "appetite" and "not eating or drinking" has been reported by parents as cues to identify pain in their children within the first three days (Reid et al. 1995) and two weeks (Gedaly-Duff et al. 1994) post-discharge respectively. The two-way relationship between pain and PB in the context of the study's theoretical framework has already been discussed.

Of the parents who reported pain in their children at home, most administered analgesics to their children on day 2 and at the end of week 1 (81% and 73.2% respectively) and around a half at the end of weeks 2 and 4 (55.8% and 46.7% respectively). The data collected in the current study did not include how many doses of analgesics parents provided to their children. In a recent study conducted in the USA, 71% of children following routine tonsillectomies received less than one half of the possible doses of analgesia they could

have received (Fortier et al. 2009b). This suggests that although parents do administer analgesics to their children at home following surgery, they may not be administering as many doses as the child should receive to ensure adequate pain control. In a review paper on parents' management of their child's postoperative pain (Bastable et al. 2005), the authors suggest that most parents have the potential to effectively manage their child's postoperative pain at home, as long as they are appropriately equipped to do so with a planned approach to discharge preparation and appropriate support once at home.

Less than 10% children complained of nausea and/or experienced vomiting at any of the follow-up time-points in the current study. This is lower than that reported by Amanor-Boadu et al. (1997) who reported that 20% children experienced nausea and vomiting within the first five days post-discharge. Wang et al. (2000) reported an incidence of 41% children who complained of nausea and 33% who experienced vomiting on day 1 post-discharge. Postoperative nausea and vomiting is multifactorial. The age of the child, type of surgery, use of opiod medications, use of antiemetics, and time from surgery to first oral intake modify the rate of postoperative nausea and vomiting. These factors were not explored in the current study and therefore, conclusions regarding the incidence of postoperative nausea and vomiting cannot be reached.

7.2.2.2 The effect of pain and problematic behaviours on the family's return to work/school

Findings from the current study revealed that child pain and PB had a significant impact on the family's return to normal following the child's admission to hospital. Working parents who had to take additional unplanned time off work as a result of their child's surgery reported higher pain scores and more PB in their children within the first two weeks post-discharge and these children were taken to their GP more as a result of their surgery. Higher pain scores were also reported in children who had to take unplanned time off school as a result of their surgery within the first two weeks. The association between family functioning in terms of work and school commitments, the use of follow-up healthcare services and child PB post-discharge has not previously been explored in the related literature. However, in a study conducted by Seid et al. (1999) the efficacy of a home-based, parent-directed pain management protocol to improve clinical, cost, and

paediatric-based outcomes was tested. Results revealed that children in the intervention group missed on average one full day of school less than children in the control group (mean school days missed 4.6 vs. 5.7, $.05 > p < .1$), and 38% parents in the intervention group (versus 48% control) phoned or visited the physician for surgery-related concerns (Seid et al. 1999).

Callery et al. (1997) explored the financial, social and personal costs incurred by parents of children during the child's admission to a day surgical ward. Financial costs to parents included loss of earnings, travel and subsistence, social costs involved alternative care for siblings and the distress related to parents' participation in their child's care resulted in personal costs (Callery 1997). In a later study by the same research group (Hughes et al. 2004), the impact of day case surgery on the child and family from the parent's perspective was explored. Findings revealed an impact for the parent relating to work, and a need for healthcare-related support in the form of reassurances, advice and information (Hughes et al. 2004).

Findings from the current and previous studies suggest that parents may not be prepared for the impact that their child's level of postoperative pain and PB at home potentially have on the family's day to day functioning within the first two weeks post-discharge.

7.2.2.3 Summary

The great majority of the children in the current study were in some pain, over half experienced moderate to severe pain, at home on day 2 post-discharge. Pain intensity decreased significantly with time post-discharge, which confirms previous research, but just over a quarter of the children were rated by their parents as being in some pain, only 3.7% had moderate pain and no children had severe pain, up to four weeks post-discharge. Although parents did report administering analgesics to their children, limitations in data collection methods in the current study did not include dosage or frequency of analgesic use. Findings from other studies suggest that parents may not be giving their children enough analgesics. These findings have important implications for clinical practice. Adequate information provided to parents regarding the importance of pain management would help to reduce the incidence of postoperative pain in children at home.

Parents and children in the current study took unplanned time off work and school and made more visits to the GP due to the child's postoperative pain and PB. Following this and other studies, clinicians are in a position to inform parents that most children experience pain and exhibit PB post-discharge and that both decrease with time. Advising parents regarding the possibility that they and their child may need to take more time off work/school would allow the parents to make necessary arrangements, e.g. additional childcare. Parents would also be assisted if they were encouraged to ask questions regarding any misgivings they may have related to analgesic use in their children. It was beyond the scope of the current study to explore the cost implications that this had to the family and healthcare services but information is lacking in this area and should be explored in future research.

7.2.3 Child pre-operative anxiety

Children in the current study were generally given low scores for pre-operative anxiety (median score 23.33, 0-100mYPAS). However, child pre-operative anxiety was measured shortly after admission and often before the child had been seen by the anaesthetic / surgical teams. It is possible that higher anxiety levels would have been observed in children if measured during induction of anaesthesia as in previous research where mean/median pre-operative anxiety scores reached > 55 on the mYPAS scale (Caldwell-Andrews et al. 2005;Kain et al. 1996c;Kain et al. 2000). In the results of an interim analysis on the pre-operative anxiety and postoperative PB in British children having repeat anaesthesias, median mYPAS scores at induction were consistently 100, the maximum score, for repeated anaesthesias (Watson et al. 2002). This evidence suggests that pre-operative anxiety, during induction of anaesthesia, in British children may in fact be higher than that reported elsewhere, as measured by the mYPAS. According to the study's theoretical framework higher pre-operative anxiety is an indication of poor immediate coping during the stressful event of hospitalisation for surgery and is a potential influencing factor for more PB and/or pain at home. The current study identified that child anxiety shortly after admission is associated with PB two weeks post-discharge, which confirmed previous research (Kain et al. 1996c;Kain et al. 1999b;Karling et al. 2007) and supports the theoretical framework.

7.2.3.1 Significant associations/correlations

A significant correlation was found between child and parent pre-operative anxiety in the current study, which confirms previous research (Davidson et al. 2006;Ellerton et al. 1994;Kain et al. 1996c;Kain et al. 2000;Li et al. 2003). This supports the emotional contagion hypothesis which claims that emotional states, especially anxiety, are transferred from one individual to another by being in each other's presence and modelling these emotions (Gump et al. 1997). It is possible that heightened parent anxiety resulted in heightened child anxiety or vice versa. A number of child, parent and in-hospital factors could potentially increase the child or parent's anxiety in the pre-operative period.

Other factors significantly correlated to child pre-operative anxiety and not explored in previous research were parents' reports of their child's anxiety and confirmation that the child experienced pain during the child's last healthcare consultation prior to their admission to hospital for surgery. These factors support the notion that a child's previous exposure to healthcare related stressful stimuli will alter their appraisal of the potential harm / benefit they are exposed to during their hospitalisation for surgery, which would affect their coping mechanisms and immediate and long-term coping outcomes.

Contrary to previous research, child age (Caldwell-Andrews et al. 2005;Kain et al. 1996c;Kain et al. 2000;Kain et al. 2006b) and temperament factors (Kain et al. 1996c;Kain et al. 2000) were not significantly correlated to / associated with child pre-operative anxiety in the current study. It would be expected that younger child age and some temperament factors would be associated with poorer coping outcomes due to the effect they would have on the child's appraisal of the stressful event, and their experience with or tendency to adopt certain coping strategies. The lack of association in the current study may be due to lower anxiety scores measured shortly after admission and not on entrance to theatre or during induction of anaesthesia. Another factor that has previously been identified as significantly associated with lower child pre-operative anxiety levels is the administration of premedication (Davidson et al. 2006;Kain et al. 1996c). Premedication most often serves as an anxiolytic and/or a sedative and minimizes the child's perception of the stressors they are exposed to. This factor was not explored in relation to child pre-operative

anxiety in the current study as child pre-operative anxiety was measured prior to administration of any premedication.

7.2.3.2 Summary

Child pre-operative anxiety levels were lower in the current study than previously reported. Despite this, child pre-operative anxiety was associated with PB at the end of week 2, which confirms previous research. Another finding that confirms previous research and supports the study's theoretical framework is the significant correlation between child and parent pre-operative anxiety levels. A limitation of the current study is that pre-operative anxiety was not measured during the most stressful times, i.e. on entrance to theatre and during induction of anaesthesia. It is possible that assessment of pre-operative anxiety during these times may have altered the results in terms of the association with PB as well as the identification of more child, parent and in-hospital factors correlated to / associated with pre-operative anxiety. This information would provide evidence to support interventions aimed at reducing both child and parent pre-operative anxiety and ultimately child PB at home.

New to this study was the significant association between the parents' reports of their child's experience of pain and higher anxiety during the child's recent prior medical consultation and higher pre-operative anxiety. These findings highlight the importance of minimising child pain and anxiety and assisting them in coping during all medical procedures to minimise the child and parent's negative appraisal of the stressors of hospitalisation for surgery and to enhance coping during times of heightened stress.

7.2.4 Preparation for surgery

7.2.4.1 Provision and uptake

Less than half of the children in the current study attended a pre-admission clinic and only a third received formal preparation for surgery in the form of meeting staff, a tour of the wards and theatre areas and/or to see a play specialist. Only half of the children received any information regarding their admission to hospital for surgery (apart from pre-admission clinic attendance). In the current study, pre-admission clinic attendance, that at the very least provided the child with some exposure to the hospital environment and/or information

about the child's hospitalisation for surgery, had both a positive and a negative association with PB. A number of intervention studies (Brewer et al. 2006;Ellerton et al. 1994;Kain et al. 1996a;Li et al. 2007;Lynch 1994;Margolis et al. 1998;Rice et al. 2008;Zahr 1998) have tested the effects of pre-operative preparation/information on child pre-operative anxiety and behaviour changes at home and have also reported mixed results in terms of improved behaviour (Brewer et al. 2006;Margolis et al. 1998;Zahr 1998), no change in behaviour (Kain et al. 1996a), improved pre-operative anxiety scores (Ellerton et al. 1994;Li et al. 2007;Lynch 1994;Rice et al. 2008;Zahr 1998), worse pre-operative anxiety scores (Brewer et al. 2006), and both improved and worse pre-operative anxiety scores (Kain et al. 1996a;Margolis et al. 1998). The timing of the preparation and/or provision of information and the age of the child are important considerations as these factors appear to influence the affects of the interventions on coping outcomes. Older and younger children seem to differ in terms of their information requirements, how they appraise the stressful event and their coping strategies. Older children are able to express their informational needs and are more resourceful when it comes to finding this information. Smith et al. (2005) explored the information needs of 7 to 11 year olds relating to planned admission to hospital for surgery and reported that children did not receive direct information from the hospital or health professionals but obtained information from a variety of sources including leaflets for parents, television and experiences of relatives and friends. The authors highlighted that children between the ages of 7 and 11 are capable of identifying their own information needs including information regarding procedures, anaesthesia, timing, the hospital environment, family support, feelings/pain, their condition and concerns (Smith et al. 2005). In a later study conducted by Fortier et al. (2009) 7 to 17 year olds expressed a desire for information about their surgery including information about pain and anaesthesia, procedural information and information about possible complications. It is not clear what the informational needs of younger children are, probably due to their inability to express themselves linguistically. However, research has shown that pre-exposure to surgery-related stressors, such as the theatre environment, clothing, anaesthetic mask and monitoring equipment 5 to 7 days prior to admission to hospital for surgery has resulted in poorer coping outcomes (Kain et al. 1996a;Kain et al. 2007a;Margolis et al. 1998). It is possible that younger children are only better off if the stress of hospitalisation for surgery is minimised through distraction techniques and administration of anxiolytics.

Most of the parents (93.5%) reported receiving some information regarding their child's surgery but almost a third (31.5%) sought additional information and suggestions were made by parents for more information to be provided to families. Previous research has confirmed that parents have unmet information needs related to their child's anaesthetic care and that written information may improve parent knowledge and enhance satisfaction, but the setting and timing of information delivery are important considerations (Spencer et al. 2005). Parents are also better able to assist their children with coping strategies resulting in improved immediate coping outcomes, i.e. pre-operative anxiety, if the parents themselves are adequately prepared (Kain et al. 2007a). As discussed previously, there is a close positive association between parents' and their children's pre-operative anxiety. Therefore, parents who are adequately prepared for their child's admission to hospital for surgery and who are provided with the skills to assist their children, particularly younger children, to cope with the stressors that they will be exposed to, will have improved coping outcomes which should in turn improve their child's coping outcomes.

7.2.4.2 Association between parents' preparation levels and their child's problematic behaviours, pain at home and pre-operative anxiety

Parents' lower levels of preparation for their child's care at home were associated with child PB at all follow-up time-points. These parents also reported higher pain intensity levels in their children while resting in hospital (inpatient group only) and at home. Both parents' levels of preparation for their child's admission and preparation for their child's home care were significantly negatively correlated to parent baseline state and trait anxiety and positively correlated to parents' beliefs regarding their role in their child's care and their child's expected behaviour following surgery. Parent preparation levels have not previously been explored in relation to child PB, pain at home and pre-operative anxiety. However, the preparation of parents prior to their child's admission to hospital for surgery (Kain et al. 2007a), prior to and at various stress-points after their child's admission to hospital for surgery (Visintainer et al. 1975), and shortly after their child's unexpected admission to intensive care (Melnyk et al. 2004) have had excellent results in terms of child and parent outcomes both during and after hospitalisation (Kain et al. 2007a;Melnyk et al. 2004;Visintainer et al. 1975). Felder-Puig et al. (2002) explored the effects of a child pre-operative preparation book on pre- and postoperative anxiety and distress in 2 to 10 year

olds, and their mothers, admitted for tonsillectomies. Results revealed that mothers whose children received the book exhibited less self-reported state anxiety prior to their child's surgery, children showed less distress, and nurses assessed the mothers as more actively involved in their child's care (Felder-Puig et al. 2003). Parents' level of preparation for their child's admission to hospital and their child's care at home were examined in this study as factors that affected the parents' cognitive appraisal of the stressful event. Results from the current study and previous research support the notion that parents who are less prepared are unable to accurately appraise the stressful event of the child's hospitalisation for surgery, resulting in poorer coping outcomes, immediate and long-term, for the parent and the child. Providing parents with information would enable them to adequately appraise the stressful event, improve coping strategies for themselves and their children and ultimately improve coping outcomes.

7.2.4.3 Summary

Less than half of the children in the current study received written information and/or formal preparation for their admission to hospital for surgery. The child's attendance of a pre-admission clinic had mixed results in terms of the association with PB. Previous research has highlighted that child age and the timing of pre-operative preparation and/or provision of information are important influencing factors on the effectiveness of preparation/information on the child's coping outcomes. Older children can identify their own informational needs and are able to source the information. Preparation and information provided to older children assists them in adequately appraising the potential harmful/beneficial aspects of hospitalisation for surgery and may assist them in adopting better coping strategies. Younger children however, cannot express their informational needs and may be worse off after being exposed to the stressors of hospitalisation for surgery before their admission date. Minimising the stressful event may be the best way to assist younger children to cope and to improve their coping outcomes.

Most parents received some information prior to their child's admission. Parents' self-reported levels of preparation and satisfaction with the information they received for their child's admission and care at home were generally high. However, lower levels of preparation were associated with child PB up to four weeks following discharge and significantly correlated to parent-reports of their child's pain intensity (in hospital and at

home), parent baseline state and trait anxiety and parent beliefs regarding their role in their child's care and their child's postoperative behaviour. Adequate preparation of parents is very important in helping the parents to cope better with the stressors of their child's hospitalisation for surgery and will assist the parents in helping their children to cope. Descriptive research is lacking regarding parents' coping outcomes following their child's admission to hospital for surgery, such as anxiety levels post-discharge, mood states, depression and post-traumatic stress symptoms and the association between child and parent coping outcomes. Further intervention research is needed to test the efficacy of adequately preparing parents for their child's admission to hospital for surgery and the child's care at home on child and parent immediate and long-term coping outcomes.

7.2.5 Parent participation in their child's hospitalised care and satisfaction with in-hospital pain management

Just less than half (45.8%) the children in the current study spent one or more nights in hospital following their surgery. Factors related to staying over night in hospital were considered as factors that would potentially increase or decrease the stress of hospitalisation for surgery for the child and the parent. Particular factors of interest were the parents' level of participation in their child's care, assuming that higher levels of participation would be indicative of less stress for the child and the parent due to fewer changes to their usual behaviours, and parents' (and children > 8 years) satisfaction with the child's inpatient pain management, assuming that higher levels of satisfaction would be indicative of less stress, i.e. better immediate coping outcomes.

7.2.5.1 Parent participation

Parents in the current study generally had high levels of participation in their child's in-hospital care (median score 66. 0-100 IPP). Higher levels of parent participation in their child's in-hospital care were associated with child PB at the end of week 2 when only in-hospital factors were taken into account. However, parent participation was no longer associated with PB when other factors, i.e. parent factors, child factors, in-hospital and home factors were considered. This is contrary to previous research where a significant association has been found between higher levels of parent participation and fewer child behavioural disturbances at home following unexpected admission to intensive care, when

parents were informed regarding the range of behaviours that young children typically display during and after hospitalization and how parents could participate in their child's emotional and physical care (Melnyk et al. 2004). It is possible that the parents' participation in their child's postoperative care heightened the stress of hospitalisation following surgery as the child's surgical wounds and postoperative pain meant that the parents' participation remained removed from normality where in previous studies it was considered a return to normality.

Positive correlations have also previously been found between parent beliefs regarding child behaviour and parent role in the child's care and parent participation in their child's hospitalised care (Melnyk 1995). No significant correlations were found between parent beliefs and their levels of participation in the current study. Parents' participation was however significantly correlated to the parents' level of preparation for their child's admission to hospital. This supports the view that adequate preparation of parents specifically for their child's postoperative care, that included aspects related to wound care, i.e. the child's altered mobility and pain management, would result in better participation, nature and level, which would minimise the stress of staying over night instead of heightening it. In a systematic review of parent participation in the care of their hospitalised child (Power et al. 2008) three principal parent needs regarding their participation emerged: to be with their child in hospital; to be given information regarding their child's hospital care; and the need for practical and emotional support to enable the parent to participate in the child's care.

7.2.5.2 Satisfaction with in-hospital pain management

Most parents were satisfied with their child's in-hospital pain management (median score 8, 0-10 NRS). Lower levels of satisfaction however, were associated with PB at the end of week 2 when only in-hospital factors taken into account. This factor was no longer associated with PB when other factors, i.e. parent factors, child factors, in-hospital and home factors were considered. Parent (and child > 8 years) satisfaction regarding their child's in-hospital pain management was explored as an indicator of the stress that parents/children would be exposed to during the child's overnight stay in hospital, with higher satisfaction levels indicating less stress and vice versa. This assumption is

supported by the results in the current study with lower parent satisfaction levels indicating heightened stress during the child's hospitalisation resulting in poorer long-term coping outcomes. Parent and child satisfaction regarding in-hospital pain management have not previously been explored in relation to child PB at home.

7.2.5.3 Summary

Levels of parent participation in their child's care and parent and child satisfaction regarding in-hospital postoperative pain management were generally high. These factors were associated with child PB when only in-hospital factors were entered into the regression models. These findings both refute and support the study's theoretical framework. Lower levels of parent participation were expected to be associated with PB and not the contrary as found in the current study. Parent participation specifically in their child's postoperative care has not previously been explored in relation to child behavioural outcomes at home. Parents who were less satisfied with their child's postoperative pain management reported more PB in their child. These children may have experienced more pain which heightened the stress of the child's hospitalisation for surgery resulting in poorer coping. Results from this study indicate that parent participation in their child's postoperative care may be more effective, i.e. decreasing the stress of staying over night, if the parents are appropriately informed regarding how they can effectively participate in their child's postoperative care, including participation in their child's postoperative pain management.

7.3 Strengths

This study described and compared children's post-hospital PB following day case or inpatient surgery and examined the association of parent, child, pre-operative and in-hospital factors with parent and child anxiety, preparation for surgery and child post-hospital PB and postoperative symptoms. A number of strengths related to the current study should be highlighted.

The relationship between parent factors and child outcomes were explored in greater detail in the current study than in previous studies. The association of a number of new parent and child factors with child PB were highlighted up to four weeks post-discharge. These

factors related to the parents' preparation for their child's admission to hospital for surgery and the child and parent's previous experience of procedure-related pain and anxiety. These results provide valuable information for clinicians and researchers in terms of identifying parent-child dyads who may be at greater risk of experiencing heightened stress and exhibiting poorer outcomes, and in planning randomised clinical trials to reduce the stress exposure of hospitalisation for surgery and improving coping outcomes.

This study provided valuable information regarding the incidence of PB in British children following admission to hospital for surgery, which appears to be higher than that reported in other countries i.e. Australia, the USA, Finland and Sweden. It also confirmed a number of factors that have previously been identified as associated factors with child PB at home. Information from this study can be used to adapt interventions that have successfully improved coping outcomes in children following admission to hospital for surgery in other countries and provide a basis on which hospitals in the UK can audit their performance.

This is the first study in the field that has examined the phenomenon in relation to a detailed theoretical framework. The development of a theoretical framework identified, defined and operationalized relevant constructs and concepts, developed relational statements and expressed the statements in a hierarchical style. The interpretation and application of the findings are enhanced by the use of a theoretical framework because it provides a structured explanation for the associations identified between potential influencing factors and child PB, postoperative pain at home and pre-operative anxiety. This has not previously been described in the context of relevant theory. Results from this study supported the theoretical framework and confirmed that a variety of parent and child factors exist that influence how the parent-child dyad appraises the stress of hospitalisation for surgery as it unfolds instead of having trait coping strategies that pre-determine how they will cope. Results support the contextual nature of the stress of a child's hospitalisation for surgery which means that person and situation variables jointly shape coping efforts.

7.4 Limitations

A number of limitations exist in the current study, which pertain largely to the study's sample and methodological shortcomings. These limitations reduce the generalisability of the study findings and highlight areas where future research is needed.

7.4.1 Limitations related to the study's sample

Parents who participated in the study all spoke English fluently and were able to complete all questionnaires in English, they were of British ethnicity (62% White British, 10.9% Black British, and 3.9% Asian British), mostly educated at a graduate/post-graduate level (58.4%), and were employed (62.8%). The parents' demographic details in this study are not representative of the entire population of parents whose children are admitted to hospital for surgery. Failure to adequately represent the whole population indicates that caution should be taken in generalising the results of this study to the greater population (Burns et al. 2001). Reasons for the unrepresentative sample could be due to the number of questionnaires that needed to be completed by parents and the time-commitment involved (± 5 to 6 weeks from recruitment to final follow-up time-point). Most of the measures used in this study are only validated for use in English. It is unlikely that an interpreter would be available for the duration of non-English speaking families' participation in the study and even if so, would possibly bias the results.

Parents who failed to return any follow-up questionnaires had significantly higher baseline state and trait anxiety levels and more catastrophic thoughts regarding their child's postoperative pain than parents who returned at least one follow-up questionnaire set. Their children also had more pre-operative behavioural difficulties. Parent baseline state and trait anxiety and child pre-operative behavioural difficulties were associated with child PB within the first two weeks post-discharge. The inclusion of these parents would have resulted in higher parent median baseline anxiety scores and higher median child pre-operative behavioural difficulties, which may have altered the final results of the study.

300 parent-child dyads were recruited to the study, exceeding the target sample of 170. However, following the identification of 62 child-parent dyads that were not eligible for participation, 74 withdrawals and 33 that were lost to follow-up, a final sample of 131 were included in the data analyses. Data analyses were conducted using SPSS version 15.0 (SPSS Inc. Chicago, Illinois). Listwise deletion of variables is the most stable and valid method for dealing with missing data using this version. It did however result in regression models including reduced numbers of participants. Using Newton et al.'s (1999) sample size estimation formula $N \geq 50 + 8k$ (where k is the number of independent variables) to test for multiple correlations, a number of the final regression models were under-powered. Adequate sample sizes reduce the chance of missing associations that are truly present and identify strong associations between possible risk factors and an outcome, i.e. larger odds ratios and smaller confidence intervals (Katz 2006). Table 7.1 provides details of all final regression models, sample sizes in the models and the sample size that would have been required for an alpha of .05, a power of .8 and a medium effect size (Newton et al. 1999).

Table 7.1 Sample size estimation for adequate power in each of the final regression models

Model*	**Model sample size**	**Independent variables**	**Required sample size**	**Comments**
Day 2				
PB total score	86	6	98	Under-powered
GA	80	5	90	Under-powered
SA	91	5	90	Adequate power
EA	57	4	82	Under-powered
AA	81	3	74	Adequate power
AW	94	3	74	Adequate power
SL	90	2	66	Adequate power
Week 1				
PB total score	86	4	82	Adequate power
GA	65	5	90	Under-powered

SA	71	5	90	Under-powered
EA	100	4	82	Adequate power
AA	91	6	98	Under-powered
AW	77	3	74	Adequate power
SL	88	2	66	Adequate power
Week 2				
PB total score	61	4	82	Under-powered
GA	89	3	74	Adequate power
SA	80	3	74	Adequate power
EA	90	3	74	Adequate power
AA	88	2	66	Adequate power
AW	111	1	58	Adequate power
SL	92	3	74	Adequate power
Week 4				
PB total score	62	3	74	Under-powered
GA	90	3	74	Adequate power
SA	88	3	74	Adequate power
EA	92	2	66	Adequate power
AA	76	2	66	Adequate power
AW	98	2	66	Adequate power
SL	80	2	66	Adequate power

*All models included in table are final models from Step 2 of the binary logistic regression analyses, PB problematic behaviours, GA general anxiety and regression, SA separation anxiety, EA eating disturbances, AA aggression towards authority, AA apathy-withdrawal, SL anxiety about sleep

7.4.2 Limitations related to the study's methodology

Child and parent pre-operative anxiety was measured at some point between the child's admission for surgery and being taken to theatre. This allowed the researcher to travel between hospital units and hospital sites within a morning/afternoon to see as many children and their parents as possible. In other related studies, child and parent pre-operative anxiety have been measured at separation of the child from the parent, on

entrance to theatre and during induction. Pre-operative anxiety levels during these periods of heightened stress may have been higher than those reported in the current study and may have been associated with PB more / less than that reported.

The current study did not measure any parent outcomes following their child's discharge from hospital. Parent outcomes following their child's discharge from unexpected hospitalisation to intensive care have been related to child PB at home (Melnyk et al. 2004). Measurement of parent coping outcomes would provide valuable information for the planning and testing of interventions aimed at improving child and family outcomes following the child's admission to hospital for surgery.

Data collected in the current study were limited with regard to the child's surgery, i.e. complexity, length of procedure, and postoperative invasive procedures. These data could have identified specific factors related to the child's over night stay in hospital that resulted in the association with child PB. Data were also limited with regard to the parents' use of analgesics for their children's postoperative pain at home, i.e. dosage and frequency of use. This additional information would have provided information regarding postoperative pain at home, the pharmacological management thereof and the association with child PB.

7.5 Implications

The results of this study, both new findings and those that confirm previous research, have important implications for clinical practice and future research.

7.5.1 Clinical practice

Most of the parents in the current study received some information about their child's admission to hospital for surgery yet nearly a third sought additional information and written comments from parents suggested that parents would have liked more information. Clinical practice could be improved by offering information to all parents, at a pre-admission clinic appointment, when their child is admitted to hospital, and/or prior to their child's discharge. By checking the parents' satisfaction with the information that they

received and by offering them the opportunity to highlight any additional concerns or areas of uncertainty, clinicians would aid the parents in being more prepared for the child's admission and care at home. This in turn would enable the parents to adequately appraise the harmful and beneficial elements of their child's admission to hospital for surgery and would hopefully improve parents' coping.

Following the results of this study and previous research, clinicians are able to inform parents regarding the high possibility that their child will exhibit PB following discharge, that the number of PB exhibited by children is generally low, and that the type of PB may change as time progresses. Clinicians are also able to inform parents of the likelihood that their child would experience pain at home and the importance of providing adequate analgesia, i.e. correct dosage and frequency. Parents who are adequately informed regarding the possible PB and pain that their children may exhibit/experience may be better equipped to prepare for the child's care at home, reducing unplanned time off work and additional visits to the GP or other healthcare services.

The National Service Framework (NSF) for children, young people and maternity services was published in September 2004 and is a 10 year programme intended to stimulate long-term and sustained improvement in children's health, ensuring fair, high quality and integrated health and social care from pregnancy, right through to adulthood (National Service Framework 2004). The results of this study highlight the need for a number of core standards of the children's NSF to be addressed in relation to children's admission to hospital for surgery and this has important implications for policy development:

- *Standard 1: promoting health and well-being, identifying needs and intervening early.*

  Every effort should be made to adequately prepare children and their parents prior to the child's admission to hospital for surgery. Children who are at greater risk for developing post-discharge PB should be identified early and their parents informed of the likelihood of PB at home and how parents can help to improve their child's (and their own) coping prior to and during hospitalisation for surgery with the aim of reducing negative immediate and long-term outcomes. This will be further enhanced following randomised controlled trials to test appropriate interventions

aimed at children and their parents to decrease negative outcomes related to the child's hospitalisation for surgery.

- *Standard 2: supporting parenting.*
  Parents need to be provided with appropriate information, services and support to enable them to care for their child during and after hospitalisation for surgery. Improving parent knowledge and enhancing parent coping will improve their self-efficacy regarding their ability to care for their child both in hospital and at home.
- *Standard 3: child, young person and family-centred services.*
  Services related to the child's hospitalisation for surgery, i.e. preparation services prior to admission, support services during admission and follow-up services post-discharge, need to be improved to ensure that all children receive age-appropriate and timely preparation for surgery, adequate emotional and physical support and care during hospital and suitable follow-up post-discharge. These services should be tailored to meet the specific needs of the child-parent dyad.
- *Standard 6: children and young people who are ill.*
  Children (and their parents) who are identified as being in need of surgery should have access to advice and services that will address their health, social and emotional needs throughout the child's medical treatment and beyond for as long as support is required.
- *Standard 7: children and young people who are in hospital.*
  Children who are hospitalised for surgery need to be offered care that is aimed at minimising the stressors related to their anaesthetic and surgery and enhancing their coping both during hospitalisation for surgery and once they are discharged from hospital.
- *Standard 10: medicines for children and young people.*
  Children and their parents need to be provided with information regarding the risks and benefits of medicines, specifically analgesics, prescribed following the child's surgery. Adequate information regarding the safe dosage and required frequency of analgesics post-surgery will allay parent anxieties related to administering analgesics to their children and will minimize postoperative pain at home, which in turn should minimize post-discharge PB.

7.5.2 Research

7.5.2.1 Descriptive research

Results of this study highlight a lack of knowledge regarding the adequate preparation of parents for their child's admission to hospital for surgery and the child's care at home. Qualitative research should be conducted in the form of interviews with parents prior to and/or after their child's admission to hospital for surgery to elicit how they feel/felt regarding their child's care both in hospital and at home, their worries and concerns and what they believe would assist them in being appropriately prepared for their child's admission and care at home.

Descriptive detail remains unclear regarding the types of PB that children exhibit at various time-points post-discharge and the dynamic nature of these specific PB. It is also unclear what factors are associated with specific PB due to a lack of consensus within and between previous descriptive studies.

The current study identified the impact that child postoperative pain and PB at home have on working parents returning to work, children returning to school and additional use of healthcare services. The financial implications for the family and/or the healthcare system are unknown. The inclusion of a health economist in future related studies would provide information regarding the costs incurred in the provision of pre-operative preparation services that are currently either ineffective or not being provided to the children and parents who need them most. It would also provide information on the costs of PB to the family and the healthcare system as a result of unplanned time off work/school and additional visits to GP practices and other healthcare services.

7.5.2.2 Intervention research

Results from this study have shown that PB and pain after day case and inpatient surgery are common in British children, and that parents may be inadequately prepared to support their children (or themselves) in coping with this stressful experience. There may be health, social, and economic consequences to this, including time lost from work or school or negative attitudes toward future healthcare. There is a pressing need for a multi-centre trial of new methods of actively engaging parents in preparing and supporting their child during

the peri-operative period and once at home so as to reduce postoperative PB and pain in children. A proposed intervention would be to include and to modify aspects of two successful clinical trials conducted in the USA by Kain et al. (2007) and Melnyk et al (2004).

Kain et al.'s (2007) ADVANCE (Anxiety reduction, Distraction, Video modelling and Education) pre-operative preparation programme consisted of a pre-operative preparation kit given to parents on a pre-admission hospital visit, brief telephone calls prior to surgery; parent-led distraction activities with children in the pre-anaesthesia holding area; and parental presence and active distraction of children during anaesthetic induction. The theoretical rationale for the preparation programme is based on reducing parental anxiety, desensitizing parents and children through non-threatening exposure to the peri-operative environment; and increasing parent sense of control and self-efficacy through improved knowledge and coping skills. Results from this trial revealed that parents and children exhibited significantly lower pre-operative anxiety, children had a lower incidence of emergence delirium after surgery, required less analgesia and were discharged from the recovery room earlier. However, it is unknown if such a structured, active pre-operative preparation programme can prevent or reduce the development of PB in children at home after surgery. Furthermore, the programme was only tested in the day case surgery setting, whereas children facing inpatient surgery may be at higher risk for postoperative pain and PB.

The proposed trial would also include aspects of another successful trial conducted in the USA by Melnyk et al. (2004). The COPE (Creating Opportunities for Parent Empowerment) programme, which was similarly delivered with audiotapes, matching written information and a parent-child activity work-book, at three time-points (shortly after unexpected admission to intensive care, on transfer to a paediatric unit, and 2 to 3 days post-discharge) aimed at (i) providing parents with information regarding the range of behaviours and emotions that young children typically display during and after hospitalisation, and (ii) directing parent participation in their child's physical and emotional care (Melnyk et al. 2004). Results from the trial showed that mothers who received the COPE programme exhibited less parental stress, they participated more in their child's physical and emotional care, and reported less parental negative mood states. Children of

mothers who received the COPE programme exhibited fewer withdrawal symptoms and fewer PB at 6 and 12 months post-discharge respectively. Adaptations to this programme related to child's admission to hospital for surgery, would include instructions for parents specifically regarding their participation in their child's postoperative care both in hospital and at home, including adequate pain management.

7.6 Dissemination plan

Preliminary results of this study have already been presented at a number of conference presentations and department study days:

- UCL Institute of Child Health: Patient Care Research and Innovation Centre's Study Day – poster presentation
  London, UK, May 2007
- 12th World Congress on Pain – poster presentation*
  Glasgow, UK, August 2008
- 2nd Congress of the European Academy of Paediatrics – poster presentation*
  Nice, France, September 2008
- UCL Institute of Child Health: Patient Care Research and Innovation Centre's Study Day – PowerPoint presentation
  London, UK, May 2009
- UCL Child Health Symposium – poster presentation
  London, UK, September 2009
- 13th World Congress on Pain – poster presentation
  Montreal, Canada, August 2010

  * Presented by Primary Academic Supervisor

The final results of this study will be disseminated in peer-reviewed scientific journals, internal reports to all the centres involved in the study, further conference presentations, and written feedback to research participants.

7.7 Researcher reflections

Over the duration of this study a number of challenges had to be overcome, including study design, data collection, data analysis and the write-up of this thesis. These challenges were

both practical and personal. This section has been written in the first person, as it is a personal reflection.

7.7.1 Practical

This study included a number of questionnaires to be completed by parents over the duration of the study period. The longest was the baseline questionnaire set that included questions for parents about their own and their child's demographic details, previous experience of admission to hospital for surgery, recent pain experience, and a number of baseline psychological measures. Due to the length of the questionnaire set, I consulted a number of parents who did not participate in the study but who had accompanied their child to hospital for surgery and who were willing to assist. Question formatting and phrasing of the questions were adapted following comments from these parents to make the questionnaires more user-friendly, e.g. tick box options replaced open-ended questions asking the parents' age. The rest of the questionnaires were shorter and easier to complete. Further amendments were made following ethics approval, e.g. the use of numeric rating scales replaced visual analogue scales to enable parents to complete the questionnaires by telephone if they chose to.

Following the development of the study's theoretical framework and data analysis there are a number of changes that I would make to the questionnaires. Firstly, the baseline psychological measure, The Monitor Blunter Style Scale (MBSS), was included in the baseline questionnaire set as a measure of parents' trait coping styles and has previously been shown to influence parents' pre-operative anxiety (Kain et al. 2000;McCann et al. 2001). In the current study parents' coping style was associated with specific PB at the end of week 1. However, use of this measure contradicts the study's theoretical framework. Lazarus and Folkman's theory of stress and coping (Lazarus et al. 1984) was chosen as the most appropriate theory on which to base the current study and one of the key features of this theory is that it focuses on what the individual actually does and how behaviour changes as the stressful encounter unfolds, which contrasts with the trait approach that focuses on what the individual usually does. It might have been more informative to include open-ended questions for parents following their child's admission to hospital for

surgery that asked how they coped with the stressors that they and their child were exposed to. Qualitative methods could have been used to determine if parents used predominantly problem-focused coping, emotion-focused coping, or a combination of the two. Other changes would include more questions for parents regarding their management of their child's postoperative pain, i.e. did they give their child any analgesics and if so what was the dosage, and frequency of administration. These questions would have provided information regarding the parents' adequate or inadequate pharmacological management of their child's postoperative pain and the association with the child's PB. Finally, in hindsight I would have included at least one measure of parent coping outcomes such as parent stress or state anxiety to be completed at each of the follow-up time-points. This would have provided information regarding the association between parent and child post-discharge coping.

I was very frustrated at times by the large number of withdrawals and families lost to follow-up. More frequent contact with the families and persistence regarding completion of the follow-up questionnaires with the parents by telephone instead of merely reminding the parents to complete the questionnaires, may have decreased the burden of participation in the study for these families and improved participant retention.

7.7.2 Personal

Following the design of the study, one of the biggest personal challenges that I was faced with was putting the study into practice. With a predominantly nursing background, I often felt out of my comfort zone regarding management of the study, e.g. meeting with senior clinicians, i.e. nurse managers, surgeons and anaesthetists, to negotiate the study procedures and the involvement of support teams at the various participating sites. A decision was made to stagger the commencement of data collection at three sites, which enabled workable recruitment and data collection systems to be established however, commencement of data collection at Hospital 2 and 3 sooner may have resulted in a larger final participant count.

Another challenge related to my nursing background was meeting families at a stressful time prior to the child's surgery. I found it difficult to act as a researcher and not as a nurse. As a researcher, I met with the families prior to the child's surgery to measure the child's anxiety, collect questionnaires and to go through the follow-up questionnaires with the parents. I had to remove myself from the clinical setting in terms of not providing the parents with information regarding the child's surgery and expected recovery both in hospital and at home. There were also a number of situations where the parents were obviously anxious and where my natural nursing tendency would have been to spend time with the parents making every effort to allay their anxiety. It was a relief at times, when families withdrew from the study prior to their child's surgery and I was able so spend this time with them and talk to them from a clinical capacity. Although it was not a study objective and I did not collect data related to parents' needs immediately prior to their child's surgery, I do believe that these parents often lack one-on-one communication with nurses and other clinicians and do have unmet emotional needs as well as informational needs.

Due to my lack of prior research experience and no prior experience with quantitative data, the design of electronic databases and data entry were new to me. I also had very little statistical experience. Through a process of trial and error, close supervision, frequent consultation with the department's electronic database and statistical specialists, and two user-friendly statistics textbooks, all database, data entry and data analysis challenges were resolved. Additional challenges related to my lack of self-confidence in terms of critiquing research conducted by more senior and experienced clinicians and researchers, and making scholarly-informed statements regarding the findings of this study. Overcoming these challenges has improved my confidence and helped me to feel more like a professional researcher and less like a neophyte.

7.8 Main conclusions

Following a systematic literature review of all empirical research conducted over the last two decades on children's post-discharge PB, postoperative pain at home, and pre-operative anxiety, and the review of relevant theories related to illness and hospitalisation in children,

a theoretical framework was proposed on which this field of research can progress. Lazarus and Folkman's theory of stress and coping (Lazarus et al. 1984) was chosen as the most suitable theory to explain the stressors that the parent-child dyad are faced with before and during the child's admission to hospital for surgery and how their appraisal of the stress affects coping strategies, and immediate and long-term coping outcomes. This theory has been supported through evidence from intervention studies that have attempted to improve child coping and/or to minimize their exposure to stressful stimuli, with positive child pre-operative anxiety and post-discharge behavioural outcomes. Through the process of substruction, factors that influence children's cognitive appraisal of the stressful event of hospitalisation for surgery and their coping were discussed in relation to theory. The study methodology, i.e. the study design, the participants and the setting were chosen as the most appropriate to address the specific study objectives.

131 parent-child dyads participated in this multi-centre study. The response rates of follow-up questionnaires at the four follow-up time-points were 89% for day 2 and the end of week 1, 91% at the end of week 2, and 84% at the end of week 4. Key results of this study included the high incidence of PB in this cohort over the first month post-discharge. PB in the current study was defined as ≥ 1 of the 27 possible PB that comprised the PHBQ. New factors associated with PB within the first two weeks post-discharge in this study were: parent factors related to their preparation for the child's care at home, parent education level and the child's previous pain experience prior to admission to hospital. The current study also confirmed factors that have previously been associated with PB within the first two postoperative weeks: children who spent ≥ 1 night in hospital, child and parent anxiety, younger child age and children who did not attend a pre-admission clinic. At four weeks post-discharge, higher parent education and child previous pain experience prior to admission to hospital for surgery, remained associated with PB.

The incidence of child postoperative pain at home within the first four weeks post-discharge ranged from 93.4% on day 2 post-discharge with a significant decrease over each of the follow-up time-points to 25.2% at the end of week 4. Higher child pain intensity was associated with PB, specifically eating disturbances throughout the follow-up period. Levels of child pre-operative anxiety were lower than that previously reported. Differences

in reported levels were most likely due to the time of pre-operative anxiety assessment. Nevertheless, child pre-operative anxiety was associated with PB at the end of week 2, which confirms previous research.

New to this field of research was the exploration of parent information needs and satisfaction with their (and their child's) preparation for the child's admission to hospital for surgery and the child's care at home. Parents' lower levels of preparation were associated with PB up to four weeks following discharge and significantly correlated to parent-reports of their child's pain intensity (in hospital and at home), parent baseline state and trait anxiety and parent beliefs regarding their role in their child's care and their child's postoperative behaviour.

This study included children admitted for both day case and inpatient surgery. Although spending ≥ 1 night in hospital was associated with PB, no other significant (clinical or statistical) findings were revealed in relation to additional factors explored in the inpatient group only, i.e. parent participation in care and parent (and child > 8 years) satisfaction with inpatient pain management.

Strengths of the study were the inclusion of additional parent factors that have not previously been explored in relation to child PB post-discharge; the development of a sound theoretical framework; the confirmation of the incidence of PB and postoperative pain in British children and the associated parent, child, in-hospital and home factors. The main study limitations related largely to methodological issues: an unrepresentative sample of parents, i.e. educated, English-speaking, White British parents, who were also less anxious and had lower catastrophic thoughts regarding their child's postoperative pain than the lost to follow-up comparison group; and reduced sample sizes in some of the final regression models that resulted in inadequate power.

Recommendations for clinical practice and policy development have been discussed. Details of a randomised clinical trial have been proposed, involving adequate preparation of the parent for the child's admission to hospital for surgery, specifically the anaesthetic, and to improve parent self-efficacy in caring for their child at home following discharge. This

trial will hopefully address flaws in the current provision and uptake of pre-operative preparation of parents and their children and reduce the incidence of negative child and parent outcomes associated with the admission of a child to hospital for surgery.

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Appendices

Institute of Child Health/Great Ormond Street Hospital Research Ethics Committee
The Institute of Child Health
30 Guilford Street
London
WC1N 1EH

Telephone: 020 7905 2620
Facsimile: 020 7905 2201

06 October 2006

Mrs Nina Power
Nursing Research Fellow
UCL Institute of Child Health
CNAHPR, 7th Floor Old Building
Great Ormond Street Hospital
Great Ormond Street
WC1N 3JH

Dear Mrs Power

Full title of study: **Children's Postoperative Symptoms and Post-Hospital Behaviour Problems**

REC reference number: **06/Q0508/110**

The Research Ethics Committee reviewed the above application at the meeting held on 04 October 2006.

Ethical opinion

Record of ethical issues discussed including important clarifications or assurances given by the applicant:-

1. The REC (Research Ethics Committee) queried that if the surgery did not go okay, would the participants still be followed up?

Mrs Power confirmed that the patients would be followed up telephonically. The participants would not be excluded from the study unless they were admitted to ICU.

2. The REC noted that there was no mention as to whether the patients' GPs would be contacted regarding the study. In A68, it is stated that if participation in the study upsets the parent or child then they will be referred to the paediatrician or GP. The REC recommends that this needs to be included in the information sheet and consent form.

3. The REC noted that there was no reimbursement for participating in the study. The REC recommended that it would be worth including prepaid envelopes for parents who wish to opt out and for participants to return questionnaires.

Professor Franck confirmed that this would be done.

4. The REC queried how useful it would be to have parents who would be anxious about their children being in theatre to complete this while their children were in theatre.

Mrs Power said that she had spoken to parents on the wards about how they would feel about answering a questionnaire. The general feeling was they would be glad to have something to keep them occupied while the surgery was going on. Professor Franck said that people in such situations were glad to be able to share their experiences.

5. The REC felt that there was some ambiguity around having mostly English speakers as participants and employing interpreters.

The researchers said that there said that it was likely that the study would have only English speakers, but they are still discussing this with other sites how this will be dealt with. Some of the other sites may have more extensive translation systems in place.

6. The REC noted that there were still not Principal Investigators named at other sites and understood that they would be notified of the PIs when they were appointed.

7. In the Perioperative Questionnaire, it was understood that number 2 should read: "If No [rather than Yes], please explain..." Please change this typo.

8. On the Parent Information Sheet, it was noted that it says that the study was approved by COREC. Please note that COREC should be replaced by the ICH/GOS REC. Please could this change be made?

9. Professor Franck pointed out that the demographic form would now ask about ethnicity. In regard to pain measures, the visual analogue scale has been exchanged for the numeric grading scale, so that the researchers can use this over the phone. Professor Franck confirmed that these measures are used interchangeably.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application		13 September 2006
Investigator CV	Mrs Nina Power	13 September 2006
Protocol	1	13 September 2006
Covering Letter		13 September 2006
Summary/Synopsis	Study Flow Chart, version 1	13 September 2006
Compensation Arrangements		01 August 2006
Questionnaire: Perioperative Course (POC)		13 September 2006
Questionnaire: Parent Information Needs and Satisfaction with Preparation (PISP)	1	13 September 2006
Questionnaire: Parent State Anxiety	1	13 September 2006
Questionnaire: Modified Yale Preoperative Anxiety Scale (mYPAS)	1	13 September 2006
Questionnaire: Baseline Questionnaire Set	1	13 September

		2006
Questionnaire: Day 2 Telephone Interview	1	13 September 2006
Questionnaire: Post-Discharge Structured Telephone Interview	1	13 September 2006
Questionnaire: Pain Assessment Tools for Parents	1	13 September 2006
Letter of invitation to participant	1	13 September 2006
Participant Information Sheet: Parent	1	13 September 2006
Participant Information Sheet: 6 - 12 (Children's)	1	13 September 2006
Participant Information Sheet: 2-5 (Children's)	1	13 September 2006
Participant Information Sheet: Heath Care Professional	1	13 September 2006
Participant Consent Form: Parent	1	13 September 2006
Participant Consent Form: Assent form for children	1	13 September 2006
Supervisor CV	Professor Linda Franck	13 September 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0508/110 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Victor Larcher
Chair

Email: t.austin@ich.ucl.ac.uk

Institute of Child Health/Great Ormond Street Hospital Research Ethics Committee
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8 November 2006

Mrs Nina Power
Nursing Research Fellow
UCL Institute of Child Health/ Great Ormond Street Hospital
CNAHPR, 7th Floor Old Building
London WC1N 3JH

Dear Mrs Power

Full title of study: **Children's Postoperative Symptoms and Post-Hospital Behaviour Problems**
REC reference number: **06/Q0508/110**

The REC gave a favourable ethical opinion to this study on the 4th of October 2006.

Further notification has been received from local site assessor following site-specific assessment. On behalf of the Committee, I am pleased to confirm the extension of the favourable opinion to the new site. I attach an updated version of the site approval form, listing all sites with a favourable ethical opinion to conduct the research.

Research governance approval

The Chief Investigator or sponsor should inform the local Principal Investigator at each site of the favourable opinion by sending a copy of this letter and the attached form. The research should not commence at any NHS site until research governance approval from the relevant NHS care organisation has been confirmed.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0508/110	**Please quote this number on all correspondence**

Yours sincerely

Taki Austin
Research Ethics Co-ordinator

Email: t.austin@ich.ucl.ac.uk

Enclosure: Site approval form
Copy to: Institute of Child Health/ Great Ormond Street Hospital R&D Department

From the **Research and Development Office**
of UCL Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust
30 Guilford Street, London WC1N 1EH

28th September

Nina Power
WellChild Pain Research Centre
UCL Institute of Child Health
CNAHPR
Level 7, Old Building
Great Ormond Street Hospital
WC1N 3JH

Dear Mrs Power

06NS05: Children's postoperative symptoms and post hospital behaviour problems

This is to confirm that the Institute of Child Health, University College London will take on Sponsor responsibilities for the above study under the Research Governance Framework.

Yours Sincerely

Emma Pendleton
Head of Research and Development Office
Great Ormond Street Hospital NHS Trust and The Institute of Child Health

(020 7905 2179, e.pendleton@ich.ucl.ac.uk)

Children's Postoperative Symptoms and Post-Hospital Behaviour Problems

HEALTH CARE PROFESSIONAL'S INFORMATION SHEET

This document is designed to provide you with background information to this study.

Background to the study

A large proportion of children suffer persistent physical and psychological problems as a result of traumatic hospital encounters. Research conducted in the USA, Finland, and Australia has shown that up to two-thirds of children may exhibit new negative behaviours in the first postoperative days and it is estimated that 18% to 54% of children continue to exhibit behaviour problems 2 to 4 weeks following surgery (Kain et al. 1999; Kotiniemi et al. 1997; Stargatt et al. 2006). Risk factors for post-hospital behaviour problems include higher child or parent anxiety preoperatively, withdrawn temperament, younger age, previous negative hospital experience, previous surgery, pre-medication and anaesthetic induction technique, pain and other postoperative symptoms (Kain et al. 1999; Watson et al. 2003). The incidence of post-hospital behaviour problems in British children is not known and potential influencing variables (i.e. child and parent characteristics; child and parent anxiety; preoperative preparation; pain and other symptoms) have not been examined in relation to child post-hospital behaviour problems in this population.

Aims of the study

This study aims to describe and compare children's post-hospital behaviour problems following day case or inpatient surgery and to examine the association of parent, child, pre-surgical, and hospital factors with parent anxiety, knowledge and child postoperative symptoms and post-hospital behaviour problems.

The results from this study will provide information on the incidence of postoperative symptoms and post-hospital behaviour problems for children undergoing day case and inpatient surgery. We will also describe the provision and uptake of preoperative preparation and examine the relationship between preoperative preparation, demographic factors and postoperative outcomes. With this information, scientifically sound randomised clinical trials can be designed and effectively carried out to definitively establish the most clinically and cost effective practices.

Study design and procedures

This is a descriptive, repeated measures study. Information about the study and invitation to participate will be sent to families with their appointment letters for surgery. The Researchers will contact the parents by telephone one to two weeks after their appointment letters have been sent out, to discuss the study in more detail and to answer any questions the parents / children may have. Parents will be given the choice to be met by the Researcher at their child's preadmission clinic visit (if booked to attend preadmission clinic and if the clinic visit is more than one week prior to the date of surgery) where consent/assent forms and a Baseline Questionnaire will be given to the parents *or* if parents prefer, the consent/assent forms and Baseline Questionnaires will be sent by post, for completion at least one-week prior to surgery. Signed consent/assent forms and completed Baseline Questionnaires will be collected from the parents at preadmission clinic; returned to the researcher by post; or handed to the researcher on the day of surgery.

The researcher will see the parents and the child on admission. The child will be briefly observed to measure preoperative anxiety and parents will be asked to complete two self-report questionnaires.

Post Discharge Telephone Interviews will be conducted on day 2 post discharge and again at the end of week 1, 2 and 4. Additional information will be recorded directly from the child's hospital notes.

Sample

All children, aged 2 to 12 years, booked for planned, general, ENT and urology surgery, under general anaesthesia, will be invited to participate. Children will be excluded if they are admitted for emergency surgery or any other types of surgery, as they are less common or more complex and therefore not comparable. Children will be excluded if they cannot adequately communicate their pain and other symptoms (e.g. special needs or mental impairment). Families will also be excluded if they cannot communicate in English or if an interpreter is not available over the study period to assist them. We aim to collect data from 200 parent-child dyads.

Ethical approval

The study has been approved by the UCL Institute of Child Health / Great Ormond Street Hospital Research Ethics Committee.

Consent

Written consent will be obtained from all parents and assent from all children of reading age. Parents and children will be given information about the study (written and verbal), the opportunity to ask any questions, and at least one week to decide whether or not they would like to participate. Parents and children will be assured that they may withdraw from the study at any stage without jeopardising their future treatment in any way.

If you would like more information about this study or if you have any queries for the research team, please feel free to contact us.

Thank you and regards,

Nina Power (Principle Researcher) n.power@ich.ucl.ac.uk
Susie Aldiss (Research Assistant) s.aldiss@ich.ucl.ac.uk
Prof. Linda Franck (Research Supervisor) l.franck@ich.ucl.ac.uk

Both Nina and Susie can be contacted by phone: 0207 405 9200 ext 0720
Prof. Franck can be reached at: 0207 829 7822

Or write to:
Centre for Nursing and Allied Health Professions Research
7th Floor Old Building
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London, WC1N 3JH

INVITATION FOR YOU AND YOUR CHILD TO PARTICIPATE IN A RESEARCH STUDY

Dear Parent,

We are writing to you because you have been given an appointment for your child to have surgery. We would like to tell you about a research study that may be of interest to you and your child.

Is your child between the ages of 2 and 12 years?
Is your child able to tell you when they hurt?

If you have answered 'Yes' to all of the above questions, please read the enclosed PARENT INFORMATION SHEET to learn more about the study. Information sheets have also been included for children: One sheet for children aged 2 to 5 years and one for children aged 6 to 12 years. Please help your child with reading the enclosed information.

A member of our research team will phone you in one to two week's time to answer any questions that you might have about the study and to ask you if you and your child would like to participate. Please feel free to call us before then if you have any questions. We encourage you to discuss the idea of participating in this study with your family and friends.

If you DO NOT wish to be contacted by a member of our research team, please return the slip attached.

Thank you for your time. We look forward to talking with you.

Dear Researcher,

□ I do not wish to be contacted about this study.

Reasons (optional):

_____

_____

If you do not wish to be contacted we will not keep any personal details about you or your child. By telling us your reasons for not wanting to be contacted we will learn more about parents' views about research.

Mail to: **Nina Power, Level 7 Old Building, Great Ormond Street Hospital, Great Ormond Street, London, WC1n 3JH**

PARENT INFORMATION SHEET

1. Study Title:
Children's Postoperative Symptoms and Post-hospital Behaviour Problems.

2. The aim of the study
This study will measure the amount of postoperative symptoms and behaviour problems in children up to one month after admission to hospital for planned surgery.

3. Why is the study being done?
Research in other countries has shown that up to two-thirds of children may have some difficulties getting back to their normal behaviour after they had had surgery. We do not know how British children feel after surgery. It is important to find out because there may be things that the parents and healthcare team can do to help children feel better sooner after surgery.

4. Why have I been chosen?
All parents and their children are being invited to participate in the study, if children are aged 2 to 12 years, having surgery and can communicate how they feel.

5. Do my child and I have to take part in the study?
No. Your participation in the study is completely voluntary. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. Your child will be asked to sign an assent form. Even if you agree to participate, you will be able to withdraw from the study at any stage without giving an explanation. Your withdrawal from the study will not affect your child's future care in any way.

6. How is the study to be done?
If you decide to participate, you will be sent a questionnaire set to complete at least one week before your child is admitted to hospital. Once this questionnaire is complete, you can either return it to the Research Assistant by post or bring it to hospital with you when your child is admitted for surgery. The questionnaire includes general questions about you and your child's previous experience with hospitals; questions about how you feel about being a parent; you and your child's attitudes toward everyday life events; and you and your child's thoughts and feelings about pain.

On the day of your child's surgery, you will be met by a Researcher, who will observe your child's behaviour for 5 minutes whilst waiting to go to theatre and ask you a few questions about how you feel. Once your child has been taken to

theatre (and whilst you wait for them) you will be asked to complete a brief questionnaire that asks you about your experience of preparing for your child's surgery.

Before you go home, you will be given a sample of the questions we will be asking you by telephone after your child has gone home.

A Researcher will phone you on day 2 and at the end of week 1, 2, and 4 after your child has been discharged from hospital. If your child spent one or more night in hospital, we will ask you a few questions about you and your child's experience in hospital (at the day 2 phone call only). At each call, we will ask about how your child feels and behaves and how you feel about their recovery.

7. Are there risks and discomforts?

There are no anticipated risks to participating in the study. If in the rare event that a parent or children were to become upset whilst answering the questions, the Researcher would stop and the parent/child would be referred to their paediatrician or GP.

8. What are the potential benefits?

There will not be any immediate benefits to you or your child, other than the opportunity to share your experiences. What we learn from this research will however benefit children hospitalised in future by providing hospital staff with a better understanding of the children's postoperative symptoms and post-hospital behaviour and what things make the experience better or worse.

9. Will my taking part in the study be kept confidential?

Yes. All information collected during the course of the study will be kept strictly confidential. Only members of the research team will have access to the completed questionnaires and your information from your child's hospital notes. The results of the research will be reported for the group as a whole and no identifying information about you or your child will be shared with the hospital staff. All completed questionnaires will be kept in the research office and destroyed following completion of the study.

10. What will happen to the results of the study?

The results of the study will be shared with the healthcare professionals and researchers at conferences and published in professional journals. We will send a summary of the results to all participants if they wish. No identifying information about you or your child will be disclosed in any reports, publications or conference presentations.

11. Who has reviewed the study?

The study has been reviewed and approved by the NHS Central Office for Research Ethics. Support for the study has been gained by the lead clinicians and hospital research and development offices at each of the hospitals participating in the study.

12. Who do I speak to if problems arise?

If you have any complaints about the way in which the study has been or is being conducted, please contact a member of the research team in the first instance. You may also wish to discuss this with your child's nurse. If the problems are not resolved, please contact the Chairman of Research Ethics Committee by post or if it is urgent, by phone and the committee administration will put you in contact with him:

Research and Development Office
Institute of Child Health
30 Guilford Street
London
WC1N 1EH
Tel: 020 7905 2620

13. How do I contact members of the research team:

Nina Power (Principle Researcher)	n.power@ich.ucl.ac.uk
Susie Aldiss (Research Assistant)	s.aldiss@ich.ucl.ac.uk
Prof. Linda Franck (Research Supervisor)	l.franck@ich.ucl.ac.uk

Both Nina and Susie can be contacted by phone:	0207 405 9200 ext 0720
Prof. Franck can be reached at:	0207 829 7822

Or write to: Centre for Nursing and Allied Health Professions Research, 7th Floor Old Building, Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London, WC1N 3JH

INFORMATION SHEET FOR CHILDREN 2 TO 5 YEARS

(You can look at this with a grown up)

How do children feel after they have been in hospital?

Before you say Yes or No,

- Take a look at this booklet
- Talk about it with your family
- Talk to your teachers, friends or anyone else you want to about it.

Then make up your mind.....

Would you like to take part in this research study?

This is an

Invitation

Why are you doing a research study?

We want to find out how children feel after they have been in hospital for an operation and we need your help.

Who did you ask to be part of this study?

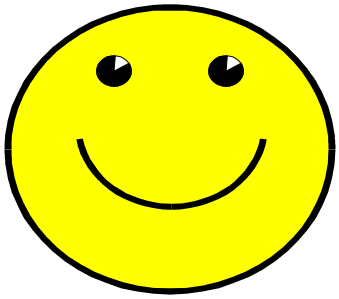
All children 2 to 12 years old who are going to hospital for an operation will be asked to be a part of our study.

What will you do with the information we tell you?

The information that we find out from talking to you and your mum or dad will help other children when they come to hospital for an operation in future.

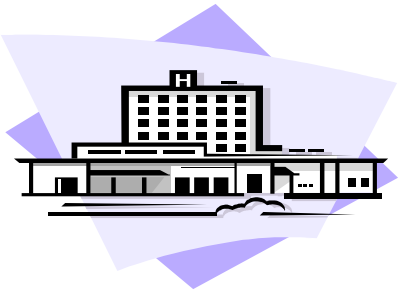
What should I do if I have more questions?

If you have any questions, please ask Nina or Susie or ask your mum or dad to ask them for you.



What will you do in the study?

We will give your mum or dad some forms to fill in and will talk to them mostly. We will come to see you on the day that you go to hospital. Once you are at home, your mum or dad will ask you how you feel and will tell us when we phone them.



Will anything bad happen to me if I am a part of the study?

Nothing bad will happen to you if you are a part of our study. Your mum and dad might ask you in a different way than usual about how you are feeling. If you are unhappy and you want to stop being in the study at any time that is OK!

Nina Power (Principal Resarcher) n.power@ich.ucl.ac.uk
Susie Aldiss (Research Assistant) s.aldiss@ich.ucl.ac.uk
Prof Linda Franck (Research Supervisor)
Both Nina and Susie can be contacted by phone on: 0207 405 9200 ext 0720
Prof. Franck can be reached on: 0207 405 9200 ext 5833

Or write to:
Centre for Nursing and Allied Health Professions Research
7th Floor Old Building
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London, WC1N 3JH

INFORMATION SHEET FOR CHILDREN AGED 6 TO 12 YEARS

(You can ask a grown up to read this with you)

How do Children feel after they have been in hospital?

What is a study and why is this study being done?

A study is what you do when you want to learn more about something or find out something new. In this study, we want to find out how children feel after their operation, once they are at home. We want to ask boys and girls like you to tell us how you feel. With this information we will be able to tell doctors, nurses and other parents what it is like for children when they go home after having an operation.

Why have I been asked to take part in the study?

All children, 2 to 12 years old, and their parents are being asked to be a part of our study.

Did anyone check the study is OK to do?

Yes. Before any study is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure the study is OK to do. Our study has been checked by the UCL Institute of Child Health / Great Ormond Street Hospital Research Ethics Committee and they have said that it is OK.

Do I have to take part?

No. It is completely up to you and your parents if you want to be a part of this study. If you don't want to be a part of the study, you can change your mind at any stage and we will stop asking you and your parents questions. This will not make any difference to the way that the nurses, doctors or other people look after you.

What will happen to me if I take part in the study?

If you are 8 or older, we will ask you to complete a questionnaire at least one week before you go to hospital for your operation. If you are younger than 8, your mum or dad will complete it for you. We will visit you when you arrive at the hospital for your operation to see how you are. Once you go home, we will phone your mum or dad to check up on you and they will ask you how feel and will let us know what you say. We will phone your mum or dad 4 times after you have gone home from hospital.

What are the good things about the study?

You can help us to help other children. The information that we find out from you and your parents will help us to help other children your age when they have an operation.

Are there any bad things about the study?

There are no bad things about the study. Your mum and dad might ask you in a different way than usual about how you are feeling. If you feel unhappy and you want to stop being in the study at any stage that is OK!

What shall I do now?

Now that you have read what the study is about, you can talk to your mum and dad about the study. If you have any questions you can ask Nina or Susie or ask your mum and dad to ask them for you.

Nina Power (Principal Researcher) n.power@ich.ucl.ac.uk
Susie Aldiss (Research Assistant) s.aldiss@ich.ucl.ac.uk
Prof. Linda Franck (Research Supervisor) l.franck@ich.ucl.ac.uk

Both Nina and Susie can be contacted by phone: 0207 405 9200 ext 0720
Prof. Franck can be reached at: 0207 829 7822
Or write to: Centre for Nursing and Allied Health Professions Research, 7th Floor Old Building, Great Ormond Street Hospital for Children NHS Trust. Great Ormond Street, London, WC1N 3JH

CONSENT FORM

Children's Postoperative Symptoms and Post-hospital Behaviour Problems.

Name of Researcher: Nina Power

Please initial box

1. I confirm that I have read and understand the information sheet dated _____. (Version 2) I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected. ☐

3. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by responsible individuals from The Institute of Child Health and Great Ormond Street Hospital, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my child's records. ☐

4. I agree to take part in the above study. ☐

5. I agree to my child's GP being informed of our participation in the study. ☐

_____	_____	_____
Name of parent / guardian	Date	Signature
_____	_____	_____
Name of person taking consent (If different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

ASSENT FORM FOR CHILDREN

Child (or if unable, parent on their behalf) to circle all they agree with, please:

Have you read (or had your mum or dad read to you) about this study?	Yes / No
Has somebody else explained this study to you?	Yes / No
Do you understand what this study is about?	Yes / No
Have you asked all the questions you want?	Yes / No
Have you had your questions answered in a way you understand?	Yes / No
Do you understand it's OK to stop being in the study at any time?	Yes / No
Are you happy to be in the study?	Yes / No

If any answers are 'No' or you do not want to take part, don't sign your name.

If you do want to be in the study, please write your name and today's date:

Your name: _____ Date: _____

Your mum or dad (or guardian) must write their name here too if they are happy for you to be in the study:

Print name: _____ Date: _____

The person who explained this project to you needs to sign too:

Print name: _____ Date: _____

Thank you for your help!!

Dear Dr_____,

Re: Research Study – Children's Postoperative Symptoms and Post-Hospital Behaviour Problems

Your patient (_____, DOB: __/__/____) and his/her parents have consented to participate in a London-based, multi-site, descriptive study to determine the incidence of postoperative symptoms and post-hospital behavioural problems in British children admitted to hospital for surgery.

I have enclosed a copy of the "Healthcare Professionals' Information Sheet" for your information. The study involves minimal risk and inconvenience to participants. In the unlikely even that the child and/or parents express that their participation is upsetting them in any way, they will be assured they can withdraw at any stage and, if necessary, they will be referred to you.

Contact details of the research team are included in the enclosed information sheet. Please feel free to contact us if you have any queries or if you would like to know more about the study.

Yours sincerely,

Nina Power

Study ID:_____

BASELINE QUESTIONNAIRE SET

Please complete the entire questionnaire set *in the week prior* to your child's date of surgery.

Demographic and Clinical Data – To be completed by a parent, about themselves and their child.

Parent Details

1. First name: _____
2. Surname:_____
3. Date of birth:____/____/_____
4. Marital Status:_____
5. Postcode: _____
6. Ethnicity (please circle one):

- White
  - British □
  - Irish □

Any other white background please state……..

- Mixed
  - White and black Caribbean □
  - White and black African □
  - White and Asian □
  - Any other mixed background please state…….

- Asian or British Asian
  - Indian □
  - Pakistani □
  - Bangladeshi □

Any other Asian background please state……..

- Black or black British
  - Caribbean □
  - African □

Any other black background please state……..

- Chinese □

- Any other ethnic group please state…….

7. Education level: Primary / Secondary / Graduate / Post-graduate
8. Occupation: _____
9. Have you ever been admitted to hospital before? Yes No
10. Have you had an operation before? Yes No

11. If yes, how many operations have you had? _____

12. On a scale of 0-10, please indicate how anxious you felt during your last hospitalization for surgery (0=not at all anxious to 10=extremely anxious):

0———1———2———3———4———5———6———7———8———9———10

13. On a scale of 0-10, please indicate the worst pain you experienced during your last hospitalisation for surgery (0=no pain at all to 10=worst possible pain)

0———1———2———3———4———5———6———7———8———9———10

14. How many children do you have? _____

15. Have any of your other children been admitted to hospital for surgery? Yes No

16. If yes, did you accompany them? Yes No

_____ (child) Details

1. Male ☐ Female ☐ 2. Date of birth: _____

3. No. of siblings: _____ 4. Order of birth: _____

5. Attending school? Yes ☐ No ☐

6. If yes, what year is your child currently completing: _____

7. Please list your child's medical conditions:

_____

_____

_____

8. Has your child had surgery before? Yes No

9. If yes, please list number of times and his/her age at each previous operation:

_____

10. Please tell us why your child is having surgery this time:

_____

11. On a scale of 0-10, please indicate how anxious you thought your child was during his / her last medical procedure (visit to GP/Clinic Nurse/Consultant at Outpatient Dept) (0=not at all anxious to 10=extremely anxious):

0———1———2———3———4———5———6———7———8———9———10

12. What was the procedure?

_____

13. Do you think your child experienced any pain? Yes No

14. On a scale of 0-10, please indicate how much pain you think your child had during the procedure (0=no pain at all to 10=worst possible pain):

0———1———2———3———4———5———6———7———8———9———10

Monitor Blunting Style Scale – To be completed by a parent, about themselves

Below are four scenarios. Read each scenario and imagine yourself in the described situation. Indicate with a check next to each of the statements that follow, which you would do if you were in the situation described.

A. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Tick all that you might apply to you.

__I would ask the dentist exactly what he was going to do.
__I would take a tranquilizer or have a drink before going.
__I would try to think about pleasant memories.
__I would want the dentist to tell me when I would feel pain.
__I would try to sleep.
__I would watch all the dentist's movements and listen for the sound of the drill.
__I would watch the flow of water from my mouth to see if it contained blood.
__I would do mental puzzles in my mind.

B. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick all that you might apply to you.

__I would sit by myself and have as many daydreams and fantasies as I could.
__I would stay alert and try to keep myself from falling asleep.
__I would exchange life stories with other hostages.
__If there was a radio I would stay near it and listen to the bulletins about what the police were doing.
__I would watch every movement of my captors and keep an eye on their weapons.
__I would try to sleep as much as possible.
__I would think about how nice it's going to be when I get home.
__I would make sure I knew where every exit was.

C. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Tick all the statements that you might apply to you.

__I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.
__I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
__I would go to the movies to take my mind off things.
__I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

__I would push all thoughts of being laid off out of my mind.

__I would tell my spouse that I'd rather not discuss my chances of being laid off.

__I would try to think which employees in my department the supervisor might have thought had done the worst job.

__I would continue doing my work as if nothing special had happened.

D. Vividly imagine that you are on an airplane thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You however, are not convinced that all is well. Tick all the statements that you might apply to you.

__I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exit was.

__I would make small talk with the passenger beside me.

__I would watch the end of a movie, even if I had seen it before.

__I would call for the stewardess and ask her exactly what the problem was.

__I would order a drink or tranquilizer from the stewardess.

__I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary.

__I would talk to the passenger beside me about what might be wrong.

__I would settle down and read a book or magazine or write a letter.

Emotionality, Activity, Sociability & Impulsivity (EASI) – To be completed by a parent, about their child.

Please rate each item on a scale of 1 to 5 (**1=a little, 5=a lot**)

	1	**2**	**3**	**4**	**5**
1. Child gets upset easily	○	○	○	○	○
2. Child tends to cry easily	○	○	○	○	○
3. Child is easily frightened	○	○	○	○	○
4. Child is easygoing or happy-go-lucky	○	○	○	○	○
5. Child has a quick temper	○	○	○	○	○
6. Child is always on the go	○	○	○	○	○
7. Child likes to be off and running as soon as he wakes up in the morning	○	○	○	○	○
8. Child cannot sit still long	○	○	○	○	○
9. Child prefers quiet games such as block play or colouring to more active games	○	○	○	○	○
10. Child fidgets at meals and similar occasions	○	○	○	○	○
11. Child likes to be with others	○	○	○	○	○
12. Child makes friends easily	○	○	○	○	○
13. Child tends to be shy	○	○	○	○	○
14. Child tends to be independent	○	○	○	○	○
15. Child prefers to play by himself rather than with others	○	○	○	○	○
16. Child tends to be impulsive	○	○	○	○	○
17. Learning self-control is difficult for the child	○	○	○	○	○
18. Child gets bored easily	○	○	○	○	○
19. Child learns to resist temptation easily	○	○	○	○	○
20. Child goes from toy to toy quickly	○	○	○	○	○

Strengths and Difficulties Questionnaire (SDQ) – To be completed by a parent, about their child.

For each item, please mark either Not True, Somewhat True or Certainly True. Please answer the items as best you can even if you are not absolutely certain.

	Not True	Some-what True	Certainly True
1. Considerate of other people's feelings	____	____	____
2. Restless, overactive, cannot stay still for long	____	____	____
3. Often complains of headaches, stomach-aches or sickness	____	____	____
4. Shares readily with other children (treats, toys, pencils etc)	____	____	____
5. Often has temper tantrums or hot tempers	____	____	____
6. Rather solitary, tends to play alone	____	____	____
7. Generally obedient, usually does what adults request	____	____	____
8. Many worries, often seems worried	____	____	____
9. Helpful if someone is hurt, upset or feeling ill	____	____	____
10. Constantly fidgeting or squirming	____	____	____
11. Has at least one good friend	____	____	____
12. Often fights with other children or bullies them	____	____	____
13. Often unhappy, down-hearted or tearful	____	____	____
14. Generally liked by other children	____	____	____
15. Easily distracted, concentration wonders	____	____	____
16. Nervous or clingy in new situations, easily loses confidence	____	____	____
17. Kind to younger children	____	____	____
18. Often lies or cheats	____	____	____
19. Picked on or bullied by other children	____	____	____
20. Often volunteers to help others (parents, teachers, other children)	____	____	____
21. Thinks things out before acting	____	____	____
22. Steals from home, school or elsewhere	____	____	____
23. Gets on better with adults than with other children	____	____	____
24. Many fears, easily scared	____	____	____
25. Sees tasks through to the end, good attention span	____	____	____

Pain Catastrophizing Scale – Parent (PCS-P) – To be completed by a parent, about themselves.

Please put a circle around the word or phrase under each sentence that best reflects how strongly you have each thought when your child is in pain.

1. When my child is in pain, I worry all the time about whether the pain will end.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

2. When my child is in pain, I feel I can't go on like this much longer.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

3. When my child is in pain, it's terrible and I think it's never going to get better.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

4. When my child is in pain, it's awful and I feel that it overwhelms me

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

5. When my child is in pain, I can't stand it anymore

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

6. When my child is in pain, I become afraid that the pain will get worse

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

7. When my child is in pain, I keep thinking of other painful events

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

8. When my child is in pain, I want the pain to go away

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

9. When my child is in pain, I can't keep it out of my mind

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

10. When my child is in pain, I keep thinking about how much he/she is suffering

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

11. When my child is in pain, I keep thinking about how much I want the pain to stop

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

12. When my child is in pain, there is nothing I can do to stop the pain.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

13. When my child is in pain, I wonder whether something serious may happen

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

Pain Catastrophizing Scale – Child (PCS-C) – To completed by child (if 8 years or older), about themselves.

Below are 13 sentences of different thoughts and feelings you can have when you are in pain. Try to show us as clearly as possible what you think and feel by putting a circle around the word under each sentence that best reflects how strongly you have each thought.

1 When I am in pain, I worry all the time about whether the pain will end.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

2 When I am in pain, I feel I can't go on like this much longer.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

3 When I am in pain, it's terrible and I think it's never going to get better.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

4 When I am in pain, it's awful and I feel that it takes over me

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

5 When I am in pain, I can't stand it anymore

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

6 When I am in pain, I become afraid that the pain will get worse

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

7 When I am in pain, I keep thinking of other painful events

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

8 When I am in pain, I want the pain to go away

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

9 When I am in pain, I can't keep it out of my mind

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

10 When I am in pain, I keep thinking about how much it hurts

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

11 When I am in pain, I keep thinking about how much I want the pain to stop

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

12 When I am in pain, there is nothing I can do to stop the pain.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

13 When I am in pain, I wonder whether something serious may happen

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

State and Trait Anxiety Index (STAI) – To be completed by a parent, about themselves**.**

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you **feel right now**, that is, **at this moment**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your **present feelings best**.

The numbers to the right indicate the following:

1=Not al all 2=Somewhat 3=Moderately so 4=Very much so

1. I feel calm……	1	2	3	4
2. I feel secure……	1	2	3	4
3. I am tense……	1	2	3	4
4. I feel strained……..	1	2	3	4
5. I feel at ease……	1	2	3	4
6. I feel upset……..	1	2	3	4
7. I am presently worrying over possible misfortunes……..	1	2	3	4
8. I feel satisfied……..	1	2	3	4
9. I feel frightened……	1	2	3	4
10. I feel comfortable……..	1	2	3	4
11. I feel self-confident……	1	2	3	4
12. I feel nervous……	1	2	3	4
13. I am jittery……..	1	2	3	4
14. I feel indecisive……	1	2	3	4
15. I am relaxed……..	1	2	3	4
16. I feel content……..	1	2	3	4
17. I am worried……	1	2	3	4
18. I feel confused……	1	2	3	4
19. I feel steady……	1	2	3	4
20. I feel pleasant……	1	2	3	4

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate **how you generally feel**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe **how you generally feel**.

The numbers to the right indicate the following:

1=Not al all 2=Somewhat 3=Moderately so 4=Very much so

21. I feel pleasant……	1	2	3	4
22. I feel nervous and restless……	1	2	3	4
23. I feel satisfied with myself……	1	2	3	4
24. I wish I could be as happy as others seem to be……	1	2	3	4
25. I feel like a failure……	1	2	3	4
26. I feel rested……	1	2	3	4
27. I am calm, cool and collected……	1	2	3	4
28. I feel that difficulties are piling up so that I cannot overcome them…	1	2	3	4
29. I worry too much over something that really doesn't matter……	1	2	3	4
30. I am happy……	1	2	3	4
31. I have disturbing thoughts……	1	2	3	4
32. I lack self-confidence……	1	2	3	4
33. I feel secure……	1	2	3	4
34. I make decisions easily……	1	2	3	4
35. I feel inadequate……	1	2	3	4
36. I am content……	1	2	3	4
37. Some unimportant thought runs through my mind and bothers me	1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
39. I am a steady person……	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns and interests……	1	2	3	4

Parent Beliefs Scale (PBS) – To be completed by a parent about themselves.

1. I know what changes in behavior to expect in my child while he (or she) is in hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

2. I do NOT know what my child's emotions will be like while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

3. I am sure that what I do for my child will be what is best to help him (or her) deal with being in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

4. I am NOT sure about how my child will behave when painful things are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

5. I know what changes in behavior to expect in my child AFTER he (or she) leaves the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

6. I am NOT sure about what I can do to best help my child get through the painful things that are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

7. I do NOT understand why my child is behaving the way he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

8. I am sure I can meet all of my child's emotional needs while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

9. I do NOT know what my child will think about the things that are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

10. I am clear about the things that I can do to best help my child deal with being in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

11. I am NOT sure how my child will act towards me while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

12. I know how my emotions will affect my child while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

13. No matter how my child behaves while he (or she) is in the hospital, I am sure I will be able to handle it.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

14. I am NOT sure of what things I can do to best help my child deal with his (or her) illness or injury.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

15. I am NOT sure about what I can do to make my child feel most secure while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

16. I feel confident in telling the nurses and doctors about what will best help my child while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

17. I am NOT sure about how my child will behave when things frighten him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

18. I do NOT know what I can do to best help my child deal with frightening things in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

19. I feel confident in asking the doctors and nurses questions about my child's illness or injury.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

20. I know how to prepare my child for things that will frighten or hurt him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Agree

Thank you!!

Study ID:_____

MODIFIED YALE PREOPERATIVE ANXIETY SCALE (mYPAS)

Observational scale – to be completed by Research Assistants on the day of the child's surgery, prior to being taken to theatre.

A. Activity _____

B. Vocalizations _____

C. Emotional Expressivity _____

D. State of Arousal _____

E. Use of Parent _____

A. Activity

0. Can't code (child not visible)

1. Looking around, curious, playing with toys, reading (or other age appropriate behavior); moves around holding area/treatment room to get toys or go to parent; may move toward OR equipment

2. Not exploring or playing, may look down, may fidget with hands or suck thumb (blanket); may sit close to parent while waiting, or play has a definite manic quality

3. Moving from toy to parent in unfocused manner, nonactivity derived movements; frenetic/frenzied movement or play; squirming, moving on table, may push mask away or clinging to parent

4. Actively trying to get away, pushes with feet and arms, may move whole body; in waiting room, running around unfocused, not looking at toys or will not separate from parent, desperate clinging

B. Vocalizations

0. Can't code (child not visible or can't hear audio)

1. Reading (nonvocalizing appropriate to activity), asking questions, making comments, babbling, laughing, readily answers questions but may be generally quiet; child too young to talk in social situations or too engrossed in play to respond

2. Responding to adults but whispers, "baby talk", only head nodding

3. Quiet, no sounds or responses to adults

4. Whimpering, moaning, groaning, silently crying

5. Crying or may be screaming "no"

6. Crying, screaming loudly, sustained (audible through mask)

C. Emotional Expressivity

0. Can't code (can't see face or child not visible)
1. Manifestly happy, smiling, or concentrating on play
2. Neutral, no visible expression on face
3. Worried (sad) to frightened, sad, worried, or tearful eyes
4. Distressed, crying, extreme upset, may have wide eyes

D. State of Apparent Arousal

0. Can't Code (child not visible)
1. Alert, looks around occasionally, notices watches what anesthesiologist does with him/her (could be relaxed)
2. Withdrawn child sitting still and quiet, may be sucking on thumb or face turned into adult
3. Vigilant looking quickly all around, may startle to sounds, eyes wide, body tense
4. Panicked whimpering, may be crying or pushing others away, turns away

E. Use of Parents

0. Can't code (child not visible)
1. Busy playing, sitting idle, or engaged in age appropriate behavior and doesn't need parent; may interact with parent if parent initiates the interaction
2. Reaches out to parent(approaches parent and speaks to otherwise silent parent), seeks and accepts comfort, may lean against parent
3. Looks to parents quietly, apparently watches actions, doesn't seek contact or comfort, accepts it if offered or clings to parent
4. Keeps parent at distance or may actively withdraw from parent, may push parent away or desperately clinging to parent and will not let parent go

Study ID:_____

PARENT INFORMATION NEEDS AND SATISFACTION WITH PREPARATION (PISP)

To be completed on the day of surgery, once child has been taken into theatre.

Questions 1-14 relate to the information that you received prior to your child's admission for surgery and the time leading up to your child's admission.

1. What was the length of time between being told that your child needed surgery and your child's date of surgery?

   _____

2. Was your child's surgery cancelled at any stage?
   Yes No
3. If yes, why?

   _____

4. Did your child attend a pre-admission clinic visit?
   Yes No
5. If yes, please tick the box/es that best describe/s this clinic visit (*tick all that apply*):
   - ☐ To ensure that your child was fit for surgery
   - ☐ To show you and your child around the ward / hospital, to meet the staff and to explain what will happen to you and your child on the day of surgery and during hospitalisation.
   - ☐ For you child to see the play specialist and / or receive preparation for admission.
   - ☐ Other. Give details:

     _____

     _____
6. Did you receive any information about your child's admission to hospital for surgery? Yes No
7. Please tell us how and when this information was given to you (e.g. information leaflet, video, discussion with Dr):

   _____

   _____
8. Did you do any information searching on your own? Yes No

9. If yes, please tell us when you searched for this information and what you did:

   _____

   _____

10. On a scale of 0-10, please indicate how well prepared you think you were for your child's admission to hospital (0=not at all prepared to 10=very well prepared):

    0———1———2———3———4———5———6———7———8———9———10

11. Do you feel that you have been well prepared to look after your child at home following discharge? Yes No
12. On a scale of 0-10, please indicate how well prepared you think you are to take care of your child at home (0=not at all prepared to 10=very well prepared)

    0———1———2———3———4———5———6———7———8———9———10

13. Did your child receive any preparatory information prior to being admitted to hospital? Yes No
14. Please tell us what type of preparation your child received and when this was done:

    _____

    _____

Questions 15 - 17 relate to how satisfied you feel with regard to the information you received.

15. On a scale of 0-10, please indicate how satisfied you are with the information that you received prior to your child's admission for surgery (0=not at all satisfied to 10=very satisfied)

    0———1———2———3———4———5———6———7———8———9———10

16. On a scale of 0-10, please indicate how satisfied you are with the information that your child received prior to your child's admission for surgery (0=not at all satisfied to 10=very satisfied)

    0———1———2———3———4———5———6———7———8———9———10

17. Please tell us how you think parents and children should be prepared for admission to hospital for surgery:

    _____

    _____

    _____

    _____

Questions 18 – 23 relate to how worried you were about your child's anaesthetic and how much information you would have liked. Please circle one answer. There are no right or wrong answers.

18. I was worried about the anaesthetic

Strongly disagree Disagree Uncertain Agree Strongly agree

19. The anaesthetic was on my mind continually

Strongly disagree Disagree Uncertain Agree Strongly agree

20. I would have liked to know as much as possible about the anaesthetic

Strongly disagree Disagree Uncertain Agree Strongly agree

21. I was worried about the procedure

Strongly disagree Disagree Uncertain Agree Strongly agree

22. The procedure was on my mind continually

Strongly disagree Disagree Uncertain Agree Strongly agree

23. I would have liked to know as much as possible about the procedure

Strongly disagree Disagree Uncertain Agree Strongly agree

Thank you!!

Study ID:_____

DAY 2 POST-DISCHARGE QUESTIONNAIRE - INPATIENTS

To be completed on day 2 only – by parents and children who were inpatients.

1. Index of Parent Participation (IPP)

Bernadette Mazurek Melnyk, PhD, RN-CS, PNP

Below is a list of 36 activities that you may have done for your child whilst your child was in hospital. Some parents do few of these things while their children are in the hospital, while some parents do more of these things. There is no set number of things that you should have done for your child. Please make a checkmark on the line in front of each activity that you are sure you did for your child whilst he/she was in hospital.

__1. Fed child or set up his/her food tray (such as opened milk carton, cut up food).

__2. Helped with elimination (changed diaper, walked child to the bathroom, placed child on bedpan).

__3. Bathed child/sponged with a washcloth.

__4. Encouraged fluids (if told that this was important or appropriate to do).

__5. Kept track of how much child ate or drank and told nurse or recorded the amount on an intake and output sheet.

__6. Kept track of how much or how often child urinated and told nurse or recorded it on an intake and output sheet.

__7. Kept track of when child had a bowel movement and told nurse or recorded it on an intake and output sheet.

__8. Took child to playroom if allowed.

__9. Comforted child when upset (does not include comforting during a painful procedure such as when having blood drawn or a shot given).

__10. Comforted child during a painful procedure (such as when having blood drawn or a shot given).

__11. Spent quiet time interacting with child (talking, reading, coloring, drawing, watching TV).

__12. Held or rocked child.

__13. Told nurse about something your child needed.

__14. Told nurse about child's daily routines or his/her likes or dislikes without being asked to do so.

__15. Told physician about something your child needed.

__16. Asked nurse for information about child's condition.

__17. Asked nurse for information about child's care.

__18. Asked physician for information about child's condition.

__19. Actively played with child in room (games, blocks, etc).

__20. Stroked child/rubbed back.

__21. Brushed teeth/performed mouth care.

__22. Made a decision regarding your child's care.

__23. Played with child for the purpose of getting him/her to talk about or show feelings by use of puppets, dolls or stuffed animals or used role play (such as letting child pretend to be a doctor or nurse while mother pretends to be the patient).

__24. Changed clothes or pajamas.

__25. Settled for sleep or nap.

__26. Combed/brushed hair.

__27. Helped nurse give medication (would include getting child to cooperate).

__28. Talked with child about why he/she is in the hospital (would include talking about his/her illness or injury).

__29. Asked a nurse or doctor to describe a certain test or procedure so that you could tell your child about it.

__30. Let child know what to expect about a treatment or test (such as an x-ray, shot, IV).

__31. Talked with child about why he/she needs a test or treatment (such as x-ray, shot, IV).

__32. Asked a nurse or physician about how your child was during the time you were not with him/her.

__33. Suggested to a nurse or doctor a different way or time of doing something that you thought would be better for your child.

__34. Took child for a walk, if allowed.

__35. Asked the nurse or doctor to explain something that you did not understand.

__36. Talked with another parent or person (besides a nurse or doctor) to gain more information about some part of the hospital experience or your child's illness or injury.

3. Adapted-Total Quality Pain Management (A-TQPM)

(i) To be completed by the child (if 8 years or older)

1. Did the nurses or doctors talk to you about ways to take away the hurt or pain?

☐ yes ☐ no

2. If yes, when did they talk to you?

☐ Before Surgery ☐ after surgery ☐ both times

3. How did you get the information about pain?

☐ Someone talked to me ☐ I was given something to read

☐ Video ☐ Other_____

4. Was it easy to understand what they said?

☐ yes ☐ no

5. Please colour the face to show the **most** hurt or pain you have had since surgery when you were lying quietly and resting.

0	2	4	6	8	10
NO HURT	HURTS LITTLE BIT	HURTS LITTLE MORE	HURTS EVEN MORE	HURTS WHOLE LOT	HURTS WORST

6. Please colour the face to show the **most** hurt or pain you have had since surgery when you were moving around in bed or when you were up out of bed.

0	2	4	6	8	10
NO HURT	HURTS LITTLE BIT	HURTS LITTLE MORE	HURTS EVEN MORE	HURTS WHOLE LOT	HURTS WORST

7. Before surgery how much hurt or pain did you think you would have after surgery? Colour the face to show us.

0	2	4	6	8	10
NO HURT	HURTS LITTLE BIT	HURTS LITTLE MORE	HURTS EVEN MORE	HURTS WHOLE LOT	HURTS WORST

8. How happy were you with the way the doctors and nurses took away your pain after surgery?

☐ Very Unhappy
☐ Unhappy
☐ Happy
☐ Very Happy

9.Tell us how we could get 'Top Marks' for pain management. (Tick all that apply)
Would you suggest:

☐ Tell you more about the medicine for the hurt or pain?
☐ Give you more or better medicine for the hurt or pain?
☐ Give you medicine faster when you have hurt or pain?
☐ Listen more to what you and your parents want us to do for the hurt or pain?
☐ Everything was fine.

10. Is there anything else that you think we should know in order to improve the way we treat patients in pain.

_____

_____

_____

(ii) To be completed by a parent

1.Did the nurses or doctors talk to you about ways to take away your child's pain?

☐ yes ☐ no

2. If yes, when did they talk to you?

☐ Before Surgery ☐ after surgery ☐ both times

3.How did you get the information about pain?

☐ Someone talked to me ☐ I was given something to read

☐ Video ☐ Other_____

4.Was it easy to understand what they said?

☐ yes ☐ no

5. On a scale of 0-10, please indicate the **most** pain you think your child has had since surgery when lying quietly and resting. (0=no pain at all to 10=worst possible pain).

0———1———2———3———4———5———6———7———8———9———10

6. On a scale of 0-10, please indicate the **most** pain you think your child has had while moving around in bed or when up out of bed. (0=no pain at all to 10=worst possible pain).

0———1———2———3———4———5———6———7———8———9———10

7. On a scale of 0-10, please indicate how much pain you thought your child would have before surgery (0=no pain at all to 10=worst possible pain).

0———1———2———3———4———5———6———7———8———9———10

8. On a scale of 0-10, please indicate how happy you were with the way the doctors and nurses managed your child's pain after surgery (0=not at all happy to 10=very happy)

0———1———2———3———4———5———6———7———8———9———10

9. Please tell us how we could get 'Top Marks' for pain management. (Tick all that apply)

Would you suggest:

☐ Tell you more about the medicine for the pain?
☐ Give your child more or better medicine for the pain?
☐ Give your child medicine faster when he/she has pain?
☐ Listen more to what you and your child want us to do for the pain?
☐ Everything was fine.

10. Is there anything else that you think we should know in order to improve the way we treat patients in pain?

_____
_____
_____

Thank you!!

Study ID:_____

POST-DISCHARGE REPEATED QUESTIONNAIRE

To be completed on day 2, and at the end of week 1, 2 and 4 post-discharge from hospital.

1. Child Pain

Please refer to the pain assessment tools that you were given on the day of your child's surgery in order to answer questions (a) and (b):

a. Please indicate the worst pain your child (if >5years) has reported, using the Wong-Baker Faces Pain Scale, since we last spoke: _____

b. Please indicate the worst pain your child (if <5years) has had, as assessed by you using the FLACC scale, since we last spoke: _____

c. On a scale of 0-10, please indicate how much pain you think your child (all ages) has had since we last spoke (0=no pain at all to 10=worst possible pain)

0———1———2———3———4———5———6———7———8———9———10

2. Child postoperative symptoms

a. Has your child complained of any symptoms since we last spoke (e.g. pain, nausea, vomiting)? Yes ☐ No ☐

b. Please tell us what he / she has complained of:

_____

_____

_____

c. Please explain what you did for your child in response to his / her complaints of pain and other symptoms:

_____

_____

_____

d. Have you taken your child to the GP or clinic or has your child been readmitted to hospital as a result of pain, other symptoms or any other complications? Yes ☐ No ☐

e. If yes, please explain briefly:

_____

_____

_____

f. Did you take time off work to look after your child because of his / her surgery since we last spoke? Yes ☐ No ☐

g. Did your child miss school because of his / her surgery since we last spoke? Yes ☐ No ☐

3. Child Post-Hospital Behaviour Questionnaire (PHBQ)

Please answer the following questions, on a scale of 1 to 5 (1=Much less than before, 2=Less than before, 3=Same as before, 4=More than before, 5=Much more than before) about specific behaviors that may or may not have changed following your child's hospital experience as compared to how these behaviours were before your child's hospital experience.

1.	Does your child make a fuss about going to bed at night?	1 2 3 4 5
2.	Does your child make a fuss about eating?	1 2 3 4 5
3.	Does your child spend time just sitting or lying and doing nothing?	1 2 3 4 5
4.	Does your child need a pacifier?	1 2 3 4 5
5.	Does your child seem to be afraid of leaving the house with you?	1 2 3 4 5
6.	Is your child uninterested in what goes on around him (or her)?	1 2 3 4 5
7.	Does your child wet the bed at night?	1 2 3 4 5
8.	Does your child bite his (or her) finger nails?	1 2 3 4 5
9.	Does your child get upset when you leave him (or her) alone for a few minutes?	1 2 3 4 5
10.	Does your child need a lot of help doing things?	1 2 3 4 5
11.	Is it difficult to get your child interested in doing things (like playing games with toys)?	1 2 3 4 5
12.	Does your child seem to avoid or be afraid of new things?	1 2 3 4 5
13.	Does your child have difficulty making up his (or her) mind?	1 2 3 4 5
14.	Does your child have temper tantrums?	1 2 3 4 5
15.	Is it difficult to get your child to talk to you?	1 2 3 4 5
16.	Does your child seem to get upset when someone mentions doctors or hospitals?	1 2 3 4 5
17.	Does your child follow you everywhere around the house?	1 2 3 4 5
18.	Does your child spend time trying to get or hold your attention?	1 2 3 4 5
19.	Is your child afraid of the dark?	1 2 3 4 5
20.	Does your child have bad dreams at night or wake up and cry?	1 2 3 4 5
21.	Does your child have irregular bowel movements?	1 2 3 4 5
22.	Does your child have trouble getting to sleep at night?	1 2 3 4 5
23.	Does your child seem to be shy around strangers?	1 2 3 4 5
24.	Does your child have a poor appetite?	1 2 3 4 5
25.	Does your child tend to disobey you?	1 2 3 4 5
26.	Does your child break toys or other objects?	1 2 3 4 5
27.	Does your child suck his (or her) fingers or thumbs?	1 2 3 4 5

Thank you!!