

PAEDIATRIC ENT SURGERY - ITS PSYCHOLOGICAL
IMPACT AND SOME FACTORS ASSOCIATED WITH
THAT IMPACT

Thesis submitted for the degree of Doctor of Clinical Psychology at the University of
Leicester

by

Peter W. Reid BA (Mod), DipStats, MA, MSc, MBA

Department of Psychology

Lucena Clinic, Dublin, Ireland

May 1999

UMI Number: U116356

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U116356

Published by ProQuest LLC 2013. Copyright in the Dissertation held by the Author.
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code.



ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

Acknowledgements

I would particularly like to acknowledge the help I received from parents and children who readily shared their experiences of hospitalisation and surgery with me. Clerical and secretarial staff played a key role by helping me obtain the maximum number of participants. Medical and nursing colleagues contributed greatly to my efforts to obtain the consent of participants to be included in the study and the gathering of data. Dr. Keith Turner provided superb supervision. The quality of the final 'product' owes much to his advice and guidance. Finally, I would like to thank Dr. Tony Kinsella for providing statistical advice and reassurance at short notice.

TABLE OF CONTENTS

Abstract	1
Introduction	2
Changes over time in hospital practice relevant to children	4
Hospitalisation and surgery: the challenge, impact and coping of children and their families	8
Preparation of the child and family for hospitalisation	16
Quantitative study	20
Developing the hypotheses	20
The concept of coping in the context of the hospitalised child	20
Parents' cognitive appraisals	29
Summary of hypotheses	34
Context	36
The local hospital and community child health services	36
Constraints under which the project was designed and executed	37
Method	40
Measures	40
State Trait Anxiety Inventory	40
Post Hospital Behavior Questionnaire	40
Behavior Upset in Medical Patients Revised	41
The Child Vulnerability Scale	42
Demographic Questionnaire	43

Method of data collection	83
Sample	84
Data collection	86
Data analysis	91
Themes elicited	94
Inadequacy of information provided before admission	94
Information about facilities	94
Information about likely date for surgery	95
The inadequacy of information supplied during the child's admission	96
Information for the immediate post hospital period	97
Where families got the information they needed	99
Care is shared rather than negotiated	101
The attitude and responsiveness of staff	104
The Teflon nurses and their very non-Teflon counterparts	105
Unexpected psychological trauma	108
The effects of cancellations	109
The induction and after-effects of anaesthesia	109
When the child needed to go back to theatre	111
Decor & ward facilities	111
Discussion	114
Recommendations to the Hospital	127
Recommendations for Future Research	130

TABLES

Table 1: The time sequence of hospital/medical and research task activity	46
Table 2: Characteristics of study participants	59
Table 3: The ten behaviours most frequently mentioned by parents as marked problems before and after hospitalisation	68
Table 4: The five behaviours most frequently mentioned by parents as causing them a lot of concern before and after their child's hospitalisation	71
Table 5: Characteristics of qualitative component participants	85

APPENDICES

Appendix A: The Questionnaires	157
Appendix B: Letter, on hospital headed paper, sent to all General Practices in the catchment area of the hospital	174
Appendix C: Children's Symptoms described by the Referrer to ENT	176
Appendix D: Letter, on hospital headed paper, sent to the mothers of children scheduled for minor ENT surgery	178
Appendix E: Information Leaflet for Parents	180
Appendix F: Consent Form	183
Appendix G: Study Raw Data	184

Appendix H: Qualitative Transcripts	BOUND SEPARATELY

Peter W. Reid

PAEDIATRIC ENT SURGERY - ITS PSYCHOLOGICAL IMPACT AND
SOME FACTORS ASSOCIATED WITH
THAT IMPACT

Abstract

Questionnaires were administered, before, during and after hospitalisation, to the parents of 49 children (aged 3.4 - 11.4 years) undergoing ENT surgery. Nurses also completed a measure of child behavioural upset during each child's admission. Although there was little evidence from the questionnaires that hospitalisation had adversely affected the children's behaviour ($r_s = .67$, $p < .0001$), the experience heightened the perception, especially in parents of younger children, about their child's general vulnerability to illness ($r_s(45) = -.40$, $p < .005$). The data also showed that when parents reported previous hospital contact for what they at that time had consider serious child health concerns, the parents were more anxious at the pre-hospital ENT appointment ($z = 1.92$, $p < .05$). Parents' ratings of their children's behaviour problems and parents' perceptions about their children's general vulnerability to illness, both measured before admission, were positively associated with parents' ratings of their children's distress during the hospitalisation ($r_s(46) = .50$, $p < .0005$; $r_s(46) = .58$, $p < .0001$, respectively). However, the agreement between parents and nurses about children's behavioural distress during the hospitalisation was very modest ($r_s(43) = .3$, $p < .05$). These findings have implications for examining and improving the quality of service provision.

Almost half of the families were also interviewed two weeks after discharge, about their hospital experience. Qualitative analysis of the interview material identified six significant issues: the inadequacy of information supplied by the hospital; the diversity of information sources accessed by families; the implicit rather than negotiated involvement of parents in the care of their hospitalised child; the attitude and responsiveness of the hospital staff, the adequacy of hospital facilities and unexpected psychological trauma. These themes provide a rich source of information about the experience of parents of hospitalised children and identify areas for service quality improvement.

This study of the psychological impact of surgery on children and their parents, and of some of the determinants of that impact, focused on children undergoing the most common types of ear, nose and throat (ENT) surgery, specifically tonsillectomy, adenoidectomy and the insertion of grommets.

Tonsillectomy and adenoidectomy are often performed together as part of the one operation. This combination of procedures is called an adenotonsillectomy. The insertion of grommets may take place with either tonsillectomy, adenoidectomy, adenotonsillectomy, or as a procedure in its own right.

Although the number of adenotonsillectomies peaked in the late 1950s and has been in decline ever since (Deutsch, 1996), there is good evidence about the value of the procedure in specified conditions (e.g., Williams, Woo, Miller & Kellman, 1991). The clinical effectiveness of grommet insertion has also been questioned but recent evidence supports its utility (e.g., Maw & Bawden, 1993).

The clinical indications for tonsillectomy and adenoidectomy overlap but are not identical, and there are no universally accepted criteria (Deutsch, 1996). For example, while recurrent throat infections would generally be seen as an indicator for tonsillectomy, there is no absolute consensus about the number of episodes per year necessary before surgery is appropriate. Similarly there is no consensus about

the number of ear infections necessary before the insertion of grommets with or without an adenoidectomy would be considered appropriate.

These procedures are performed under general anaesthetic. Adenotonsillectomy takes approximately 20 - 25 minutes and afterwards children can be expected to have a significantly sore throat, halitosis and possibly a stiff neck. Postoperative nausea and vomiting affect 50 - 70% of children (Paxton, 1996) and are associated with the use of opioids such as morphine and diamorphine (Dundee, Loan & Clarke, 1996). Immediate postoperative bleeding is a serious potential complication of the procedure but it affects only a small percentage of children and is thought to be related to surgical technique (Handler, Miller & Richmond, 1986). Where there is active bleeding postoperatively, the child must be returned to the theatre for identification of the site of the bleed and its control. Death is a very rare complication of the procedure. Following the operation children are encouraged to eat and drink as normally as possible. This helps to clear the throat and prevent further infection. The insertion of grommets is a much less significant procedure than is adenotonsillectomy. The child undergoes a short anaesthetic and the grommets are inserted in a procedure which takes 5 - 10 minutes. Typically the child recovers very rapidly.

Changes over time in hospital practices relevant to children

Pioneering work in the 1950s (e.g., Robertson, cited in Eiser, 1985) led to a very significant shift in thinking about the role of parents, who previously had not been encouraged to visit their hospitalised children. Such visits were believed to upset children and bring an increased risk of infection to the ward (Belson, 1993).

The Platt Report (DHSS, 1959) was a formal recognition of the emotional issues for children of being hospitalised and of the significant role played by their parents at such a time. Key recommendations of the Platt Report were that children should only be admitted to hospital if absolutely necessary, if admitted should never be nursed on an adult ward, that parents should have free and regular access to their hospitalized children and take part in their care, and that mothers should be admitted with their children especially if the child was less than five years of age.

Three years later a survey by the National Association for the Welfare of Children in Hospital (NAWCH, 1962) indicated that there had been very wide variation in the response of individual hospitals to the Platt Report's recommendations about the need to facilitate parental involvement and in particular the issue of parental visiting. In retrospect, as Belson (1993, p.199) notes, "the need for change went unrecognised, and the likely effects of change were exaggerated or mistaken". However, in time, and in particular due to the work of NAWCH, changes did occur. For example, Thornes (1983) reported that by the early 1980s more than 75% of

wards offered some form of accommodation for parents and almost 50% allowed unrestricted 24 hour visiting. However even in the early 1990s there were still serious deficiencies in the provision of parent accommodation (Audit Commission, 1993).

A second major DHSS report - Hospital Facilities for Children (DHSS, 1972) reiterated the recommendations made in the Platt Report and additionally emphasised the importance of children's services being located within a comprehensive children's department under the supervision of a Consultant Paediatrician and with a Registered Sick Children's Nurse (RSCN) in charge of every children's ward. The importance of play and education for the hospitalised child was also recognised as was the preference for day care and day surgery where practicable.

The Court Report (DHSS, 1976a) further emphasised the importance of services being integrated, centred on the child and family and staffed by trained RSCNs.

Play schemes have been available in some hospitals since the 1970s with the NAWCH and the Pre-School Playgroups Association (PPA) playing an early and key advocacy role in the establishment of such facilities. Unfortunately, despite Department of Health support the availability of this type of provision is still very variable (Belson, 1993).

The change in perceptions about the role of parents in the care of their hospitalised children and of the emotional needs of hospitalised children was clearly very important but so too have been more recent changes in the pattern and admission practices adopted by hospitals. The length of the hospital stay for children admitted for the most common surgical procedures i.e. removal of tonsils, adenoids, appendectomies, insertion of grommets and hernia repairs (Routh & Sanfilippo, 1991), has been steadily decreasing over the past 10 - 15 years (Edwards, 1996) with day-care surgery increasingly advocated and used. Day-care surgery is seen as having a number of advantages for example, there is reduced exposure to the risk of cross infection, a reduction in costs and waiting times, it is more convenient for children and their families and it makes it more likely that the child's parents can remain with the child throughout the hospital stay (Scaife & Campbell, 1988).

In the UK children are likely to stay in hospital overnight after adenotonsillectomy. However day care surgery for this procedure is common in a number of other countries including the US where many medical insurers will not reimburse families for the additional costs of inpatient care (Deutsch, 1996). While day care surgery for adenotonsillectomy is uncommon in the UK, recent evidence from a cohort of families in Portsmouth suggests that with careful perioperative care it is a safe procedure with a high level of acceptance among families (Church, 1996). Ensuring good fluid intake and the control of postoperative pain are the main challenges faced at home by such parents (Bartley & Connew, 1994). When the

insertion of grommets is the only procedure carried out children in the UK are unlikely to need to stay in hospital overnight.

Hospitalisation and surgery: the challenges, impact and coping of children and their families

The pattern and duration of hospital admissions for children have changed over recent decades but many of the stresses experienced by children and their parents remain. For example, while many hospitals offer pre-hospital preparation programmes which can help address the 'fear of the unknown', not all families can or do avail of these (Peterson & Ridley-Johnston, 1980, p.5). Similarly while the internet is a very rich source of useful preparatory information families' access to the technology is limited. Thus inevitably a proportion of parents and children still approach hospitalisation and surgery with an incomplete understanding of what will happen and how they will feel. (Melnyk, 1995). The increasing availability of hospital accommodation for parents and the reduced length of hospital stay for children greatly reduce the likelihood of significant parent child separations however these may still occur e.g. in the anaesthetic room prior to the induction (Lansdown, 1996, p180). Additionally, hospitalised children still come into contact with a very wide range of hospital staff although, as Cleary's study (cited in Lansdown, 1996) shows, nowadays the stress of this is usually mitigated by their parents' reassuring ongoing presence.

Parents and children in hospital may experience a loss of self control in the face of altered routines (Schepp, 1991) and the undermedication of postoperative pain (Routh & Sanfilippo, 1991). Parents have been reported to experience anxiety and

confusion particularly in their attempt to negotiate their own role vis-à-vis nursing staff (Dearmun, 1992). Parents also report feelings of powerlessness, guilt, anger and exhaustion (Berebaum & Hatcher, 1992). The induction of anaesthesia is still a very very stressful time for many parents (Freiberg, 1991). Finally as Bradford (1991) indicates, hospital ward staff may underestimate the emotion distress experienced by parents of hospitalised children and overestimate their own (i.e. the staff's) availability to such parents.

Early studies from North America (e.g., Gofman, Buckman & Schade, 1957) and a more recent literature review of non-UK studies, Fletcher (1981) suggested that children's behaviour was adversely effected by hospitalisation. However, many of the studies, particularly earlier ones, were methodologically weak. More recently, Thompson & Vernon (1993) carried out a meta-analysis of studies published between 1967 and 1990, on children's posthospital adjustment following minor elective surgery. Each of the studies included in the analysis used the Posthospital Behavior Questionnaire (Vernon, Schulman & Foley, 1966) as an outcome measure. Thompson & Vernon (1993) concluded that in the absence of intervention children's negative behaviours tended to increase significantly after discharge, but diminished with time and had largely disappeared after two weeks.

However, Rudolph, Denning & Wise (1995, p. 351) "urge researchers to be cautious in drawing wide ranging conclusions on the basis of a single type of

measure" such as the PHBQ. Clearly, different perspectives are relevant, including that of the child. Outcome can be considered to include other variables, for example, parents' thoughts and feelings, the child's physiological state, as well as the long term emotional sequelae for all members of the family. Different methodologies may be relevant to obtaining these perspectives. For example, Ogilvie (1990) has suggested that a qualitative approach would be particularly apposite for obtaining insights into how parents experienced their child's hospitalization and that such knowledge is one important element in service improvement.

As Perrin (1993, p.51) notes, it is conceivable that hospitalization may have a number of other useful outcomes for children and their families which counterbalance the negative effects. For example, it may provide some families with opportunities for personal growth and may provide professionals with opportunities too, for example, to develop alliances with parents, to observe parents interacting with their children and to provide educational inputs.

The findings from British studies are broadly in line with those from the United States. Scaife and Campbell (1988) compared the medical and behavioural outcome of day care versus inpatient care for children (aged 6 years or less) admitted to a paediatric surgical ward in Leicester. Parents of children who had been admitted as inpatients were more likely to rate their children, at three months follow-up, as still effected by the hospital experience than were parents of children treated on a day

care basis. However as Scaife & Campbell (1998, p.196) note “as this was not manifested in behavioural ratings, it may reflect a feeling experienced by the parents rather than a change of behaviour in the children”. McLeod (1989) surveyed parents of children (average age 5 years) following tonsillectomy at the Hospital for Sick Children, Edinburgh. Ninety-five percent of the parents considered their child to be over the operation by the two to two and a half week follow up. Walker, Harris, Baker, Kelly & Houghton (1999) measured post-traumatic stress symptoms in eighteen children (mean age = 11 years and 9 months, standard deviation = 3 years and 7 months) who had undergone routine ENT procedures at least three months previously at two hospitals in the British Midlands. These children served as a control group in a study of post-traumatic stress disorder in older children who had had liver transplants. Walket et al. (1999, p.368) found that “only two ENT children had symptoms in the mild range. Specific symptoms were experienced by less than 50% of the ENT subjects”. Finally, a group of researchers from the U.K. (McFaul, Stewart, Werneke, Taylor-Meek, Smith & Smith, 1998) point out that many of the studies showing adverse psychological effects of hospitalisation on children and their families were carried out several decades ago. Improved conditions in hospital, greater involvement of parents, availability of wards and facilities specifically for children and specialist staff are likely to have reduced the impact of hospitalisation. McFaul et al. (1998, p. 217) state that “contemporary studies of the effects of admission are required”.

Given what is known about the challenges posed by hospitalisation and its impact on children and families it is not surprising that there is also a body of research focusing on how children and families actually cope with the experience. As Compas (cited in Christiano & Russ, 1998) has stated, coping style refers to the tendency to consistently implement certain coping strategies either across different stressors or at different times in the context of the same stressor. The sensitizer repressor classification is one of the most developed and researched coping style and has been applied to adult patients for some time and more recently used in a paediatric setting by researchers such as Field, Alpert, Vega-Lahr, Goldstein & Perry (1988). Sensitizers are said to actively seek information in order to prepare for a stressful event while repressors tend to avoid information and distract themselves with thoughts unrelated to the upcoming stressor. While there is some evidence that preparatory interventions consistent with children's coping style are more effective than incongruent interventions (e.g. Christiano & Russ, 1998) problems in the measurement of coping style remain and behavioural measures need to be developed.

A good deal of the research effort has been on how children cope with specific painful and distressing experiences in hospital and on the strategies they use i.e. has taken a process rather than a trait approach (Siegel & Smith, 1989a). Successful coping has been associated with using a greater variety of strategies for dealing with stress (which itself is positively correlated with age), with a better understanding of the reasons for hospitalisation, with an information seeking approach, and with less

use of negative self statements (Siegel, 1983). Similarly Worchel, Copeland & Barker (1987, p. 157) found that specific behaviours displayed by child and adolescent oncology patients e.g. “holding parent’s hands and deep breathing (behavioral), thinking and talking about one’s illness and treatment (cognitive), and perceived control over activities, treatments and meals (decisional) were significant predictors of emotional adjustment.”

Much of the research on the effects of children's hospitalisation on their parents has focused on the reactions of mothers (Graves & Ware, 1990) or as Hayes & Knox (cited in Graves & Ware, 1990) have done, combined data from mothers and fathers. The evidence suggests that hospitalisation of a mildly or moderately ill child does not necessarily increase maternal emotional distress (Berenbaum & Hatcher, 1992); however, unexpected admission, at least to an intensive care unit, has been shown to be a very stressful experience for both parents (Eberly, 1985). There is generally a discrepancy between professional’s perceptions of parents’ stress and parents’ experience of stress (Hayes & Knox, 1984) and professionals overestimate parents’ desire for clinical involvement (Strull, Lo & Charles, 1993).

The research suggests that parents adopt a range of approaches to cope with their child’s hospitalisation. These approaches include assuming an advocacy role for the child (e.g. Ogilvie, 1990), use of intrapsychic strategies such as denying risks or intellectualising about the minor nature of the surgery and direct action e.g.

expressing anger or seeking information (Lazarus & Launier as cited in Pervin & Lewis). Many parents, mothers particularly, participate in child care and provide the child with emotional support (Coty, Ritchie & Elerton, 1989; Coyne, 1995). There is some evidence at least in the case of day surgery that mothers learn to manage their child's pain through a process of trial and error (Gedaly-Duff & Ziebarth, 1994). Finally as Kinderman, Feather & McDowell (1996, p. 20) state

Parents of children with serious illnesses apparently fear that their children may be unable to understand or cope with distressing information. As a result, the amount of information they consider appropriate for their children to receive is significantly lower than the amount of information they feel they need themselves.

Knafl & Dixon (1984), carried out one of the few studies on the involvement of fathers during their children's hospitalization. They found that the majority of fathers (76%) described their own behaviour as "a rather straightforward enactment of their usual fathering role in an unusual setting" (p. 275). For a minority of fathers (24%) there was an extension in role to include for example, preparation of the child for hospital, decision making about treatment and monitoring and initiation of care from professionals. Overall, fathers were more likely to alter their routines e.g. by visiting before and after their work or taking annual leave than by altering their usual fathering role.

There is very limited evidence about the impact of hospitalization on a child's siblings. In an early study, Sipowicz & Vernon (as cited in Goslin, 1978) studied 24 pairs of twins, one of whom was hospitalized. The twins were aged between 5 and 48 months and the hospitalised twin was admitted for between 1 and 21 days. Using the Post Hospital Behavior Questionnaire they found that while there was a difference between the two groups, the magnitude of this difference was not statistically significant. Older home twins (i.e. twins not hospitalised) were more likely to be affected than were younger home twins. However, there is evidence that parents underestimated the emotional trauma reported by healthy siblings (Craft, Wyatt & Sandell (1985) and overestimated the extent to which they cope with their sibling's illness (Walker, 1988). In general, impact on siblings of children experiencing acute hospital admissions appears to be associated with a number of factors including age, relationship with the hospitalised child, perceived change in parenting during the hospitalisation and explanation of the hospitalisation given to siblings by the children's parents (Craft et al., 1985). More recently there have been several studies focusing on the impact for a child of having a sibling with a chronic condition (e.g., Stallard, Mastroyannopoulou, Lewis, & Lenton, 1997). Stallard et al. (1997) found that the majority of healthy children wanted more information about their sibling's condition but boys and younger children in particular, felt unable to talk to their parents or indeed anyone else. Clearly, the psychological impact of hospitalisation is not limited to the child patient alone but affects other family members too.

Preparation of the Child and Family for Hospitalisation

With increasing recognition of the impact of hospitalization on children came efforts to enhance, through preparation, children's ability to cope with the psychological stress associated with the experience. Many of the preparation programs, particularly in the United States, targeted subpopulations of well children and were often delivered in a school setting. These programmes relied on approaches which had not been empirically validated for example, verbal descriptions of procedures and guided hospital tours (Peterson & Mori, 1988) and it is perhaps not a surprise as Azarnoff (cited in Peterson & Mori, 1988) has noted, that many were discontinued because of a lack of financial support.

More empirically sound approaches have included nondirective child-centred play therapy (e.g., Rae, Worchel, Upchurch, Sanner & Daniel, 1989); filmed modelling (e.g., Melamed & Siegel, 1975); puppet models (e.g., Peterson, Ridley-Johnson et al., 1984); preadmission visits by nursing staff to the child's home (e.g., Ferguson, 1979) and stress point preparation (e.g., Wolfer & Visitainer, 1975).

Stress point preparation seems the more effective intervention to help children cope with preplanned surgical procedures. According to Vernon & Thompson (1993, p.42) this is not surprising since it involves several special features; (a) comforting children after stress, (b) preparing children intermittently, just before the occurrence

of potentially stressful conditions, rather than in a single session, and (c) tailoring the preparation routines to the perceived needs and abilities of the individual children.

However there is still a need to identify the critical components in effective hospital preparation packages, and to compare the effectiveness of different interventions (Peterson & Mori, 1988). Unfortunately many of the published studies are methodologically weak (Eiser, 1984; Perrin, 1993). In addition, while there is research supporting the effectiveness of "psychological" intervention in the case of preplanned admissions, it is not clear whether all children need such programmes nor whether all children benefit equally from them (Eiser & Eiser, 1990). Furthermore the evidence about the benefits of preparing children before (as opposed to at the very beginning of) a preplanned hospital admission is equivocal (Vernon & Thompson, 1993). There is also little data on the effectiveness of interventions for children repeatedly hospitalized for serious medical conditions or who experience prolonged admissions.

Perrin (1993, p. 50) summarises thus, "it has become clear that variations in the format, and timing of interventions are important to make them maximally effective for children of varying ages, temperamental styles, and previous experience with illness, medical procedures and hospitalization."

It is also the case that hospital preparation programmes can facilitate children's coping only if they are used and as Peterson & Ridley-Johnson (1980, p.5) have noted, "even in hospitals offering procedures to all children admitted many families do not take advantage of the program." Indeed Schmeltz & White (1982) suggests that it is those who do not avail of preparation who are most in need.

To summarise: preparation of children and their families for hospital can reduce the psychological impact of admission for them. However, many factors influence the effectiveness of preparation interventions. What constitutes necessary and sufficient preparation may vary widely between children and families.

There is little research on the styles adopted by parents, in the absence of formal hospital based preparation programmes, to prepare their children for hospitalisation and surgery. Early work from the US (Gofman, Buckman & Schade, 1957) suggests that at that time, only a minority of children were actively prepared for the experience. Gofman et al. (1957) reported that 26% of their study's one hundred 3 - 15 year olds said they had been told nothing about the hospitalisation by their parents, 22% were able to give vague reasons only and a further 27% had got information only by overhearing conversations between the adults. The situation in the UK, at least by the early 1980s appears to have been a good deal better but as Reissland (1983) study suggests, there were still significant numbers of children

unable to explain why they were to be admitted to St. Charles Hospital London, for their planned tonsillectomy.

There is evidence, at least in the case of serious life threatening conditions, that parents erroneously believe that telling less protects their child from emotional distress (Clafin & Barbarin, 1991). It is not clear to what extent parents whose children face minor surgery adopt a similar approach. Much more research has focused on increasing the effectiveness of the support provided by parents to their children in anticipation of and during acute procedural distress. Blount, Sturges & Powers (1990) for example have shown that parents' use of distraction techniques is helpful in the anticipatory stage of painful procedures. A contemporary study on how parents actually prepare their child for hospitalisation and surgery would be useful.

QUANTITATIVE STUDY

Developing the Hypotheses

The Concept of Coping in the Context of the Hospitalised Child

The term coping has not been used in a consistent way throughout the literature.

While this "conceptual diversity ... provides the benefits derived from a multidimensional framework" (Rudolph et al., 1995, p.352) it also makes it difficult to compare the results of different studies which have focused on the impact of hospitalisation on children and their families.

Conceptually coping has often been seen as a mediator between a stressor and the outcome of exposure to that stress (Peterson, 1989) but empirically, coping attempts and outcome may be difficult to distinguish. For example, children often cry during a painful injection. Does crying mean that a child is coping successfully in that crying relieves tension and distress or that s/he is failing to cope as evidenced by her/his behavioural indications of emotional disturbance?.

In a model which attempts to clarify this type of ambiguity Rudolph, Denning & Weisz (1995) have differentiated between a coping response, a goal underlying that response and an outcome. While the model does provide some conceptual clarity it leaves significant issues unresolved. For example, it is likely to be difficult, especially with younger children, to reliably assess the goal underlying their coping

response. Where the model is helpful is in its emphasis on the need to consider the adaptiveness of an outcome from the different perspectives of all the participants.

There is little empirical data about the efficacy of children's coping attempts in the face of the sort of painful medical procedures which for many children are associated with hospitalization (Rudolph et al., 1995). However evidence is accumulating that the effectiveness of a coping response may depend on the stage of the stressor (e.g., LaMontagne, Hepworth, Johnson & Cohen, 1996; Peterson & Toler, 1986). For example, information seeking may be a useful coping strategy for a child anticipating hospitalization but when that child is actually in hospital and about to have an injection distraction may be more helpful.

Numerous intervening variables have been suggested as involved in the process of coping. Baron & Kenny (1986, p. 1074) have proposed that these be categorised as either moderators or as mediators. Moderators reflect pre-existing characteristics of the child e.g. age or sex, or they are contextual e.g. the need for all children undergoing ENT surgery to have an anaesthetic. Mediators are variables activated during the coping episode e.g. feelings of anxiety prior to surgery or a child's belief about the amount of control s/he can exercise over what happens during the hospitalisation. Such variables are likely be influenced by the medical stressors with which the child is faced and also by the success or otherwise of the child's coping responses.

Child specific moderators e.g. age, developmental level, gender, and previous experience have received much research attention. Key findings from the research are described below.

Although there is considerable variation in the conceptual ability of same age children, there appear to be clear developmental trends in children's understanding of bodily functions, illness and treatment (Bibace & Walsh, 1982). Additionally, in the face of painful medical procedures, older children are more likely than younger children to resort to secondary control coping e.g. cognitive rationalisations, when primary control coping e.g. efforts to escape, fail (Band & Weisz, 1988). There is also evidence that older children show fewer overt signs of distress in response to painful medical procedures but report similar level of pain to those reported by younger children (LeBaron & Zeltzer, 1984). It is clear that age and developmental level are key variables which predict children's response to hospitalization (e.g., Rutter, 1981).

There is some evidence which suggests that girls report more pain and anxiety associated with painful medical procedures than do boys. However findings from observational studies (e.g., Melamed & Siegel, 1975) suggest that gender differences are less clear cut. As McGrath & Pisterman (cited in Bush & Harkin, 1991) found, there is little evidence that girls are more inclined than boys to interpret sensations as pain. Rudolph et al. (1995) suggest that the variables age and gender may interact.

As boys grow older they may be socialised to adopt a more stoic attitude towards pain while girls may be reinforced for passive affective responding.

Previous experience is likely to affect the way a child copes with hospitalisation and surgery. Peterson, Mori & Carter's study (cited in Saylor et al., 1987) suggests that previous negative experience and lack of control, and the child's prehospital adjustment (Carson et al., 1991) are likely to be important determinants.

Research on situation specific moderators has focused on characteristics of the clinical procedure and of the environment. Procedure characteristics studied include (a) stage e.g. the anticipation of, engagement with and recovery from a clinical procedure such as surgery; and (b) the type of clinical procedure e.g. the range from minor routine immunisations to the severe pain of bone marrow aspiration in the treatment of childhood cancer. One of the most frequently studied environmental moderators is parental influences e.g. the effect of allowing the parent to accompany the child into the anaesthetic room. The relevant research evidence is now briefly reviewed.

It was Folkman & Lazarus (1988) who suggested that the stages of the clinical procedure i.e. anticipation, engagement and recovery, need to be distinguished. Their contention is supported by evidence that children cope in different ways during different stages (Blount, Sturges & Powers, 1990) and that the effectiveness of a

coping strategies is determined by the stage of the clinical procedure during which it is used (Weisz, McCabe, & Dennig, 1994). There is also evidence that children who tend to focus on rather than distract themselves from stressful clinical procedures respond differently within different stages of the procedure. Children who are inclined to distract themselves experiencing more anxiety before procedures while those who are inclined to focus on medical procedures experience more anxiety during and after the procedure (Field, Alpert, Vega-Lahr et al. cited in Rudolph et al., 1995). What matters may not be a particular method of coping but rather the child's ability to switch strategies as the demands and controllability of the component in the clinical procedure change.

Painful diagnostic procedures, for example, venipunctures, presurgical sedation, induction of anaesthesia, and postoperative pain, are common experiences for many children admitted to hospital for surgery (Routh & Sanfilippo, 1991). Clearly the variable 'type of stressor' can vary along a range of dimensions which include intensity, frequency, duration, novelty, and meaning (Rudolph, et al., 1995). The potential or scope that the child has to relieve procedure related distress is likely to vary between components of the procedure and with variations in the type of stressor dimension described above. In addition actual controllability needs to be differentiated from the child's perception of controllability (i.e. secondary appraisal) and this distinction partly underlays the efficacy of the child's coping efforts.

Some of these central concepts e.g. the need to consider coping from the viewpoint of different participants; and some of the key variables identified in the literature and reviewed above e.g. the nature of previous medical experience, have been incorporated into the research design of this study.

As mentioned previously, the most commonly employed paediatric measure of general adjustment to hospitalisation has been the Post Hospital Behavior Questionnaire. Using this measure Thompson & Vernon (1993) concluded that hospitalisation for minor elective surgery increased children's negative behaviours but that these changes diminish with time and largely disappear after two weeks. However since the PHBQ focuses exclusively on parental reports about the occurrence or non occurrence of specified child behaviour problems, it may underestimate of the number of families where parents have significant concerns about their child or their children (Stallard, 1993). Therefore it was hypothesised that there would be no relationship between parents' overall rating of their children's posthospital behavioural disturbance and the number of discrete behaviours (PHBQ questionnaire items) about which parents had a lot of concern.

Attachment theory predicts that parental presence during the child's hospitalization will ameliorate potentially the most harmful psychological aspect of the experience - separation of the child from caretakers (Fahrenfort, Jacobs, Miedema & Schweizer, 1996). Fagin (cited in Fahrenfort et al., 1996) provides

empirical support for the protective effect of allowing parents to stay close to their children during hospitalisation. There is also evidence, from the study by Wells & Schwebel (as cited in Carson et al., 1991), of an association between the child's attachment status and the psychological outcome for the child of hospitalization. However it may simply be the case, as Hardgrove & Dawson (cited in Peterson & Mori, 1988) suggest that hospitalized children simply get better care when their parents are able to stay with them. This may be particularly relevant where staffing levels are reduced to the minimum in order to help hospitals manage within financial constraints. Overall there is a strong case that parental presence effects the child's psychological experience of hospital admission. The government reports reviewed in an earlier section acknowledge the importance of parental presence during a child's admission. From the above it can be hypothesized that there will be a significant and negative correlation between the amount of time a child is accompanied during their hospitalization and deterioration in that child's behaviour following hospitalization.

Mediators are variables “that explain the relations among different components of a coping episode - stressors, coping responses, and outcome/adjustment “ (Rudolph et al., 1995, p. 346). Two of these (i) primary and secondary appraisal and (ii) deployment of attention have received some research attention.

Primary appraisal involves a judgment about what is at stake in a given situation. Expectation (primary appraisals) are clearly very important. For example, Palermo &

Drotar (1996) found that anticipatory anxiety regarding surgery was a significant predictor of children's postoperative pain rating. Children who rated themselves one week before their admission as anxious and nervous about the surgery also rated themselves postoperatively as experiencing more intense pain than other children. Furthermore the intensity of reported pain was unrelated to the medical severity of the surgery. The child's perceptions about the controllability of hospital related experiences are also likely to have an influence on the child's adjustment. Increased predictability, sense of mastery or control and competence may be key mediating variables (Siegel & Smith, 1991). There is good research evidence that when children are involved in treatment decisions and in the actual treatment they are more willing to cooperate with it (Melamed & Siegel, 1980). Unfortunately children are even less likely than adults to be consulted about the adequacy of pain relief provided to them and to have the dose of analgesic adjusted based on their feedback (Beyer, Degood, Ashley & Russell, 1983). An opportunity to improve the quality of the medical encounter for child and hospital staff is thus often missed.

Folkman (cited in Rudolph et al., 1995) has suggested that when children undergo stressful experiences they may judge that they are at risk of harm or loss; or that there is a threat to themselves and their well being. They may also see stressful experiences as ones in which there is a challenge or opportunity for them to grow and develop. The three types of primary appraisal (a) harm or loss, (b) threat and (c)

challenge are helpful in considering parents' and children's coping with hospitalisation and surgery.

Primary appraisals are likely to influence individual's approach to coping and may themselves be influenced by a wide range of factors such as the child's age and developmental level. There is evidence that younger children are more likely to see medical treatments as punishment while older children are more likely to appreciate the need for it and its benefits (Gedaly-Duff, 1991). On the other hand older children may appraise medical treatments as being a greater threat to their self esteem if, for example, they anticipate that they will not be able to respond to it in a 'mature' fashion. It is highly probable that the quality of previous experience, and possibly the similarity of previous and current experience (Rudolph et al., 1995) are very important in determining the expectations children and their parents hold about how they will both cope in the face of impending or present procedural stress. While hospitalisation of a mildly or moderately ill child does not necessarily increase maternal emotional distress (Berenbaum & Hatcher, 1992) it seems likely that when previous hospital experience was very anxiety laden parents will be more anxious in anticipation of an impending hospitalisation than will parents without such experience. It was hypothesised that mothers with families where at least one of the children is reported by the mother as having had a previous hospitalization for what was rated by the mother at the time as serious, would be more anxious at the preassessment clinic than mothers without such experience.

Secondary appraisal is concerned with a judgement about the extent to which one, as an individual and the extent to which people in general, can influence the outcome of a stressful encounter e.g. can control the pain and stress of a clinical procedure. Band & Weicz's study (cited in Rudolph, Dennig, & Weisz, 1995) provides evidence that perceptions of self efficacy and illness adjustment, at least in children with diabetes, are positively correlated. There is also evidence that children who perceive themselves as having little control over medical decisions which involve them, display more internalizing and externalizing symptoms (Worchel, Copeland & Barker, 1987) and, as LaMontagne (cited in Rudolph et al., 1995) found, those with a more internal locus of control display more active coping styles.

Clearly for parents and hospitalised children the issue of control can be expressed in a variety of ways e.g. control in the sense of having a say in decision making; having accurate information about what will happen; parents having a negotiated role in the care of the hospitalised child; and is the central theme throughout the literature on secondary appraisal.

Parents' Cognitive Appraisals

Parental anxiety and cognitive appraisal are intricately linked. Many sources of parental anxiety have been identified. These include lack of information about the child's illness and prognosis, about what they (the parents) can expect behaviourally from their child during and after the hospitalisation and how they can facilitate their

child's adjustment (Melnik, 1995); difficulty in negotiating with nursing staff about the parental role in the child's hospital care (Darbyshire, cited in Coyne, 1995); lack of information about hospital routines and procedures (Schepp, 1991); anxiety over seeing other ill children in the hospital (Freiberg, 1972), and concerns about the results of surgery and the anaesthetic procedures (Zuckerberg, 1994). A parent variable which has not been researched but which is probably important is the parent's recollection of their own childhood experience of hospitalization.

There are many possible sources of parental anxiety in the context of the hospitalised child, and significant consequences of such anxiety for parent and child. Spielberger (1971, p.1) has suggested that trait anxiety is reflected in anxiety proneness i.e. "the tendency to perceive stressful situations as dangerous or threatening and to respond to such situations with elevations in the intensity of their state anxiety reactions". In a model of postoperative coping developed by LaMontagne, Hepworth, Johnson & Cohen (1996) they predict that such anxiety will directly and indirectly affect a child's adjustment. Research evidence supports this in that heightened anxiety impairs the judgements parents make about the clinical severity of, and the threat posed by their child's symptoms (McCarthy, Cicchetti & Sznajderman, 1991). It follows, and is hypothesised, that the more anxious a parent the more likely will they rate their child as disturbed by the hospitalisation, compared to the rating of disturbance made by the child's (less emotionally invested) named nurse. It was hypothesized that there would be a significant positive

correlation between parent's level of prehospitalisation anxiety and the size of the discrepancy between nurse rated and parent rated child behavioural disturbance during the child's admission.

Parents' perception of the seriousness of their child's medical condition rather than the objective medical assessment is the most important determinant of parents' perception of their child's vulnerability and children who are perceived by their parents as vulnerable have significantly more behaviour problems and acute medical consultations than do other children (Forsyth, McCue Horwitz, Leventhal & Burger, 1996).

The contextual nature of parents' perceptions of child vulnerability is only beginning to be explored (Thomasgard & Metz, 1997). In general parents do not need to exercise the same level of physical care and vigilance as their children grow older. Furthermore older children are better able to communicate about their internal states and are likely to have acquired more complex, less 'parent dependent' coping strategies than younger children. Younger children, on the other hand, are more frequent users of health care resources, and as Thomasgard & Metz (1997) note in younger children "the signs of illness are both less specific and potentially more ominous". Finally parents may be aware of emerging medical conditions in their children before these conditions are capable of being diagnosed. In such instances parent's perceptions of their child's vulnerability may well be accurate. In light of

the above it is not surprising that Thomasgard & Metz (1995, p. 50) have hypothesized that "the younger the child the less objectively severe the stress or medical condition need be, as judged by the clinician, ... to set in motion an increased parent perception of child vulnerability". In the context of this study it is hypothesised that there will be a significant, negative correlation between the age of the child and increases in the parent's perceptions of the child's vulnerability following hospitalisation for a minor surgical procedure.

Anxiety hinders parents ability to listen to, understand and use information presented to them. It also has a negative impact on treatment compliance and satisfaction. Children of highly anxious parents have been found to be more fearful and uncooperative before and after treatment or hospitalization (Jay, Ozolins & Elliott, 1983). Children whose parents are less anxious have also been shown to have a better understanding about the surgery they face, show less distress and better coping (Wolfer & Visitainer, 1975). Thus parent's perceptions of their child as vulnerable and parental anxiety are likely to influence the child's response to hospitalisation and the child's posthospital adjustment. Therefore it can be concluded, and it is hypothesised, that children who are perceived by their parents as vulnerable prior to an admission will show more behavioural disturbance during the hospitalisation and higher levels of parent rated behavioural disturbance following discharge, than will other children.

A second key mediator is the extent to which an individual attends to, or deflects attention from, stressful medical procedures. Paradoxically attention enhancement and attention reduction have both been shown to facilitate children's adjustment to medical stressors (Thompson, 1994). Variables such as the stage in a stressful medical procedure and the extent to which the pain and stress can be controlled by the child may determine which approach, attention reduction or enhancement, will be most effective (Rudolph et al., 1995). In addition the improved outcomes associated with information seeking may reflect the type of child rather than the value of the information itself. Thompson (1994, p. 94) found that the most anxious children were those who "seemed to feel that there was something threatening about the anticipated hospitalization and were for some reason unwilling to be reassured." Thompson goes on to suggest that "perhaps these children desired more information but were unable, for whatever reason to obtain it" (p.95). One possibility is that children may not get the information they desire because there is a mismatch between their preferred coping style and that of their parent. Therefore it is hypothesised that children will show less behavioural disturbance during their hospitalization when their parents match their own style of child hospital preparation to the child's preferred coping style.

Summary of the Hypotheses

1. There will be no relationship between parents' overall rating of their children's posthospital behavioural disturbance and the number of discrete behaviours (PHBQ questionnaire items) about which parents have a lot of concern.
2. There will be a significant and negative correlation between the amount of time the child was accompanied during the hospital stay and change in the child's behaviour following hospitalization.
3. Mothers with families where at least one of the children is reported by the mother as having had a previous hospitalization for what was rated by the mother at the time as serious, will be more anxious at the preassessment clinic than mothers without such experience.
4. There will be a significant positive correlation between parent's level of prehospitalisation anxiety and the size of the discrepancy between nurse rated and parent rated child behavioural disturbance during the child's admission.
5. There will be a significant and negative correlation between the age of the child and change (i.e. an increase) in the perception of the child's parents about the child's vulnerability following hospitalization for a minor surgical procedure.

6. Children who are perceived as vulnerable by their parents prior to the hospitalization will cope less well with the hospital experience as measured by their parent/s' and nurse's perception of the child's behavioural adjustment during the admission.

7. Where there is a match between a child's coping style and the parent's preferred method of preparing the child for medical experiences, the child will show significantly less behavioural upset (as rated by the parent and the nurse) during the hospitalization than in the case of child parent mismatches.

Context

The Local Hospital and Community Child Health Services

At the time of this project the hospital trust served the needs of a local population of approximately 196,000 people of whom 6.4% were children aged below 4 years and 16% children and young people aged below 16 years. The local area 'covered' by the hospital was largely a rural one with three large towns and there was a high proportion of local authority housing. High scoring communities (Jarman UPA scores > 8) were common. A community trust served this local area and the neighbouring acute trust area. The hospital also provided an ENT service to a different neighbouring and very rural county. Satellite ENT out-patient clinics were held in the main town of this county with patients traveling the sixty miles to the hospital for preadmission appointments and in-patient and day case surgery.

The hospital's ENT out-patient department and ward were quite 'run down'. Adults and children were nursed on the same ward although in separate six bedded sub-units. None of the ENT ward nurses was paediatrically trained. Towards the end of the project the ENT out-patient department moved to new premises on the same hospital site and all children are now nursed on the new paediatric ward following ENT surgery.

The ENT Department staff carried out a range of physical checks on children at the preassessment clinic prior to their admission. Beyond this there was no agreed

and explicit protocol for preparing children and their families for admission and surgery. The clinical teams were very loosely defined. A career senior registrar worked 'across' the three ENT consultants. Nursing staff rotated through the ward, preassessment clinic and theatre according to needs and staffing levels.

Constraints under which the Project was Designed and Executed

There were four significant constraints. Firstly, it was decided on balance that it would be more practical and potentially useful to carry out the work in the ENT Department. It would have been much easier to have been able to link with the Paediatric Ward where the researcher was familiar with staff and ward procedures. However paediatric ward surgery involved both a wide diversity of surgical procedures and many individual consultants. While this decision helps increase the extent to which the findings can be generalised, in that the focus was on the most common paediatric surgical procedures, counterbalancing this is the study's non-paediatric ward context.

The second major constraints had to do with time. It took longer than anticipated to obtain a 'slot' to present the proposal to the Ethics Committee. Indeed on the day that the proposal was approved the researcher successfully interviewed for a new post in a different country. The start date for this new post had to be progressively delayed until the full data set was obtained. The rate of data collection was also limited to the rate of ENT 'ward throughput' which itself was compromised by the

‘flu epidemic of Christmas 1996. Paradoxically at the same time, the researcher contracted an ear infection which resulted in significant hearing loss and was thus unable to interview families even had it not been professionally inappropriate in those circumstances to do so. The main consequence of the time pressure was that the sample size fell somewhat short of the intended 60 families.

Thirdly while the three ENT Consultants had agreed as individuals to the research project they did not seem to coalesce professionally very successfully and did not provide support as a group. In addition to this they tended to practice in somewhat different ways. The diversity in their practice had a ripple effect which made it difficult to understand and keep track of how children experienced and proceeded through the hospital system particularly as none of the consultants held out-patient clinics specifically for children. Much energy and time was expended maintaining relationships with, and the flow of information from, secretarial and administrative staff to ensure the maximum possible subject recruitment.

Finally, the project was originally intended for the paediatric ward and staff there had been involved in discussing its value in the context of service quality improvement. ENT ward staff, secretaries and hospital office staff were not so involved and did not have anything like the same sense of ownership and personal commitment to the project as the researcher. While this certainly made it more challenging to keep the project ‘on track’ the most important audience for the

findings, from the service quality viewpoint is arguably the original paediatric ward and staff. Since the senior Consultant Paediatrician is responsible for service quality throughout the hospital the findings of the project are likely to receive attention.

Method

Measures

The questionnaires used are contained in Appendix A.

State-Trait Anxiety Inventory - Spielberger et al. (1977)

This is a valid and highly reliable measure for use with adults (Spielberger & Sydeman, 1994). There are two 20 item parts to the questionnaire. The first part measures current feelings of anxiety (A-State) and the second part an individual's anxiety proneness (A-Trait).

Posthospital Behavior Questionnaire - PHBQ (Vernon et al., 1966)

This is the most commonly used questionnaire for assessing posthospital behaviour in children aged from 1 month to 16 years of age (Thompson & Vernon, 1993). The PHBQ has 27 items. In the original version, parents were requested to make a single rating of their child's posthospital behaviour relative to the child's behaviour prior to hospitalisation, using a five point rating. In the modified or 'absolute' format parents are asked to rate the child's behaviour on two separate occasions i.e. before and after the child's hospitalization. The modified or 'absolute' format appears to be a more sensitive measure of change than the comparative format (Thompson & Vernon, 1993).

Vernon et al. (1966) identified 6 factors (a) General Anxiety and Regression, (b) Separation Anxiety, (c) Anxiety about Sleep, (d) Eating Disturbance, (e) Aggression towards Authority, and (f) Apathy-Withdrawal, but typically only the total score is used as a measure of the child's psychological distress. Vernon et al. (1966) found significant age effects for two of the six factors; Separation Anxiety and Aggression. However the age differences were due primarily to the higher scores exhibited by the preschool children (6 months to 3 years 11 months).

The internal consistency of the PHBQ has been found to be satisfactory ($\alpha = .76$) and scores reasonably stable over a one month period, $r = .65$, $p < .001$ (Vernon et al., 1966).

The validity of the PHBQ has not been firmly established since only a single, modest validity study has been conducted (Vernon, Schulman & Foley, 1966, p.): it reported $r(20) = .47$, $p < .02$, between PHBQ scores and ratings of change in behaviour following hospitalisation, made following a brief interview of parents, by a child psychiatrist.

Behavior Upset in Medical Patients - Revised - BUMP-R (Saylor et al., 1987)

This is a revision of the 32 item nurse rating scale, developed by Zeldow & Braun (as cited in Rodriguez & Boggs, 1994) to measure behaviours that nonpsychiatric adult patients might show in medical settings (e.g. is impatient, is irritable, is

uncooperative, has to be reminded what to do). Zeldow & Braun arranged for the 32 item BUMP checklist to be reviewed by a panel of five psychologists and psychiatrists. Items considered inappropriate for a paediatric setting were eliminated. The resulting form - the BUMP-R, consists of 28 item with a 5 point rating scale ranging from 0 (never) to 4 (always). As previously used, respondents have been asked to rate the child's behaviour during, and since, the current admission and to retrospectively rate the child's behaviour for the period prior to the admission (e.g., Rodriguez & Boggs, 1994).

Four factors have been identified (a) Negativity/Agitation, (b) Amiability, (c) Dysphoria, and (d) Non-Compliance. The internal consistencies were .86, .79, .68 and .68, respectively. Cronbach's coefficient alpha for the BUMP-R was .87 (Rodriguez & Boggs, 1994). There is no published data on test- retest reliability and inter-rater reliability. There is a weak relationship between BUMP - R scores and age, $r = -.17$, $p < .05$.

The Child Vulnerability Scale (Forsyth, 1987)

This scale, originally with 12 items, was developed by Green & Solnit (as cited in Thomasgard & Metz, 1995) to measure general parental concerns about their child's health as well as the extent to which parents perceive their child as vulnerable to illness and injury. Forsyth (cited in Thomasgard & Metz, 1995) suggests that the

measure is sensitive to changes in parents' perception of their child's vulnerability post hospitalisation.

Based on work with a sample of 1,095 4 - 8 year olds, the original scale has subsequently been modified and now has only 8 items. Each item is scored on a four point scale ranging from 0 (definitely false) to 3 (definitely true). The test retest reliability coefficient was .84 ($p < .001$) over a 3-5 week period (Forsyth et al., 1996) with a Cronbach's alpha = .76 (Thomasgard & Metz, 1997). The two year stability for high parental perceptions of child vulnerability was 31% (Thomasgard & Metz, 1996).

Higher CVS scores have been associated with the following variables: - maternal depression (Field, Estroff, Yando, & del Valle, 1996), single mothers of lower socioeconomic status, increased use of primary care services and first child status (Thomasgard & Metz, 1995).

Demographic Questionnaire

This questionnaire sought information from the child's mother about the number, and perceived significance to the mother, of previous hospital experiences of the target child and the child's siblings; the ages and marital status of the target child's mother and father; information from the mother about how she usually prepared the

child for visits to doctors, dentists and nurses and about how information seeking the child was about impending medical procedures.

Procedures

Table 1 describes the study's main steps, related activity, the number of participants involved and the time scales.

Table 1

The Time Sequence of Hospital/Medical and Research Task Activity

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main	step	
				1. Ethics Committee approval obtained for the study on 23/10/1996
2. Family attended GP, child referred for ENT consultation	55			

(table continues)

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main step		
3. ENT consultation occurred	55	Mean = 70 s.d. =51		
(i) surgery recommended and agreed with family	54			
(ii) child discharged - surgery unnecessary	1			
(iii) for ENT review (participant numbers 6,23,28,29,39 - all of whom subsequently underwent surgery and whose data is included)	5			5. ENT surgery and PAC lists checked weekly and possible research participants identified

(table continues)

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main step		
<hr/>				
4. Clerical Officer provisionally scheduled child’s PAC appointment and date for surgery	54	< 7		
6. Clerical Officer sent PAC appointment to family	54			
				7. Standard approach made to families about inclusion in the study
		4 - 6		
(table continues)				

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main	step	
	51			families 'opted in'
				8a family completed pre- hospital study measures
8. Family attended PAC	51	6 - 8		8b pilot testing of questionnaires and study procedures

(table continues)

Hospital/Medical	Number of	Time (in days)	Research
Activity	participants	since last main step	Task/Activity
(i) surgery temporarily deferred by the hospital (participants Nos. 17, 18, 19, 26, 27), all subsequently had surgery and data included	5		
(ii) child 'not presently fit for surgery' (participants Nos. 5 and 35), all subsequently had surgery and data included	2		
(iii) date for surgery scheduled	51		

(table continues)

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main step		
(iiia) but child subsequently transferred to another hospital (No. 24)	1			
(iiib) but surgery “too late” for participant inclusion (no. 44 and 49)	2			
(iiic) but child ‘not presently fit for surgery’ (Nos. 10,16,20, 24 and 44), Nos. 10, 16 and 20, had surgery later, data included	5			

(table continues)

Hospital/Medical Activity	Number of participants	Time (in days)	
		since last main step	Research Task/Activity
(d) but surgery temporarily deferred by the hospital (Nos. 20,21,24,28,36,38,45,49), all except 24 and 49 got a new date and had their surgery	8		
9. child admitted and surgery completed	48	3 - 10 days since PAC attendance	9a pilot testing of questionnaires and procedures 9b in-hospital measures completed (table continues)

Hospital/Medical Activity	Number of participants	Time (in days)	
		since last main step	Research Task/Activity
	25		9c postal follow-up arrangements agreed with families
	21/23		9d selected families agreed to participate in qualitative component
	26		10a Follow-up questionnaires successfully ‘administered by post’
			(table continues)

Hospital/Medical Activity	Number of participants	Time (in days)		Research Task/Activity
		since last main step		
				10b Follow-up qualitative interview
		Mean = 15.4 s.d. = 3.1		undertaken and questionnaires
	20/21	(since surgery)		completed

Ethics Committee Approval (Step 1)

The hospital ethics committee required that a standard, but individualized letter be sent to the Senior Partner and to the Practice Manager in each relevant GP surgery (i.e. within the hospital catchment area) before the study began (see Appendix B). This letter described the study, specified the start date and asked practices to indicate if they would prefer their patients not to be involved in the study. Three practices responded to the letter. All indicated support for the study with one practice asking for more details.

The Referral of the Child to ENT and the Initial ENT Consultation (Steps 2 and 3)

Appendix C details the symptoms described in the GP's referral letter for 53/55 children referred to the ENT Department during the study period (October 1996 to March 1997). Children were seen for initial assessment at community clinics or in the hospital's ENT Department. On average while children waited for 10 weeks from the date of referral to the date they were first seen by the ENT department, there was considerable variation ($SD = 50.7$ days). However only one child waited longer than 6 months for this first appointment. Two of the three ENT Consultants were relatively new to the hospital. They routinely gave families a date for their child's operation at the same time as the diagnosis. The third Consultant, who had the longest tenure and the longest waiting lists, relied on the clerical officers in the hospital admissions department to allocate dates for surgery.

There was no agreed ENT Departmental protocol for assessing and 'processing' children referred for ENT assessments and surgery. As described earlier membership of clinical teams was loosely defined.

The Work of the Hospital's Admissions Department : I (Step 4)

Irrespective of whether the consultant gave the family an operation date, the names of the children requiring operations were passed to one of three clerical officers in the hospital's admissions department. On receiving these names the clerical officers scheduled a date for the child's operation and a provisional

appointment date for the child to attend the preassessment clinic in the ENT department. These preassessment clinic appointments were intended to identify children who would not be 'medically fit' for the operation for example, because of upper respiratory tract infections (URTIs), to get signed parental consent to the procedure and to answer any queries parents might have about their child's hospital stay. Staff in the ENT department believed that these clinics had greatly reduced the number of operations being cancelled at short notice and allowed maximum use of theatre time.

Identification of Possible Participants for the Study (Step 5)

Experience showed that it was essential, particularly during the 'flu epidemic in late 1996/early 1997 when many operations were cancelled and others rescheduled at short notice, for the researcher to keep in regular contact (at least thrice weekly) with each of the three clerical officers in the hospital's admissions department and also with the secretaries of the two consultants who themselves gave patients their operation dates. This effort ensured minimal subject and data loss.

The Work of the Hospital's Admissions Department : II (Step 6)

The preassessment clinic appointment dates and times were sent to families 10 - 14 days before they were due to attend. Preassessment clinic appointments were generally scheduled for between 3 and 10 days before the child's operation date. For

patients of two of the three Consultants these letters also confirmed what the parents already knew i.e. the date for their child's operation.

Standard Approach made to Families about Inclusion in the Study (Step 7)

In order to recruit subjects for the study the parents of each of the 55 children due to attend the preassessment clinic during the study period (31/10/1996 - 31/3/1997) were sent, 6-8 days before the child's appointment, an individualised letter signed by the relevant ENT Consultant (Appendix D), an information leaflet describing the study (Appendix E) and a consent form (Appendix F). Parents who were willing to participate in the study were asked to return the signed consent form either (a) in an enclosed stamped addressed envelope or (b) to the receptionist at the preassessment clinic when they attended.

Fifty-one of the 53 families (94%) agreed to participate in the study . However for two children (C44 - 11 year old female and C49 - 9.6 year old female) the operation was rescheduled for a date beyond that established as the study completion date and no data from these children is included in the analysis.

Table 2 describes the 49 participants. They were aged between 3.4 years and 11.4 years ($\underline{M} = 6.44$, $\underline{SD} = 2.20$) and ten of them had had previous hospital admissions. The surgery for 80% of the participants involved at least a tonsillectomy and none of the children in the sample had the simplest and least traumatic form of surgery i.e.

the insertion of grommets, on its own. The score of each participant on all of the study variables is contained in Appendix G.

Table 2

Characteristics of Study Participants (N = 49)

Age Range	N	Gender	N
>3<6 years	23	Males	22
>6<9 years	16	Females	27
>9<12 years	10		

Surgical Procedure					
Tonsils &					
	Tonsils &	Adenoids &	Tonsils &	Adenoids &	
	Tonsils	Adenoids	Grommets	Grommets	Grommets
Number of					
Children	17	12	8*	2	10

* for N=1 the surgery was subsequently carried out at another hospital

table continues

Previous hospital contact for 'study child' - mother's perception		Previous hospital contact for siblings - mother's perception	
	Number		Number
not serious	11	not serious	4
quite serious	6	quite serious	13
very serious	8	very serious	7
not applicable	24	not applicable	25

Mother's marital relationship	Number
Lives with partner	40
Separated/divorced	9

The Preassessment Clinic Attendance (Step 8)

Hospital/medical activity

During the period of the study 18 (37%) of the scheduled operations were cancelled. Six of these 18 were cancelled because the child was temporarily medically unfit for the procedure. The remaining twelve were rescheduled by the hospital itself. Most of the 12 cancellations by the hospital occurred during January 1997. During that month there was nationally a particularly virulent influenza epidemic, a second respiratory virus and a bout of exceptionally cold weather

(Burrell, 1997). These factors in combination greatly increased bed occupancy throughout the hospital, including on the ENT ward, and considerably reduced the number of nursing staff available for work. Only a minority (39%) of the children whose operation were cancelled had to attend for a further preassessment clinic appointment.

Research task/activity

The questionnaires and the study procedures were piloted on the first three families. Their comments lead to relatively minor changes to the wording of all questionnaires with the exception of the PHBQ which required no modifications. Changes to wording were agreed with parents and the opinion of subsequent parents sought about their meaningfulness.

The pilot study established that the questionnaires would take a good deal less time to complete than originally anticipated and the Information Sheet for Parents was altered accordingly.

When participating families attended the preassessment clinic they were met by the researcher. While the child waited to be seen by the clinic staff, one of the child's parent, generally the mother, completed the following measures: (i) PHBQ, (ii) the CVS, (iii) the STAI and (iv) the demographic questionnaire. In the current study parents were asked to use the PHBQ to rate their child's behaviour "over the past 2 to

3 days” and to rate the extent to which they thought the child's behaviour over the past 2 - 3 days varied from the child's norm i.e. was the child's behaviour better than usual, the same as usual or worse than usual.

In the case of two children (C31 - an 8.4 year old female and C38 - a 9.7 year old female) the forms were completed by the child's father since the mother did not accompany the child to the preassessment clinic.

Families were assured that their responses were confidential and would be known only to the researcher and that names would be deleted from all questionnaires and confidential codes inserted in their place. In the case of a small number of families the questionnaires had not been completed by the end of the child's preassessment clinic appointment. The parent in these families was asked to complete the measures at home (that same day) and return the questionnaires in a supplied stamped addressed envelope. All did so.

The Hospital Admission and Surgery (Step 9)

Hospital/medical activity

Most of the children were admitted to the ENT ward at about 8 a.m. on the morning of their surgery. A minority (N=4) were admitted later in the morning i.e. at 10 -11 a.m. and had their operations in the late afternoon. These few later admission were part of a drive to reduce the waiting list which had developed as a

result of the influenza epidemic. In 2/4 cases the child had to be returned to the theatre to control postoperative bleeding.

Research task/activity

During the pilot study period feedback from parents and from the nursing staff about the questionnaires was noted. Nurse feedback related mainly to their feelings about the inappropriateness of two items on the BUMP-R-N. These items were says s/he feels blue/depressed and sleeps unless directed into activity. The nursing staff felt that the first item was inappropriate for young children and that the second was not always appropriate as there were occasions when the child was still recovering from the anaesthetic when the BUMP-R was administered.

It also became clear during the pilot study that it would be administratively more difficult to obtain completed BUMP-R data than had been expected. In particular it proved necessary to have parents and nurses complete much of the questionnaire relatively early in the child's admission since the working shift for the relevant named nurse frequently ended at 4 p.m. Given the absence of any research data on interrater reliability it was considered important to ensure that the parents' ratings and the nurses' ratings covered the same time period in the children's admission. A further consequence was the need, at least initially, to involve the relevant night nurse in rating the child's sleep and the need to make an additional visit to the ward (the morning after the surgery) to obtain the parent's rating of the child's sleep.

For all study subjects, within 7 - 8 hours of admission and after the surgery, the child's mother was asked to complete all items on the BUMP-R-P questionnaire except those which asked the parent to describe the child's sleeping on the postoperative night and about the amount of time the child was accompanied during the admission. At the same time the child's named nurse was asked to complete a BUMP-R-N questionnaire for the child, with the exception of the item on sleeping) and to report the time the child first took fluids after the operation and the ease of fluid intake. At the same time as collecting this data, but in the case of the first twenty participants only, the researcher left a letter for the night nurse asking her to rate the child's sleeping that night.

For the first twenty participants the researcher also visited the ENT ward the morning after each child's surgery. At that point the child's parent completed the outstanding items on the BUMP-R-P and the night nurse's report of the child's sleeping was collected.

At the two week follow up the first twenty parents were asked again about their child's sleeping on the postoperative night and the extent to which their child was accompanied by a parent during the admission. There were no differences between the parents' report on the two occasions. Similarly, two weeks after discharge, a review of the medical notes for each of the first twenty participants showed that the night nurses recorded details of the children's sleep on the postoperative night in the

same way as they reported it separately to the researcher. Since the second ward visit i.e. the morning after the child's surgery had to be made before 8 a.m. and since eliciting night nurse reports on sleeping was more labour intensive than consulting medical notes, both were dropped from the study protocol.

Arrangements were made with the parents before each child's discharge for the collection of the follow up questionnaires. In some instances, for example where families lived a considerable distance from the hospital or were not asked or did not want a researcher to visit their home, it was arranged that the mother would receive and return the follow up assessment questionnaires through the post. In two instances (C3 - 3.5 year old male and C12 - 4.7 year old female) it was necessary to provide one or more telephone prompts in order to obtain the postal follow-up questionnaires. In both instances the mother indicated that the delay was in posting, rather than completing, the questionnaires. The dates on the returned questionnaires supported their assertion.

The parents of 23 of the 49 children in the study were asked to contribute qualitative information, 21 agreed to do so and 20 follow-up interviews actually took place. An attempt was made to use systematic, non-probability sampling rather than random sampling. The first two months of the overall study was used to test, check and become familiar with the study procedures. During this period no qualitative interviews were undertaken. Thereafter an attempt was made to improve validity by

gathering qualitative data from small cohorts of two and sometimes three individual families who had been in hospital at the same time. There were eight of these small cohorts during the remainder of the study period and it was possible to gather data from 6 of them.

The follow up assessments were scheduled to take place between 2 - 3 weeks after each child's discharge (M =15.4 days, SD = 3.1 days). Eighty-nine percent took place within the 2-3 weeks post hospital period.

Results

Tables 3 and 4 give an indication, from the PHBQ results, of the sorts of child behaviours most frequently reported by parents as marked problems before and after hospitalisation and the five behaviours causing parents most concern. Table 4 contains the only two behaviours about which five or more percent of parents had a lot of concern after the hospitalisation. Similarly all of the behaviours causing five or more percent of parents concern before hospitalisation are contained in Table 4. The two tables taken together show that while parents were not necessarily concerned about all the reported high frequency behaviour problems, 4 of the 5 behaviours causing them concern were reported as high frequency.

Table 3

The Ten Behaviours Most Frequently Mentioned by Parents as Marked Problems*
Before and After Hospitalisation

Behaviour	Percent saying marked problem before hospitalisation	Percent saying marked problem after hospitalisation
1. Child was afraid of the dark.	25	24
2. Child made a fuss about eating.	10	7
3. Child was made a fuss about going to bed at night.	10	20

* i.e. occurring 'very often' or 'all the time'

table continues

Behaviour	Percent saying marked problem before hospitalisation	Percent saying marked problem after hospitalisation
4. Child had trouble getting to sleep at night.	8	11
5. Child had temper tantrums.	8	<5
6. Child seemed to be shy or afraid around strangers.	8	9
7. Child bit his/her finger nails.	8	7
8. Child needed a dummy.	6	<5
9. Child followed parent everywhere around the house.	6	<5
<u>table continues</u>		

	Percent saying marked problem before hospitalisation	Percent saying marked problem after hospitalisation
10. Child had a poor appetite.	6	13

Table 4

The Five Behaviours Most Frequently Mentioned by Parents as Causing Them a Lot of Concern Before and After Their Child's Hospitalisation

Behaviour	Percent concerned before hospitalisation	Percent concerned after hospitalisation
1. Child had bad dreams at night or woke up and cried	12	< 5
2. Child made a fuss about eating	10	<5
3. Child was afraid of the dark	8	11
4. Child had temper tantrums	8	11
5. Child had a poor appetite	6	<5

The hypotheses

The first hypothesis, that there would be no association between children's posthospital parent rated behavioural disturbance and the number of such behaviours causing parent a lot of concern was rejected $r_s(46) = .81, z = 5.43, p < .0001$, two tailed. Where parents expressed a lot of concern about at least one behaviour before their child's hospitalization their child's PHBQ prehospital score was also significantly higher, $r_s(49) = .83, z = 5.75, p < .0001$, two tailed. Thus there is no evidence that low overall PHBQ scores may be masking significant parental concern.

The second hypothesis, that there would be a relationship between the amount of time the child was accompanied during the hospital stay and changes in the child's behaviour pre to post hospitalization could not be tested. The vast majority of parents stayed with their child throughout the entire hospital stay. The inclusion of what proved to be an untestable hypothesis is explained in the discussion section.

The third hypothesis that mothers with families where at least one of the children is reported by the mother as having had a previous hospital contact for what was rated by the mother at that time as serious, would be more anxious at the preassessment clinic than mothers without such experience, was accepted, $z = 1.92, p < .05$, one-tailed.

The fourth hypothesis was that the more anxious the parents the more likely that they would rate their children's behaviour as relatively more disturbed by the hospitalisation compared to ratings made by the children's nurses. This hypothesis was rejected ($r_s(42) = .22$, $z = 1.41$, ns). The expected positive correlation between the STAI-S and the parent rated BUMP-R was very modest and fell just short of statistical significant, $r_s(46) = .24$, $z = 1.63$, one-tailed.

The fifth hypothesis, that there would be a significant negative correlation between the age of the child and change in the parent's perception of the child's vulnerability following hospitalization was accepted, $pr(45) = -.40$, $z = 2.65$, $p < .005$, one-tailed.

The sixth hypothesis, that parent's ratings of their child's vulnerability prior to hospitalization would be positively associated with the parent's and the nurse's rating of the child's behavioural distress during hospitalisation was accepted for parents $r_s(46) = .58$, $z = 3.89$, $p < .0001$, one tailed, and was also accepted for nurse ratings although here the relevant correlation was a good deal smaller and less statistically significant ($r_s(44) = .28$, $z = 1.83$, $p < .05$, one tailed).

Further to this hypothesis, the correlation between parent and nurse ratings of the child's behavioural distress during the admission was very modest and was statistically significant $r_s(43) = .3$, $z = 1.92$, $p < .05$, one-tailed. In addition the more

vulnerable the parents perceived their child before hospital the more they reported the child's post-hospital behaviour as disturbed

$r_s(46) = .48, z = 2.59, p < .005$, one-tailed. The prehospital PHBQ scores also correlated strongly with parent rated behavioural disturbance during the child's admission $r_s(46) = .50, z = 3.35, p < .0005$, one-tailed.

The seventh hypothesis that where there was a positive agreement between the child and parent preferred coping style the child would show significantly less behavioural upset (as rated by the parent and the nurse) during the hospitalization was rejected for both parent ratings $z = .69, \underline{ns}$ and for nurse ratings $z = .55, \underline{ns}$.

QUALITATIVE STUDY - WHAT PARENTS SAID ABOUT THE EXPERIENCE OF HAVING THEIR CHILD IN HOSPITAL

General Introduction

A significant proportion of this project was undertaken during the normal working hours of the author and in addition, required a good deal of co-operation from nursing, medical and administrative staff. Therefore it was essential to maximize the number of practical/applicable findings. The quantitative component, described earlier, explored some child and family characteristics associated with hospital impact. However impact is likely to be mediated, at least in part, by the quality of the service provided to children and their families e.g. by hospital and staff characteristics (Jimmieson & Griffin, 1998). Unfortunately, as Berger notes (cited in Jimmieson & Griffin, 1998) hospital satisfaction surveys typically provide very little guidance about areas where providers should focus their efforts to improve service quality and the service components typically assessed are not necessarily those of most importance to users. A qualitative approach seemed particularly apposite for addressing such concerns.

Qualitative Research as a Methodology

... qualitative research is multi-method in focus, involving an interpretative naturalistic approach to its subject matter qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.

Denzin & Lincoln (as cited in Phillips, 1998)

Stiles (1993) has listed the characteristics features of qualitative research which differentiate it from a quantitative approach. The first and most obvious feature is that results are expressed as words rather than numbers and significance levels and data reduction is in the form of summaries and illustrative excerpts from the text. In qualitative research the use of empathy is considered a legitimate strategy to better understand participants' thoughts, feelings and beliefs. There is an emphasis on the significance of experience for the participants and the meaning they attached to their experience. Events are understood and reported in their particular context and this context includes the qualitative researcher's own cultural background, belief system and personal history. Crucial, in the context of this research project, is the belief of qualitative researchers that very many dimensions are needed to adequately capture experience and "research that is limited to a small number of dimensions may not detect major effects of a psychological manipulation or intervention that any human observers would recognize" (Stiles, 1993, p.596). Qualitative research assumes nonlinear causality in that thoughts and actions and their reactions are believed to create a constant feedback loop which influences subsequent thoughts and actions. While thoughts and actions are caused they are difficult to accurately predict. Many qualitative researchers see participants empowerment as a legitimate goal of research. For example, Stiles (1993, p. 598) stated "Taking this perspective directs attention to (a) constructing interpretations that further participants' interests rather than maintaining vested interests, and (b) involving participants in the construction of the interpretations".

Reliability and validity in qualitative research concern trustworthiness, in the case of the former the trustworthiness refers to observations and data i.e. procedural trustworthiness and in the case of the latter to the trustworthiness of interpretations (Stiles, 1993). The steps taken to ensure procedural trustworthiness are discussed later in the Design and Data Collection sections. With respect to trustworthiness of interpretations, as Stiles (1993, p. 602) states, “words do not mean the same thing to everybody events look different from different perspectives.” Stiles goes on to recommend procedures to address these issues. These procedures include “disclosure and explication of the investigator’s personal orientation, context and internal processes during the investigation.” While it is acknowledged that a researcher may lack sufficient insight or ability to articulate his/her assumptions and preconceptions, a description of the researcher’s personal history, orientation and beliefs, such as that contained in the next section helps the reader put in perspective the interpretations and conclusions drawn from the data.

Disclosure of Personal History, Orientation, and Belief System

As a child, probably because of my asthma, my mother tended to overprotect me. Through experience I acquired a range of coping skills to deal with asthmatic attacks and later, when I was a Trainee Clinical Psychologist, had many of these same techniques recommended to me as clinically effective with children. My early experiences with the asthma had a profound effect on my personal health locus of control orientation.

I had an adenotonsillectomy when I was about 6 years old. My one and only hospital stay was a long one and my parents were only allowed visit for an hour per day. I remember being visited by a teacher who made a point of telling me that Harold was asking after my health. Harold was a boy from my class with whom I had had a row shortly before the hospitalisation. I took this to mean, and was rather happy to think, that Harold felt that he was in some way responsible for my hospitalisation. While I was in hospital I was reluctant to use the toilet and became very constipated. The nurses gave me a strong laxative and I was 'cleared out'. I can still remember how powerful a figure one of the senior nursing staff was and the little cut at the side of my mouth where the surgeon's knife must have slipped.

When I was a child I saw a lot of the general practitioner. I also saw and learned from my parents great respect for 'the doctor'.

My first job as a clinician was in a rural Irish psychiatric 'bin' with some sessions working with children in a community setting. After 6 years of this I choose to work in paediatric because I had had success in working with children and because I looked forward to learning about diseases and illnesses.

I worked in the Paediatric Department of the study hospital for 8 years. I was very proud of the work of the department and immensely enjoyed my relationship with

staff at all levels. I was quite involved in departmental audit and was funded to undertake an M.A. In Quality Assurance in Health and Social Care.

In my day to day clinical work I saw examples of poor service quality particularly on the paediatric ward but felt that given the complexity of the processes and the number of staff involved that it was inevitable that at times there would be shortfalls in standards. I heard the message repeatedly from my Consultant Paediatric colleagues that children should not be nursed on adult wards i.e. children should not be nursed on the hospital's ENT ward following their surgery. Given that many of the nurses on the Paediatric ward were not paediatrically trained either I did not really take too much note.

I believed that the overwhelming majority of hospital staff work hard and believe they are 'doing their best'. I believed that lack of clarity about management structures and poor communication were the underlying causes of energy and quality sapping conflict, rather than 'personalities' (e.g. Ovretveit, 1993).

Descriptions of Internal Processes of Investigation

“... investigators may be unaware of some aspects of their internal processes or may unintentionally overlook or distort them. Readers cannot assume that reports of internal processes are complete or unfailingly veridical, but must use them judiciously to construct their own interpretation”

Stiles (1993, p. 604)

When I ‘sat in on’ several PAC appointments I felt that although the nursing staff were very pleasant they were unwittingly pitching their explanations well above the cognitive ability of the children. During one of the PAC appointments a mother had questions which could only be answered by the consultant but he wouldn’t discuss the issues again with her. She had to choose whether or not to proceed and eventually decided not to do so. I felt it was a very bruising experience for her as did the nurses at the clinic.

I was shocked at my own emotional distress on seeing mothers in the immediate post operative period with tears in their eyes, often alone in a small ward and a very small bundle of a child close-by sleeping off the effects of the anesthetic. Many of the mothers were as shocked as I was at the emotional impact of the experience. While the effect of hospitalisation may be a short term one I had not been aware of how acute it could be ‘in the moment’ and of the underutilised opportunity to provide short term emotional support to families.

It seemed to take a very long time for the ENT nursing staff to reliably recognize who I was and why I was visiting their ward. I felt I needed to cajole several of the older staff nurses in order to ensure their cooperation, that I was dependent on them. When I advocated on behalf of a group of thirsty mothers and was told by the staff nurse that once one mother complains (“the ringleader”) they all start, I felt that I could not really stand up to her even if I had wanted to do so. However several of the nurses were exceptionally helpful, particularly the younger ones and I felt very grateful to them. Several shared their frustrations about ‘the system’ and in particular its inflexibility. One sought advice about the management of her own child.

I increasingly felt the need to ‘keep in with’ the administrative staff and that really I was a bit of a nuisance to them. Despite tracking nearly 50 patients I never really grasped exactly how the administration system worked. They always seemed in a hurry and I really had to scribble to write down details. While I still enjoyed my relationship with colleagues in the hospital and felt proud to work there I became aware in a different way of the lack of a clear, agreed and explicit strategy directing and coordinating the work of the different staff groups and departments. Prior to the study I understood this from my MBA(almost theoretical) perspective. Following the study I understood it more clearly from the user perspective. I felt that during the data collection phase of the study I had been almost the ‘mystery shopper’.

As time passed I became more aware that there was a good chance that I could gather the data in the time that was available provided I kept completely on top of the booking system and follow-up arrangements. I felt that I would do whatever I needed to do to gather the data. For example, I was quite prepared to make several domiciliary follow-up visits involving a round trip of 120 miles. I was willing to visit families at any time of the day or the night. If families were not at home for the agreed domiciliary follow-up visit I returned to my office, typed a letter and delivered the letter and the questionnaires with a stamped addressed envelope by hand within hours.

Finally, in writing up the project I have a sense of regret that I cannot play any significant role in promoting or implementing the findings from the study and at times I wonder whether the impact will be sufficiently 'deep' to change anything.

Design

General Introductory Comments

The parents of 23 of the 49 children in the study were asked to contribute qualitative information. An attempt was made to use systematic, non-probability sampling rather than random sampling. The first two months of the overall study was used to test, check and become familiar with the study procedures. During this period no qualitative interviews were undertaken. Thereafter an attempt was made to improve procedural trustworthiness by gathering qualitative data from small cohorts of two and sometimes three individual families who had been in hospital at the same time. There were eight of these small cohorts during the remainder of the study period and it was possible to gather data from 6 of them.

Method for Data Collection

A number of qualitative methodologies were considered (see VFM, 1995 for an excellent review) and the Critical Incident Technique (Flanagan, 1954) chosen. This technique, according to VFM (1995, p.14)

provides a useful tool for allowing respondents to talk in some depth about what is important to them without creating the volumes of data associated with in depth interviews. The basic premise is that people will automatically highlight those aspects of a service which are of most significance to them. .. the key points are recorded and provide useful insights into user priorities and

opportunities for service improvement ... the method is very responsive.

The use of this technique helped increase the validity of the report because it allowed the responses of a relatively large sample of participants to be represented i.e. triangulation, despite the absence of a strong child and nurse perspective.

Sample

Table 5 describes the characteristics of the participants in the qualitative part of the study. Participants did not differ from the broader study population in terms of their preassessment clinic parents' STAI-S, $z = .03$, ns, two-tailed; or VCS scores, $z = 1.07$, ns, two-tailed; nor in terms of gender ratios, Chi Square (1, $N = 49$) = .02, ns; parents' previous experience of hospitalization in a child of theirs which at the time was considered by the parent as serious, Chi Square (1, $N = 49$) = .02, ns; nor in parents' response to the global question "how has your child's behaviour been since discharge?", Chi Square (1, $N = 49$) = 0.45, ns. However the children in the qualitative study tended to be older, $\underline{M} = 6.9$, $\underline{SD} = 2.23$ than those in the other group $\underline{M} = 5.85$, $\underline{SD} = 2.03$, $z(49) = 2.29$, $p < .05$, two tailed.

Table 5

Characteristics of Qualitative Component Participants (n = 21)

Age Range	N	Gender	N
>3<6 years	9	Males	9
>6<9 years	7	Females	12
>9<12 years	5		

Surgical Procedure

Number of children	Tonsils &				
		Tonsils &	Adenoids &	Tonsils &	Adenoids &
	Tonsils	Adenoids	Grommets	Grommets	Grommets
	11	4	1	0	5

table continues

Previous hospital contact for 'study child' - mother's perception		Previous hospital contact for siblings - mother's perception	
	Number		Number
not serious	4	not serious	2
quite serious	3	quite serious	4
very serious	7	very serious	3
not applicable	7	not applicable	12

Data Collection

Prior to discharge the selected children's parents were asked to participate in the qualitative component of the study and arrangements made for the follow-up domiciliary visit.

Parents who agreed to participate in the qualitative component of the study were sent a postal reminder of the visit about 6 - 7 days before it was due with a telephone number should they wish to reschedule. Only one of the domiciliary visits was rescheduled by a mother.

One mother was not at home when the scheduled domiciliary visit was made. In this case the researcher returned to the house later the same day and left the final two questionnaires together with a covering letter and a stamped addressed envelope. The completed questionnaires were returned several days later. Twenty of these domiciliary visits were achieved. Feedback from a further family was via the telephone with questionnaires being returned through the post. One family was not in at the prearranged time for the visit and one family agreed to complete follow-up questionnaires but did not want a domiciliary visit.

At the beginning of the domiciliary visits the families were reminded that the researcher was a staff member of the Paediatric Department but was working with colleagues in the ENT Department to explore the impact of hospitalisation and surgery on children and their families. The mothers (usually without any paternal input) then completed the questionnaires. Following this, families were encouraged to comment on their experience of hospitalization and surgery. However prior to any questioning families were reassured that anything they said was confidential and that while group feedback would be provided to the ENT Department, individual's comments would not, and could not, be linked by the ENT staff to any specific family. The families were prompted to comment on their experience with the question "is there anything we should learn from your experience, what could we do better?". As Ericsson & Simon state (cited in Stiles, 1993) an emphasis on 'what' rather than 'why' increases the trustworthiness of the data. It was also hoped that

this more positive focus i.e. on how the hospital could improve the experience of families rather than on what was wrong with what the families had experienced, would help to overcome the traditional reluctance of grateful patients to provide constructive criticism. Further questions were asked where clarification was necessary. At the end of the interviews the researcher checked with participants that their views and remarks had been accurately recorded. This 'recycling' process gives participants the opportunity to correct or elaborate upon the meaning of observations. On numerous occasions families inquired about others who had been in the hospital during their own child's admission.

Unfortunately the perceptions of the children themselves were rarely directly elicited. It would have been particularly interesting to find out from the children themselves how well they felt they had been prepared for the hospital experience and what their parents and others had lead them to expect. The absence in the feedback of a strong child's perspective represents a significant and regrettable gap in the study and a missed opportunity to more extensively test the validity of the data through the process of triangulation. In large measure it reflected pragmatic considerations. The brief nature of the follow up had been emphasized in the Information Leaflet for Parents and again when the mothers were interviewed during their child's admission, in order to maximize continued participation and the collection of feedback from a relatively large proportion of the sample. In addition to this most of the follow up interviews took place during term time and by then all of the school age children had

recuperated sufficiently from their surgery to return to school. When the follow up interviews were scheduled for 'after school' hours, several families were understandably more interested in their children getting on with homework and mealtimes than in engaging with the researcher. The school age children may have been more forthcoming with a different interview technique and in the absence of their parents.

There was little opportunity to obtain a nursing staff perspective. However some comments made by them during normal social interactions with the researcher are relevant to understanding how children are prepared for ENT surgery, and these comments are included here. The nursing staff maintained that while it was not a common occurrence, some children attended the preassessment clinic having had no information at all from their parents about the impending hospitalization and surgery. The nurses had found themselves during preassessment clinics appointment with children and their parents expected, by parents, to break the news about surgery to the child. The research suggests that parents of children hospitalized with serious medical conditions tend not to provide their children with all the information about the child's condition that they, the parents, have. It has been suggested, in the context of childhood cancer, that this may be intended to protect the child from distress but the evidence suggests that telling less does not protect more (Clafin & Barbarin, 1991). It is not known whether these findings would apply in the case of

minor elective paediatric surgery and these would be useful research topics to explore.

Data Analysis

The twenty one interviewed families generated 76 individual statements or ideas in response to the question "is there anything we should learn from your experience, what could we do better?". The number of statements per family varied from 0 - 10 ($M = 3.6$, $SD = 2.2$). All the interview transcripts are included in Appendix H (bound separately). The responses (including many direct quotations) of the families were transcribed in short hand during the interview and typed immediately afterwards.

Flanagan (1954, p.335) emphasised that the Critical Incident Technique "does not consist of a single rigid set of rules governing data collection. Rather it should be thought of as a flexible set of principles which must be modified and adapted to meet the specific situation at hand". The approach to data analysis here was similar to that used by Schneider (as cited in Stiles, 1993). The 'recycling' process described in the Data Collection section was intended to ensure that the experiences reported by the participants were reliably captured. In addition to this the handwritten contemporary notes from the interviews were reviewed usually within 5-10 minutes of the interview to ensure that all the details and nuances had been recorded. Generally within two hours of the interviews the notes were typed by the researcher.

When all the interviews were completed the researcher read and reread the transcripts until very familiar with the text. This process involved several intense periods of concentration each lasting approximately 90 minutes.

Individual units of information which touched on participants' hospital and related experiences were then highlighted with coloured markers on the scripts. These 76 units were then written onto individual postcards - one unit of information per card.

Through reading and rereading the transcripts six tentative themes began to emerge. These were used as tentative criteria to sort the cards. This process of sorting the cards was repeated on a number of occasions and the labels given to the tentative themes modified until they encompassed as completely as possible the content of the cards sorted into each set and the number of cards not included in any set was minimal. Sufficient time was left between the different sorting episodes in order to create a sceptical or critical distance from the previous results.

When the six themes were finalised the researcher randomly selected 20 of the postcard statements. An A Grade Clinical Psychologist independently sorted these cards using the six themes. There was a 90% level of agreement between the this independent sort and that made by the researcher using the same twenty cards.

There are various checks on the validity of qualitative reports (see Stiles, 1993). One is the extent to which the "interpretation produces change or growth in the perspective of the reader." A condensed version of the report which follows has been accepted by the lead ENT Consultant as a useful set of practical steps the

hospital can take to improve the quality of the service provided and he wrote “I will do my best to implement them” (personal communication). Other comments on the validity of the report are scattered throughout the text.

Themes Elicited

In what follows 'M' refers to mother and 'C' to child with the appropriate subject number attached to each, 'm' or 'f' described the sex of the child and the attached number is the child's age in years and decimal years e.g. 'C34-7m' refers to participant number 34 who was a 7 year old male.

The first, very broad theme to emerge was what some, but by no means the majority of families felt was the inadequacy of information supplied to them by the hospital before, during and after the admission.

Inadequacy of Information Provided Before Admission

Information About Facilities

One mother (M12) came to the hospital apparently unprepared for what she perceived to be an unexpected absence of hospital supplied food and drink. Interviewed the morning after her child's operation, she said that she had brought no money with her and had nothing but water to drink and nothing at all to eat in the past 24 hours. However several others (e.g., M16, M35) when questioned directly about this issue (after their own follow-up interviews) indicated that they were well aware in advance about arrangements for eating and that the ward staff had been very attentive in this respect. Two possibilities explanations suggest themselves. The most obvious is that the hospital may have neglected to supply the information to M12. However it may be relevant that M12 had many, many concerns about her

child's behaviour, had a very high STAI scores herself, and perceived her child as more vulnerable than any of the other mothers in the study. These factors may have impeded her from processing the information which should have been routinely provided by the hospital during the child's preassessment clinic appointment. On balance the second possibility seems the more likely.

Several parents (e.g., M34) seem to have been under the impression that they would definitely have the use of a bed for the night of their child's admission and were disappointed when either the ward's demand for beds meant that they could not have one or they were not offered the opportunity to use vacant beds. M52 was aware that she might not have a bed but seemed unprepared for the absence of blankets so that she, sleeping in a chair beside her child's hospital bed, could keep warm.

Information About Likely Date for Surgery

The mother and father in one family (C34 - 7m) remarked that they had found it particularly helpful to receive a date for surgery from the Consultant during the appointment at which the decision to operate was made. This made it much easier for them to prepare their child, and to plan for and anticipate the admission. The family was able to compare this experience with that of the child's father who had himself and in the recent past, been listed, but not specifically scheduled, for an operation, and called at short notice for the procedure. Another mother (M35) said

that she had received relatively short notice of her child's operation date and that she would have appreciated knowing the admission date earlier.

The Inadequacy of Information Supplied During The Child's Admission

The shortfall in information during the admission often focused on the topic of postoperative nausea and vomiting. Two parents (M19, mother of an 11.1 year old female and M41 mother of 9.3 year old female) felt that they should have been more effectively prepared for their child's postoperative nausea and vomiting. While M19 acknowledged that it would probably have been difficult for the nursing staff to have given this type of preparatory information at the pre-assessment clinic, "because the child was there", there should have been some written information that would have better prepared her for such an occurrence.

The parents of C42 (6.2f i.e. a 6.2 year old female) felt that they had not been kept fully informed about the significance and management of their daughter's postoperative bleeding. One of the consequences of this lack of information was that the child's father in particular had felt very stressed indeed and had threatened his wife that he would pick the child up and take her home. When it was decided to return the child to theatre her parents did not know whether the staff were being very efficient or whether their speed reflected medical urgency or emergency. When the child's parents had sought information by asking the Anaesthetist how long the child "would be down" which for them an indication of medical severity, they received

what the mother described as a short and abrupt reply "it could be 5 minutes it could be 50". This comment together with the lack of information reinforced their feelings of anxiety and powerlessness. Although there is considerable individual variation, the research suggests that parents of hospitalized children generally want to be consulted and to have more information about clinical matters than they receive from hospital staff (Bradford, 1991). In the context of the experience of the parents of C42 it is particularly relevant that parents want comprehensive perioperative information and that highly detailed anaesthetic risk information does not increase parents' anxiety level (Kain, Wang, Caramico, Hofstadter & Mayes, 1997). Unfortunately the staff perspective on their management of C42's return to theatre was not elicited. The medical notes indicated that the child was a "little restless" on return from theatre the first time and was returned to theatre at 2200 for the control of postoperative bleeding. The nurse entry indicated that "observations were satisfactory" on return to the ward and that the child "slept well".

Information for The Immediate Post Hospital Period

The mother of C27 (6.4 f) felt that she should have been given more information prior to discharge. When she took the child home this mother was still not at all clear about what restrictions were to be placed on her daughter as a result of the insertion of grommets. She wondered for example whether the grommets would come out themselves and if they did how she would recognise them. She had expected to receive a leaflet answering her questions.

The mothers of C19 (11.1f) and C16 (9.5f) said that their daughters had expected to have only a mildly sore throat after the operation. The reality was considerably worse and by the time of the two week follow up visit both children were still getting upset about, and did not want to talk about, hospital and doctors. There was little evidence from the questionnaire data of any other changes in their behaviour post hospitalisation.

The parents of several children (e.g., M51 and M53) were very impressed at how well the ward responded to and dealt with a telephone query about their child after the discharge. M51 found that the nursing and medical staff "were easy to speak to, you could ask them things" and they gave very specific information and management advice. M27 was less satisfied with the response to her query and eventually called the family general practitioner. In context this seems to have been an appropriate use of different medical resources but actually left the mother feeling that "she was falling between two stools".

The general need that patients have for better information before, during and after hospitalizations has been a consistent finding in other studies (see Ogilvie, 1990, for a review).

Where Families Got The Information They Needed

A second and related theme which emerged from the qualitative analysis was that parents and children had used a variety of sources of information to predict what would happen to them and what was happening to them, before and during the hospitalisation. Several parents were able to rely on their own experience. M33 said that she had used her own nursing experience in preparing her child. M52 & M37 reported that this was their second child to have a tonsillectomy. M37 and her husband were able to recall the benefits tonsillectomy had brought for their daughter 12 months previously. The mother said "we remembered how it had helped (sibling's name) and that got us through". While M34 felt that her seven year old son had had a very good explanation about the procedures when he attended the preassessment clinic she also remarked that she and her husband had spent a good deal of time preparing the child for the experience drawing on recent and highly relevant family experience.

M33 felt that it would have been a good idea had the staff at the preassessment clinic been able to give out a leaflet about the medical and surgical procedures the child would undergo during the admission. M33 had herself discovered and read a story about glue ear while waiting for her child (4.4f) to be seen. She and the child found helpful the story which was made up of five line drawings with some text.

M23 felt that it would have been much better for her child (5.8f) to have actually seen the ward and the surgical equipment when they attended the preassessment clinic rather than have the nurse give a verbal explanation to the child about what would happen. There is research evidence to support her contention (Demarest, Hooke & Erickson, 1984). M23 also felt that her daughter had not understood what she was told at the clinic and when the child was in hospital she kept asking her mother "what would happen next". Unlike M23, M33 said that the doctor at the preassessment clinic had offered her child (4.4m) the chance to have a look at the ward when the child had first attended at ENT. This had been very helpful and the mother felt that it had made the concept "of staying overnight" more real for the child who had been excited at the prospect of identifying which would be "his bed".

A third mother, M50 felt that she had had enough information prior to her child's (4.1m) hospitalization. She said "they were very good at the (preassessment) clinic. I had a list of questions and the doctor answered them all". M50 described her child as "very, very laid back ... like his father" and said "I'm the one who does the worrying".

The needs and priorities of M23 and M50 may have differed although they had almost identical prehospital STAI scores and both perceived their child as vulnerable before and after hospitalisation. It may be relevant that M23 had worked in an ENT Department. During the follow up interview M23 spoke about her fear of a post operative bleed and the need to return her child to theatre. Perhaps the real difference between M23 and M50 was their differing perception of the likelihood of post

operative complications. It is also of course possible that their preparation by the hospital, and in the absence of an agreed protocol was in fact quite different.

Finally, two parents (C34 and C27) remarked on the effect of their own child's postoperative distress or post operative appearance (e.g., blood stained gown or blood smeared face and neck) on another child who was in the same ward waiting for theatre. In one case an observing child had apparently been very reluctant to go down to theatre.

Care is Shared Rather Than Negotiated & Shared

The third theme was that hospital care of children was shared though not necessarily as a result of a clear and explicit process of negotiation between hospital staff and the children's parents. The Children Act (1989) emphasises the importance of parent partnership in the care of children who have been hospitalized and much current health care assumes, indeed depends on parental participation. However it is not certain that parents always wish to play a role in the care of their hospitalized children (e.g., Ogilvie, 1990) and parents are more willing than hospital staff expect to devolve clinical decision making to professionals (Kinderman, Feather & McDowell, 1996). However as Sabbeth & Leventhal's study (as cited in Snowdon & Kane, 1995) shows, parents find it difficult to communicate their needs and often do so in a "veiled" manner.

Dearmun (1992) and Darbyshire (cited in Coyne, 1995) found that while parents expected to play an active role in the care of their hospitalized child the nature and extent of this participation was within the nurses' control. Dearmun and Darbyshire also found that the relevant expectations of nursing staff were not made explicit to parents. This lack of clarity about role, in combination with a lack of information in general and conflicting advice would be expected to create considerable anxiety for parents. Such anxiety could in turn be expected to hamper parents' ability to participate, and to indirectly and negatively impact on the child's adjustment to hospitalization. These research findings were reflected in the experience of some of the mothers in this study as can be seen in the next excerpts from the transcripts.

During the initial stages of her two week follow up interview M53 indicated that she felt that the nurses were not checking on her child (5.2m) as frequently as she had expected. She wondered was this because she (M53) was staying with the child all the time. M52 also remarked that she was "not sure if the mothers were supposed to be there" and what they were suppose to do (i.e. their role). M50, on the other hand, felt she had been able to negotiate her own role with the nurses on the day shift but she was exceptionally critical of the evening and night shift.

M28 (7.3m) had clear ideas herself about her role in caring for her hospitalized child. Her report echoes the theme 'mothers who felt they provided essential labour' described in Callery & Luker (1996). M28 said it was important for her to stay with

her child as someone had to act on behalf of the child. The mother said that she could provide a high level of emotional support, could keep the child occupied, could reinterpret and explain to her child anything that was said to him by staff and could facilitate staff in their administration of tests and treatment to the child. M28 felt that this was her proper role and emphasised that her comments were not a negative reflection on the nursing staff as individuals, she described them as "lovely", but rather that they were too busy to undertake all of these tasks. Research on children's perceptions of the hospital experience and of their own need for the supportive presence of their parents during the hospitalization (e.g., Reissland, 1983) and the evidence that medical and nursing staff are inclined to provide therapeutically insufficient pain relief medication postoperatively (Routh & Sanfilippo, 1991) is in tune with the role described for herself by M28. However a parent's specific behaviours and the quality of the parent-child relationship seem crucial rather than simply the presence or absence of the parent during a procedure (Bush, Melamed, Sheras & Greenbaum, 1986) and presumably by extension, during a hospital admission.

While many, but by no means all parents in this study indicated that nurses were available when needed several of the parents who left their children alone overnight sought out what amounted to a child minder from within the group of parents staying overnight in the same section of the ward. For example, the father of C31 (8.4f) stayed until his daughter fell asleep at about 2230 and made arrangements for her to

be "looked after" during the night by the mother of another child admitted at the same time for the same procedure. The mother of C41 (9.3 f) noted that there seemed to be fewer nurses on the ward than when her daughter was admitted to the same ward 5 years previously. M41 felt that the nurses spent a lot of their time "running around" and had less time to check on how the patients were. M41 said that it was "a shame and not what they (the nurses) came into the profession for. But that's the way everything is going ". While she clearly did not blame the nurses themselves (echoing the findings of Callery & Luker, 1996) she felt that her daughter was less well looked after during this hospital stay than during the previous one and that part of the child's care this time very much depended on her (M41) being present during the admission.

The Attitude and Responsiveness of Staff

A fourth theme concerned the attitude and responsiveness of staff some examples of which have been touched on earlier. Many of the mothers were very positive indeed in their evaluation of the standard of care received during their child's admission. Theatre staff were described as "fantastic ... so sleek ... excellent" by M33 (mother of a 4.4 m) and as "wonderful" by M52. One of the doctors (Dr. 'Named'.) came in for special praise from a number of mothers because "he smiled" and because of "his attitude to children" (M52), "he was wonderful, he was really nice" (M50). A third mother (M53) was extremely impressed at how Dr. 'Named'. had been able to win the confidence of her 5 year old son and explain the surgery in a

very clear and simple way. The mother of C28 (7.3 m) described nursing staff as "lovely". M42, whose child (6.2f) had to be returned to theatre because of postoperative bleeding, said the night nurse and doctor were "brilliant". The same mother was also very impressed that the consultant visited her son before and soon after the operation, "he came himself rather than sending someone else". M51, who was highly critical of the evening and night nursing staff (see below) was very positive in her evaluation of two of the younger nurses on duty the day of her child's operation. They were "lovely" and one in particular was "what I would call a nurse". M50 felt that the nurses during the day shift were very helpful "they didn't mind being pestered repeatedly for keys for the video". The impression gained from talking to mothers at the follow up visit was that they had expected first class care from the staff during their child's admission and usually felt that they received it. Their plaudits ring true given the context in which the mother's found themselves i.e. dependent, considerably relieved and understandably grateful. In addition any human activity carried out with skill can evoke a feeling of awe in observers.

The Teflon Nurses and Their Very Non-Teflon Counterparts

There were several exchanges where mother's negative comments about aspects of care were tempered by comments about how this was not the fault of the staff and particularly not the fault of the nurses. M53 for example, initially said of some of the nurses that "their bedside manner could be better". However on inquiry M53 volunteered that she was highly anxious about her child's impending surgery and her

comment about the nurses was based on what one nurse had said to her prior to her child going down to theatre. The mother felt that while the nurse had been trying to ease the anxiety she had erred by suggesting that the mother could say her “goodbyes at the door of the theatre”. For the mother this sounded terribly final and presumable mirrored her anxious thoughts. At the follow up interview M42 said that during the admission she had felt that the need to return her child to theatre was because of "sloppiness" by theatre staff. However on reflection and with distance she attributed that thought to her own distress at the time. With some exceptions (see below) parents showed a marked reluctance to criticize staff, and particularly nursing staff. This was a strong finding in Callery & Luker (1996, p.344) who stated

Parents were reluctant to appear critical of the hospital staff but when given the opportunity to tell the whole story and to explain problems they had experienced ... parents provided detailed accounts which identify unsatisfactory aspects of the service ... where criticism of the service were made these were often qualified by explanations of the good intentions of the staff, and the lack of choices experienced were excused by reference to the staffing levels.

It would have been useful to have carried out some in-depth interviewing of relevant families to assess, as Kirk & Miller did (cited in Stiles, 1993) the extent to which this reflected people reporting what they felt people in their circumstances are suppose to report.

However, as previously mentioned one cohort of mothers (M50, M51, M52) who were on the ward at the same time were exceptionally critical of the evening and night staff. The evening and night nurses were described by M50 as "horrendous", "they had no time for anybody", and in reference to the senior night nurse on duty it felt "like you were just bothering her", "they sat in the office all night the pair of them". This mother wanted to make up a bottle for her 4 year old as he was in the habit of falling to sleep with one. She said to the nurse that she was willing to do so herself but was told to "go and sit by the bed and wait, we're busy". It was an hour before the child got his bottle. M52 vividly recalled when she was interviewed that C50 had cried considerably during the hour long wait for the bottle. M50 also felt that the night staff, who themselves were apparently able to smoke in the dayroom, could have facilitated the mother to herself have a cigarette during the night. Instead they indicated that although she could have a cigarette outside, if the door closed over she might not be able to get back in. On another occasion when this mother asked for some more Calpol for her child the night nurse checked the time of his last dose and made the mother and child wait for the remaining 4 minutes of the 4 hour period prescribed between doses. M51 (the mother of the third child-6.8f) said that she had been awake until 5 a.m. on her daughter's postoperative night because of the child's repeated vomiting. This experience had only been manageable because of the support the mother received from the other two mothers (M50 & M52) on the ward. The evening and night staff were perceived by M51 as very unsupportive, and unable or unwilling to give information and guidance. M51 felt that she and her child "were

never human beings that day", the mothers were "just in the way", the staff behaved as if "even the children shouldn't have had problems". At the two week follow up interview M51 said "I was trying to be nice to them because if there's an emergency I can't do it". The nursing notes painted a different picture. The relevant entry indicated that the child had vomited small amounts of bile stained fluid early in the night and had then settled and slept for long periods. M52 said that although she needed little help, she too had not found the evening and night staff approachable. She was quite bothered at how neglected and unsupported she felt M51 had been. Following the two week follow up interview one of the trio requested information from the researcher on how to make a formal complaint, evidence, according to Lather (as cited in Stiles, 1993) that the research had catalytic validity.

Unexpected Psychological Trauma

A fifth theme was the, often unexpected, psychological impact or trauma experienced by children and their parents. At the follow up interview M28 indicated that her own child's recent experience of hospital had been so traumatic that he would remember it for life. Another mother (M42) present during C28's admission and interview shortly before M28 also thought that C28 would be sensitized by his experience and that the effect would be lifelong. Many mothers, especially those whose children had had adenotonsillectomies, had clearly not expected themselves and their child to be so traumatised following the surgery. This seemed especially the case (e.g., M27 & M42) when the parent/s were not aware that other children on the

ward had had less significant procedures and had therefore recovered much more rapidly than had their own child

The Effect of Cancellations

For one family (i.e. of C16- a 9.5f) cancellation of the operation occurred one hour before the procedure. The mother said that she and her husband had "geared ourselves up" for the experience and found the delay, caused by the child's tonsillitis, very and unexpectedly upsetting. Another mother (C20 - 4.5 year old male) whose child had had his previous operation date deferred because of his own upper respiratory tract infection was also very distressed at the hospital cancelling the rescheduled operation, at short notice and due to the January bed shortage.

The Induction and Aftereffects of The Anaesthetic

The mothers of several children described the sense of loss or loneliness they experienced when their children were taken into the theatre after the anaesthetic had been administered. M46 and M51 felt that that had been the worst part of the whole experience, echoing the experience of a significant proportion of parents in Rossen & McKeever (1996). M46 saw no way in which it could be made any easier.

M51 described how by the time her child (6.8f) went down to theatre the anaesthetic cream had worn off and as the child cried and screamed she was anaesthetised with gas through a mask. This had been a harrowing experience for

M51. One mother (C27 - 6.4f) had been shocked at how quickly her daughter had "gone under" when the anaesthetic was administered. These mother's experience appears common. Vessey, Bogetz, Caserza, Liu & Cassidy (1995) found that the three worst aspects of anaesthetic induction for parents were, in order of significance (a) separation from the child after induction, (b) feeling the child go limp and (c) seeing the child upset before induction.

M19 recalled having been very frightened about her child's postoperative vomiting and having had to go and show the bloody discharge to one of the ward staff. One of the Staff Nurses felt that there was considerable variation between the Anaesthetists in the drugs and the dosages they used and that this variation had a significant impact on children's postoperative physical and emotional state. This type of issue, unfortunately not measured here, could well have a significant psychological impact on children and their families.

Another mother (M23), and one of several, was surprised and disconcerted by her inability to comfort her daughter (5.8f) who cried for an hour on return from the theatre. At the two week follow up interview M23 said that she remembered observing another mother who was finding it very difficult to comfort her child recently returned from theatre. M23 had thought "we wont be like that," but they were. Perhaps M23 was, at an interpersonal level, trying to gain a sense of control through downward comparison (e.g., Taylor, 1983).

Several mothers also mentioned how distressing it had been to have had to deny their child fluids in the period after the child's recovery from the anaesthetic. Two (M52, M37) had come prepared for this with towelling to moisten their child's lips. Both had known from previous experience that this would help and it had done so on this occasion.

When The Child Needed to go Back to Theatre

The need to return a child to theatre to control postoperative bleeding was experienced as very stressful by mothers. M42 felt that she had not really taken in the possibility of complications although she had been warned about them when she attended the preassessment clinic. The mother said she had 'psyched herself up' for the first anaesthetic induction and found the second one exceptionally distressing.

Decor and Ward Facilities

The final, sixth, theme was about actual hospital and ward facilities and decor. M16 whose child's first scheduled operation was cancelled just prior to surgery, had not been aware that the rules about parents using ward facilities for making tea and coffee had changed between her daughter's two hospital admissions. The mother was quite annoyed about this when seen in the immediate postoperative period. Indeed several of the other mothers present at the time clearly voiced their dissatisfaction too. While a staff perspective is rarely included in this study it was of interest that when the researcher diplomatically lobbied on the mothers' behalf the relevant staff

nurse remarked rather dismissively that she had found that if one of a group of parents was vociferous in their complaints about aspects of their child's stay this seemed to result in the group as a whole becoming dissatisfied.

M23 had appreciated having a bed beside her child for the night so had M35 but she had felt reluctant to leave the child because his bed only had one cot side. M27 was one of several mothers (e.g., M28 and M46) who commented on the very long delay between admission and surgery. She had had to spend this time with little to do but make conversation with the child's father from whom the mother had recently divorced. Other families seem to have been better able to access resources. For example M35 (4.5 m) used a ward television to distract her child from his postoperative nausea. The parents of C50 (4.1 m) had also been able to use the video in the ward's dayroom to show the child his new and usefully distracting video "Toy Story" during his period of postoperative nausea. Presumably a menu of strategies - including psychological ones, could be made available on the ward for the management of postoperative symptoms including nausea.

M46 felt that the ward was "grotty" and M52 said it was "a very depressing place" and that the atmosphere "rubbed off on staff". The parents of C53 (5.2m) complained that the ward was cold. However they said that that was better than having it too hot as "you can easily get another blanket". The mother of the child also herself suggested that because she "was feeling low" she might have felt the cold more than

usual. She then went on to talk about the projected move of the ward to the new site and how the new outpatient department for ENT was "very nice".

DISCUSSION

The first hypothesis, that there would be no association between children's posthospital, parent rated, behavioural disturbance and the number of such behaviours causing parent a "lot of concern" was rejected. When parents were concerned about their children's behaviour the concern was about behaviour in general rather than about discrete behaviours. Thus there was little evidence of significant parental concern hidden in low overall PHBQ scores. Furthermore, the strong, positive and statistically significant correlation between pre and post hospital summary PHBQ scores ($r_s = .67$, $z = 4.49$, $p < .0001$, two tailed) is consistent with the finding that the reported differences between pre and posthospital behaviour are less clearcut when the PHBQ is administered on two separate occasions i.e. before and after hospitalisation, rather than on one occasions i.e. posthospitalisation when parents are asked to compare their children's behaviour pre and posthospital.

However there are a number of methodological issues relevant to the PHBQ itself and to the way in which it was used in this study which may confound the interpretation of some of the results and which are now considered. For example, it has been suggested that the PHBQ measure, generally administered early on in the child's hospitalisation, may not be an accurate measure of baseline adjustment (Carson, Council & Gravley, 1991). Parents in this study were administered the questionnaire 3-10 days before their child's hospitalisation and were asked about

changes in the child's behaviour "over the past 2-3 days" relative to the child's norm. There was also a strong and statistically significant correlation between pre and posthospital PHBQ scores in cases where parents said there had been no change in the 2-3 days preceeding each administration of the questionnaire. Nevertheless the first administration of the PHBQ took place in an hospital environment, albeit at an out-patient clinic and, since the follow up interval was two weeks, families may have had sufficient time to recover from their ordeal and return to their normal pattern of behaviour. There is some research which suggests that the latter is a common occurrence. For example, McLeod (1989) found that eighty-one per cent of parents considered that their child was 'over' tonsillectomy 2 - 2 1/2 weeks after the operation. In addition to this several parents (e.g., C42 and C46) in the qualitative sample in this study spontaneously reported that their responses on the PHBQ would have been different, specifically reporting more behavioural difficulties and higher parental concern, if the researcher had "come a week earlier". Although there is no published normative data for the PHBQ, approximately one third of parents in this study expressed a lot of concern about at least one aspect of their child's behaviour before hospital and this is higher than expected for a community group (e.g., Stallard, 1993, N.H.S. Health Advisory Service, 1995). It is also the case that some of the items on the PHBQ would be expected to show change as a direct result of surgery. For example, obstructive sleep apnoea which is a definite indicator for adenotonsillectomy when caused by adenotonsillar hypertrophy, is associated with chronic nighttime sleep disruption which, as Brooks states (cited in Deutsch, 1996)

is likely to negatively impact on a child's daytime behaviour and school performance. Indeed the evidence suggests that following, and as a result of, adenotonsillectomy, children's sleeping, eating and concentration can improve significantly (Ahlqvist-Rastad, Hultcrantz & Svanholm, 1988; Stradling, Thomas, Warley, Williams, & Freeland, 1990). There is also evidence that in children with a moderate sleep and breathing disorder (SBD) adenotonsillectomy is associated with a significant reduction in aggressive behaviour, inattention and hyperactivity at three months follow up (Ali, Pitson & Stradling (1996). Therefore it is possible that deterioration in behaviour resulting from the stress of hospitalisation may be negated by an improvement in symptoms following surgery. A further study could usefully establish whether or not there is a consensus among surgeons about the likely areas of improvement and the likely extent of improvement in children's symptoms and behaviour following surgery. If such consensus exists then relevant items from the PHBQ could be separated out and changes in children's behaviour pre to post hospitalisation reexamined in a more comprehensive manner.

It is worth reiterating the warning from Thompson & Vernon (1993, p.32) that "one cannot be sure of the meaning or long term implications of transitory (posthospital) behaviour changes. Different or additional data might lead to different conclusions with respect to either children's emotional status just after hospitalisation or in later years". It is clear that changes in children's behaviour or emotional functioning may not immediately manifest themselves (e.g., Scaife &

Campbell, 1988) and that reported change may reflect parental perceptions rather than child behaviour. Finally as Ellerton & Merriam (1994, p.1058) point out even if changes are only short term "unfamiliar experiences associated with a hospital encounter of any sort can be painful and distressing, especially for very young children".

The second hypothesis, that there would be a relationship between the amount of time the child was accompanied during the hospital stay and changes in the child's behaviour following hospitalization could not be tested because only three of the 49 children were unaccompanied overnight (i.e. C31, C32 & C36). Clearly some miscommunication occurred before the start of the project as the hypothesis proved untestable. By the time this fact emerged i.e. after data had been collected from 5 or 6 families it was too late to restructure the hypothesis. It has been retained in the write up because some of the qualitative findings are relevant. C31 and C32 were included in the qualitative part of the study. Their parents' report suggests that a core issue may be the meaning for the child and family of the child being accompanied or unaccompanied. For example, C31 (8.4f) said that she had not had a problem with being left overnight, her parents "needed their sleep" as they were both working the next day. She said that her father stayed until she fell asleep. She also said that she had had lots of experience of "staying over with friends" and the night in hospital was "a bit like that". Her father added that he had arranged for another parent, who was staying overnight with her child, to "keep an eye on" his daughter. The second

child, C32 (6.7m), apparently told his lone parent mother to go home at 2030 so that she could look after his younger siblings.

Three other children (C2, C7, & C46) were left for an hour or two in the daytime during their hospital stay, usually so that their mothers could go home and take care of domestic responsibilities. Only C46 (11f) was included in the qualitative part of the study. Although her questionnaire data suggested that she had coped well with the whole experience she was quite clear during the follow up interview that she had not been at all happy to be left on her own. It may also be relevant that C46 was one of the minority of children in the study who had had no previous contact with a hospital in either herself or a sibling and it reinforces the need to more directly and reliably capture the experience of the children and young people themselves. The child's perspective has been very neglected in the research literature.

The qualitative data also helped to explore why parents were disinclined to leave their children during the hospital stay. Four of the mothers (M16, M28, M35, M41) spontaneously mentioned how uncomfortable they would have felt doing so. M16 cited the apparent open nature of the ward and the stream of people, "without hospital identification badges", passing up and down the ward corridor. M 28 stayed with her child because she saw this as a key part of her role. M35 had experienced a previous unsatisfactory hospitalization with her child. At that time she decided "never will I leave him again". Finally, M41 felt that she needed to stay with her

child so that she could reassure herself that her child “was all right”. She saw this as an issue of her own anxiety rather than the quality of the care provided on the ward.

The third hypothesis was accepted. Mothers who reported that they had had a previous hospital contact with one of their children, not necessarily involving an admission nor the child currently admitted, but which was rated by the mother at that time as 'serious', were more anxious at the preassessment clinic than mothers without such experience. However such mothers were not more likely to perceive their child as vulnerable ($z = 1.01$, ns). The practical significance of this is that nursing staff at the preassessment clinic should seek information from parents about previous hospitalizations in the children within the family. Where such hospitalizations have occurred and were considered serious by the parents these parents may, because of their own heightened anxiety, be less well able to process information about the impending hospitalization. They would probably benefit from more careful information giving and perhaps from a simple leaflet about all relevant aspects of the impending hospitalisation. If such a leaflet could be sent in advance of the PAC then that appointment could be used to ease any remaining parental worries and fears. The need for more information was referred to repeatedly in the qualitative interviews.

The finding here is congruent with the experience of parents of hospitalised children in a qualitative study reported by Callery (1997, p.993). Those parents "referred to previous contacts with hospitals, for example visiting relatives who had

subsequently died, illustrating that just being in a hospital could be a difficult experience". This appears to be in conflict with Litman, Berger & Chhibber (1996) who found that mothers were significantly less anxious in the immediate (5-30 minute) preoperative period, if their children had undergone surgery in the past ($p = .004$), although the reverse appears to hold for children themselves (Kain, Mayes, O'Connor & Cicchetti, 1996). However since Litman et al. (1996) do not provide data on parent's perceptions of the seriousness of the previous surgery it is not possible to directly compare their results with those here. It is likely that parents' perceptions of the quality of the service delivery associated with previous hospitalisations and their own success in coping with the experience are crucial. If previous hospital experience is recalled positively it could serve as a useful source of information about how to react and what to expect, and thus would reduce anxiety. For example, in this study M52 and M37, unlike M34, knew from previous experience of having another child hospitalized for tonsillectomy that thirst was a major factor postoperatively but could be addressed by applying a moistened flannel to the child's parched lips. M52 and M37 reported feeling good about their ability to cope with the 'thirst challenge' whereas the father of C34 in particular, found this part of the experience very distressing. Similarly, previous negative experience may increase anxiety, as in the case of M28, who recalled her own very traumatic childhood tonsillectomy and reported that her child had had previous hospital contact which at that time she had thought was very serious. M28 was visibly shaking at the preassessment clinic and proved to have a high STAI score. Similarly, M53 had

been concerned that the staff were not checking on her child frequently enough following his surgery. She recalled her experience many years previously when her older child had a serious head injury following a road traffic accident and received very close monitoring in intensive care. More generally, given the historical popularity of tonsillectomy and the relatively harsher hospital environment for children at that time one wonders how many parents need desensitization as part of the preparation of themselves and their children for hospitalization today. Given that so many parents seem to successfully manage the hospital experience there is likely a wealth of untapped ideas for surviving the experience. These ideas should be elicited and made available e.g. in a menu format, to children and families who are about to experience surgery and hospitalisation.

There was only a small and statistically insignificant relationship between the parents' prehospital self reported anxiety state rating and differences between the parent and nurse rating of the child's behavioural disturbance during the child's admission. There are a number of factors which may contributed to the rejection of this, the fourth hypothesis. Firstly it had been based on the assumption that the BUMP-R-N, as a measure of behavioural disturbance would have been less 'contaminated' by anxiety than the BUMP-R-P. However as the qualitative data often illustrated there were occasions when the parents felt the nursing staff were adopting a very 'hands off' approach to care. In addition to this the BUMP-R had to be administered relatively early in the child's hospital stay. This was necessitated by the

nursing rosters which resulted in many of the Named Nurses finishing their shifts at 1600. In order to ensure that the Named Nurse and the child's parent rated the child's behaviour over the same period it was decided to administer the BUMP-R after the child's operation but nevertheless still within 7-8 hours of the child's admission. Thus nursing staff had limited opportunities to observe the children after surgery. This was especially the case for children further down the operation list. Nurse ratings of children's pain intensity and affect following tonsillectomy mirror children's self reported pain more closely when nurses use formal pediatric pain scales (Colwell, Clark & Perkins, 1996) but these were not employed at the study hospital. It is of course also possible that parents' report of their child's behavioural disturbance is more accurate than that of nursing staff in the case of short term hospital admissions. Parents are likely to engage in more protracted and intense observation and are much more familiar with their own children's subtle or unique signs of emotional distress although some of these are clearly more difficult to rate than others (Wachtel, Rodrigue, Geffken, Graham-Pole et al., 1994). It is also possible that children in this study were more willing or able to express distress when they were alone with their mothers. An assessment of the perspective of the children themselves would have been very useful.

It would also have been illuminating to have interviewed individual nurses about what behavioural disturbance they expected from the typical ENT surgery child and then compare those descriptions with what the individual nurses reported of actual

children. It would be interesting and useful to establish whether or not there is an child ENT surgery stereotype among nursing staff.

Although the STAI has good test retest reliability it is not clear whether the STAI-S scores of parents in this study would have been significantly different had they been measured again during the children's hospitalisation when, for example, appraisals of control may have been different and different perceptions differentially helpful. The qualitative data suggests that for at least some parents there would have been differences. However the mean STAI-S score in this study ($\underline{M} = 39.1$, $\underline{SD} = 11.7$) is similar to that obtained from parents in the immediate preoperative period in Kain et al. (1996) (though with much less variability) and at a similar point in Litman et al. (1996).

As predicted by Thomasgard & Metz (1995) there was a modest, negative and statistically significant correlation between the age of the child and change in the parent's perception of the child's vulnerability following hospitalization. Several factors may account for this finding. In general parents do not need to exercise the same level of physical care and vigilance as their children grow older. Older children are better able to communicate about their internal states and are likely to have acquired more complex, less 'parent dependent' coping strategies than younger children. As Thomasgard & Metz (1997) note "the signs of illness are both less specific and potentially more ominous". Finally parents may be aware of emerging

medical conditions in their children before these conditions are capable of being diagnosed. In such instances parents perceptions of vulnerability may well be accurate.

Parents who rated their child as vulnerable before hospital admission gave significantly higher BUMP-R ratings than parents without such perceptions. Their children were also rated by nurses as more behaviourally disturbed during the hospitalization than those of other parents. While there was a modest statistically significant correlation between parents' and nurses' ratings of child behavioural disturbance there was unfortunately no independent check on the validity of the ratings made by either. The validity of the BUMP-R ratings has been discussed above. Comparisons with other cohorts (e.g., Kain et. al., 1996) suggests that this cohort was by no means particularly anxious. The implication for clinical practice is that there is a readily identifiable group of parents may benefit from more support. This would be a useful topic for further research. Theoretically the finding here also provides some support for the contention of Thomasgard & Metz (1995, p.47) that a "combination of a history of previous salient losses or threats to important attachments in the parent's life and a history of threatened loss of the child increases the risk for PPCV".

A very high proportion of children were perceived vulnerable by their parents, relative to community norms, (e.g., Thomasgard & Metz, 1997) when assessed

before and after hospital (78% and 62% respectively). This may provide support for Thomasgard & Metz (1996, p. 226) who suggest that there "may be substantial variation in parental perception of child vulnerability based on the child's present health status". A longer follow up period would help to clarify which parents have a heightened perception of vulnerability only when their child is ill or anticipating hospitalisation as distinct from parents who have a generally heightened perception of their child's vulnerability.

Following on from Thomasgard & Metz (1996) it is possible that the high VCS scores in this study reflected a group of children who actually were vulnerable for example, were frequently ill with sore or infected throats and ears. Since the mothers would have been aware that the surgery was intended to reduce such symptoms the mothers' predictions about future symptoms could be expected to mirror changes in their perception of child vulnerability from pre to posthospital. To test this seven mothers from the qualitative cohort were requested, at the time of the follow up interview, to project themselves forward "three or more months" and asked if they thought their child would be getting fewer colds (item 1 on the VCS). C19, C20, C30, C32 and C37 expected no change, C45 said she thought her child was and would continue to be healthier following surgery and C40 expected fewer colds. The changes of these seven mothers' VCS scores tended to shadow their predictions about the frequency of children's colds. There was no change in VCS scores for C19, C20 and C30, a change of 1.5 points for C37 and 3 points for C32 but with none of

these changes shifting the child's vulnerability status. C40 showed a drop in VCS scores of 4 points (although still above the cut off of 10 points) and C45 dropped from 13 to 2 and thus no longer perceived her child as vulnerable. It is worth noting for the sample as a whole there was no relationship between changes in parents' perceptions of their children's vulnerability and mother's STAI scores ($r = .07$).

Finally it was hypothesised that where there was a match between the child and parent preferred coping style for medical situations the child show significantly less behavioural upset during the hospitalization. This hypothesis was rejected for parent and nurse rating of behavioural distress. Notwithstanding the comments made earlier about the reliability and validity of the BUMP-R measure not having been established, it may be the case that a relationship would have emerged had the parents and child been asked about coping and preparation for this particular hospitalization rather than about coping and preparation for medical experiences in general. Additionally the coping style measure used here could be improved by adding more items tapping individual components of the child's behavioural and emotional reaction and taking account of the variety of quite different ENT surgery related stressors for which different coping strategies might be most effective.

RECOMMENDATIONS TO THE HOSPITAL

1. Mothers attending the preassessment clinic should be asked about previous contacts their children have had with hospital. Where previous contact is described as 'serious' then the mother and child are likely to require even more careful assessment and psychological preparation for the admission.
2. The Vulnerable Child Scale should be routinely administered to families attending at the preassessment clinic. In cases where a mother perceives her child to be vulnerable before admission the family should receive more psychological support during the admission.
3. Parents and children need the nursing and medical staff, as a group, to think through and agree what they (the staff) consider the range of appropriate roles or the parameters of an appropriate role for parents in caring for their hospitalised child. The actual role to be assumed by individual parents should be explicitly negotiated with them. This discussion could take place when the child attends the PAC with the details confirmed by the child's named nurse and parent/s at the time of the child's admission to the ward.

4. When parents and children receive their Preassessment Clinic (PAC) date they should also receive written information about the purpose and content of that appointment. Help could be sought from the Children's Psychological Care Service in the hospital about the best ways to communicate this information effectively to children and prepare them for the appointment.

5. Nursing and medical staff should develop a written protocol for use in the PAC. As well as specifying necessary medical and nursing tasks the protocol should set forward a clear process for informing and generally preparing parents and children for hospitalisation. There are excellent sources of simple and useful ideas available on the internet which could be adapted for local use (e.g. <http://cmc.mcg.edu/handbook/prepare.htm>). Parents and children should also be provided with a simple written explanation of the ENT procedure applicable to them. These explanations should include reasons for the procedure; how long it may take; how the child may feel afterwards; possible complications and how these would be managed by the hospital staff; information about how the child may behave before and after the procedure and typical recovery patterns following surgery and following discharge. Parents should be explicitly alerted to the possibility of their being stressed and distressed by the anaesthetic induction, their child's possible preoperative and postoperative behaviour and postoperative appearance. Again there are several useful internet sites providing this type of information (e.g. <http://www.pedisurg.com/PtEducENT/Post-tonsillectomy.htm>).

Parents and children also need information about hospital facilities prior to admission (e.g. the availability of toys and play facilities, sleeping arrangements for parents, availability of food and drink machines, location of toilets etc.) and a realistic time schedule outlining the key events which will take place during a child's admission. All of this information should be provided in written and verbal form at the PAC and an evaluation made, from the parent's and child's perspective, of its quality and the appropriateness of its timing. An information leaflet outlining facilities in the hospital should be provided in each bedspace together with information about how to complain about the quality of service.

6. Hospital management should give serious consideration to the potential gains to be made, in terms of service quality and efficiency, by relocating responsibility for secretarial and administrative support to this part of the hospital services in a very much smaller number of staff.

RECOMMENDATIONS FOR FUTURE RESEARCH

1. Strategies for coping with the psychological impact of hospitalisation, hospital practices and possible symptoms should be elicited from children, parents, and staff. These strategies should be routinely shared with families anticipating ENT surgery. Since most families cope successfully with the experience researchers should concentrate on what it is that they do rather than on those who have difficulty.
2. The child's perspective on the hospital experience needs to be more specifically and directly assessed.
3. It would be useful to assess the different perspectives of parent, child and staff on preparation for hospitalisation and surgery provided to individual children.
4. A longer term follow up of changes in parents' perceptions of child vulnerability would help to identify the extent to which, and for whom, such changes are transient.
5. A study should be undertaken of nurses' expectations about children's behaviour change following ENT surgery e.g. is there a stereotype? Nurses ratings of actual behaviour change postsurgery in individual children under their care could be usefully compared with their view of the 'average ENT surgery child'.

6. There is a need to partial out the positive effects of surgery and the negative effects of hospitalisation, possibly through seeking a consensus about the former among surgeons.

7. Families who excuse nurses from any responsibility for poor service quality could be usefully interviewed in depth with a view to establishing the extent to which such sentiments reflects people's belief about what they are supposed to feel and think rather than their actual thoughts and feelings.

REFERENCES

Ahlqvist-Rastad, J., Hultcrantz, E., & Svanholm, H. (1988). Children with tonsillar obstruction: indications for and efficacy of tonsillectomy. Acta Paediatrica Scandinavica, 77, 831 - 835.

Ali, N. J., Pitson, D., & Stradling, J. R. (1996). Sleep disordered breathing: effects of adenotonsillectomy on behaviour and psychological functioning. European Journal of Paediatrics, 155, 56 - 62.

Audit Commission. (1993). Children First. HMSO.

Azarnoff, P. (1982). Hospital tours for school children ended. Pediatric Mental Health, 1, 2.

Bartley, J. R., & Connew, A. M. (1994). Parental attitudes and postoperative problems related to paediatric day stay tonsillectomy. New Zealand Medical Journal, 107, 451 - 452.

Band, E. B. (1990). Children's coping with diabetes: understanding the role of cognitive development. Journal of Pediatric Psychology, 15, 27 - 41.

Band, E. B., & Weisz, J. R. (1988). How to feel better when it feels bad: children's perspectives on coping with everyday stress. Developmental Psychology, 24, 247 - 253.

Band, E. B., & Weisz, J. R. (1990). Developmental differences in primary and secondary control coping. Journal of Clinical Child Psychology, 19, 150 - 158.

Baron, R., & Kenny, D. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. Journal of Personality and Social Psychology, 51, 1173 - 1182.

Belson, P. (1988). A Policy for Play. Play in Hospital Liaison Committee.

Belson, P. (1993). Children in Hospital. Children and Society, 7, 196 - 210.

Berenbaum, J., & Hatcher, J. (1992). Emotional distress of mothers of hospitalised children. Journal of Pediatric Psychology, 17, 359 - 372.

Beyer, J. E., DeGood, D. E., Ashley, L. C., & Russell, G. A. (1983). Patterns of postoperative analgesic use with adults and children following cardiac surgery. Pain, 17, 71 - 81.

Bibace, R., & Walsh, M. (1982). Development of children's concepts of illness. Pediatrics, 66, 912 - 917

Blount, R., Sturges, J., & Powers, S. (1990). Analysis of child and adult behavioral variations by phase of medical procedure. Behavior Therapy, 21, 33 - 48.

Bradford, R. (1991). Staff accuracy in predicting the concerns of parents of chronically ill children. Child: Care Health & Development, 17, 39 - 47.

Brooks, L. J. (1993). Treatment of otherwise normal children with obstructive sleep apnea. Ear Nose and Throat Journal, 72, 77. .

Burrell, I. (1997, February 22). Inquiry as pneumonia kills 11,000 in January cold spell. The Independent, p. 5.

Bush, J. P., & Harkins, S. W. (1991). Children in pain: Clinical and research issues from a developmental perspective. New York: Springer-Verlag.

Bush, J. P., Melamed, B. G., Sheras, P. L., & Greenbaum, P. E. (1986). Mother-child patterns of coping with anticipatory medical stress. Health Psychology, 5, 137 - 157.

Callery, P. (1997). Caring for parents of hospitalized children: a hidden area of nursing. Journal of Advanced Nursing, 26, 992 - 998.

Callery, P. & Luker, K. (1996). The use of qualitative methods in the study of parents' experience of care on a children's surgical ward. Journal of Advanced Nursing, 23, 338 - 345.

Carson, D. K., Council, J. R., & Gravley, J. E. (1991). Temperament and family characteristics as predictors of children's reactions to hospitalization. Developmental & Behavioral Pediatrics, 12, 141 - 147

Church, J. J. (1996). Day surgery tonsillectomy for children. The Journal of One-Day Surgery, 5, 8 -9.

Clafin, C. J., & Barbarin, O.A. (1991). Does "telling" less protect more ? Relationship among age, information disclosure, and what children with cancer see and feel. Journal of Pediatric Psychology, 16, 69 - 191.

Cohen, J. (1988). Statistical power analysis for the behavioral science. New Jersey: Erlbaum.

Colwell, C., Clark, L., & Perkins, R. (1996). Postoperative use of pediatric pain scales: children's self-report versus nurse assessment of pain intensity and affect. Journal of Pediatric Nursing, 11, 375 - 382.

Coyne, I. T. (1995). Parental participation in care: a critical review of the literature. Journal of Advanced Nursing, 21, 716 - 722.

Craft, M. J., Wyatt, N., & Sandell, B. (1985). Behavior and feeling changes in siblings of hospitalized children. Clinical Pediatrics, 24, 374 - 378.

Darbyshire, P. (1993). Parenting in public: a study of the experiences of parents who live-in with their hospitalised child, and their relationship with paediatric nurses. Unpublished doctoral dissertation,. University of Edinburgh, Edinburgh.

Dearmun, A. (1992). Perceptions of parental participation. Pediatric Nursing, 4, 6 - 9.

Demarest, D. S., Hooke, J. F., & Erickson, M. T. (1984). Preoperative intervention for the reduction of anxiety in pediatric surgery patients. Children's Health Care, 12, 179 - 183.

Deutsch, E. S. (1996). Tonsillectomy and Adenoidectomy: changing indications. Pediatric Clinics of North America, 43, 1319 - 1338.

DHSS (1959). The Welfare of Children in Hospital: The Platt Report. HMSO.

DHSS (1972). Hospital Facilities for Children HM(71)22. HMSO

DHSS (1976a). Fit for the Future: The Court Report. HMSO.

Dundee, J. W., Loan, W. B., & Clarke, R. S. J. (1996). Studies of drugs given before anaesthesia XI: Diamorphine (heroin) and morphine. British Journal of Anaesthesia, 38, 610 - 619.

Eberly, T.W. (1985). Parental stress after the unexpected admission of a child to the intensive care unit. Critical Care Quarterly, 8, 57 -65.

Edwards, N. (1996). Temperature rises for Paediatrics. Health Service Journal, 1 Feb., pp. 24 - 25.

Eiser, C. (1984). Communicating with sick and hospitalized children. Journal of Child Psychology and Psychiatry, 25, 181 - 189.

Eiser, C. (1985). The psychology of childhood illness. New York: Springer-Verlag.

Eiser, C. (1990b). Psychological effects of chronic disease. Journal of Child Psychology & Psychiatry, 31, 85 - 98.

Eiser, C., & Eiser, J. R. (1990). The effects of personal and family hospital experience on children's health beliefs, concerns and behaviour. Social Behaviour, 5, 307 - 314.

Ellerton, M. L., & Merriam, C. (1994). Preparing children and families psychologically for day surgery: an evaluation. Journal of Advanced Nursing, 19, 1057 - 1062.

Fagin, C. M. R. N. (1966). The effects of maternal attendance during hospitalization on the post-hospital behavior of young children. Philadelphia, PA: Davis.

Fahrenfort, J. J., Jacobs, E. A. M., Miedema, S., & Schweizer, A. T. (1996). Signs of emotional disturbance three years after early hospitalization. Journal of Pediatric Psychology, 21, 353 - 366

Ferguson, B. F. (1979). Preparing young children for hospitalization: a comparison of two methods. Pediatrics, 64, 656 - 664.

Field, T., Alpert, B., Vega-Lahr, N., Goldstein, S., & Perry, S. (1988). Hospitalization stress in children: sensitizers and repressor coping styles. Health Psychology, 7, 433 - 445.

Field, T., Estroff, D. B., Yando, R., & del Valle, C. (1996). "Depressed" mothers' perceptions of infant vulnerability are related to later development. Child Psychiatry & Human Development, 27, 43 - 53.

Flanagan, J. (1954). The Critical Incident Technique. Psychological Bulletin, 51, 327 - 358.

Fletcher, B. (1981). Psychological upset in post-hospitalised children: a review of the literature. Maternal Child Nursing Journal, 10, 185 - 195.

Folkman, S., & Lazarus, R. S. (1988). The relationship between coping and emotion: implications for theory and research. Social Science and Medicine, 26, 309 - 317.

Forsyth, B. W. C. (1987). Mother's perceptions of their children's vulnerability after hospitalization for infection. American Journal of Diseases in Children, 141, 377.

Forsyth, B. W. C., & Canny, P. (1991). Perceptions of vulnerability 3 1/2 years after problems of feeding and crying behavior in early infancy. Pediatrics, 88, 757 - 763.

Forsyth, B. W. C., Horwitz, S. McC., Leventhal, J. M., and Burger, J. (1996). The Child Vulnerability Scale: an instrument to measure parental perceptions of child vulnerability. Journal of Pediatric Psychology, 21, 89 - 101.

Freiberg, K. (1972). How parents react when their child is hospitalized. American Journal of Nursing, 72, 1270 - 1272.

Gedaly-Duff, V. (1991). Developmental issues: preschool and school-age children. In J. P. Bush, and S. W. Harkins (Eds.), Children in pain: Clinical and research issues from a developmental perspective. (pp. 195 - 230). New York: Springer-Verlag.

Gedaly-Duff, V. & Ziebarth, D. (1994). Mothers' management of adeno-tonsillectomy pain in 4 - 8 year olds: A preliminary study. Pain, 57, 293 - 299

Gofman, H., Buckman, W., & Schade, G.H. (1957). The child's emotional response to hospitalization. American Medical Association Journal of Diseases of Children, 93, 157 - 164.

Goslin, E. R. (1978). Hospitalization as a life crisis for the preschool child: a critical review. Journal of Community Health, 3, 321 - 346.

Graves, J.K., & Ware, M.E. (1990). Parents' and health professionals' perceptions concerning parental stress during a child's hospitalization. Child Health Care, 19, 37 - 42.

Green, M., & Solnit, A. J. (1964). Reactions to the threatened loss of a child: a vulnerable child syndrome. Pediatrics, 34, 58 - 66.

Handler, S. D., Miller, L., & Richmond, K. H. et al., (1986). Post-tonsillectomy hemorrhage: incidence, prevention and management. Laryngoscope, 96, 1243.

Hardgrove, C. B., & Dawson, R. B. (1972). Parents and children in the hospital: the family's role in pediatrics. Boston: Little Brown.

Hayes, V., & Knox, J. E. (1984). The experience of stress in parents of children hospitalized with long term disabilities. Journal of Advanced Nursing, 9, 333 - 341.

Jay, S. M., Ozolins, M., & Elliott, C. H. (1983). Assessment of children's distress during painful medical procedures. Health Psychology, 2, 133 - 147.

Jimmieson, N., and Griffin, M. A. (1998). Linking client and employee perceptions of the organization: A study of client satisfaction with health care services. Journal of Occupational and Organizational Psychology, 71, 81 - 96.

Kain, Z. N., Mayes, L. C., Caramico, L. A., Silver, D., Spieker, M., Nygren, M.M., Anderson, G., & Rimar, S. (1996). Parental presence during induction of anaesthesia: a randomized control trial. Anesthesiology, 84, 1060 - 1067.

Kain, Z. N., Mayes, L. C., O'Connor, T. Z., & Cicchetti, D. V. (1996). Preoperative anxiety in children. Archives of Pediatric & Adolescent Medicine, 150, 1238 -1245.

Kain, Z. N., Wang, S.M., Caramico, L. A., Hofstadter, M., & Mayes, L. C. (1997). Parental desire for perioperative information and informed consent: a two phase study. Anaesthesiology, 84, 299-306.

Kinderman, P., Feather, S., & McDowell, H. (1996). Someone to watch over them: the role of parents in their children's hospitalization. Clinical Psychology Forum, 88, 20 - 23.

Knafl, K.A., & Dixon, D.M. (1984). The participation of fathers in their children's hospitalization. Issues in Comprehensive Pediatric Nursing 7, 269 - 281.

Lansdown, R. (1996). Children in hospital: A guide for families and carers. Oxford: OUP.

LaMontagne, L. (1984). Children's locus of control beliefs as predictors of preoperative coping behavior. Nursing Research, 33, 76 - 85.

LaMontagne, L.L., Hepworth, J. T., Johnson, B. D., & Cohen, F. (1996). Children's postoperative coping and its effects on postoperative anxiety and return to normal activity. Nursing Research 45, 141 - 147.

LeBaron, S., & Zeltzer, L. (1984). Assessment of acute pain and anxiety in children and adolescents by self report, observer reports, and a behavioral checklist. Journal of Consulting and Clinical Psychology, 52, 729 - 738.

Levy, D. M. (1931). Maternal overprotection and rejection. Archives of Neurology & Psychiatry, 25, 886 - 889.

Litman, R. S., Berger, A. A., & Chhibber, A. (1996). An evaluation of preoperative anxiety in a population of parents of infants and children undergoing ambulatory surgery. Paediatric Anaesthesia, 6, 443 - 447.

Mabe, P.A., Trieber, F.A., & Riley, W.T. (1991). Examining emotional distress during pediatric hospitalization for school age children. Children's Health Care, 20, 162 - 169.

Mathews, A. (1990). Why worry? The cognitive function of anxiety. Behavior Research & Therapy, 28, 455 - 468.

Maw, R., & Bawden, R. (1993, July 1). Spontaneous resolution of severe chronic glue ear in children and the effect of adenoidectomy, tonsillectomy, and the insertion of ventilation tubes (grommets). British Medical Journal, 306, 756 - 760.

McCarthy, P. L., Cicchetti, D.V., Sznajderman, S.D. (1991). Demographic, clinical, and psychosocial predictors of the reliability of mother's clinical judgements. Pediatrics, 88, 1041 - 1046.

MacFaul, R., Stewart, M., Werneke, U., Taylor-Meek, J., Smith, H.E., & Smith, I.J. (1998). Parental and professional perception of need for emergency admission to hospital: prospective questionnaire based study. Archives of Disease in Childhood, 79, 213 - 218.

McGrath, P. J., & Pisterman, S. (1991). Developmental issues: adolescent pain. In J. P. Bush & S. W. Harkin (Eds.), Children in pain: clinical, and research issues from a developmental perspective (pp. 231 - 250). New York: Springer-Verlag.

McLeod, R. (1989, January 25). Tonsillectomy and after. Nursing Times, 85, 66 - 67.

Melamed, B.G., & Ridley-Johnson, R. (1988). Psychological preparation of families for hospitalization. Journal of Developmental & Behavioral Pediatrics, 9, 96 - 102.

Melamed, B.G., & Siegel, L. J. (1975). Reduction of anxiety in children facing hospitalization and surgery by use of filmed modeling. Journal of Consulting and Clinical Psychology, 43, 511 - 521.

Melnyk, B.M. (1995). Coping with unplanned childhood hospitalization: the mediating functions of parental beliefs. Journal of Pediatric Psychology, 20, 299 - 312.

Ogilvie, L. (1990). Hospitalization of children for surgery: the parents' view. Children's Health Care, 19, 49 - 56.

Ovretveit, J. (1993). Coordinating community care: multidisciplinary teams and care management. Buckingham: OUP.

Palermo, T.M., & Drotar, D. (1996). Prediction of children's postoperative pain: the role of presurgical expectations and anticipatory emotions. Journal of Pediatric Psychology, 21, 683 - 698.

Paxton, D. (1996). Treating postoperative nausea in children. Hospital Update, 22, 428 - 430.

Perrin, J. M. (1993). Children in hospitals. Developmental & Behavioral Pediatrics, 14, 50 - 52.

Pervin, L. A. & Lewis, M. (Eds.). (1978). Perspectives in interactional psychology. New York: Plenum Press.

Peterson, L. (1989). Coping by children undergoing stressful medical procedures: some conceptual, methodological, and therapeutic issues. Journal of Consulting & Clinical Psychology, 57, 380 - 387.

Peterson, L., & Mori, L. (1988). Preparation for hospitalization. In D.K. Routh (Ed.), Handbook of pediatric psychology (pp. 460 - 491). London: Guilford Press.

Peterson, L., Mori, L., & Carter, P. (1985). The role of the family in children's responses to stressful medical procedures. Journal of Clinical Child Psychology, 14, 98 - 104.

Peterson, L., & Ridley-Johnson, R. (1980). Pediatric hospital response to survey on prehospital preparation for children. Journal of Pediatric Psychology, 5, 1 - 7.

Peterson, L., Ridley-Johnson, R., Tracy, K., & Mullins, L. L. (1984). Developing cost-effective presurgical preparation: a comparative analysis. Journal of Pediatric Psychology, 9, 439 - 455.

Peterson, L., & Toler, S. M. (1986). An information seeking disposition in child surgery patients. Health Psychology, 4, 343 - 359.

Phillips, L. (1998). Community psychology: theory, practice and the link with qualitative research. Clinical Psychology Forum, 114, 16 - 18.

Rudolph, K. D., Dennig, M. D., & Weisz, J. R. (1995). Determinants and consequences of children's coping in the medical setting: conceptualization, review, and critique. Psychological Bulletin, 118, 328 - 357.

Reissland, N. (1983). Cognitive maturity and the experience of fear and pain in hospital. Social Science and Medicine, 17, 1389 - 1395.

Rende, R.D., & Plomin, R. (1991). Child and parent perceptions of the upsettingness of major life events. Journal of Child Psychology & Psychiatry, 32, 627 - 633.

Richtsmeier, A. J., & Hatcher, J.W. (1994). Parental Anxiety and minor illness. Developmental & Behavioral Pediatrics, 15, 14 - 19.

Robertson, J. (1952). A two year old goes to hospital [Film] New York: New York University Film Library.

Rodriguez, C. M., & Boggs, S. R. (1994). Behavioral Upset in Medical Patients - Revised: evaluation of a parent report measure of distress for pediatric populations. Journal of Pediatric Psychology, 19, 319 - 324.

Rossen, B. E., & McKeever, P. D. (1996). The behavior of preschoolers during and after brief surgical hospitalizations. Issues in Comprehensive Pediatric Nursing, 19, 121 - 133.

Rothbaum, F., Weisz, J. R., & Snyder, S. (1982). Changing the world and changing the self: a two-process model of perceived control. Journal of Personality and Social Psychology, 42, 5 - 37.

Routh, D.K., & Sanfilippo, M.D. (1981). Helping children cope with painful medical procedures. In J. P. Bush & S. W. Harkins (Eds.), Children in Pain: clinical and research issues from a developmental perspective (pp. 397 - 424). New York : Spring-Verlag.

Rudolph, K. D., Dennig, M. D., & Weisz, J. R. (1995). Determinants and consequences of children's coping in the medical setting: conceptualization, review, and critique. Psychological Bulletin, 118, 328 - 357.

Rutter, M. (1981). Stress, coping and development: some issues and some questions. Journal of Child Psychology & Psychiatry, 22, 323 - 356.

Sabbeth, B., & Leventhal, J. (1988). Trial balloons: When families of ill children express needs in veiled ways. Children's Health Care, 17, 87 -92.

Saylor, C. F., Pallmeyer, T. P., Finch, A. J., Eason, L., Trieber, F., & Folger, C. (1987). Predictors of psychological distress in hospitalized pediatric patients. Journal of the American Academy of Child and Adolescent Psychiatry, 26, 232 - 236.

Scaife, J.M., & Campbell, I. (1988). A comparison of the outcome of day-care and inpatient treatment of paediatric surgical cases. Journal of Child Psychology & Psychiatry, 29, 185 - 198.

Schepp, K. G. (1991). Factors influencing the coping effort of mothers of hospitalized children. Nursing Research, 40, 42 - 46.

Schmeltz, K., & White, G. (1982). A survey of parent groups: prehospital admission. Maternal - Child Nursing Journal, 11, 75 - 86.

Shaw, E.G., & Routh, D. K. (1982). Effect of mother presence on children's reaction to aversive procedures. Journal of Pediatric Psychology, 7, 33 - 42.

Siegel, L. J. (1983). Hospitalization and medical care of children. In E. Walker & M. Roberts (Eds.), Handbook of clinical child psychology (pp. 1089 - 1108). New York:Wiley.

Siegel, L. J. (1988a). Dental treatment. In D.K. Routh (Ed.), Handbook of pediatric psychology (pp. 460 - 491). London: Guilford Press.

Siegel, L. J. & Smith, K. E. (1989a). Children's strategies for coping with pain. Pediatrician: International Journal of Child and Adolescent Health, 16, 110 - 118.

Sipowicz, P. R., & Vernon, D. T. A. (1965). Psychological responses of children to hospitalization. American Journal of Disease in Children, 109, 228 - 231.

Snowdon, A. W., & Kane, D. J. (1995). Parental needs following the discharge of a hospitalized child. Pediatric Nursing, 21, 425 - 428.

Spielberger, C.D. & Sydeman, S. J. (1994). State-Trait Anxiety Inventory and State-Trait Anger Expression. In M. E. Maruish (Ed.), The use of psychological testing for treatment planning and outcome assessment. (pp. 292-321). NJ: LEA.

Stallard, P. (1993). The behaviour of 3-year-old children: prevalence and parental perception of problem behaviour. Journal of Child Psychology & Psychiatry, 34, 413 - 422.

Stallard, P., Mastroiannopoulou, K., Lewis, M., & Lenton, S. (1997). The siblings of children with life-threatening conditions. Child Psychology & Psychiatry Review, 2, 26 - 33.

Stiles, W. (1993). Quality control in qualitative research. Clinical Psychology Review, 13, 593 - 618.

Stradling, J.R., Thomas, G., Warley, A.R.H., Williams, P., & Freeland, A. (1990). Effect of adenotonsillectomy on nocturnal hypoxaemia, sleep disturbance, and symptoms of snoring in children. The Lancet, 335, 249 - 253.

Strull, W. M., Lo, B. & Charles, G. (1993). Do patients want to participate in medical decision making? Journal of the American Medical Association, 252, 2990 - 2994.

Taylor, S. (1983). Adjustment to threatening events: a theory of cognitive adaptation. American Psychologist, 38, 1161 - 1173.

Thomasgard, M., & Metz, W. P. (1995). The Vulnerable Child Syndrome Revisited. Developmental & Behavioral Pediatrics, 16, 47 - 53.

Thomasgard, M., & Metz, W. P. (1997). Parental overprotection and its relation to perceived child vulnerability. American Journal of Orthopsychiatry, 67, 330 - 335.

Thomasgard, M., & Metz, W. P. (1996). The two year stability of parental expectations of child vulnerability and parental overprotection. Developmental & Behavioral Pediatrics, 17, 222 - 228.

Thomasgard, M., Metz, W. P., Edelbrock, C., & Shonkoff, J. P. (1995). Parent-child relationship disorders. Part 1. Parental overprotection and the development of the Parent Protection Scale. Developmental and Behavioral Pediatrics, 16, 244-250.

Thompson, M. L. (1994). Information-seeking coping and anxiety in school-age children anticipating surgery. Children's Health Care, 23, 87 - 97.

Thompson, R. H., & Vernon, D. T. A. (1993). Research on children's behavior after hospitalization: a review and synthesis. Developmental and Behavioral Pediatrics, 14, 28 - 35.

Thornes, R. (1983, July 10). Parental access and family facilities in children's wards in England. British Medical Journal, 287.

Value for Money Unit. (1995). A guide to undertaking user feedback projects. NHS Cymru: Caerdydd.

Vernon, D. T. A., Schulman, J. L., & Foley, J. M. (1966). Changes in children's behavior after hospitalization: some dimensions of response and their correlates. American Journal of Diseases of Childhood, 111, 581-593.

Vernon, D. T. A., & Thompson, R. H. (1993). Research on the effect of experimental interventions on children's behavior after hospitalization: a review and synthesis. Developmental and Behavioral Pediatrics, 14, 36 - 44.

Vessey, J.A., Bogetz, M.S., Caserza, C.L., Liu, K.R., & Cassidy, M.D. (1995). Parental upset associated with participation in induction of anaesthesia in children. Canadian Journal of Anaesthesiology, 41, 276 - 280.

Wachtel, J., Rodrigue, J. R.T., Geffken, G. R., Graham-Pole, J., et al. (1994). Children awaiting invasive medical procedures: Do children and their mothers agree on child's level of anxiety? Journal of Pediatric Psychology, 19, 723 - 735.

Walker, C.L. (1988). Stress and coping in siblings of childhood cancer patients. Nursing Research, 37, 208 - 212.

Walker, A.M., Harris, G., Baker, A., Kelly, D., & Houghton, J. (1999). Post-traumatic stress responses following liver transplantation in older children. Journal of Child Psychology & Psychiatry, 40, 363 - 374.

Weisz, J. R., McCabe, M., & Dennig, M.D. (1994). Primary and secondary control among children undergoing medical procedures: adjustment as a function of coping style. Journal of Consulting and Clinical Psychology, 62, 324 - 332.

Wells, R. D., & Schwebel, A. L. (1987). Chronically ill children and their mothers: predictors of resilience and vulnerability to hospitalization and surgical stress. Journal of Developmental and Behavioral Pediatrics, 8, 83 - 89.

While, A., & Crawford, J. (1992). Day surgery: expediency or quality care? Pediatric Nursing, 4, 3, pp. 18 - 20.

Williams, E.F., Woo, P., Miller, R., & Kellman, R.M. (1991). The effects of adenotonsillectomy on growth in young children. Otolaryngology, Head & Neck Surgery, 104, 509 - 516.

Wolfer, J. A., & Visitainer, M. A. (1975). Pediatric surgical patients' and parents' stress responses and adjustment. Nursing Research, 24, 244 - 255.

Worchel, F. F., Copeland, D. R., & Barker, D. G. (1987). Control-related coping strategies in pediatric oncology patients. Journal of Pediatric Psychology, 12, 25 - 38.

Zeldow, P. B., & Braun, L. (1985). Measuring regression in hospitalized medical patients: the BUMP scale. General Hospital Psychiatry, 7, 49 - 53.

Zuckerberg, A.L. (1994). Perioperative approach to children. Pediatric Clinics of North America, 41, 15 - 29.

Appendix A

The Study Questionnaires

DEMOGRAPHIC QUESTIONNAIRE

- a) Child's (i) date of birth
- (ii) previous contacts with hospital
when?
for what?
how serious did **you** think this was?.....
- b) Mother's age Father's age
- c) Parents' marital status (please tick one)
- | | |
|----------------------------------|--------------------------|
| living with husband/wife/partner | <input type="checkbox"/> |
| divorced/separated | <input type="checkbox"/> |
| widowed | <input type="checkbox"/> |
| not living with other adults | <input type="checkbox"/> |
- d) brothers and sisters
- (i) age/s
- (ii) previous contact with hospital
when?
for what?
how serious did **you** think this was?.....
- e) Think of the child who is going to have the operation. Now tick which of the following best describes that child when s/he has to see a doctor, dentist or nurse.
- | | |
|---|--------------------------|
| 1 The child concentrates on what is happening, wants to know what will happen and how it will feel. | <input type="checkbox"/> |
| 2 The child wants more information but prefers to pay little attention. | <input type="checkbox"/> |
| 3 The child prefers to totally distract him/herself and not pay attention to the procedure. | <input type="checkbox"/> |

Now please tick which of the following best describes the way you prepare that child for painful medical procedures e.g. injections, dental work etc.

- 1 I tell the child in detail everything that is going to happen. ☐
- 2 I tell the child a little about what is going to happen. ☐
- 3 I do not tell the child until the procedure must happen. ☐

POST HOSPITAL BEHAVIOR QUESTIONNAIRE

Instructions: Please complete a - c

- a. Today's date is
- b. The child's name is
- c. My relationship to the child is

Could you please complete each of the 28 items listed below. The **first** part of each item asks about your child's behaviour **OVER THE PAST 2-3 DAYS** and the **second** part asks whether this behaviour is of concern to you.

1. Did the child make a fuss about going to bed at night? Not at all On some nights only Everynight
- ☐ ☐ ☐

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

2. Did your child make a fuss about eating? Not at all Sometimes Quite often Very often Every mealtime
- ☐ ☐ ☐ ☐ ☐

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

3. Did your child spend time just sitting or laying and doing nothing? Not at all Sometimes Quite often Very often All the time
- ☐ ☐ ☐ ☐ ☐

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

4. Did your child need a dummy/pacifier? Not at all Sometimes Quite often Very often All the time
- ☐ ☐ ☐ ☐ ☐

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

there are more questions on the next few pages

5. Did your child seem to be afraid of leaving the house with you?	Not at all	Sometimes	Quite often	Very often	Every time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

.....

6. Was your child <u>un</u> interested in what was going on around him/her?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

.....

7. Did your child wet the bed at night?	Not at all	Quite often	Every night
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

.....

8. Did your child bite his/her nails?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

.....

9. Did your child get upset when you left him/her alone for a few minutes?	Not at all	Sometimes	Quite often	Very often	Every time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

.....

10. Did your child need a lot of help doing things?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) Not at all A little A lot

11. Was it difficult to get your child interested in doing things (like playing games with toys and so on)?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

12. Was your child <u>un</u> interested in what was going on around him/her?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

13. Did your child have difficulty making up his/her mind?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

14. Did your child have temper tantrums?	Not At all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

15. Was it difficult to get your child to talk to you?	Not at all	Sometimes	Quite often	Very often	Every time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

16. Did your child seem to get upset when someone mentioned doctors and hospitals?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

17. Did your child follow you everywhere around the house?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

18. Did your child spend time trying to get or hold your attention?	Not at all	Sometimes	Quite often	Very often	All the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

19. Was your child afraid of the dark?	Not at all	Sometimes	Quite often	Very often	Every night
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

20. Did your child have bad dreams at night or wake up and cry?	Not at all	On some nights only	Every night
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

21. Did your child wet/soil him/herself?	Not at all	Sometimes	Quite often	Very often	Every time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

22. Did your child have trouble getting to sleep at night?	Not at all	On some nights only	Every night
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

	Not at all	Sometimes	Quite often	Very often	Every time
23. Did your child seem to be shy or afraid around strangers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

	Not at all	Sometimes	Quite often	Very often	Every mealtime
24. Did your child have a poor appetite?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

	Not at all	Sometimes	Quite often	Very often	All the time
25. Did your child tend to disobey you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

	Not at all	Sometimes	Quite often	Very often	All the time
26. Did your child break toys or other objects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

	Not at all	Sometimes	Quite often	Very often	All the time
27. Did your child suck his/her fingers or thumbs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How concerned are you about this? (Underline) *Not at all* *A little* *A lot*

.....

Finally

In general over the past 2-3 days has your child's behaviour been

worse than usual ☐

same as usual ☐

better than usual ☐

BEHAVIORAL UPSET IN MEDICAL PATIENTS - REVISED (NURSE VERSION)

BUMP-R/N

Instructions: Please complete a - d

- a. Today's date is
- b. The child's name is
- c. My relationship to the child is
- d. Time of operation today.....

Please rate the child's behaviour as you have seen it **since s/he arrived at the hospital**. Mark one box per question to indicate your choice.

		Never	Sometimes	Often	Usually	Always
1	is impatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	cries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	gets angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	becomes easily upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	is irritable or grouchy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	refuses to speak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	says s/he feels depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	has to be reminded what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	has to be told to follow hospital routines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Sometimes	Often	Usually	Always
10	looks worried, tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	looks depressed or sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	clinging, needs lots of reassurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	is uncooperative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	complains	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	stubborn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	is very, very quiet, just lets things happen to him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	demanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	tries to get his/her own way by being sneaky	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	able to ask for help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	tries to be friendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	accepts advice or instructions easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	starts conversations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Sometimes	Often	Usually	Always
23	laughs or smiles at funny comments or events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	pleasant to be with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	shows interest in recovery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	does what s/he is told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

the following to be completed the morning after the operation

		Good	Restless	Poor
27	was the child's sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Finally:

(i) when did the child first take fluids after the surgery.....

(ii) please tick one option to describe how you would rate the child's ease of first fluid intake:

a) great ease ☐

b) ease ☐

c) difficulty ☐

d) great difficulty ☐

BEHAVIORAL UPSET IN MEDICAL PATIENTS - REVISED (PARENT VERSION

BUMP-R/P

Instructions: Please complete a - d

- a. Today's date is
- b. The child's name is
- c. My relationship to the child is
- d. Time of operation today.....

Please rate the child's behaviour as you have seen it **since s/he arrived at the hospital**. Mark one box per question to indicate your choice.

	Never	Sometimes	Often	Usually	Always
1 is impatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 cries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 gets angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 becomes easily upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 is irritable or grouchy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 refuses to speak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 says s/he feels depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 has to be reminded what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 has to be told to follow hospital routines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Sometimes	Often	Usually	Always
10	looks worried, tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	looks depressed or sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	clinging, needs lots of reassurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	is uncooperative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	complains	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	stubborn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	is very, very quiet, just lets things happen to him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	demanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	tries to get his/her own way by being sneaky	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	able to ask for help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	tries to be friendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	accepts advice or instructions easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Sometimes	Often	Usually	Always
22	starts conversations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	laughs or smiles at funny comments or events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	pleasant to be with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	shows interest in recovery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	does what s/he is told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

the following to be completed the morning after the operation

		Good	Restless	Poor
27	was the child's sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Finally:

(i) what day/time did your child come into hospital

(ii) please colour in on the chart the times your child had company from a member of your family or friends during his/her stay

DAY	MON	TUES	WED	THURS	FRI	SAT	SUN
Time							
6 a.m.							
7 a.m.							
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 midday							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
12 midnight							
1 a.m.							
2 a.m.							
3 a.m.							
4 a.m.							
5 a.m.							

STATE TRAIT ANXIETY INVENTORY

Directions: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the response to the right of each 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 statement but give the answer which seems to describe your present feelings best.

- | | | | | |
|--|------------|----------|---------------|--------------|
| 1. I feel calm | not at all | somewhat | moderately so | very much so |
| 2. I feel secure calm | not at all | somewhat | moderately so | very much so |
| 3. I am tense | not at all | somewhat | moderately so | very much so |
| 4. I feel strained | not at all | somewhat | moderately so | very much so |
| 5. I feel at ease | not at all | somewhat | moderately so | very much so |
| 6. I feel upset | not at all | somewhat | moderately so | very much so |
| 7. I am presently worried over possible misfortune | not at all | somewhat | moderately so | very much so |
| 8. I feel satisfied | not at all | somewhat | moderately so | very much so |
| 9. I feel frightened | not at all | somewhat | moderately so | very much so |
| 10. I feel comfortable | not at all | somewhat | moderately so | very much so |
| 11. I feel self-confident | not at all | somewhat | moderately so | very much so |
| 12. I feel nervous | not at all | somewhat | moderately so | very much so |
| 13. I feel jittery | not at all | somewhat | moderately so | very much so |
| 14. I feel indecisive | not at all | somewhat | moderately so | very much so |
| 15. I am relaxed | not at all | somewhat | moderately so | very much so |
| 16. I feel content | not at all | somewhat | moderately so | very much so |
| 17. I am worried | not at all | somewhat | moderately so | very much so |
| 18. I feel confused | not at all | somewhat | moderately so | very much so |
| 19. I feel steady | not at all | somewhat | moderately so | very much so |
| 20. I feel pleasant | not at all | somewhat | moderately so | very much so |

Directions: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the response to the right of each statement to indicate how you ***generally*** feel. There are no right or wrong answers. Do not spend too much time on any statement but give the answer which seems to describe how you generally feel.

21. I feel pleasant	almost never	sometimes	often	almost always
22. I feel nervous and restless	almost never	sometimes	often	almost always
23. I feel satisfied with myself	almost never	sometimes	often	almost always
24. I wish I could be as happy as others seem to be	almost never	sometimes	often	almost always
25. I feel like a failure	almost never	sometimes	often	almost always
26. I feel rested	almost never	sometimes	often	almost always
27. I am "cool, calm and collected"	almost never	sometimes	often	almost always
28. I feel that difficulties are piling up so that I cannot overcome them	almost never	sometimes	often	almost always
29. I worry too much over something that really doesn't matter	almost never	sometimes	often	almost always
30. I am happy	almost never	sometimes	often	almost always
31. I have disturbing thoughts	almost never	sometimes	often	almost always
32. I lack self confidence	almost never	sometimes	often	almost always
33. I feel secure	almost never	sometimes	often	almost always
34. I can make decisions easily	almost never	sometimes	often	almost always
35. I feel inadequate	almost never	sometimes	often	almost always
36. I am content	almost never	sometimes	often	almost always
37. Some important thought runs through my mind and bothers me.	almost never	sometimes	often	almost always
38. I take disappointments so keenly that I cannot put them out of my mind.	almost never	sometimes	often	almost always
39. I am a steady person.	almost never	sometimes	often	almost always
40. I get in a state of tension or turmoil as I think over my recent concerns and interests.	almost never	sometimes	often	almost always

CHILD VULNERABILITY SCALE

Instructions: Please complete a - c

- a. Today's date is
- b. The child's name is
- c. My relationship to the child is

Now please tick **one box** for each of the 8 items below

	Strongly Agree	Agree	Disagree	Strongly Disagree
1 My child gets more colds than other children I know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 I often think about calling the doctor about my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 When there is something going around my child usually catches it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 In general my child seems less healthy than other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 I often have to keep my child indoors because of health reasons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Sometimes I get concerned that my child does not look as healthy as s/he should	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 I get concerned about circles under my child's eyes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 I often check on my child at night to make sure s/he is o.k.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B

Letter, on hospital headed paper, sent to all General Practices in the catchment
area of the hospital

Drs.

Address.

Date

Dear Drs.

Re: Research Project - The effects of a minor surgical procedure on children and
their families.

Many children and their parents sail through minor operations with little upset and
distress. We want to identify what sorts of parents and children need more
preparation for hospital, and support during their stay. With this knowledge we can
in the future more adequately meet the needs of all our patients.

We would like to approach the parents of all children (aged 3.5 - 13 years) who are
due to have their tonsils or adenoids removed at the Named Hospital.

Parents who agree to participate will complete some questionnaires before, during and after their child's hospital stay (the questionnaires are available on request from Peter Reid, Paediatric Department).

Obviously parents are in no way obliged to participate and theatre treatment unaffected by refusal to do so.

We would like to involve relevant patients from your practice. We hope to start the project in mid November. Could you please let either of us know before then if you would like more information about the project or are not happy for your patients to be involved.

Yours sincerely,

Mr. Name

Consultant ENT Surgeon

Peter Reid

Clinical Psychologist

Appendix C

Children's symptoms described by the referrer to ENT

Table A:

Symptoms Described in the Referral Letter for the 51 Children Scheduled for Surgery

S. No.	<u>Symptoms</u>											
	N1*	N2	N3	E1	E2	E3	T1	T2	T3	G1	G2	G3
1	X			X			X					
2					X		X	X				
3	X	X		X						X		
4	X								X			
5	X	X										
6							X					
7				X			X					
8				X			X					
9	X				X	X					X	X
10	X			X					X			
11									X		X	
12					X		X					
13	X						X					
15	X				X							
16		X	X						X			X
17					X							
18			X				X					
19			X				X					
20							X					
21							X					
23					X							
24	X	X			X	X						X
25				X	X	X						
26					X							
27		X				X			X			
28							X					
29					X		X					
30					X							
31							X					
32			X	X								X
33				X								X
34									X			

(table continues)

S. No.	<u>Symptoms</u>											
	N1	N2	N3	E1	E2	E3	T1	T2	T3	G1	G2	G3
35			X	X	X							
36	X								X			X
37							X					
38							X					
39							X					
40					X							
41						X	X					
42	X	X	X									
43	X	X	X						X			
44							X					
45			X		X		X					
46							X					
47	X	X			X				X			
48									X			
49							X	X	X			
50				X	X				X			
51					X			X	X			
52							X					
53	X	X					X	X				

*N1 = snoring; N2 = mouth breather; N3 = persistent blocked nose

E1 = ear infections; E2 = hearing loss; E3 = glue ear

T1 = tonsillitis; T2 = difficulty swallowing; T3 = sore throats

G1 = "lots of infections"; G2 = upper respiratory tract infections; G3 = concern re speech

Appendix D

Letter, on hospital headed paper, sent to the mothers of children scheduled for
minor ENT surgery

Mrs. or Ms. Name

Address

Date

Dear Mrs. or Ms. Name,

As you know child's name has been offered an appointment for the operation at the
hospital name.

I am writing to you now about a study we are undertaking with Peter Reid, a
colleague from the Paediatric Department. We want to look at the effects of surgical
procedures on children and their families. Our goal is to understand more about the
ways we could support patients undergoing this type of surgery.

Would you be willing to help by filling in some questionnaires ? I am enclosing a
copy of the Parents' Information Leaflet which describes the study. If you feel you
can take part in the study could you please sign the enclosed consent form and return
it either by post (there is a stamped addressed envelope enclosed) or give it to the
receptionist when you come to the preassessment clinic in ENT.

If you agree to help you can be sure that the information you give will be completely confidential. It would be known only to the researcher. Neither your name nor child's name would be linked with the information you provide.

Whether or not you agree to help with the study, will have no effect whatsoever on the care you receive during child's name stay on the ward.

Many thanks.

Mr. Consultant's Name

Consultant ENT Surgeon.

Appendix E

Information Leaflet for Parents

The Effect of an Operation on Children and their Families: Information Sheet for Parents

What is the project ?

A questionnaire study about the effects of a surgical operation on children and their families.

Why have I been contacted ?

We are approaching the parents of all children (aged 3.5 - 13 years) who are due to have their tonsils and/or adenoids removed at the Name Hospital.

What will I be asked ?

If you agree to take part we will ask you to fill out some questionnaires. The first questionnaires are completed when you attend at the preassessment clinic in the ENT Department before your child's operation. The second questionnaire is filled in after your child's operation but before s/he goes home. You complete the last two questionnaires 2 - 3 weeks after your child's discharge. A researcher would visit you at home at a time to suit you to complete these and to hear any comments you have

about the stay in hospital. If you prefer you can post the questionnaires back to us instead.

How long will it take ?

The bulk of the questionnaires are completed when you attend at the preassessment clinic in ENT before your child is admitted. This first set will take about 10 - 15 minutes and can be completed while you are waiting to be seen. The other sets take about 5 minutes.

Who is carrying out the research ?

The research is being jointly planned and carried out by Surgeons in the ENT Department (Mr. Consultant's Names) and Peter Reid, a Clinical Psychologist from the Paediatric Department. A Research Assistant (Name) is also helping with the project.

What if I choose not to take part ?

You are under no obligation to take part. If you choose not to take part, it will not in any way effect your child's right to have whatever treatment s/he needs.

Who benefits from this project and how ?

Many children and their parents sail through operations without any problems. However for some children and their families it is not that easy.

We want to identify what sorts of children and parents are more likely to have difficulty. We can then provide these types of people with better preparation, and more support during the hospital stay and after discharge.

What if I agree to take part but afterwards feel unhappy about the way the research was conducted ?

If you decide to help with the project we hope you find it helpful and interesting. However if you do not like the way the research is carried out you are entitled to complain to the Project Co-ordinator (Peter Reid at telephone number) or to the Senior Administrator (Name and telephone number).

Other questions ?

If you have other questions about the project please feel free to contact Peter Reid (telephone number). There is an ansaphone and a message can be left after 5 p.m. by phoning the same number.

Appendix F

Consent Form

The Effect of an Operation on Children and their Families

I have read the Information Leaflet for Parents and I agree to take part in this study.

I can withdraw from the study whenever I wish without having to give a reason. I understand that this will have no effect whatsoever on the services we receive now or in the future.

Signed

Relationship to the Child

Date

Child's Name

Appendix G

Study Raw Data - Codes

Participants are numbered consecutively from C1 to C53 with no number 14, 22, 44 or 49

Second column begins with the STAI

*STAI-S

*STAI-T

*Operation

- 1= tonsils only
- 2 =adenoids only
- 3= grommets only
- 4= tonsils and adenoids
- 5= tonsils, adenoids and grommets
- 6= tonsils and grommets
- 7= adenoids and grommets

*Wait 1 - Days between GP/AMO's referral to ENT and the first time actually seen in ENT

*Wait 2 - Days between the first time seen in ENT and the final PAC attendance

*Wait 3 - Days between the final PAC attendance and the operation

*Cancel - Cancellation of operation -

- 1 = cancelled by the hospital
- 2 = cancelled by the patient
- 3 = cancelled by ? i.e. don't know
- 4= not cancelled

*Dr. - Consultant

- DS = 1
- MC = 2
- DC = 3

* Child's age

* Gender - Male = 1, Female = 0

- * Usual R. - child's response to medical procedures, Usual Prep. - parent's usual method of preparation
- * Prev. H. Study S and Prev. H. Sib - Previous hospital contacts - yes = 1, no = 0
study child
sib
- * How serious - not = 0, quite = 1, very = 2, n/a = 3
study child
sib
- * PHBQ (12 columns) - PHBQ1B = total of factor 1 scores before hospitalisation, PHBQ1A = total of factor 1 scores after hospitalisation, and so on
- [not at all = 0, every = 4; if only three options then score mid point as 2 i.e. 0,2,4]
- Factor 1 (items 4, 5, 6, 8, 12, 13, 21, 27) - Before & After
- Factor 2 (items 9, 16, 17, 18, 20) - Before & After
- Factor 3 (items 1, 19, 22) - Before & After
- Factor 4 (items 2, 3, 24) - Before & After
- Factor 5 (items 14 & 25) - Before & After
- Factor 6 (items 7, 10, 11, 15, 23, 26) - Before & After
- * PHBQ Concern (none = 0, little = 0.5, lots = 1.0) - Before (B) and After (A)
- * PHBQ - Total scores (Before and After)
- * PHBQ -General question - 1= worse, 2 = same, 3 = better
- * VCS - Before and After
- * BUMP-R-N
- * BUMP-R-P
- *Ease of fluid intake
1 = great ease, 2 = ease, 3 = difficulty, 4 = great difficulty

Table F

Quantitative Raw data

Number	STAI-S (Mother)	STAI-T (Mother)	Surgery	Wait 1	Wait 2	Wait 3	Cancel	Dr.
C1	31	24	7	66	3	3	4	1
C2	67	76	6	112	4	2	4	1
C3	40	39	5	120	32	7	4	2
C4	47	28	4	44	33	7	4	2
C5	34	21	4	42	62	3	2	3
C6	25	33	1	42	110	5	4	1
C7	44	54	6	30	10	9	4	2
C8	47	51	5	25	24	3	4	3
C9	31	42	5	102	184	3	2	3
C10	45	44	5	182	51	39	2	3
C11	28	55	4	42	19	8	4	2
C12	54	51	5	49	3	12	4	1
C13	33	36	4	66	6	5	4	1
C15	34	39	5	47	5	7	4	3
C16	37	35	1	114	43	7	2	3
C17	20	20	5	16	33	72	1	2
C18	23	26	1	48	19	32	1	2

(table continues)

Number	STAI-S (Mother)	STAI-T (Mother)	Surgery	Wait 1	Wait 2	Wait 3	Cancel	Dr.
C19	30	25	4	88	34	27	1	1
C20	39	38	1	194	55	31	2	3
C21	24	31	1	-	-	12	1	1
C23	55	56	4	43	30	6	4	1
C24	48	33	5	31	56	-	1	3
C25	62	52	7	43	40	7	4	2
C26	37	39	7	173	41	4	1	3
C27	55	51	7	155	41	39	1	3
C28	52	31	1	-	-	39	1	3
C29	31	29	1	65	368	7	4	2
C30	34	35	7	162	101	3	1	3
C31	21	44	1	54	61	7	4	2
C32	23	38	1	-	-	7	4	2
C33	32	29	7	21	24	4	4	1
C34	22	25	1	95	27	6	4	1
C35	29	31	7	28	95	7	2	2
C36	45	47	4	14	38	6	1	1
C37	45	29	4	87	192	5	4	1

(table continues)

Number	STAI-S (Mother)	STAI-T (Mother)	Surgery	Wait 1	Wait 2	Wait 3	Cancel	Dr.
C38	36	39	1	18	38	6	1	1
C39	-	-	4	63	186	6	4	1
C40	28	38	7	27	31	6	4	1
C41	39	35	1	30	42	6	4	1
C42	59	69	4	195	76	4	4	3
C43	39	44	4	83	37	6	4	1
C45	46	39	4	41	53	28	1	2
C46	40	30	1	26	15	5	4	1
C47	57	54	7	15	20	5	4	1
C48	40	40	1	-	-	5	4	1
C50	54	57	7	41	56	6	4	1
C51	37	35	1	66	28	6	4	1
C52	33	31	1	63	49	6	4	1
C53	49	47	1	66	34	5	4	1

Number	Age	Gender	Usual R.	Usual Prep.	Prev. H. Study Child	Prev. H. sibs	Study child's H. How serious	Sib's H how serious
C1	3.4	1	1	2	0	1	3	1
C2	5.3	0	3	1	1	1	0	2
C3	3.5	1	1	2	0	0	3	3
C4	6.1	1	1	2	1	0	0	3
C5	5.2	1	1	2	0	1	3	2
C6	7.0	1	3	3	1	1	0	1
C7	6.6	0	1	1	1	1	0	2
C8	4.0	1	1	2	0	0	3	3
C9	4.9	1	1	1	1	3	0	3
C10	6.0	0	1	1	1	1	1	1
C11	4.5	0	3	2	0	1	3	0
C12	4.7	0	1	1	1	3	2	3
C13	7.0	0	1	2	1	3	0	3
C15	4.2	1	1	2	0	0	3	3
C16	9.5	0	1	1	0	0	3	3
C17	6.5	0	1	1	0	0	3	3
C18	9.2	0	2	2	0	1	3	1
C19	11.1	0	1	1	0	3	3	3

(table continues)

Number	Age	Gender	Usual R.	Usual Prep.	Prev. H. Study Child	Prev. H. sibs	Study child's H. How serious	Sib's H. How serious
C20	4.5	1	1	2	1	1	1	1
C21	5.2	0	1	2	0	0	3	3
C23	5.8	0	1	2	1	1	2	1
C24	3.7	1	1	2	0	1	3	1
C25	5.3	0	1	1	0	0	3	3
C26	6.2	0	1	3	0	0	3	3
C27	6.4	0	1	2	1	1	1	1
C28	7.3	1	1	2	1	3	2	3
C29	11.1	0	1	2	1	1	1	1
C30	4.7	1	1	2	0	1	3	1
C31	8.4	0	1	1	1	0	2	3
C32	6.9	1	1	2	1	1	0	0
C33	4.4	1	1	1	1	0	0	3
C34	7.3	1	1	2	0	0	3	3
C35	4.5	1	1	1	1	1	1	2
C36	5.2	1	1	2	0	1	3	1
C37	4.2	1	2	2	0	1	3	1
C38	9.8	0	1	1	1	1	1	1

(table continues)

Number	Age	Gender	Usual R.	Usual Prep.	Prev. H. Study Child	Prev. H. sibs	Study child's H. How serious	Sib's H how serious
C39	9.2	1	1	1	1	1	0	0
C40	6.7	0	1	2	0	0	3	3
C41	9.3	0	1	1	1	1	0	0
C42	6.2	0	1	1	1	3	2	3
C43	8.1	0	1	1	0	0	3	3
C45	4.3	0	2	2	0	3	3	3
C46	11.4	0	1	2	0	0	3	3
C47	4.7	0	2	2	1	1	2	2
C48	9.6	0	1		0	0	3	3
C50	4.1	1	1	2	1	0	2	3
C51	6.8	0	2	2	1	0	2	3
C52	10.2	1	1	2	0	1	3	2
C53	5.2	1	1	1	1	1	0	2

Number	PHBQ1 before	PHBQ1 after	PHBQ2 before	PHBQ2 after	PHBQ3 before	PHBQ3 after	PHBQ4 before	PHBQ4 after
C1	8	0	4	3	6	0	1	2
C2	4	4	7	5	8	10	3	1
C3	6	3	1	5	2	5	4	6
C4	3	1	2	2	3	1	2	0
C5	0	0	3	5	1	3	0	0
C6	1	1	1	0	0	5	4	2
C7	3	2	2	3	8	10	2	3
C8	0	0	5	4	12	12	3	1
C9	4	4	3	4	3	4	3	2
C10	2	5	5	6	0	4	3	6
C11	6	6	10	7	4	8	2	3
C12	8	15	14	15	6	12	6	6
C13	0	0	3	2	3	1	0	0
C15	0	1	5	5	8	3	1	2
C16	1	0	1	1	0	0	0	0
C17	2	2	2	2	0	2	1	3
C18	0	-	0	-	0	-	0	-
C19	1	0	0	5	0	0	1	2
C20	2	4	8	15	5	8	4	4

(table continues)

Number	PHBQ1 before	PHBQ 1 after	PHBQ 2 before	PHBQ 2 after	PHBQ 3 before	PHBQ 3 after	PHBQ 4 before	PHBQ 4 after
C21	0	1	0	0	0	4	0	0
C23	4	5	5	4	10	8	2	0
C24	5	-	4	-	2	-	0	-
C25	1	0	1	3	0	4	2	3
C26	0	-	1	-	3	-	1	-
C27	3	4	1	0	1	2	1	3
C28	2	1	1	1	6	5	1	0
C29	1	1	1	1	2	3	1	5
C30	7	2	3	3	3	3	4	2
C31	2	0	1	1	3	0	2	1
C32	4	0	6	2	5	0	3	2
C33	1	1	3	3	0	0	0	0
C34	0	0	3	0	1	0	0	0
C35	1	0	5	1	5	8	6	2
C36	4	3	6	2	5	7	1	2
C37	2	1	3	2	3	3	4	4
C38	0	3	1	4	5	3	4	4
C39	1	1	1	0	0	0	0	0

(table continues)

Number	PHBQ 1 before	PHBQ 1 after	PHBQ2 before	PHBQ 2 after	PHBQ 3 before	PHBQ 3 after	PHBQ 4 before	PHBQ 4 after
C40	2	3	2	1	0	1	2	4
C41	4	2	4	1	2	0	1	2
C42	1	2	7	8	7	6	5	4
C43	3	1	8	0	7	2	1	0
C45	0	0	0	1	6	2	0	0
C46	0	0	0	0	0	2	0	0
C47	3	7	5	5	6	8	4	3
C48	5	5	3	1	12	4	4	3
C50	5	8	3	1	4	2	4	1
C51	0	4	0	2	8	12	5	7
C52	3	2	0	0	0	0	0	1
C53	1	0	0	1	0	1	4	4

Number	PHBQ5 Before	PHBQ5 After	PHBQ6 Before	PHBQ6 After	PHBQ concern score before	PHBQ concern score after	PHBQ total scores before	PHBQ total score after
C1	2	1	3	1	3.5	0	24	7
C2	3	2	8	6	7.5	4.5	33	28
C3	2	3	2	5	1	4	17	27
C4	0	0	3	3	0	0	13	7
C5	0	1	1	0	0.5	2.5	5	9
C6	2	2	1	3	0.5	1	9	11
C7	4	3	6	1	1.5	1.5	25	24
C8	2	2	2	4	4	3	24	20
C9	2	2	5	5	5.5	3.5	20	20
C10	3	3	4	4	5	8	17	29
C11	7	4	7	4	6.5	1.5	36	32
C12	7	8	16	13	14.5	18.5	57	69
C13	2	2	1	0	0.5	0	9	5
C15	2	3	0	2	0.5	0	16	16
C16	0	0	0	0	0	0.5	2	1
C17	2	2	3	3	1	1	10	14
C18	0	-	0	-	0	-	0	-

(table continues)

Number	PHBQ 5 before	PHBQ 5 after	PHBQ 6 before	PHBQ 6 after	PHBQ concern score before	PHBQ concern score after	PHBQ total scores before	PHBQ total score after
C19	0	2	0	1	0.5	1	2	10
C20	2	2	4	5	3.5	10	25	38
C21	0	0	0	0	0	0	0	5
C23	1	1	3	2	4	2	29	22
C24	3	-	4	-	6.5	-	18	-
C25	1	1	1	2	0	0	6	13
C26	1	-	0	-	0	-	6	-
C27	0	0	0	3	0.5	2.5	6	12
C28	0	0	1	1	1.5	0.5	11	8
C29	2	2	1	2	1	2.5	8	14
C30	0	1	3	4	2.5	0.5	20	15
C31	2	2	2	0	1	0	12	4
C32	1	0	8	2	5.5	0.5	27	6
C33	1	2	3	1	0	0	8	7
C34	2	1	1	0	0.5	0	7	1
C35	3	2	2	1	5.5	0	22	14
C36	3	2	6	1	5.5	5	25	17

(table continues)

Number	PHBQ 5 before	PHBQ 5 after	PHBQ 6 before	PHBQ 6 after	PHBQ concern score before	PHBQ concern score after	PHBQ total scores before	PHBQ total scores after
C37	1	1	2	1	5.5	2.5	15	12
C38	0	0	0	0	1.5	2.5	10	14
C39	1	0	0	0	0	0	3	1
C40	2	1	6	1	3	1	14	11
C41	1	0	2	0	5.5	0	14	5
C42	3	4	4	2	8	6	27	26
C43	1	0	6	0	4.5	0.5	26	3
C45	2	2	0	0	0	0	8	5
C46	0	0	0	0	0	0	0	2
C47	2	2	4	3	12	13	24	28
C48	2	1	4	1	1.5	1.5	30	15
C50	1	0	3	3	2	3.5	20	15
C51	1	1	1	2	1	5	15	28
C52	2	0	2	2	2	0	7	5
C53	0	2	0	0	1.5	0.5	5	8

Number	PHBQ Gen. Q. - B	PHBQ Gen. Q. - A	VCS before	VCS after	BUMP- R-N	BUMP- R-P	ease of fluid intake
C1	2	2	16	9	14	14	2
C2	2	2	20	16	37	59	2
C3	2	1	13	14	31	36	2
C4	2	2	15	12	27	30	2
C5	2	2	12	9	19	4	1
C6	2	2	9	9	14	25	2
C7	2	1	11	9	31	14	1
C8	2	2	11	10	17	34	2
C9	2	2	12	12	12	17	2
C10	3	2	14	15	18	31	2
C11	2	2	15	16	36	40	2
C12	2	1	22	21	28	71	2
C13	2	2	15	10	18	14	2
C15	2	3	3	11	11	29	2
C16	2	2	1	0	-	21	3
C17	2	1	12	11	9	13	2
C18	2	-	13	-	-	-	-

(table continues)

Number	PHBQ Gen. Q.- B	PHBQ Gen. Q.- A	VCS before	VCS after	BUMP- R-N	BUMP- R-P	ease of fluid intake
C19	2	2	8	8	11	13	1
C20	2	1	16	16	45	47	1
C21	2	2	21	11	10	15	2
C23	2	2	22	16	27	49	1
C24	2	-	11	12	-	-	-
C25	2	2	12	-	11	23	2
C26	2	-	9	-	0	30	2
C27	2	2	6	8	8	4	2
C28	2	2	12	10	17	15	-
C29	2	2	18	15	18	39	3
C30	2	2	11	11	3	17	-
C31	2	1	4	9	3	29	2
C32	2	2	16	13	3	34	-
C33	2	2	3	5	13	6	1
C34	2	2	6	3	31	13	1
C35	2	2	12	7	15	19	2
C36	2	2	19	-	15	24	3

(table continues)

Number	PHBQ GEN. Q.-B	PHBQ Gen. Q.- A	VCS before	VCS after	BUMP- R-N	BUMP- R-P	ease of fluid intake
C37	2	2	14.5	12	22	25	1
C38	2	2	8	9	-	12	-
C39	2	2	10	11	29	31	1
C40	2	2	17	13	30	33	1
C41	2	2	12	10	28	23	-
C42	1	1	19	17	11	-	2
C43	2	3	13	8	-	17	-
C45	3	3	13	2	3	24	2
C46	2	2	10	10	1	8	2
C47	2	1	18	19	5	37	1
C48	2	3	12	11	34	20	2
C50	2	2	13	14	16	8	1
C51	2	2	12	9	7	32	-
C52	2	2	10	9	2	23	2
C53	2	2	9	3	33	13	2