The experiences and emotional responses of parents with hospitalised children: an examination of possible contributory factors

Thesis

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THE EXPERIENCES AND EMOTIONAL RESPONSES OF PARENTS WITH HOSPITALISED CHILDREN

AN EXAMINATION OF POSSIBLE CONTRIBUTORY FACTORS

A thesis submitted in partial fulfilment of the requirements of the Open University for the degree of Doctor of Clinical Psychology

July 2000

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE
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ABSTRACT

**Background and Aims:** Research has highlighted some of the parental stressors experienced in hospitals by parents of children that required repeated admissions. Little had been written about parents of essentially healthy children with a first admission for an acute condition/needling surgery. A small qualitative study investigating the hospitalisation experiences of this group of parents was completed by the author earlier. The aim of the present study was to find out if the factors identified previously as being the most stressful, do in fact contribute to the distress experienced by parents in hospital.

**Design and Participants:** This cross-sectional study used comparative and correlational analyses. The sample included 75 parents of children in hospital.

**Measures:** Variables were measured using a range of constructed questionnaires.

**Results:** The results showed that parents experienced a higher level of psychological distress while at the hospital, compared to a couple of weeks prior to their child’s admission. Parents’ perceived seriousness of their child’s condition, was correlated with higher level of anxiety while at the hospital. Other results indicated that parents were satisfied with hospital procedures, staff communication and parental role. However, parents of children with first admissions were less satisfied with some aspects of communication and more confused about parental role compared to parents of children with repeated admissions. Findings highlighted the levels/sources of support parents received. It was noted that there was a significant relationship between depression and support from family and a significant trend was also found for depression and support from other parents on the ward.

**Implications:** The discussion considers explanations for the findings, which are discussed in relation to previous literature. Clinical implications for undertaking work with health care professionals and working with parents on paediatric wards are examined. The limitations of this study are explored and further research is suggested.
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1. INTRODUCTION

1.1 HISTORICAL PERSPECTIVE

In the early 19th century, children were rarely admitted to hospital. Nursing care was unskilled and children in hospital usually only had their mothers to look after them. The developments of anaesthesia and antisepsis demanded trained, skilled nurses, and the perception of hospitals as places where people got better rather than died brought about a dramatic increase in the number of children’s hospitals in the mid to late 1880’s (Darbyshire, 1993).

The emphasis on cleanliness and fresh air however, meant that hospitals were often built in remote places. Parents were able to visit infrequently and children were often distressed as the parents left these visits. As a result, professionals assumed that parental visiting of children in hospitals should be discouraged (Cleary, 1992).

The emotional impact on young children as a result of maternal deprivation is now well documented by Bowlby (1953). In Britain, however, the most important recognition of children’s social and psychological needs while in hospital occurred in 1956 when the Government formed the Platt Committee. The resultant report’s most controversial proposal was open visiting for parents at any ‘reasonable’ time, and also the admission of mothers with children, especially for those under the age of five. The report also recommended that parents should help as much as possible with the care of their child. However, progress in implementing the recommendations of the report
was slow, and there was considerable geographical variation. It was argued that while the Platt Report considered the psychosocial needs of children, it failed to consider the implications for, and the effect on, parents and indeed nursing staff as a result of this increased parental participation (Hall, 1978).

Today, parents are encouraged, and in some hospitals required, to stay with their children 24 hours a day. However, this situation has introduced new problems. Although sources have long since stated the advantages of incorporating parents into the health care team (Mahaffy, 1965; Fletcher, 1981), professionals may hesitate to relinquish care of a sick child to his or her parents. Moreover, some parents may try to assume too much responsibility for a hospitalised child. Some research suggests that role ambiguity occurs when the role occupant (i.e. the parent) experiences a loss or change in their role or lacks the information necessary to adequately perform that role (Rizzo, House & Litzman, 1970). This has been found to be associated with stress and having to adopt coping behaviours to try to deal with the situation parents may find themselves in (Fisher, 1994).

Over the past twenty years, many studies focusing on parental stress have been carried out in paediatric intensive care units (Miles & Carter, 1985; Kasper & Nyamathi, 1988). Some of these papers reported on the psychosocial impact of childhood illness on the children and their families. Many were also conducted from the perspective of health care providers, hence their design may have been less sensitive to the concerns of parents (Burke, Kauffmann, Costello & Dillon, 1991). As the main focus of the present study is on parents' experiences in hospital, in the literature review that
follows, papers that specifically addressed the psychological impact of the hospitalisation experience on the parents will be examined and discussed.

1.2 LITERATURE REVIEW

A CD ROM literature search using Psychlit, BIDS and Medline, (Jan 1989 - April 2000) was carried out. Key words were used singularly and in various combinations to identify relevant papers including: children in hospital, chronic/acute illness, parental anxiety, parents' experiences, parents' expectations, parents' satisfaction, medical staff, communication, parental role, child health, hospitalisation, medical procedures, parent participation and maternal distress.

Forty-five publications in all were identified, thirty-nine of which are included in the in-depth review that follows. Both qualitative and quantitative studies are included. The remaining papers which were excluded were either published in non-English language journals, or did not have a rigorous study design and sufficient data collection to allow for meaningful statistical analyses. Some others simply did not cover the area of investigation, that is studies on adult patients or children rather than parents, or the effects of having a chronically sick child on the family, rather than the effect of the hospitalisation experience on the parent.

Theory driven research in the field of paediatrics is lacking (Wallander, 1992). As a result, suggestions regarding the processes by which interventions exerted their effects are merely a matter of speculation (Melnyk, 1995). However, it is possible at this
point to add some theoretical examination of the possible or likely psychological components to the situation of parents in hospitals with their children. The following theoretical strands are addressed: stress and coping, role, in particular parental role, role ambiguity and crisis theory.

Following this, the empirical studies will be examined to try to ascertain whether the evidence supports any particular models. There have also been some studies on interventions which will be covered in the next section, together with an outline of an earlier qualitative study by the present author. This will be followed by the rationale and research questions for the present study.

1.3 RELEVANT THEORETICAL FRAMEWORKS

1.3.1 Stress and Coping:

As referred to earlier (Fisher, 1994), the hospitalisation experience for parents can be associated with stress, often resulting in adopting coping behaviours to try to deal with the situations they may find themselves in. Thus, a useful conceptual framework for looking at what happens to parents could be derived from theories of stress, adaptation and coping. This framework postulates that the intensity of an individual’s stress response is determined by multiple variables which include personal factors, situational conditions and environmental stimuli. According to this theory, the environmental stimuli facing a parent in this situation include the interpersonal dimensions of the hospital ward. Other factors include possible relationships between selected personal
and situational variables and parents' perceptions of environmental stressors on the ward (Fisher, 1994).

Folkman and Lazarus (1984) defined coping as constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. It is generally agreed that coping efforts serve two main functions: (a) the management or alteration of the person-environment relationship that is the source of stress (problem focused coping) and (b) the regulation of stressful emotions (emotional focused coping), (Folkman & Lazarus, 1984; Moos & Schaefer, 1986; Rutter, 1981).

Problem focused strategies include efforts directed at solving the problem or doing something to alter the stressful event. Examples of problem focused coping strategies include seeking information and support, taking action to deal with a crisis or its aftermath, and establishing goals or working on a specific task. Emotion focused strategies are aimed at decreasing or managing negative emotions associated with the stressful situation. These strategies include activities such as cognitively redefining a situation, venting one's emotions, and/or taking drugs or alcohol. Although most people use both problem and emotion focused strategies in dealing with a stressful event, problem focused forms are used more frequently when an individual feels that something constructive can be done about the situation (Folkman & Lazarus, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). In contrast, individuals tend to use more emotion focused strategies when they lack the ability to alter the stressful encounter (Folkman et al. 1986).
The outcomes of coping seem to be directly related to the problem solving and emotional regulating functions of coping (Johnson & Lauver, 1989). Outcomes of emotion focused coping for an individual would be changes in the level of emotion and morale experienced such as anxiety, fear, depression, self esteem and life satisfaction. The extent to which an individual is able to resolve problems, attain goals, or maintain usual life activities and social roles would be indicative of the efficacy of their problem solving coping.

Further to this, self regulation theory is a cognitive theory that uses concepts from information processing theory to explain human behaviour (Johnson, 1984; Leventhal & Johnson, 1983). It focuses on how individuals cope with stressful situations. For example, the theory contends that provision of concrete objective information facilitates coping through the formation of a cognitive schema that is analogous to the real life experience. The processes by which coping schemas are thought to operate include: (i) decreasing the discrepancy between what is expected and what actually occurs; (ii) increasing predictability; and (iii) enhancing one’s ability to understand and interpret the experience (Johnson & Lauver, 1989). The schema that is formed from concrete objective information provides a structure for monitoring the stressful event. Subsequently, when the event matches the schema, less energy is expended in trying to classify and interpret the incoming information (Johnson, 1984).

Expected events are also less likely to stimulate negative emotional reactions than events that are uncertain or unexpected (Leventhal & Johnson, 1983). When events are predictable and reduced to concrete elements that may have been previously experienced, an individual can gain confidence in his or her already existent coping.
repertoire and use more problem solving strategies (Johnson, 1984, 1988). Once again, energy can be preserved because the strain of learning and using new strategies to cope with the stressful event is unnecessary (Johnson, 1984).

Evidence to support self regulation theory has been gathered from a series of studies that investigated the effects of concrete objective (sensory) information. These studies compared sensory information with other types of information on the coping processes and outcomes of patients experiencing stressful procedures (Johnson, Kirchhoff & Endress, 1975; Johnson, Morrissey & Leventhal, 1973). Provision of concrete objective information was found to result in beneficial outcomes of emotion and problem focused coping. One can speculate from the above implications, that factors such as clear communication and information to parents may make for a less stressful experience for parents while at hospital with their children.

1.3.2 Role Theory:

As mentioned earlier, according to Jay (1977), one of the greatest stressors for parents in hospital is role revision, which is described as giving up the role of parent of a healthy child and taking on the role of parent of a ‘sick’ child. Miles (1979) identified a change in parental role as one of three major stressors that parents in hospital with their children may experience.

The concept of role has been defined in various ways, with Levinson, (1959) for example, defining a role as a set of shared normative expectations that people hold for
the behaviour of someone in a given social position. In view of this, a role is regarded as something that exists apart from the specific person who assumes it.

The process of mentally constructing the attitudes and expectations others have for a person in a given role is known as role taking. Wofford, Gerloff and Cummins (1979) distinguish between perceived, expected and enacted roles. The perceived role is the set of behaviours that the occupant of the position believes he or she should perform. The expected role is the set of behaviours that others believe he or she should perform. Enacted role is the actual set of performed behaviours.

Although a high level of agreement may occur between perceived, expected and enacted roles, frequently the three differ. This may lead to role ambiguity which occurs when the role occupant lacks the information necessary to adequately perform a role (Rizzo, House & Litzman, 1970) leading to coping behaviour by the role incumbent (Kahn, Wolfe, Snock & Rosenthal, 1964). Role ambiguity also increases the probability that a person will perform less effectively in their own or others' eyes. It could be speculated that this is likely to affect parents' satisfaction with nursing care because parents who are uncertain of their role in caring for their hospitalised children are likely to perceive that they are not performing effectively. They may make external or internal attributions about the responsibility for that performance deficit, either feeling inadequate or feeling dissatisfied with the setting and the hospital staff.
1.3.3 Parental role theory and crisis theory:

Before examining more closely the parental role in hospital, it is probably helpful to define what it means to be a parent in the wider context. Biological theories stress the inherent instinctive drive that casts motherhood as a natural and almost a biological inevitability (Bolton, 1983). Social theories, however, view parenthood as a socially constructed job or role, where the required social skills need to be learnt (La Rossa, 1986). Darbyshire (1994) takes this further by suggesting that parenting is more than a way of cognitively knowing, but is a way of being. For a parent to stay with his or her child in hospital, or become a live-in parent, it is important to recognise that it is not just the environment that has changed for the parent, but also the social setting (Callary & Smith, 1991). For example, home is a place that carries concepts of control, privacy and a sense of security. It is at home that a parent is able to relax. In hospital, however, there is no privacy, either geographically or physically.

Development and organisation of the parental role is cyclic in relation to the child’s growth and development and focuses on meeting the needs of the child. More specifically, the parental role includes physical, psychological and sociological responsibility for a child from infancy through to adolescence. Parents must meet the broad spectrum of the child’s needs in addition to all of their own (Bell & Vogel, 1968).

During a child’s critical illness, the complementary parent-child role structure and process is disrupted. As a result of this role interruption and change, significant unfamiliar needs become apparent that are likely to increase parental stress.
A crisis is defined by Caplan (1964) as an event facing an individual or family for which normal problem-solving or coping mechanisms are not effective. It is a period of disequilibrium that overpowers homeostatic mechanisms because it is linked with fundamental, instinctual needs. These needs are defined as requirements of the individual that, if supplied, decrease immediate distress or improve immediate sense of adequacy or well being. In order to deal adequately with stress, an individual must have adequate "supplies" to meet the needs commensurate with his or her current stage of growth and development. These supplies or needs can be roughly classified into three groups, physical, psychological and sociological. When an individual's needs in one or more of these areas are not met, and alternate resources are not available, a stressful situation becomes a crisis. This theory might imply that if parental role needs are neglected when a child is in hospital, a very stressful situation or crisis might result.

1.4 PREVIOUS RESEARCH ON PARENTAL EXPERIENCES OF HOSPITALISATION

1.4.1 Parental Needs:

Up until the late 1980's, relatively little research had been carried out into the needs of parents of children in Paediatric Intensive Care Units (Kasper & Nyamathi, 1988). Identified needs of parents had been based on clinical observations rather than systematic research. Among the needs identified in this manner were the need to receive information, trust in the child's caretakers, continue the parental role and
receive support. However, Miles and Carter (1985) maintained that parents' unmet needs can decrease parental coping, resulting in increased stress. They also reported that one source of stress identified by parents was the disruption of the normal parental role. Therefore, a growing area of research has been the quest to try to identify the sources of stress and the needs of parents in hospital with their children.

The concept of total patient care of a critically ill child in the paediatric intensive care unit includes the child's parents, according to Kasper and Nyamathi (1988). They carried out a qualitative descriptive study to determine parental needs, as identified by the parents of children in an intensive care unit. Using a flexible semi-structured interview guide, they asked 15 parents about individual and parental role needs. Internal validity and reliability were established and the interview transcripts underwent content analysis which categorised needs as physical, psychological or sociological in origin, with the majority of parental needs being psychological. Subcategories identified most frequently were "visit or stay with the child" and "child related information". The authors concluded from this that the specific needs were to be with the child and to receive frequent, accurate and truthful information about the child's condition. Other identified needs related primarily to the parental role function and the alleviation of parental stress in the existing situation. These findings fit with the self regulation theory discussed earlier as well as supporting the findings by Robinschon (1969).
1.4.2 Measuring parental satisfaction with care provided:

Many studies have looked at parent satisfaction. Callery and Luker (1995) examined user satisfaction with the care of hospitalised children. They argued that parents are proxy consumers but that their status is conditional on the way in which they exercise choices. Parents' involvement in the care of their children means that the term 'user' is more appropriate than that of 'consumer'. They analysed the experiences of 24 parents of children discharged from a children's surgical ward. The study found that 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 in context, parents provided detailed accounts which identified unsatisfactory aspects of the service. However, it is not possible to generalise from this study, due to the small number of participants.

Quantitative studies that devised questionnaires include one by King, Rosenbaum and King (1996), who were seeking a psychometrically sound measure that in particular, could discriminate parents' perceptions of differences in the nature of the services they experienced. They were especially interested in the behavioural and interactional aspects of professional activities, rather than the structure or content of the services. In their study they describe the development of a 56 item questionnaire, the Measure of Processes of Care (MPOC-56) designed to discover what parents of a child with a chronic health problem think of the services they and their child receive and how these services affect psychosocial outcomes.
The instrument was found to be internally consistent and reliable on re-tests. Its validity was shown by positive correlations of the five scales with parents' satisfaction, and negative correlations with parents' stress in relation to services received. They found that interactional aspects were indeed linked to satisfaction. The MPOC-56 is a generic measure which can be used for clinical, quality assurance and research purposes. However, the authors acknowledged that further work was needed to evaluate the generalisability of the concepts and contents.

Similar findings to the above were reported by Brown, Sheehan, Sawyer, Raftos and Smyth (1995) on levels of satisfaction of parents in an emergency department located at a paediatric teaching hospital, but generalisability may be limited, especially to parents on an in-patient ward.

It is well established that parents of chronically ill children experience many stressors (Turk & Kearns, 1985) and are a group at risk of developing emotional problems (Koocher, O'Malley, Gogan & Foster, 1980). Bradford (1991) looked at an area that had received little systematic attention, such as the relationship between parents' satisfaction with hospital services and their subsequent adjustment, and suggested that the accurate identification of parental worries by staff is a pre-requisite for providing emotional support. The parents of 54 children with a chronic physical illness completed the Survey of Parental Satisfaction (SPS) (Dare & Hemsley, 1986). This questionnaire was specifically designed to identify emotional distress and its causes in parents of children with liver disease. It comprised of 35 items, assessing parental dissatisfaction with information and emotional support, the magnitude of emotional problems experienced and perceptions of the opportunities available to discuss
concerns with staff throughout the child’s care. The authors report good reliability and validity in its use as a postal survey. Six groups of paediatric staff were used and relevant parents were identified by inspection of hospital records.

Comparisons were made between the actual rate of parental satisfaction with information and emotional support, the magnitude of emotional problems experienced and opportunity to discuss concerns with medical, paramedical and nursing staff. It also assessed staff estimates of the same problems. Staff estimates were calculated and deemed ‘accurate’ if they fell within plus or minus 10 per cent of the actual average frequency reported by the parents. The data were analysed and results demonstrated a large variability both within and between staff groups in accuracy.

Overall, staff significantly underestimated the magnitude of emotional problems experienced, whilst significantly overestimating the opportunities available for parents to discuss concerns. All staff significantly underestimated parental satisfaction with information. The small number of parents in this study raises the question of bias however, and in particular whether the group was representative of families generally seen within the liver unit, or indeed other specialities. However, the author states that studies of other illness groups suggest similar frequencies of both distress and dissatisfaction (Koocher et al. 1980). The results highlight the need for staff training to increase both awareness and accuracy in identifying parents’ psychological adjustment.

Feather, Kinderman and McDowell, (1996) compared the desires, opinions and views of parents with those of staff caring for their children. They found that staff tended to
underestimate parental needs for information. Feather et al. (1996) proposed a model (The Guardianship Model) which accords both with qualitative data derived from written and verbal comments by parents and with the subjective experience of parents in this study. The most important implication of this guardianship role, is for staff communicating with parents, in particular for those who convey information about clinical matters, diagnosis, prognosis, treatment options and side effects, etc. However, it is not particularly novel to suggest that a prime responsibility of parents is to act as the guardians of their children. The guardianship model seems to suggest that while there may be variations in the desire for involvement in clinical decisions, there is a more universal need to monitor and check the decisions of staff.

Another study which compared parents’ satisfaction with hospital staff’s satisfaction (and unlike many of the other studies in this area, starts off from the service’s viewpoint), was carried out by Adams (1994). She interviewed 18 nurses to identify behaviours appropriately performed by 76 parents for their hospitalised children, and formal rules were drafted from the findings. The rules were communicated orally as well as in writing to a group of parents who were compared with a group of parents who had no formal communication. The areas being measured were impact on both nurses’ job satisfaction and parents’ satisfaction with nursing care, as well as nurses’ and parents’ role ambiguity. The formal rules were found to enhance both nurses’ job satisfaction and parents’ satisfaction with professional competence. Moreover, both nurses and parents perceived a reduction in role ambiguity as measured by the information that nurses gave and the communication of expectations.
Street (1991) studied 151 parents who, in evaluating their children’s health care, felt it was influenced by perceptions of physicians’ informativeness, interpersonal sensitivity and partnership building. Another problem to emerge for parents who experience hospitalisation with their children was examined by Marais (1996), who surveyed 64 parents by questionnaire pertaining to their knowledge, attitudes and experiences both before and two months after their children underwent an adenoidectomy and grommet insertion. Although a positive image of, and high satisfaction with, both procedure and in-patient stay were demonstrated, the findings suggest that many parents failed to appreciate the existence, nature and frequency of possible complications.

Marais’ retrospective study using postal questionnaires is not without problems. For example, one could question whether parents are going to have an accurate memory of what happened in hospital eight weeks later, when they are back in their own home environment and lifestyle. Perhaps parents could have been interviewed during their child’s admission to get a better understanding of these parents’ experiences and their needs could have been identified and met at the time (i.e. explicit description of the most common post operative complications, in this case). However, this study also highlights the need for better communication between parents and professionals to enhance the hospital experience for parents.

These studies highlighted staff-parent communication as an important determinant of satisfaction. They also fit with the findings of parental needs studies, which found that parents need clear, concise and truthful information about their child. All these studies could be linked to the stress coping model discussed earlier.
1.4.3 Parental Stressors:

Many papers address the psychosocial impact of childhood illnesses on the child and their family, but few specifically address the psychological impact of the hospitalisation experience on the parents. In their comprehensive overview of services and research on children with chronic conditions, Pless and Perrin (1986) do not mention hospitalisation per se, as an issue for these families. Increasingly, in a nursing literature review by Burke and Roberts (1990), they also found that when health care professionals as researchers asked parents to list stressors, repeated hospitalisations did not emerge as a construct. In contrast, when inductive methods were used and when parents' perceptions were studied, Burke and Roberts found hospitalisation emerged as very stressful indeed.

Robinson (1987), Thorne and Robinson (1988), Bradford (1991) and Burke et al. (1991), all studied parents' experiences of hospital admissions for children with a variety of chronic illnesses. Despite current trends which have resulted in an increased focus on chronic, long term illnesses, little is written about the impact of repeated hospitalisations from the parents' perspective.

A phenomenological study was carried out by Robinson, (1987) which explored parents' views on hospital stays using a semi-structured interview schedule. She interviewed nine parents of children with chronic illnesses, such as muscular dystrophy and meningomyelocele. They were selected by virtue of their status as "expert witnesses" to the phenomenon under study. The findings that were selected for presentation were those shared aspects of the parents' perspectives that illustrated the
difficulties they experienced with care in hospital, and gave direction for implementing ‘family centred care’. The difficulties have been termed by Robinson as “road blocks” because it appeared that both health care professionals and parents were trying to reach the same destination, such as mutually satisfying care. However, there are obstacles along the road that parents perceive as negatively affecting progress toward this goal and led to parents becoming stressed. The roadblocks parents discussed as interfering with their trust and confidence in care revolved around a common theme of discrepant expectations arising from differing perspectives. The four areas in which discrepancies caused significant difficulties for the parents according to their accounts were:- orientation to sickness, therapeutic goals, expectations about hospitalisation and perspectives about family involvement.

Burke, Kauffmann, Costello and Dillon (1991) also carried out a qualitative piece of research to study the effect of repeated hospitalisations. Their study entailed theoretical sampling that is, data collection, data analyses and then further data collection in a tightly interwoven process, with collection and analyses occurring alternately because the analysis directs the sampling of the data. The whole process spanned four years, and included 30 mothers of children who had chronic illness or disability and 30 mothers of healthy children; 100 parents of disabled children who attended a weekend retreat, six community health nurses, and nine mothers of chronically ill and disabled children, before, during and after a hospitalisation. They developed a grounded theory (Glaser & Strauss, 1967) of the stresses and coping responses of parents to the repeated hospitalisation of chronically ill and disabled children.
The resulting theory identified the most stressful aspect as "hazardous secrets", (i.e. receiving information of a negative nature regarding diagnoses, medications and treatments, observing variations and gaps and/or omissions in management based on parental experience with similar situations, and dealing with a solo, inexperienced health care worker). Parents dealt with these kind of situations through polite enquiry or request and when the information or action was forthcoming the matter was resolved. In cases where there was insufficient information or no resolution, "reluctantly taking charge" was the eventual response to the "Hazardous Secrets".

The authors found that "reluctantly taking charge" involved four types of actions, which are: vigilance - being there just in case; taking over - occurs when the parent takes on an activity or task the health care system is unable to do; calling a halt - occurs when the parent feels that the child has had enough, and insists for example that his/her child is tended by the doctor instead of an inexperienced health care worker; and/or tenaciously seeking information. The process of taking charge is a gradual one that is taken with much reluctance it seems, on the part of a parent for fear of being seen as a "trouble maker". However, through the activities of taking charge there is the risk of mounting "exhaustion" and stress. The authors concluded that their findings are set in a theory with identified stages, causes, consequences and conditions. This theory seems suitable for cognitive applications in nursing practice as well as application to other age groups and settings.

The findings from this study fit with Lazarus and Folkman's (1984) model of stress and coping in that the parents are constantly changing their cognitive and behavioural efforts to manage the specific external demands that they appraise as taxing. The parents needed to adopt problem focused strategies by making efforts at solving the
difficulties by seeking information, taking action to deal with a crisis and establishing goals or working on specific tasks, i.e. by taking charge. Further to this, the parents appeared to change role, which support the findings of Jay (1977) who suggested that one of the greatest stressors for parents in hospital was role revision. Burke et al.'s (1991) findings support Feather et al.'s Guardianship model, in that both sets of parents had to make adjustments to their role while at the hospital.

In a study published earlier, similar findings had been reported by Thorne and Robinson (1988), who studied the relationship between parents of children with chronic illness and professionals to determine the most stressful stages for parents. They found in their quantitative study three stages: "trust" where parents had faith in medical experts, "disenchantment" when parents learnt medical staff were not infallible and "guarded alliance" where parents showed a mixture of trust and watchfulness.

Hughes and Lieberman (1990) examined the psychosocial stresses of having a child with cancer. One hundred and fifty parents were invited by letter to take part, but out of the 38 parents interested, the first 18 to reply were interviewed, thus further biasing an already highly selective sample. The findings, which are similar to the ones already mentioned, confirmed that staff/patient communication was difficult in a large institution and was the main stressor identified, but that it can be facilitated by staff who are aware of the difficulties.

Berenbaum and Hatcher (1992) compared 20 mothers of hospitalised children on a paediatric intensive care unit (PICU), 20 mothers of hospitalised children on a general paediatric medical surgical unit, and 20 mothers of non-hospitalised ill children on
standardised measures of anxiety and negative mood. The mothers of children admitted to the PICU experienced greater state anxiety, depression, confusion and anger than the other mothers. There were no differences between the mothers of children admitted to the general paediatric floor and mothers of non-hospitalised ill children. Maternal age, family stress, number of prior hospitalisations and the mother's rating of the severity of her child's illness were predictive of emotional distress. Results indicate that hospitalisation of a mildly or moderately ill child per se, may not necessarily increase maternal emotional distress.

1.4.4. Summary

Some of the main themes to emerge from these studies, appears to be that parents undergo multiple stressors during hospitalisation of their children, with emotional upset, lack of knowledge, uncertainty about what is happening, and communication problems being the predominant ones.

Researchers using both qualitative and quantitative methodology have helped to highlight some of the parental stressors experienced in hospitals, but only one paper actually highlighted the hospital stay itself as the main stressor (Burke et al. 1991). Most of the papers reviewed, indicated their implications for clinical practice and suggested ways of implementing these, but interestingly, none of the studies did follow up to investigate further as to whether the recommendations had been implemented or reviewed parents' resulting experiences. In today's health care culture of 'evidence
based practice', it would be essential to consider and measure the outcomes of studies, in order to inform good practice and policy decisions within the health service.

One must bear in mind, that this review is only a selection of the literature in this area. What did emerge was:-

1. Studies tended to look at one type of illness and perhaps not much comparison of different illnesses or acute versus chronic illnesses have been investigated. For example, the lack of research into the experiences of parents with essentially healthy children who have acute hospitalisations, did not receive much mention. One can surmise that their experiences may be quite different from those of parents with repeated hospitalisation stays, but nonetheless, can be very stressful in different ways. For example, unlike the repeated attenders, they do not know what to expect of staff, treatment, advice, care or their role. One can only suggest, from the evidence presented in the literature, that their experiences may lead parents to feeling bewildered and uncertain, which may lead to difficulties affecting their anxiety with a possible consequence on their child's health and recovery.

2. No study compared or contrasted the effects on the two different groups, that is, parents of first time attenders, and parents of repeated attenders to see whether their experiences were similar or different, so that interventions designed to meet the needs of one group may be modified or similarly articulated to both groups.
The literature review found that several of the studies on parental stress in paediatric intensive care units tended to report on the experiences of parents of those children with chronic conditions that required repeated hospitalisation. What was apparent was a lack of research into the experiences of those parents who attended hospital for the first time, with an essentially healthy child who either had an accident, an acute medical condition or required elective surgery.

A small qualitative study (O'Dwyer, 1997) looked at the hospitalisation experiences of parents of children admitted for the first time to hospital. This found that these parents experienced feelings of bewilderment, uncertainty about role expectations, and frustrations with communicating with the staff, leading to difficulties that affected their anxiety levels and coping strategies employed. A grounded theory approach to the data identified the most stressful aspects of the hospitalisation experience for the parents as: lack of knowledge about expected roles, poor level of parental support received, as well as the way in which the admission, treatment and discharge procedures were handled by medical staff.

Where parents felt that they had experienced the hospital stay as positive, with minimum stress and felt they had coped well, they described good, clear communication between themselves and staff about the more stressful aspects mentioned above. On the other hand, where some parents experienced what was termed 'barriers/erosions' with communication, (i.e. inconsistencies within and between staff, unavailability of staff, disagreements, medical jargon being used,
excuses being given by staff and assumptions being made often incorrectly on either or both sides), these parents found themselves having to make adjustments to their perceived role and/or lost confidence in the medical staff. When they did not feel supported or had experienced some of the procedures as difficult, these parents described their experiences of hospitalisation in extremely negative terms. They found being at hospital very distressing and anxiety provoking, and they had difficulty coping. This was in contrast to the findings of Berenbaum and Hatcher, (1992).

The theory devised was conceptualised into a working model for use by the Clinical Psychology Paediatric Liaison team, for teaching and training healthcare professionals in order to increase awareness and inform good child health care practice. The results were also acknowledged by the team as providing an understanding and insight into parents’ experiences while on the ward. This highlighted the possible need to offer a service to support some parents and help them address their psychological needs and stress while on the ward, in conjunction with the on-going child work that took place.

The inductive method used in this study showed that the parents’ perceptions of their experiences in hospital were very similar in part to those reported in some of the studies of parents of children with repeated hospitalisations. However, as this was a small scale study, it does not allow for generalisations. One of the questions left unanswered was whether parents of first time attenders and parents of children with repeated admissions do actually have the same experiences, the same levels of stress and report the same concerns.
Further to this, almost all the research acknowledges that aspects of the hospitalisation experience are stressful for parents. This may affect their child's recovery rate, anxiety levels and experience of hospital. As a result of findings from these studies, many researchers and clinicians have emphasised the urgent need to develop and evaluate interventions for parents of ill children in order to facilitate clinical practice strategies that are empirically based (Fisher, 1994; Halm, 1992; Kirschbaum, 1990).

1.4.6 Studies of interventions to reduce parental stress:

Despite some 30 years spent researching this area, parents continue to be relatively powerless in health care settings. For example, in Australia, Whelan and Kirkby (1998) examined parent empowerment when a child is hospitalised for elective surgery. Fifty three parents of children aged between two and eleven were interviewed to assess their involvement in medical procedures and satisfaction with information and care. In addition, the anxiety of parents was investigated. Examination of the data, using content analysis, revealed that parents lacked empowerment in terms of not being allowed to be present while their child was anaesthetised, being prevented from going to the recovery room soon enough to help their child as he/she regained consciousness, and having poor communication experiences with medical practitioners. In addition, parents reported high levels of anxiety. It was concluded that greater understanding of the preferences of parents regarding their involvement in the care of their child is still needed by health care professionals.
In continuing to find ways to empower parents, some of the more recent studies have examined the effects of a wide range of psychological preparation techniques that have been developed to help adults and children prepare for hospitalisation (see reviews by Eiser, 1988; Horne, Vatmandis & Careri, 1994; Johnston & Vogele, 1993; Vernon & Thompson, 1993). Most of these strategies can be categorised as either information provision (behavioural, procedural and sensory), modelling, or coping skills training. Outcome studies have indicated that these approaches result in specific benefits to child patients and their families, including reduced anxiety, fewer problem behaviours, shorter hospital stays and the need for less medication. However, as noted by Koetting Byrne, Peterson and Saldana (1997), studies have been inclined not to provide parents with an active role, but rather allowed them to be present during the child’s preparation without any specific instructions.

Melnyk (1994) hypothesised that providing information about the parental role would affect the coping process by empowering parents and boosting their confidence. Two types of information, separately and in combination were evaluated for their effects on the process and outcomes of parental coping with unplanned childhood hospitalisation. The sample consisted of 108 mothers of hospitalised children aged two to five. Child behavioural information and parental role information were both shown to have positive effects on maternal state anxiety as well as on parental support and participation in their children’s care during hospitalisation. However, the results of this study need to be considered with caution, since there were no tools reported in the literature with established validity and adequate reliability to measure the process and problem solving outcome of parental coping with childhood hospitalisation. Three
new instruments were developed, which would require further studies to support the validity of these instruments.

Following this, Melnyk (1997) tested an experimental intervention programme which was developed based on a combination of self-regulation theory (Johnson, 1984; Leventhal & Johnson, 1983), control theory (Carver, 1979; Carver & Scheier, 1982), and the emotional contagion hypothesis (Jimerson, 1982; Smitherman, 1981). This framework was chosen because it seemed to receive strong empirical support in prior work with mothers of young hospitalised children (Melnyk, 1994, 1995).

The pilot test study examined the effects of the theoretically driven intervention programme (COPE = Creating Opportunities for Parent Empowerment) on the coping outcomes of critically ill children and their mothers. Thirty mothers of one to six year old children in a paediatric intensive care unit (PICU) were randomly assigned to receive COPE or a comparison programme. Mothers who received the COPE programme: (1) provided more support to their children during intrusive procedures; (2) provided more emotional support to their children overall; (3) reported less negative state and less parental stress related to their children’s emotions and behaviours; and (4) reported fewer post traumatic stress symptoms in their children and less parental role change in the four weeks following hospitalisation. Results indicate the need to educate parents regarding their children’s responses as they recover from illness and how they can assist their children in coping. However, the small sample size of this pilot study resulted in large variances and a lack of sufficient power to detect statistical significance on some of the dependent measures.
Although interventions based on research findings for parents in hospital with their children are beginning to emerge and be evaluated, perhaps it is still necessary to ascertain more precisely which aspects of communication and interaction with staff are problematic, what aspects of role ambiguity, whether particular kinds of hospital procedures cause particular problems, and whether any parent variables, such as whether or not they are attending for the first time, together with demographic factors, are associated with stress. Indeed, if some of these factors could be identified, then professionals would know more clearly where to direct these interventions, in order to reduce stress for parents of children in hospital with acute and chronic conditions, regardless of the number of admissions. An expanded literature review took place early in the year 2000, which found that these questions were still unanswered.

1.5 RATIONALE FOR PRESENT STUDY

The present study using the theoretical frameworks mentioned above, builds on the author’s earlier, qualitative study, as well as other research in the area. However, in order to attempt to answer the questions raised above, as well as clarify, strengthen and validate the results from the qualitative study, it is necessary to test a larger sample of parents, using quantitative measures.

This study aims to find out if the factors identified by the parents in the qualitative study mentioned above as being most stressful, (i.e. hospital procedures, staff communication, support, and parental role) do in fact contribute to the distress and
anxiety experienced by either or both parents of children of singular, first time admissions, and parents of children with repeated admissions.

Some of the studies discussed earlier (e.g. Berenbaum & Hatcher, 1992) indicated that parents of children hospitalised for sudden illnesses, experience more negative psychological consequences than parents of children hospitalised for other reasons. On the other hand, Cella, Perry and Poag, (1988) report that certain chronic illnesses and emergency hospitalisations of children cause greater distress in parents, but descriptions of emotional distress are similar among parents of hospitalised children, regardless of the type of illness or onset. This suggests that parents of children, whether admitted for the first time or on a repeated admission, may experience equivalent levels of anxiety and general distress.

Therefore, there may be factors, other than the child’s illness or onset which may have a relationship with parents’ distress. One such factor may be the perceived severity of a child’s illness, which may have a relationship with the degree of emotional distress a parent experiences. This study aims to examine this possible relationship, in addition to the factors outlined above, so that interventions designed to meet the needs of the parents in these different situations can be articulated.
1.6 HYPOTHESES AND QUESTIONS

Research has shown that experiences of parents in hospital with their children will be stressful and difficult. However, parents of children with repeated admissions may find it less stressful than parents of first time attenders, as a result of prior knowledge and experience. Where distress is experienced, the factors that may contribute to the distress will be: parent’s perceived seriousness of their child’s condition, confusion about roles in hospital; level of support parents receive; satisfaction with the handling of hospital procedures, that is, admission, treatment and discharge. Further to this, how the parents experience the staff’s communication will also have an effect on whether the parents experience psychological distress.

1.6.1 Aims of the study

The main aims of the study were:-

1) To explore the experiences of parents in the hospital, that is, how they experienced staff communication, the procedures of admission, treatment and discharge, the support they received and what their role was.

2) To assess the parents’ level of psychological distress at the time of hospitalisation.

3) To identify the factors associated with distress.

The study is designed to a) examine descriptive data and b) to test hypotheses.
1.6.2 Descriptive Data Questions

A. How satisfied are parents with the hospital procedures that take place, such as, admission, treatment and discharge?

B. What level and what source of support do parents report they get while in the hospital?

C. Which aspects of parental role in hospital cause the most confusion?

D. What aspects of staff communication are parents dissatisfied with?

E. What is the level of psychological distress of parents during their child’s hospitalisation?

1.6.3 Hypotheses to be tested

1. Parents of first time admissions will have higher levels of confusion around their role at hospital, compared with parents of repeated admissions.

2. Parents of children with first time admissions will have more difficulty with staff communication compared to parents of children with repeated admissions.

3. Higher levels of psychological distress will be found in:
   (a) Parents with greater confusion with parental role while in hospital.
   (b) Parents with lower levels of support while in hospital.
(c) Parents who have poor understanding or experience difficulties and are less satisfied with hospital procedures, (i.e. admission, treatment and discharge).

(d) Parents of children with first time admissions, compared with repeated admissions.

(e) Parents with a high level of perceived seriousness about their child’s condition.

4. Lower levels of psychological distress will be found in:-

(a) Parents who are satisfied with and experience concise, clear communication and information giving and receiving between the parents and hospital staff.
2. METHODOLOGY

2.1 DESIGN

This was a questionnaire-based study using a cross-sectional design. Parental distress was the dependent variable and the independent variables were:- whether or not parents were first time or repeated attenders, their satisfaction with staff communication and hospital procedures, confusion with parental role in hospital and levels of support received and parents’ perceived seriousness of their child’s condition. Hypothesised associations were tested using correlational analyses. A between group design for comparison of parents of children attending for the first time, and parents of children on repeated admissions was used. As parents’ levels of distress at the time of the hospitalisation may have been high, a measure of stress at the time of hospitalisation was taken, although this may have been influenced by factors other than those being measured.

Based on previous qualitative research (O’Dwyer, 1997) using a small un-selected sample, one could tentatively project that a ‘moderate’ effect size might be expected for associations between higher levels of psychological distress and the following variables:- a) parents who are dissatisfied with hospital staff’s communication and hospital procedures, i.e. admission, treatment and discharge, b) being confused with parental role, c) low levels of support while in the hospital, d) parents perceived seriousness of their child’s condition and e) parents of children with first time admissions.
If one were to read 'moderate' as equivalent to 'medium' effect size in terms of Cohen's (1988) classification, then it is possible to obtain the corresponding appropriate sample size needed to detect this size of effect from power tables (Clark-Carter, 1997). Assuming a medium effect size (i.e. $r = 0.3$ with a significance level at .05 and power of .80 (80 per cent), the size of sample required was 75.

2.2 PARTICIPANTS

The participants were recruited from a paediatric department of a large teaching hospital. The inclusion/exclusion criteria were as follows:

**Inclusion:**

1) Parents of children who attended the hospital for the first time, whose child stayed for at least 24 hours, who may have had an accident, or an acute medical condition (i.e. meningitis) or who had undergone elective surgery.

2) Parents of children who were at the hospital with a child who had at least one previous admission, or who had had an admission with another child of the family, and stayed for at least 24 hours. These children may have had a chronic condition, or may have needed on-going surgery. (It was anticipated that the child might also return again to the hospital at some date in the future, either for planned or unplanned re-admission).

3) Only parents of children aged 3 - 14 years were invited to participate.
Exclusion:

4) Parents of infants were excluded, as the nature of the child’s dependency, (i.e. feeding, changing, dressing, bathing and playing) would mean that these parents might have had a very different set of expectations, a more clearly defined role and as such, a different experience of hospitalisation.

5) Similarly, parents of older children were excluded because this group of children may not have needed to have had a parent present at the hospital.

6) Children who were fostered were excluded.

7) Children who arrived at the hospital with suspected non-accidental injuries were excluded.

One hundred and eighty parents, who met the inclusion criteria were approached and invited to participate in the study. They all received verbal and written information about the study, what participation would involve, and accepted a questionnaire pack.

Seventy-five fully completed questionnaire packs were returned, (representing a 42 per cent response rate). Some of the reasons given for refusal to complete questionnaires included :- lack of time; unable to care/nurse child and complete questionnaires at same time; too tired; put off by length of questionnaires; and although all parents spoke English, some had insufficient competence in reading and writing to complete the questionnaires.
2.3 MEASURES

After an extensive search was carried out, no British questionnaires were found to measure the identified variables. Therefore, the measures used in this study were chosen and adapted from some measures mainly utilised in studies in America, that examined some of the relevant issues.

2.3.1 The Staff Communication Questionnaire

The Staff Communication questionnaire (Appendix 1) was adapted from a study by Street (1991) which looked at parents' perceptions of doctors' communicative behaviour. This scale was chosen because it was considered the most relevant and appropriate measure available. Street (1991) selected fifteen likert-type statements to represent parents' perceptions of doctors' informativeness, interpersonal sensitivity and partnership building. Of these fifteen items, four were written specifically for the purposes of his study, and eleven were derived from a British study by Arntson, Makoul, and Pendleton (1989). In its pure form, the Arntson et al. measure was not deemed suitable for the Street (1991) or the present study because: a) it examined patients' perceptions of their own health care, b) perceptions related to doctors' informativeness and interpersonal sensitivity were placed into one general category labelled 'responsiveness' and c) the authors examined only individual items and not composite measures in their analyses.
The second step Street (1991) employed in creating communicative measures was to select items that, when summed, would create relatively reliable measures of doctors' communication. He proposed that six of the statements, i.e. item numbers, 1) 'the doctor did not fully discuss with me what was causing my child's problem', 6) 'the doctor thoroughly explained everything to me', 8) 'the doctor was very informative about my child’s health', 12) 'the doctor’s explanations and recommendations were clear and easy to understand', 14) 'The staff identified themselves clearly' and 15) 'The staff used simple to understand language', were sufficiently inter-correlated to create a measure of doctors' informativeness (Cronbach's alpha = .69). Three further items, i.e. numbers, 2) 'the doctor showed a genuine interest in my child’s health', 4) 'the doctor made me feel completely at ease' and 13) 'the doctor seemed to care about my child’s feelings', were selected to represent interpersonal sensitivity (Cronbach's alpha = .80). Finally, six more statements, i.e. numbers 3) 'the doctor encouraged me to express my concerns and worries', 5) 'the doctor did not treat me as an equal', 7) 'the doctor asked for my opinion on what to do', 9) 'the doctor asked for my thoughts about my child’s health', 10) 'the doctor reassured me about how I had been caring for my child' and 11) 'the doctor gave me quite a bit of responsibility regarding how to deal with my child’s medical condition', were summed to measure partnership building (Cronbach’s alpha = .65).

This self report scale was used in its complete form, but the wording 'doctor' in the fifteen statements was changed to 'staff' for the broader purposes of this study (see Appendix 1). This questionnaire comprised fifteen likert type statements which the parents were asked to complete by either strongly agreeing, agreeing, disagreeing or
strongly disagreeing with each one. The questionnaire was piloted with a group of parents at hospital for face and content validity, (which is discussed in section 2.4).

The scale was scored on a points system of 1, 2, 3, 4, with positive responses gaining a 4 and negative responses 1. Therefore the higher the score, the more positive the parents deemed the communication to be. Two items were 'reversed scored' due to being worded negatively, i.e. 'the staff did not fully discuss with me what was causing my child's problem', and 'the staff did not treat me as an equal'. The scores for these were converted to fit the direction of the scale as a whole in data analysis.

2.3.2 The Parental Role Questionnaire

In order to assess parental involvement, perceptions and confusions about their role while in hospital with their children, the Parental Role Questionnaire was developed (Appendix 2). This was partly based on and adapted from other measures in the field, which were deemed unsuitable for use in their pure form, because many of the items were not considered appropriate for parents to perform in British hospitals. One, the Index of Parent Participation/Hospitalised Child (Melnyk, 1994) was devised to measure the problem solving outcome of mothers' coping while in hospital. This instrument contained 36 parenting behaviours that mothers may engage in during their childrens' hospitalisation. Examples of these behaviours included bathing, monitoring fluid intake and output, playing actively with toys and explaining a test or procedure.
Melnyk’s questionnaire was developed by undertaking a systematic review of the literature and interviewing parents to determine typical parenting behaviours during childhood hospitalisation. Next, eight paediatric clinical nurse specialists examined the original list of 42 items to suggest modifications and support content validity. As a result of this review, two of the items were eliminated because at least three reviewers believed the items were not performed routinely by parents of hospitalised children. Face validity of the instrument was established and a further four items were excluded. Cronbach’s alpha for the final 36 item scale was .77.

In consultation with an expert in Health Psychology, it was decided that the questionnaire was extremely long and wordy, so a further six items which were considered less relevant and were mostly covered in some of the other questionnaires used in this study, were removed. The list was condensed into 30 shorter statements employing more anglicised language. This amended list was presented to four medical staff to obtain face validity of the constructs. They agreed that four of the items were not routinely performed by parents in British hospitals and so these items were removed.

The remaining 26 items can be divided into four sub-sections, namely: Basic body functions (i.e. encouraged child to drink fluids and recorded, obtained urine sample, emptied, kept record of number of bowel movements); Medication (i.e. took temperature, took pulse, gave pills and liquid medication, changed dressing); Holding, (i.e. went with child to X-Ray, stayed with child during painful procedure, restrained child for painful procedure), and Parenting (i.e. comforted child, fed child, bathed
child, got items from canteen, obtained linen and changed bed, entertained child); which were constructed into a self report questionnaire.

As it has been shown in the literature that there can be confusion around parental role while in hospital (Miles, 1979), one of the aims of this questionnaire was to try to get a measure of what parents considered was appropriate for them to do, and which tasks they considered were appropriate for staff to do. A Likert type scale was used. Parents’ questionnaire items received a score of 1 if they ‘ticked’ either end of the scale, i.e. ‘definitely appropriate for parent or staff to do’, a score of 2 if they ticked ‘appropriate’ for parent or staff to do and a score of 3 if they ticked the ‘uncertain who should do this’ box. Sub-scale scores were obtained by summing the items. The sub-scale score ranges were:  
- basic body functions = 8 - 24; medication = 6 - 18; holding = 4 - 12 and parenting = 8 - 24. Face validity for this version was obtained by piloting, and any changes made are discussed in Section 2.4.

2.3.3 The Hospital Procedures Questionnaire

From previous research, some of the procedures at the hospital have been shown to be anxiety provoking and distressing for parents. In order to measure this variable, it was necessary to construct a scale. The nearest approximation found was that of Palisin, Cecil, Gumbardo and Varley, (1997) who devised the In-patient Discharge Questionnaire (IDQ) to sample parents’ satisfaction with their children’s hospitalisation in a psychiatric unit.
Thirty items were grouped into four sub scales: Admission, Assessment, Treatment and Discharge. Self ratings were made on a likert scale ranging from 1 (very dissatisfied), 2 (dissatisfied), to 3 (satisfied) and 4 (very satisfied). The content of the items was generated from staff suggestions, anecdotal comments from parents and reviews by the unit management team.

As many of the items on this scale were clearly only relevant to children with a psychiatric illness and admission, the IDQ was shortened for use with general medical hospital procedures. This resulted in The Hospital Procedures Questionnaire (Appendix 3) which was adapted for use in the present study. There were 13 items in this questionnaire which were grouped into three sections, i.e. Admission, Treatment and Discharge. The same rating/scoring as the IDQ was employed, i.e. a 4 point scale indicating that the higher the score the more satisfied the parents were and the lower scores indicated dissatisfaction. The score range was 13 - 52. The questionnaire was piloted for face validity and no changes were necessary as a result.

2.3.4 Support While in Hospital Questionnaire

The Support While in Hospital Questionnaire was partly based on the Significant Others Scale (SOS) Short Form (Power, Champion & Aris, 1988). This measure elicits information on the perceived form and function of social support for a range of key relationships in an individual’s life. The forms or ‘structure’ of support are assessed by considering a number of role relationships. The functions of social support
are divided broadly into 'emotional' and 'practical' support, on the logic that the other functions indicated in the literature are in fact subcategories of these two.

The short version of the SOS is based on four functions or items. The functions are, ‘can you trust, talk frankly and share feelings with x?’ ‘can you lean on and turn to x in times of difficulty?’ ‘does x give you practical help?’ and ‘can you spend time with x socially?’ The short SOS is set out in questionnaire format, unlike the full SOS which takes the form of a grid. On both versions of the SOS, the higher the score the greater the frequency of social support.

The Support While in Hospital Questionnaire (Appendix 4) is a self administered scale containing three sections, i.e. 1) Medical Staff, 2) Other Parents on the Ward and 3) Partner/Family/Friends. Unlike the SOS which can wield scores for ‘actual’ support, ‘ideal’ support, the discrepancy between the two and rank order the frequency of the listed role relationships, as well as calculating the discrepancy between scores for ‘emotional’ and ‘practical’ support, this questionnaire only gave a measure of the actual support, both emotional and practical, at the time the parent was in the hospital. The items were:- ‘Can you talk frankly and share your feelings with x?’ ‘Can you lean on, and turn to x to discuss any worries you may have?’ ‘Do you get practical help from x?’ ‘Do you get practical advice from x?’

The questionnaire was scored on a five point frequency scale, ranging from 1 = ‘not at all’ to 5 = ‘definitely’. The score range for each sub-scale was 4 - 20, and for the total scale 12 - 60. The higher the score the greater the frequency of support. To ascertain who the participants considered the most significant source of support, they were
invited to fill in a question at the end of the questionnaire which asked, 'Who out of this group, do you feel is offering you support while you are at the hospital with your child?'

2.3.5 The adapted HADS

The assessment of parental distress was based on the slightly amended version of the widely used Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). This was developed and found to be a reliable instrument for detecting mood in the setting of a hospital medical out-patient clinic. The sub-scales were also valid measures of severity of the emotional disorder. The authors point out that the HADS has been constructed from data supplied by outpatients between the ages of 16 and 65 attending general medical clinics.

The HADS contains seven items in each of the anxiety and depression sub-scales. The scale is scored on a four point scale, ranging from 0 - 3 for each item, giving a total rating for each sub-scale of 0 - 21. If the scale is to be used in research, the authors suggest that the cut-off point for a 'case' may be either the upper or lower end of the borderline range. Where the research requires the inclusion of only those patients who have a high probability of suffering from the mood disorder, i.e. a low proportion of false positives: then the upper end of the borderline score range (10/11 for each of the sub-scales) should be used. However, where the research requires inclusion of all possible cases, i.e. a low proportion of false negatives, the lower end of the borderline score range (8/9 for each of the sub-scales) should be used.
This scale was felt to best measure the feelings and emotions that parents may have experienced while at hospital with their children. Therefore in order to measure parents' mood they were asked to complete the adapted HADS questionnaire at the time they were at the hospital (Appendix 5). The conventional scoring of a four point scale ranging from zero to three for each item, giving a total scoring range of 0 - 21 was used for the anxiety sub-scale.

On the pilot study (see page 52) it was found that, while the anxiety sub-scale worked well, some of the items on the depression sub-scale may not have been an accurate indication of levels of depression for in-patients or parents in hospital, due to the environmental constraints. Therefore, three items were removed: 'I still enjoy the things I used to enjoy', 'I have lost interest in my appearance' and 'I look forward with enjoyment to things'. It was felt that while parents were in hospital, they did not have access to things they normally enjoyed, they did not have the usual facilities to take care of their appearances as they did at home and parents reported that because they were uncertain about how long their child would be in hospital, they found it difficult to comment on the third statement about looking forward to things.

The total scoring range for the adapted depression sub-scale was 0 - 12. This meant that the normal cut-off score for depression 'caseness' would not apply to the current study. However the scale still indicated relative levels of distress, in that the greater the score the higher the psychological distress. (The internal reliability of the adapted depression sub-scale was examined and is shown in the Results section and possible problems and implications of adapting standardised measures are discussed in the Discussion section).
The matter of the optimal number of items to be included in mood scales is a matter for debate (Snaith, Baugh, & Clayden, 1982). Snaith et al.'s (1982) work showed that some assessment scales with five and eight items performed as well as each other and both were better than a scale with 12 items. Moreover, they also found that the number of items (varying between four and ten) composing the scale, made little difference to its performance.

The items on the adapted HADS questionnaire examining distress in parents were divided into anxiety items and depression items, as on the original. The total score on each sub-scale (anxiety and depression) was computed for each participant. This meant that the anxiety scores had a comparable range with those of the original HADS, but for the depression sub-scale, the score range was not comparable due to the adapted version used in the present study having a different number of items in that sub-scale.

2.3.6 Demographic Information

A number of factors which may have had a confounding effect on influencing distress were recorded on the background information sheet which was completed by each participant (Appendix 6). This provided information on age, gender, ethnicity, marital status, child's condition, perceived seriousness, number of children, child care arrangements and whether or not they were employed outside the home.
2.4 PILOTING

Prior to the study commencing, the measures were piloted with nine parents, who were at the hospital with their children. The purpose of the pilot work was to check that the basic aspects of the design and procedure worked. For example, the pilot looked at whether the measures had face and content validity, and whether the participants understood the instructions and questions. This also gave an indication of the length of time required to complete all the questionnaires.

Following completion of the pilot work, the participants were debriefed. They offered feedback on the length of time taken to complete the questionnaires, so this could be incorporated into the instructions in the main study. Most participants indicated that it took them fifteen to twenty minutes to read through and complete the questionnaires, but pointed out that if English was not a person's first language, it might take longer. All questionnaires were deemed by the participants to be comprehensive, relevant and non-intrusive, with easy to follow completion instructions.

However, some of the participants commented on the relevance of some of the questions on the HADS. For example, some parents felt it simply was not possible to enjoy their usual things, such as having coffee with friends, going to the gym, going shopping, because they were staying at the hospital. Similarly, some commented that it was not really possible or there was not time to find a mirror to brush their hair, have a shower, and/or put their lipstick on. In addition, as mentioned earlier, parents said they were only able to focus on the moment, and did not know how long their child would be ill/in hospital for, therefore they were not able to look forward to things. As
a result of this feedback, three items were removed from the depression sub-scale of the HADS.

In addition, it also became apparent that some adjustments were necessary to some of the questionnaires in order to make analyses of the data more robust. The other changes were as follows:

1. In the background information section, the participants were asked an open question: "How serious do you think his/her condition is?" Piloting revealed that some of the parents put "I don't know", or "very serious" or "enough to cause concern". In order to standardise the responses, a five point scale of 'not at all serious', 'slightly serious', 'not sure', 'serious' and 'very serious' was added.

2. The Parental Role Questionnaire gave parents a list of tasks and asked them to tick the appropriate box on a scale which was - 'I did this', 'Appropriate for parent to do', or 'Appropriate for staff to do'. In addition, the parents were asked at the end of the form, to 'briefly tell us if there were other things that you would have liked to do and did not and for what reasons?' As parental role is known from the literature to cause confusion, which this questionnaire was designed to access, it was clear from the piloting responses that it would not. Therefore the questionnaire was rewritten using a five point scale which asked - 'Definitely appropriate for parent to do', 'Appropriate for parent to do', 'Uncertain who would do this', 'Appropriate for staff to do', and 'Definitely appropriate for staff to do'. In addition, parents were asked to underline the tasks that they actually did. The question at the end of
the questionnaire, mentioned above, was removed, as none of the pilot participants had filled it in.

3. The Support While in Hospital Questionnaire asked the participants to respond to a list of questions on the type of support they received from identified groups of people by circling ‘Yes/No’ answers. While this worked well with the participants, it was felt that the data gained by using a five point scale, (in keeping with the other questionnaires) would be amenable to slightly more advanced statistical analysis.

2.5 PROCEDURE

A list of criteria for inclusion in the study (Appendix 7) was handed to the senior ward nurse by the researcher on the days when the researcher was present on the ward. Parents of children who had been on the ward for longer than 24 hours and who met all of the criteria for inclusion in the study, were identified from the ward staffs’ daily current cases list, by the staff nurse to the researcher. This took approximately 10-15 minutes each day. The researcher then made a list of the child’s name and their bed number, as well as noting whether a parent was currently present, or if not, if staff knew what time a parent was expected that day. This freed up the need to keep checking with the staff’s list.

Having identified possible participants, parents were then approached by the researcher who introduced the purpose of the visit and the nature of the study. This was done verbally. Written information about the study and what participation would involve
was handed to the participants to read (Appendix 8). It was explained to the potential participants that involvement in the study would be voluntary and based upon their informed consent. If they were willing to be involved, they were asked to sign the consent form saying they had read and understood the information and agreed to take part in the study. They were allowed half an hour approximately to consider participation. After signing the forms, they were handed the questionnaires pack and asked to complete it in their own time. They were told that the researcher would return in approximately half an hour to either collect the completed questionnaires or answer any further queries or concerns they might have had while attempting to complete the questionnaires. It was necessary to return to some of the parents two or three times to allow them more time for completion. When this was not possible, parents were given an envelope to place their completed questionnaires in. These could be sealed and left in a folder clearly marked ‘Parents’ Research Forms’, which was placed in the Parents’ Kitchen. No medical or nursing staff used the kitchen and the folder was collected by the researcher on the next visit. Twelve of the questionnaire packs were returned in this way.

2.6 ETHICAL CONSIDERATIONS

Ethical approval was gained for the study from the local research ethics committee (Appendix 9). Participation was voluntary and based upon informed consent. Anonymity and confidentiality were assured.
It was not anticipated that the participants would suffer any adverse effects from participating in the study, but where they appeared to be unduly stressed, as a result of taking part in the study, upon collection of the questionnaire pack, parents were offered the time and opportunity to be debriefed by the researcher. This involved actively listening to the parents' worries, offering empathy, addressing their concerns and directing them to the relevant member of staff for further discussion. Although it had been informally agreed with the Paediatric Clinical Psychologist on the ward prior to the study starting, that if a parent needed more than debriefing, that it would be possible to make a referral, it was not necessary to do so.

As mentioned earlier, children who were fostered and those who arrived at the hospital with suspected non-accidental injuries were excluded on ethical grounds.
3. RESULTS

The results obtained from the quantitative analyses are presented in three parts. Firstly, the integrity of the data is examined and the choice of statistical tests is discussed. Secondly, the internal reliability of the constructed measures is reviewed. Thirdly, the demographic data are presented and finally, the factors that affect distress in parents in hospital are explored and the results obtained for each hypothesis are presented.

3.1 ESTABLISHING THE INTEGRITY OF THE DATA AND CHOICE OF STATISTICAL TESTS

Data were analysed using the statistical package for Social Science for Windows, Version 9 (SPSS Inc, 1999). Levene’s test of homogeneity of variance and Kolomogorov-Smirnov’s test for a normal distribution were used to assess the suitability of parametric analyses on all except the nominal data. Histograms were also plotted. The results indicated that in the majority of cases there was homogeneity of variance and that the data were normally distributed. It was noted that some variables did not meet all the criteria for parametric analyses. However, given that the majority of variables met the criteria and that there was a similar number of participants within each of the two parent groups, it was decided to cautiously use parametric analyses. Further to this, for variables in which parametric conditions were not fully met, any significant differences were checked using non-parametric tests. If non-parametric
tests disagreed, the tests giving fewest significant results were preferred, to avoid Type I errors.

Alongside descriptive statistics, the statistical tests used in this study included: independent t-tests, correlations using Pearson’s coefficient and Spearman’s coefficient (where data were skewed, i.e. the Staff Communication Questionnaire and ordinal data, i.e. Perceived Seriousness) and a $2 \times 2$ Chi Square test.

3.1.2 Internal Reliability of Constructed Measures

The Cronbach’s alpha statistic was used on the constructed questionnaires, to establish the internal consistency of the scale items, because they were adapted from other measures.

- On the Parental Role questionnaire, the four sub-scales gave alpha scores respectively of: $Basic \text{ body functions} = .84$, $Medication = .85$, $Holding = .88$ and $Parenting = .77$, indicating that there was good internal consistency among sub-scale items.

- Similarly, a Cronbach’s alpha score of .96 was obtained for the full Hospital Procedures questionnaire, with a score of .84 for the first 7 items. (The majority of participants only completed the first seven items, as the remaining six were not always applicable).

- Cronbach’s alpha gave a score of .86 for the Support While in Hospital questionnaire.
• Although the Staff Communication questionnaire had previously computed alphas by the original author, due to some changes, it was decided to compute Cronbach’s alpha for the version of the Staff Communication questionnaire constructed for this study. An alpha co-efficient of .78 was obtained for the full questionnaire. The three sub-scales yielded scores of: *staff informativeness* = .77, *interpersonal sensitivity* = .71, and *partnership building* = .55. Due to this low level of internal consistency, it was decided to carry out more fine grained analyses of the data item-by-item.

• Due to changes made to the depression sub-scale of the HADS, Cronbach’s alpha were computed for each of the sub-scales. A score of .78 was obtained for the anxiety sub-scale and a score of .57 was obtained for the depression sub-scale.

*(Low level of internal consistency are discussed in the Discussion section)*
3.2 DEMOGRAPHIC INFORMATION

The demographic data for the 75 participants are presented in Table 1.

Table 1: Demographic Data of the Parents in Hospital Participants

| Age of Parent | Mean = 35, SD = 6.21  
| Minimum = 18, Maximum = 53 |
|----------------|------------------------|
| Gender | Female n = 51 (68%)  
| Male n = 4 (5.3%)  
| Unspecified n = 20 |
| Marital Status | Single n = 15 (20%)  
| Married n = 27 (36%)  
| Divorced n = 5 (7%)  
| Separated n = 5 (7%)  
| Co-habiting n = 1 (1.5%)  
| Unspecified n = 22 |
| Ethnicity | White n = 43 (57%)  
| Black Caribbean n = 2 (2.7%)  
| Black African n = 4 (5.3%)  
| Black Other n = 1 (1.3%)  
| Asian Chinese n = 1 (1.3%)  
| Asian Other n = 3 (4%)  
| Unspecified n = 21 |
| Number of Children | 1 child n = 17 (22.7%)  
| 2 children n = 31 (41%)  
| 3 children n = 21 (28%)  
| 4 children n = 6 (8%)  
| Relationship to Child | Mother n = 68 (91%)  
| Father n = 7 (9%)  
| Age of Ill Child | Mean = 6.4, SD = 3.76  
| Minimum = 3, Maximum = 14 |

3.2.1 Additional Participant Data

Of the 75 participants, 38 (50.7 per cent) were attending the hospital for the first time, and 37 (49.3 per cent) had attended before. Forty-four (58.7 per cent) of the participants were in employment and 37 (49.3 per cent) needed to take time off work to be at the hospital. The remaining 31 (41.3 per cent) did not work outside the home. Of the 37 participants who needed time off work, 11 (34.4 per cent) found it difficult to get while 21 (65.7 per cent) found it easy. Five participants failed to respond to this
question. Forty-two (58 per cent) of the participants also needed to make child care arrangements while at the hospital.

Thirty-nine of the 75 participants (52 per cent) answered the question as to why their child was in hospital. The data received is presented in Table 2, together with all the parents' perceived seriousness of their child's condition.

The length of time children and parents were at the hospital, was not recorded.

Table 2: Child's Condition and Parents' Perceived Seriousness

<table>
<thead>
<tr>
<th>Child's condition/illness</th>
<th>Injury</th>
<th>n = 7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Surgery</td>
<td>n = 12</td>
</tr>
<tr>
<td></td>
<td>Breathing and chest problems</td>
<td>n = 8</td>
</tr>
<tr>
<td></td>
<td>Vomiting and diarrhoea</td>
<td>n = 4</td>
</tr>
<tr>
<td></td>
<td>Scan/tests/observation</td>
<td>n = 3</td>
</tr>
<tr>
<td></td>
<td>Convulsions</td>
<td>n = 2</td>
</tr>
<tr>
<td></td>
<td>Epilepsy</td>
<td>n = 1</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>n = 1</td>
</tr>
<tr>
<td></td>
<td>Eczema</td>
<td>n = 1</td>
</tr>
<tr>
<td></td>
<td>Unspecified:</td>
<td>n = 36</td>
</tr>
</tbody>
</table>

| Parents' perceived seriousness of child's condition | Not at all serious | n = 11 (14.7%) |
|-----------------------------------------------------|-------------------|
|                                                     | Slightly serious  | n = 17 (22.7%) |
|                                                     | Not sure           | n = 19 (25.3%) |
|                                                     | Serious            | n = 22 (29.3%) |
|                                                     | Extremely serious  | n = 6  (8%)    |
3.3 DESCRIPTIVE DATA QUESTIONS

3.3.1 A: How satisfied were parents with hospital procedures i.e. admission, treatment and discharge?

The means, standard deviations and scoring range of parents' satisfaction with the first seven items on the Hospital Procedures questionnaire are shown in Table 3.

Table 3: Means, Standard Deviations and Scoring Range of Parents' Satisfaction with Hospital Procedures (7 items only)

<table>
<thead>
<tr>
<th>Hospital Procedure Questionnaire Items</th>
<th>No. of participants</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range (min - max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff's welcome</td>
<td>74</td>
<td>3.23</td>
<td>.73</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Appearance and comfort of child's bed space</td>
<td>75</td>
<td>2.87</td>
<td>.81</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Ward's general appearance</td>
<td>75</td>
<td>2.77</td>
<td>.83</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Length of time to complete admission procedure</td>
<td>74</td>
<td>2.82</td>
<td>.82</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Diagnostic tests and results completed and reported promptly</td>
<td>68</td>
<td>2.97</td>
<td>.75</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Medication treatment</td>
<td>72</td>
<td>3.08</td>
<td>.75</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Quality of health care received</td>
<td>67</td>
<td>3.18</td>
<td>.76</td>
<td>1 - 4</td>
</tr>
</tbody>
</table>

On a scale of 1 - 4, with 1 = very dissatisfied and 4 = very satisfied, the graph on the following page shows that the parents were mostly satisfied with the hospital's procedures for admission and treatment. These were the first seven items on this measure. The remaining items which covered transfer to theatre and discharge procedures, were not completed by most participants as they were not applicable, therefore these data are not included.
3.3.2 B: What level and what source of support did parents have while at the hospital?

The means, standard deviations and scoring range for levels of support parents received while in hospital are shown in Table 4 on the following page.
Table 4: Means, Standard Deviations and Scoring Range for Support Parents received in Hospital

<table>
<thead>
<tr>
<th>Support Questionnaire Items</th>
<th>No. of Participants</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range (min - max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you trust, talk frankly, share feelings with family</td>
<td>74</td>
<td>4.35</td>
<td>1.10</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Can you trust, talk frankly, share feelings with medics</td>
<td>75</td>
<td>3.67</td>
<td>1.04</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Can you trust, talk frankly, share feelings with other parents on the ward</td>
<td>74</td>
<td>2.35</td>
<td>1.42</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Can you lean on/turn to family to discuss worries</td>
<td>74</td>
<td>4.23</td>
<td>1.18</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Can you lean on/turn to medical staff to discuss worries</td>
<td>75</td>
<td>3.52</td>
<td>1.20</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Can you lean on/turn to other parents to discuss worries</td>
<td>74</td>
<td>1.97</td>
<td>1.23</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical advice from family</td>
<td>74</td>
<td>3.91</td>
<td>1.41</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical advice from medical staff</td>
<td>74</td>
<td>3.35</td>
<td>1.28</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical advice from other parents</td>
<td>74</td>
<td>1.72</td>
<td>1.12</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical help from family</td>
<td>73</td>
<td>4.16</td>
<td>1.24</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical help from medical staff</td>
<td>74</td>
<td>3.46</td>
<td>1.24</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Do you get practical help from other parents</td>
<td>74</td>
<td>1.84</td>
<td>1.21</td>
<td>1 - 5</td>
</tr>
</tbody>
</table>

On a scale of 1 - 5, where 1 = not at all and 5 = definitely, the graph in Figure 2 on the following page shows that parents received high levels of support while in hospital from their family, but lower level of support from the medical staff. There was very poor support from other parents on the ward.
3.3.3 C: Which aspects of parental role in hospital caused the most confusion?

Table 5 on the following page shows the means, standard deviations and scoring range for parental role confusion.
### Table 5: Means, Standard Deviations and Scoring Range for Parental Role Confusion

<table>
<thead>
<tr>
<th>Parental Role Questionnaire Items</th>
<th>No. of Participants</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range (min - max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraged child to drink</td>
<td>71</td>
<td>2.33</td>
<td>1.30</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Changed child</td>
<td>69</td>
<td>1.75</td>
<td>0.85</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Obtained urine sample</td>
<td>69</td>
<td>2.90</td>
<td>1.29</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Placed child on bedpan</td>
<td>64</td>
<td>2.81</td>
<td>1.10</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Kept record of urination</td>
<td>67</td>
<td>3.52</td>
<td>1.19</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Emptied bedpan</td>
<td>65</td>
<td>3.09</td>
<td>1.21</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Gave enema</td>
<td>65</td>
<td>3.82</td>
<td>1.10</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Kept record of bowel movements</td>
<td>69</td>
<td>3.17</td>
<td>1.32</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Took temperature</td>
<td>71</td>
<td>3.97</td>
<td>0.99</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Took pulse</td>
<td>69</td>
<td>4.22</td>
<td>0.82</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Took blood pressure</td>
<td>66</td>
<td>4.29</td>
<td>0.82</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Gave medication</td>
<td>69</td>
<td>3.81</td>
<td>0.20</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Did physical therapy</td>
<td>65</td>
<td>3.68</td>
<td>1.20</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Changed dressings</td>
<td>66</td>
<td>3.79</td>
<td>1.13</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Accompanied child to X-Ray</td>
<td>72</td>
<td>2.28</td>
<td>1.30</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Held child for examination</td>
<td>70</td>
<td>2.04</td>
<td>1.30</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Stayed during painful procedure</td>
<td>71</td>
<td>2.01</td>
<td>1.31</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Restrained during painful procedure</td>
<td>67</td>
<td>2.00</td>
<td>1.24</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Accompanied child to theatre</td>
<td>67</td>
<td>2.01</td>
<td>1.25</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Comforted child</td>
<td>72</td>
<td>1.49</td>
<td>0.75</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Fed child</td>
<td>71</td>
<td>1.39</td>
<td>0.62</td>
<td>1 - 3</td>
</tr>
<tr>
<td>Got items from canteen</td>
<td>71</td>
<td>1.46</td>
<td>0.67</td>
<td>1 - 4</td>
</tr>
<tr>
<td>Bathed child</td>
<td>71</td>
<td>1.79</td>
<td>0.98</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Obtained linen and changed bed</td>
<td>71</td>
<td>2.75</td>
<td>1.24</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Entertained/played with child</td>
<td>72</td>
<td>1.62</td>
<td>0.86</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Escorted child to playroom</td>
<td>70</td>
<td>1.63</td>
<td>0.82</td>
<td>1 - 4</td>
</tr>
</tbody>
</table>

A graph showing parents’ level of confusion for the four sub-scales of the parental role questionnaire, are shown in graphs on the following page. The graphs suggest that for the sample as a whole, none of the categories led to confusion, bearing in mind that the scale goes from 1 - 3 but some of the roles were less clear than others, i.e. the higher points on the graphs. This is more apparent for the Basic Body Functions and Medication sub-scales, than for the Holding and Parenting sub-scales.
Figure 3: Graphs showing levels of confusion for the four sub-scales of Parental Role

Bodily Functions and Medication sub-scales

Holding and Parenting Sub-scales
3.3.4 D: What aspects of staff communication were parents dissatisfied with?

Table 6 shows frequencies of satisfied and dissatisfied parents for Staff Communication overall rather than for the three sub-scales. This identifies areas where parents were satisfied with most aspects of staff communication, but highlights where a proportion of the parents were more critical.

**Table 6: Number of Parents who agreed or disagreed with individual items on the Staff Communication Questionnaire**

<table>
<thead>
<tr>
<th>Items</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>(%)</td>
</tr>
<tr>
<td>Staff did not fully discuss cause of child's problem</td>
<td>17</td>
<td>(22.7)</td>
</tr>
<tr>
<td>Staff showed genuine interest in child's health</td>
<td>70</td>
<td>(93.3)</td>
</tr>
<tr>
<td>Staff encouraged me to express concerns and worries</td>
<td>61</td>
<td>(81.3)</td>
</tr>
<tr>
<td>Staff made me feel completely at ease</td>
<td>57</td>
<td>(76.0)</td>
</tr>
<tr>
<td>Staff did not treat me as an equal</td>
<td>20</td>
<td>(27.1)</td>
</tr>
<tr>
<td>Staff thoroughly explained everything</td>
<td>59</td>
<td>(80.8)</td>
</tr>
<tr>
<td>Staff asked my opinion</td>
<td>34</td>
<td>(45.9)</td>
</tr>
<tr>
<td>Staff were very informative about my child's health</td>
<td>63</td>
<td>(84.0)</td>
</tr>
<tr>
<td>Staff asked for my thoughts about my child's health</td>
<td>55</td>
<td>(73.3)</td>
</tr>
<tr>
<td>Staff reassured me about my care of my child</td>
<td>43</td>
<td>(58.9)</td>
</tr>
<tr>
<td>Staff gave quite a lot of responsibility</td>
<td>41</td>
<td>(56.2)</td>
</tr>
<tr>
<td>Staff explanation &amp; recommendations were clear and easy to understand</td>
<td>63</td>
<td>(85.2)</td>
</tr>
<tr>
<td>Staff seemed to care about child's feelings</td>
<td>68</td>
<td>(91.9)</td>
</tr>
<tr>
<td>Staff identified themselves clearly</td>
<td>63</td>
<td>(84.0)</td>
</tr>
<tr>
<td>Staff used simple to understand language</td>
<td>69</td>
<td>(93.2)</td>
</tr>
</tbody>
</table>

The table shows that almost half of the participants did not agree with some of the statements that make up the *partnership building* sub-scale, that is, ‘staff asked for my opinion about my child’s health’, ‘staff reassured me about my care of my child’ and ‘staff gave me quite a bit of responsibility’, thus indicating less satisfaction.
3.3.5 E: What is the level of psychological distress of parents during their child’s hospitalisation?

A score of three signified a high level of anxiety and depression and a score of zero was taken as low anxiety and depression. Each participant’s mean score was calculated for each of the two sub-scales. The sum of the means was obtained. The means, standard deviations and scoring range for the anxiety and depression sub-scales of the HADS are shown in Table 7.

Table 7: Means, standard deviations and scoring range for the HADS

<table>
<thead>
<tr>
<th>HADS sub-scales</th>
<th>No. of Participants</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range (min - max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>75</td>
<td>9.18</td>
<td>4.17</td>
<td>1 - 19</td>
</tr>
<tr>
<td>Depression</td>
<td>75</td>
<td>5.25</td>
<td>2.60</td>
<td>0 - 11</td>
</tr>
</tbody>
</table>

Frequency data for the anxiety sub-scale showed that thirty-nine per cent of this sample scored at the upper end of the borderline range (i.e. 10 or above) indicating definite ‘caseness’. Therefore a high proportion of parents in hospital experienced case level anxiety.

3.4 TESTING THE STUDY HYPOTHESES

3.4.1 Hypothesis 1: Parents of children with first time admissions will have higher levels of confusion around their role at hospital compared with parents of children with repeated admissions

Parents’ questionnaire items received a score of one if they ticked ‘definitely appropriate’ at either end of the scale indicating at one end, for parents to do, or at the
other for staff to do. A score of two was given if they ticked ‘appropriate’ for parent or staff to do and a score of three if they ticked the ‘uncertain as to who should do this’ box. Mean sub-scale scores were obtained by summing the items. The results are shown in Table 8.

Table 8: Results of t-tests between first time parents and those on repeated admission for confusion with the four sub-scales of Parental Role

<table>
<thead>
<tr>
<th>Items on Parental Role Confusion</th>
<th>Mean (SD) First time parents</th>
<th>Mean (SD) Repeated parents</th>
<th>t</th>
<th>d.f</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic body functions</td>
<td>16.31 (4.27)</td>
<td>14.17 (4.14)</td>
<td>1.98</td>
<td>59</td>
<td>.05*</td>
</tr>
<tr>
<td>Medication</td>
<td>10.72 (3.43)</td>
<td>10.03 (2.67)</td>
<td>.90</td>
<td>62</td>
<td>.37</td>
</tr>
<tr>
<td>Holding</td>
<td>6.33 (2.55)</td>
<td>6.33 (2.24)</td>
<td>.00</td>
<td>64</td>
<td>1.00</td>
</tr>
<tr>
<td>Parenting</td>
<td>13.09 (4.53)</td>
<td>12.63 (4.46)</td>
<td>.40</td>
<td>60</td>
<td>.69</td>
</tr>
</tbody>
</table>

Note: * = significant at p .05 (one tailed)

The results—show—that—confusion—was—significantly—lower—for—parents—of—repeated admissions compared to parents of first time admissions for the Basic body functions sub-scale items only. (For example ‘Obtained urine specimen’ ‘Gave enema’ ‘Encouraged child to drink fluids and recorded’ etc.) Thus, these analyses provide only minimal support for Hypothesis 1.

3.4.2 Hypothesis 2: Parents of children with first time admissions will be less satisfied with staff communication compared with parents of children with repeated admissions

Because statistics were performed on individual scale items, which are expressed by a scale of 1 - 4, parametric statistics were not considered appropriate. Hence the ratings on the Staff Communication questionnaire were converted from a four-point scale to a
dichotomy (agree-disagree) then Chi Square tests were performed to determine whether there is a relationship between perceived communication problems and being parents of children with first time admissions or parents of children with repeated admissions. The results are shown in Table 9.

Table 9: Results of Chi square (2 x 2) test between parents of first time admissions and parents of repeated admissions for staff communication dissatisfaction

<table>
<thead>
<tr>
<th>Items</th>
<th>Cell count First time</th>
<th>Cell count Repeated</th>
<th>X²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff did not fully discuss with me the cause of child's problem</td>
<td>Agree 6</td>
<td>Agree 11</td>
<td>2.08</td>
<td>.15</td>
</tr>
<tr>
<td></td>
<td>Disagree 32</td>
<td>Disagree 26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff showed genuine interest in child's health</td>
<td>Agree 37</td>
<td>Agree 33</td>
<td>2.02</td>
<td>.16</td>
</tr>
<tr>
<td></td>
<td>Disagree 1</td>
<td>Disagree 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff encouraged me to express my concern and worries</td>
<td>Agree 32</td>
<td>Agree 29</td>
<td>.42</td>
<td>.52</td>
</tr>
<tr>
<td></td>
<td>Disagree 6</td>
<td>Disagree 8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff made me feel completely at ease</td>
<td>Agree 29</td>
<td>Agree 28</td>
<td>.01</td>
<td>.95</td>
</tr>
<tr>
<td></td>
<td>Disagree 9</td>
<td>Disagree 9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff did not treat me as an equal</td>
<td>Agree 9</td>
<td>Agree 11</td>
<td>.27</td>
<td>.60</td>
</tr>
<tr>
<td></td>
<td>Disagree 28</td>
<td>Disagree 26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff thoroughly explained everything to me</td>
<td>Agree 29</td>
<td>Agree 30</td>
<td>.29</td>
<td>.59</td>
</tr>
<tr>
<td></td>
<td>Disagree 8</td>
<td>Disagree 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff asked me for my opinion</td>
<td>Agree 15</td>
<td>Agree 19</td>
<td>.87</td>
<td>.35</td>
</tr>
<tr>
<td></td>
<td>Disagree 22</td>
<td>Disagree 18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff were informative about my child's health</td>
<td>Agree 31</td>
<td>Agree 32</td>
<td>.34</td>
<td>.56</td>
</tr>
<tr>
<td></td>
<td>Disagree 7</td>
<td>Disagree 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff asked for my thoughts about my child's health</td>
<td>Agree 23</td>
<td>Agree 32</td>
<td>6.46</td>
<td>.01*</td>
</tr>
<tr>
<td></td>
<td>Disagree 15</td>
<td>Disagree 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff reassured me about the care I provided to my child</td>
<td>Agree 20</td>
<td>Agree 23</td>
<td>.33</td>
<td>.57</td>
</tr>
<tr>
<td></td>
<td>Disagree 16</td>
<td>Disagree 14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff gave me quite a bit of responsibility</td>
<td>Agree 16</td>
<td>Agree 25</td>
<td>3.96</td>
<td>.05*</td>
</tr>
<tr>
<td></td>
<td>Disagree 20</td>
<td>Disagree 12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff's explanations were easy to understand</td>
<td>Agree 33</td>
<td>Agree 30</td>
<td>.96</td>
<td>.33</td>
</tr>
<tr>
<td></td>
<td>Disagree 4</td>
<td>Disagree 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff seemed to care about my child's feelings</td>
<td>Agree 35</td>
<td>Agree 33</td>
<td>.73</td>
<td>.39</td>
</tr>
<tr>
<td></td>
<td>Disagree 2</td>
<td>Disagree 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff identified themselves clearly</td>
<td>Agree 32</td>
<td>Agree 31</td>
<td>.11</td>
<td>.74</td>
</tr>
<tr>
<td></td>
<td>Disagree 5</td>
<td>Disagree 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff used simple to understand language</td>
<td>Agree 35</td>
<td>Agree 34</td>
<td>.21</td>
<td>.64</td>
</tr>
<tr>
<td></td>
<td>Disagree 2</td>
<td>Disagree 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note 1: * = significant at p .05
Note 2: df = 1 in all cases
Note 3: ' = reversed score items
The results show that parents of first time and repeated admissions differed significantly on only two items which are in the *partnership building* sub-scale. Parents of children with first time admissions were less likely to agree with the statements that 'staff asked for their thoughts about their child’s health' and that 'staff gave them quite a bit of responsibility'. These findings provide only minimal support for Hypothesis 2.

3.4.3 **Hypothesis 3a**: Higher levels of psychological distress will be found in parents who have greater levels of confusion with parental role in hospital

The relationship between parental role confusion and both anxiety and depression was examined using Pearson's co-efficient correlation. The results failed to support Hypothesis 3a, since neither anxiety or depression were significantly correlated with confusion with parental role in hospital. The correlation coefficient for anxiety is: $r = -.07$, $(p = .57, N = 59)$. The correlation coefficient for depression is: $r = .10$, $(p = .45, N = 59)$.

3.4.4 **Hypothesis 3b**: Higher levels of psychological distress will be found in parents with lower levels of support

The relationship between the three components of support and anxiety and depression was examined using Pearson's co-efficient correlation. The results failed to support Hypothesis 3b, since neither anxiety or depression were significantly correlated with
support in hospital from medical staff, other parents on the ward or family and friends.

The results are shown in Table 10.

Table 10: Results of Correlation between levels of support and anxiety and depression

<table>
<thead>
<tr>
<th>Support from Medical Staff</th>
<th>Anxiety</th>
<th></th>
<th>Depression</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
<td>n</td>
<td>r</td>
</tr>
<tr>
<td>Support from other parents in hospital</td>
<td>.05</td>
<td>.61</td>
<td>74</td>
<td>-.06</td>
</tr>
<tr>
<td>Support from family and friends</td>
<td>.01</td>
<td>.93</td>
<td>73</td>
<td>.04</td>
</tr>
</tbody>
</table>

3.4.5 Hypotheses 3c: Higher levels of psychological distress will be found in parents who are dissatisfied with hospital procedures (i.e. admission, treatment and discharge).

The relationship between parental satisfaction with hospital procedures and both anxiety and depression was examined using Pearson’s co-efficient correlation. No support was provided for this hypothesis since neither anxiety or depression were significantly correlated with dissatisfaction with hospital procedures. The correlation co-efficient for anxiety is: $r = .01$, ($p = .91$, $N = 63$). The correlation co-efficient for depression is: $r = .01$, ($p = .94$, $N = 63$).
3.4.6 Hypotheses 3d: Higher levels of psychological distress will be found in parents of children with first time admissions compared to parents of children with repeated admissions.

An independent sample t-test was performed on parents of first time admissions for anxiety and depression and compared to anxiety and depression scores for parents of repeated admissions. No support was provided for this hypothesis since there were no significant differences in either case. The mean anxiety scores for parents of first time admissions and repeated admission respectively are: 9.37, (SD = 3.82) and 9.00 (SD = 4.56), (t = .38, d.f. = 73, p = .70). The mean depression scores for parents of first time admissions and repeated admission respectively are: 5.52, (SD = 2.62) and 4.97, (SD = 2.56), (t = .92, d.f. = 73, p = .36).

3.4.7 Hypothesis 3e: Higher levels of psychological distress will be found in parents who have a high level of perceived seriousness concerning the child’s condition.

The relationship between parents’ perceived seriousness of their child’s condition and both anxiety and depression was examined using Spearman’s co-efficient correlation, as the data was ordinal. There was partial support for this hypothesis since parents with a higher level of perceived seriousness concerning their child’s condition/illness, were found to have significantly higher anxiety in hospital but not depression. The correlation co-efficient for anxiety is: rho = .27 (p = .02, N = 75). The correlation co-efficient for depression is: rho = .01 (p = .94, N = 75).
3.4.8 Hypotheses 4a: Lower levels of psychological distress will be found in parents who are satisfied with staff communication

The data for the staff communication variable were skewed and did not meet the criteria for parametric analysis. Therefore a Spearman's co-efficient correlation test was performed. This hypothesis was not supported since neither anxiety or depression was significantly correlated with dissatisfaction with staff communication. The correlation co-efficient for anxiety is: rho = .03 (p = .79, N = 71). The correlation co-efficient for depression is: rho = .09 (p = .46, N = 71).

3.5 PARENTS' COMMENTS

As this was a quantitative study, parents were not asked for their comments. However some parents did provide qualitative statements written on the questionnaires, all of which are given as follows.

3.5.1 Staff Communication Questionnaire

"The ward staff have been brilliant but the medical people have been very unhelpful - to the point of being rude".

"House doctors are not helpful at all".
"Staff are generally very pleasant although I feel the lack of communication from staff is purely because they are overworked and understaffed and for no other reason at all".

"If I had completed this questionnaire when I first came in, I would have disagreed with everything, but now four days on I am most satisfied with the staff communication".

3.5.2. Hospital Procedures Questionnaire

"It took four hours to get her creams".

"We had to wait until 7 p.m. since being told he could go home at 3 p.m. to get his medication".

"The ward is scruffy and dirty".

"The facilities for the parents are very poor, who if they did not stay would make life very difficult for the nurses".

"The furniture is broken and they expect a parent to sleep next to a bin full of dirty, smelly nappies".

3.5.3 Parental Role

"I have been in several times and do much of my son's care myself - I do all his stuff at home so it would be crazy to expect someone else to do them here".
"I know not all parents can do the things I have been doing here".

3.5.4 Hospital Distress

"I felt very anxious initially".

"...when I first came in".

"...while first waiting for information".

"This statement only applied before my son went to theatre".

It is clear from these statements that a minority of parents were very dissatisfied with some aspects of hospitalisation.

3.6 SUMMARY OF RESULTS

The results indicated that parents were satisfied with hospital procedures, staff communication and parental role, but none of these factors were correlated with levels of distress. However, parents of children with first time admissions were less satisfied with some aspects of staff communication, and were more confused about basic body functions items on the parental role questionnaire, compared to parents of children with repeated admissions. The findings showed reported levels and sources of support parents received at hospital. Finally, parents’ perceived seriousness of their child’s condition, was correlated with higher levels of anxiety, but not depression while at the hospital.
4. DISCUSSION

The present study was designed to examine the experiences and levels of distress of parents of hospitalised children. In particular it looked at the extent to which the following variables, i.e. previous experience of hospitalisation, parental perceptions of levels of support, parental satisfaction with hospital procedures and staff communication, and the perceived severity of their child's condition/illness, were associated with levels of distress.

Firstly, the findings will be discussed in relation to previous research in this area. Secondly, there will be a critique of the methodology employed. This will be followed by suggestions for future work in this field and finally, the implications for clinical practice will be discussed.

4.1 DISCUSSION OF THE RESULTS IN RELATION TO PREVIOUS RESEARCH

Despite the small number of statistically significant correlations found in this study, the results provide some useful information about parents' experiences of hospitalisation, as well as clarifying, strengthening and validating some of the findings from the author's qualitative study completed earlier, (O'Dwyer, 1997).
4.1.1. **Staff Communication**

Overall, the results revealed that the parents as a sample reported themselves satisfied with most aspects of staff communication, i.e. areas of *staff informativeness, interpersonal sensitivity* and *partnership building*. However, the use of the structured questionnaire allowed the researcher to examine many specific areas of staff communication and it was decided to examine scores on the individual items. Moreover, these more fine grained analyses were completed with individual items on the communication measure because of the low internal consistency on the *partnership building* sub-scale. Focusing on the individual items, the results showed that parents of children with first time admissions differed significantly from parents of children with repeated admissions in that they felt dissatisfied about not being asked by staff for their thoughts on their child’s health and also they were not given enough responsibility for their child’s care. Further to this, when the frequency data were examined, half the sample disagreed with some of the statements. For example, parents did not feel staff had asked for their opinion on what to do, staff had not reassured them about the care they were offering to their child and the staff had not given them much responsibility.

This indicates that the parents did not feel they were working in partnership with the medical staff. This is consistent with one of the findings of Street’s (1991) study, which showed that parents of children with repeat visits to hospital expressed greater satisfaction than did parents of children with singular visits.

However, because the aim of most paediatric professionals is problem solving and assessing the status of a child’s health, Street (1991) argued that paediatric health
professionals' informativeness would be the communicative feature most relevant to these tasks and thus would reveal a stronger relationship to parents' satisfaction than would other types of responses.

Some of the parents went as far as to add some comments (see Results section), which helped gain an understanding of the situation, but would normally get lost in a purely quantitative piece of work. These more critically qualifying statements about staff communication are similar to the qualitative study findings (O'Dwyer, 1997), which found the majority of parents were satisfied, but when they were critical of staff, they felt they had to justify the statements with a reason, for example, staff overworked.

Similarly, Callery and Luker, (1995) found that parents were reluctant to appear critical of the hospital staff, but when given the opportunity to tell the whole story and to explain the problems they had experienced in context, parents provided detailed accounts which identified unsatisfactory aspects. This may mean that the high satisfaction rates for the sample as a whole, are not as representative of true opinions.

4.1.2 Hospital Procedures

The results showed that the parents in hospital were also highly satisfied with the hospital's procedures for admission and treatment, and where applicable, discharge, as measured by the satisfaction questionnaire. These findings are similar to other studies. For example, Brown et al.'s (1995) descriptive study of parents of children with non-life threatening illnesses, attending an emergency department completed questionnaires.
which showed that the majority of the parents were satisfied with the services provided, including staff communication.

However, in the present study where some parents felt it was necessary to provide some additional information, some discrepancies with satisfaction began to emerge. For example, the main complaint was in relation to provision of post hospitalisation medication, the lack of cleanliness of the ward and the poor facilities. Parents appeared to recognise the importance of their position and role at the hospital, but felt in some way it was undermined by the staff who did not provide adequate facilities for them. These findings support earlier qualitative research findings, and in both cases parents appeared to justify these criticisms by saying the ward was understaffed and the staff were overworked. They argued that the staff's main concern (correctly so) should be focused on their child. However, the Audit Commission in 1993 found that 32 per cent of parents questioned in a hospital study felt that their role was to substitute for lack of staff.

These findings are similar to the findings of Marais' (1996) postal questionnaire study, in which she reported that parents were highly satisfied with the procedures at the hospital, both at the time of the hospitalisation and two months post hospitalisation.

4.1.3 Parental Role

In an attempt to determine what Wofford, Gerloff and Cummins (1979) describe as role ambiguity (i.e. the difference between perceived, expected and enacted roles),
which can cause high levels of distress in groups such as parents during hospitalisation of their children, parents were asked to complete the Parental Role Questionnaire which was constructed for the purposes of this study.

What was evident from the findings, was that overall parents did not appear to be confused about what they felt were appropriate roles for parents and appropriate roles for nursing staff on most items. Qualitative findings from earlier research indicated that the parents' role at the hospital had not been made explicit and that they made assumptions and divided the roles into 'basic care' and 'medical care'. They perceived their own role to be one of attending to the basic care needs of their child, which they defined as toileting, washing and feeding, while at the same time, identifying the staff's role as tending to the medical needs of their child, that is, treatment and medication.

Therefore it is interesting to note that in the present study, confusion on parental role was significantly higher for parents of first time admissions compared to parents with children of repeated admissions on some items. The items that caused greatest confusion were on the basic body functions sub-scale:- 1) encouraged child to drink fluids and recorded, 2) changed child, 3) obtained urine specimen, 4) placed child on bedpan, 5) kept record of amount of urination, 6) emptied bedpan, and 7) kept record of number of bowel movements.

One possible explanation for this group of parents experiencing confusion, may be derived from Seligman's (1975) model of learned helplessness, where people experience an event that they cannot control, and they develop an expectation of lack of control in similar situations. This learning results in the helplessness syndrome,
which consists of motivational, cognitive and emotional deficits. In addition, the learned helplessness model makes the prediction that in stress situations, coping activities will essentially be abandoned, if the causes of uncontrollability are perceived as internal, stable and global (Stroebe & Stroebe, 1996). However, this model assumes that a characteristic attributional style exists which constitutes a risk factor for depression.

On the other hand, one can speculate that perhaps parents who had been to the hospital with their child in the past were more experienced, had prior knowledge and knew what to expect. As a result they may have been more confident and assertive in taking on these roles themselves. Further to this, parents on repeated visits may have learnt how to cope and adapt to the environment. For example, Folkman and Lazarus, (1984) postulate that problem focused coping strategies including seeking information and taking action to deal with a crisis or its aftermath, and establishing goals, are used when an individual feels that something constructive can be done about a situation. In addition, when events are predictable and reduced to concrete elements that may have been previously experienced, an individual can gain confidence in his or her already existent coping repertoire (Johnson, 1984).

Research has shown as far back as 1985, parents reported that staff do not communicate to them what role they may assume or ask parents what role they would prefer to assume (Algren, 1985). This is still very much evident in the present study, and while areas of confusion still exist, it is necessary to find ways of addressing them. Derbyshire (1993) reported an overwhelming reluctance on the part of nursing staff to allow parental participation in aspects of nursing which they described as "technical"
but expected parents to participate in ‘basic mothering’. However, a cardinal principle of the NHS is that child health care is shared with parents and carers, and that they are closely involved in the care of their child at all times, unless, exceptionally, it is not in the best interests of the child (Department of Health, 1991).

One way to define roles more clearly for parents has been suggested by Adams (1994) who proposed providing formal ‘rules’ to define parental and nursing roles. When these rules were communicated by nurses, in writing, orally, or both and were compared to no formal communication, the formal rules were found to enhance parental satisfaction with hospital procedures and parents perceived a reduction in role ambiguity. Melnyk (1994) also advocated the use of providing parental role information, which had been found to show positive effects on maternal state anxiety as well as on levels of participation in their children’s care during hospitalisation.

4.1.4 Support

The relationship between the three components of support (i.e. medical staff, other parents on the ward, and family) and anxiety and depression examined in the current study, failed to support the hypothesis that higher levels of psychological distress would be found in parents with lower levels of support. However, it was found that parents in the current study received high levels of support from their families and friends, but lower levels of support from the medical staff and hardly any support at all from the other parents on the ward. This finding was similar to the earlier qualitative study. It is not clear why this is so, but one can speculate that perhaps parents felt
sufficiently supported by their family and friends and did not need support from other sources. Alternatively, Bradford (1991) suggested that the accurate identification of parental worries by staff at the hospital, which was not measured in the current study, is a pre-requisite for providing emotional support.

One could argue, that the effectiveness of social support depends on how an individual uses a social support network. Some people may be ineffective in extracting the support they need from others. For example, findings from Dunkel-Schetter, Folkman and Lazarus (1987) found evidence that genetic predispositions or personality factors (such as sociability or likeability) relate strongly to emotional support, but not strongly to informational support. In line with the idea of Sarason, Shearin, Pierce and Sarason (1987) that social support is as much a dispositional measure as an indication of social resources available, stressful events themselves have been found to interfere with the ability to use potential social support effectively. One can speculate that parents in hospital under stress and continually expressing distress to others trying to provide support, may lead to driving them away, or the providers feeling over burdened (Matt & Dean, 1993, McLeod, Kessler & Landis, 1992).

An inability to reciprocate support (for example by parents who are in the hospital while their partner/family is ‘outside’ the hospital) may reduce the probability that people will ask for help from others and the amount of help they receive. Equally, social support can be a stressor in its own right rather than as an absence of support. It can be intended to be positive by the provider, but can be perceived as negative by the recipient. It can be seen as an invasion of privacy, which may have applied to some of the parents in this study.
It is unclear why no relationship was found between social support and parental distress in hospital. Perhaps in future work an examination of the more specific types of social support may help shed some light on this matter.

4.1.5 Hospital Distress

Parents' levels of distress were measured using the HADS at the time of the hospitalisation, in order to look at the possible relationships with other factors. The HADS scores revealed that parents in hospital were a highly anxious group, since 39 per cent scored above the case cut-off for this scale. Also, compared with data on 500 early diagnosed cancer patients, (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991)-whose mean anxiety-score on the HADS was 5.44 (SD 4.07), the mean score for parents in hospital was 9.18 (SD 4.17). Some parents added qualifying statements on the questionnaires stating that they were highly anxious. This area still needs to be addressed with hospital staff, as it is generally recognised in the literature that uncertain and unexpected events are more likely to stimulate negative emotional reactions (Leventhal & Johnson, 1983). Despite the many changes and improvements incorporated into hospital practice and policy for parents in hospital, the finding that parents experience distress while in hospital with their children, still supports all the findings from previous research in this area, (i.e. Miles & Carter, 1985, Kasper & Nyamathi, 1988, Pless & Perrin, 1986, Hughes & Lieberman, 1990, and Burke et al. 1991).
Further to this, parental anxiety, lack of experience with their child's condition, incomplete information or faulty cues about the meaning of their child's symptoms, have all been shown to interfere with effective communication (Callery & Luker, 1995). Indeed, it has been noted by Melnyk (1994) that highly anxious parents can experience immobilisation which inhibits them from providing appropriate care and support for their child. She also argued that only when parents themselves have adapted to the hospital setting are they able to focus on meeting their child's needs. Recently, Whelan and Kirkby (1998) indicated that, for some parents, a high level of anxiety can be adaptive, provided it was not excessive or chronic, but their study found that parents felt disempowered and expressed high levels of anxiety when their children were in hospital.

One of the difficulties with attempting to address parental anxiety, is the fact that people respond very differently to stress. It has been argued that response to stress is substantially influenced by an individual's personality, perceptions and biological constitutions (Folkman & Lazarus, 1984), all of which are not obvious to others. Therefore selection of coping efforts is guided by internal and external resources. Internal resources include preferred coping style and other personality factors, such as, negativity, hardiness, optimism, high self esteem and control. External resources include time, money, the presence of other simultaneous life stressors, and support.

On the other hand, the question of what factors have a causal relationship with parental distress in hospital was only partially clarified by the present study. This study showed that while higher levels of psychological distress were linked with parent's perceived seriousness of their child's condition, they were not found to significantly correlate
with either high levels of confusion with parental role while in hospital, parents' dissatisfaction with hospital procedures or dissatisfaction with staff communication and whether or not parents were attending for the first time or with a child for a repeated admission. However, Berenbaum and Hatcher, (1992) found that prior experience with hospitalisation predicted parental anger more than parental anxiety or depression. They argued that in a dynamic sense, depression is anger turned inward. Perhaps parents of children with repeated admissions became more accustomed to illness related behaviours and hospital routines, and felt less helplessness, guilt, and self blame over their child's illness. As they move out of depression, the anger turns outwards towards the health care system. Some of the individual, qualitative statements made by parents in the present study seem to indicate a more angry, critical stance.

4.1.6 Perceived seriousness

Based on other studies findings (see Cella et al., 1988) where it has been found that parents experience equivalent levels of distress regardless of the type of illness or onset, parents in the current study were asked to indicate the nature of their child's illness/condition and the reason for the hospitalisation.

However, according to Folkman and Lazarus (1984) an individual's appraisal of the stress of a situation rather than the 'objective' measure of the stress is important in determining response. This hypothesis suggests that the parents' beliefs about the severity of their child's condition will be more influential and predictive of their behaviour than medical indices of severity. Therefore, the current study was more
interested in the parents’ perception of the seriousness of their child’s illness, rather than the actual illness per se.

Correlation results found that parents with a higher level of perceived seriousness concerning their child’s condition/illness, had a significantly higher level of anxiety, but not depression, while at the hospital. This was highlighted by one parent who added the following comment, “If my son was in for an operation rather than tests, I would have been much more anxious and worried - as I have been on previous occasions”.

In trying to understand the relationship between parents’ perceived seriousness of their child’s condition and the level of distress experienced, it may be possible to draw parallels with the research on patient’s perceptions of their illness. For example, in Leventhal et al.’s (1983) self regulatory model of illness behaviour, it describes how patients develop their own cognitive representation of the health problem. This incorporates five different dimensions and a key component is the patient’s perceived consequences of the illness, which reflect the patient’s perception of the seriousness of the problem. Researchers on illness perceptions have shown not only that perceived consequences have major effects on outcome, but also that the perceptions of significant items can influence outcome (Weinman & Petrie, 1997).

From the medical staff’s perspective, it is important for them to provide concrete, objective information and to understand how parents might interpret the information they have been given. They need to be aware that there may be a discrepancy between what is expected and what actually occurs, and they should enhance parents ability to
understand and interpret the experience so that parents’ perceptions of their child’s illness, will be analogous to the actual experience and provide a basis for understanding how parents will cope.

It appears that the determinants of parental distress are diverse and multi-factorial. The present study indicates that some variables may account for levels of distress, but that there may be other external variables, some of which were tracked but were not accounted for in the present study, which may also have a relationship with levels of distress. For example, age of parent, ethnicity, number of children, and marital and employment status. These factors too should be taken into account when conceptualising parental distress in hospital.

4.2. CRITIQUE OF METHODOLOGY

4.2.1 Questionnaire Construction

Even though all the questionnaires were piloted, some of them still contained wording errors, including ambiguities and double negatives. This may have led to confusion and uncertainty for the participants. The layout of the questionnaires and information pack in general, could have been given more consideration. One can speculate whether more information could have been obtained if, for example, it was made clear that the signed consent form would be detached from the questionnaires, and the demographic information sheet had been placed at the end of the pack, as suggested by Creswell, (1994).
This may explain why some parents (29 per cent of the sample) resisted giving demographic information. Despite the fact that the very act of asking for information on ethnicity and nationality is heavily laden with political baggage, these were two pieces of information that were considered useful to track at the time of construction, (although they were not used in any statistical analyses). Many parents confused nationality with ethnicity. It has been shown that research which may reveal important differences between ethnic groups may be regarded as politically suspect by whichever group perceives itself likely to come out worst in the survey (Breakwell, Hammond & Fife Schaw, 1995). Therefore, perhaps more careful consideration should have been applied to the use of gaining this information.

The use of attitude scales is based on a number of assumptions. First of all, it assumes that the parents actually had attitudes towards the issues and then that they had ready access to them. Secondly, it is assumed that these can be adequately reflected in simple ratings or forced choice judgements. Perhaps the questionnaires failed to access the areas identified as causing stress. For example, Bradford's study (1991), showed a number of areas where parents reported dissatisfaction. The survey highlighted that at admission, parents needed basic information about what procedures were likely to be carried out, and why and how long the admission would last. More careful wording or addressing parents' needs rather than satisfaction may have elicited similar findings which would have supported previous qualitative literature (O'Dwyer, 1997).

One of the main problems with the constructed questionnaires, was that of reliability and validity. Nunally, (1978) suggests that the internal reliability co-efficients should
be greater than 0.7. The reliability of a measure is partly dependent on the number of items in it, and one reason for low reliability is often to do with the low number of items (Oppenheim, 1992). Thus, the Cronbach's alpha score of 0.5 obtained for the partnership building sub-scale of the Staff Communication questionnaire, might have been inadequate because it did not have enough items to describe the underlying characteristics.

Similarly, by removing three of the items on the depression sub-scale of the HADS, this gave a low Cronbach's alpha of 0.57 which again meant that the remaining items may not have been sufficiently coherent. Although Snaith et al. (1982) had indicated that the HADS sub-scales could be reduced without affecting the internal reliability, the present findings challenge this assertion. This casts doubt on the usefulness of the sub-scales of these measures. Further to this, other implications of adapting the depression sub-scale of the HADS questionnaire, means that the validity may be compromised as it will not allow for comparisons with other studies. In the present study, no significant findings were obtained with the depression sub-scale, and this may be a true reflection of the data. However, by adapting the sub-scale and reducing its reliability, it is possible that the study failed to detect true findings (i.e. Type II error).

However, Cronbach's alpha may be only one way of assessing reliability and examining internal consistency, which assumes that the internal structure of the items reveal inter-item homogeneity. Another commonly hypothesised structure is that the items of a measure form a uni-dimensional scale, in which the items are expected to have a particular pattern of correlations which reflect their order along a single latent trait. A possible method of assessing the uni-dimensionality of the constructed scales, might
have been to use factor analytic methods which would have allowed for the examination of the underlying structure of the questionnaire items (Hammond, 1995). This was not employed in the current study, as this method tends to make assumptions about the possible patterns between variables, which is quite a controversial technique (Clark-Carter, 1997). Also, for the longer scales (e.g. Parental role), the sample was not large enough to warrant factor analysis.

4.2.2. Concepts of Satisfaction

The results of the study seemed to indicate very high level of satisfaction, but this might reflect some of the conceptual and methodological problems in satisfaction measurement, which have been identified in recent years (e.g. Fitzpatrick, 1997).

While user satisfaction has become an increasingly important concept in health care, there are problems of definition with the term ‘user’, and there are particular problems when the term is used in the context of the hospitalisation of children. Callery and Luker (1995) argued that parents are proxy consumers, but that their status is conditional on the ways in which they exercise choices. Parents’ involvement in the care of their children means that the term ‘user’ is more appropriate than that of ‘consumer’. Therefore, due to parents’ position in hospital, parallels can be drawn between parents’ satisfaction and the wealth of literature on patients’ satisfaction.

Although the concept of satisfaction has good face validity, there is a singular lack of good theory or consensus about its nature or structure (Weinman, 1998). Fitzpatrick
(1997) has promoted the idea of satisfaction as a multidimensional concept, given that patients have been found to have differing views about different aspects of their health care, such as the health care professionals' behaviour towards them, the information provided, the technical skills of the health care professional, and the access to and quality of the health care setting. Despite this, there is evidence that the behaviour of the health care professional is the critical determinant and one which can significantly influence ratings of all the other aspects of health care.

Although satisfaction appears to be a relatively straightforward concept, there remain a number of difficulties in measuring it. Results from most satisfaction surveys reveal skewed data, apparently indicating very high levels of satisfaction across samples, particularly amongst older adults (Hall & Dornan, 1988). Part of this problem appears to lie in the reluctance of people to criticise health care services and part of it is due to the structure of the questionnaires which have been used to assess satisfaction. Comparative studies of different methods have shown variability in satisfaction across measurement approaches. Wide variation in satisfaction scores between three commonly used methods has been reported (Counte, 1979). For example, consistently lower rates of satisfaction are found when the same respondents use a five point rating scale ranging from "poor" to "excellent" compared to a six point rating scale ranging from "extremely satisfied" to "very dissatisfied" (Ware & Hays, 1988).

4.2.3 Study sample

Another reason for some skewed data and few statistically significant correlations, may be due to the fact that the sample was biased. For example, 180 parents in all were
approached on the ward, but only 75 (42 per cent) agreed to participate. Of these only 4 (5.3 per cent) were male and 43 (57 per cent) were white, which is not a very representative sample. Of those that were approached but refused to participate, some gave reasons for refusal, such as being too tired or too busy, many were from ethnic minorities and although they had very good spoken English and agreed to participate when first approached, they declined when asked to read and write. Similarly, parents who were crying or visibly upset at the time of the proposed data collection were not approached on instruction from the medical staff. There may have been other reasons for refusal but the clear absence of this group may well have compromised the sample’s representativeness.

4.2.4 Completion of Questionnaires

One can speculate from some observations on the context of parents filling in questionnaires while still at the hospital. Perhaps a clearer and more honest picture might have emerged if questionnaires were completed reflectively at home. However, one had to weigh up the benefits of gaining data at the time of the hospitalisation, with depending on postal questionnaires that have a poor response rate (Clark-Carter, 1998). On the other hand, it has been shown that the use of more in-depth methods which require individuals to describe their experiences of health from their own perspective, typically give rise to a more critical view (Fitzpatrick & Hopkins, 1993).

The complexity of all the questionnaires might have been too great, causing parents to miss out questions, especially if they were feeling anxious at the time. Parents may have needed more guidance/instructions to understand the questionnaires fully. For
example, on the Parental Role Questionnaire, participants were also asked to underline what tasks they did complete, as well as ticking which were the most appropriate for either parents or staff to do. However, no parents underlined any of the statements.

Parents often appeared to find the process of completion quite lengthy, and the researcher needed to return to the parents on several occasions to collect the completed questionnaires. Often up to an hour had to be allowed for completion, thus indicating that the completion time had been underestimated. It was also apparent that some did not fully read all the instructions. On some occasions it was necessary to approach some parents a second time who had returned incomplete questionnaires.

Perhaps while in the hospital environment, parents felt uncomfortable being critical, in case this affected their own or their child's future treatment (although it was made clear on the written information about the study provided to the parents that this would not be the case). Further to this, from some of the comments directed at the researcher, it became clear that parents were under the impression that the researcher was part of the hospital (again, all this was stated in the written information and reiterated verbally to all participants prior to agreement to participate).

However, in stressful situations where parents are being constantly approached by health professionals and given a lot of information to absorb, perhaps completing questionnaires, which would not benefit their experience and/or their children, had low priority for them. Further to this, because it was not possible to establish a relationship with participants completing questionnaires, Clark-Carter, (1998) suggests that they have less personal investment in the survey.
Other weaknesses of this data collection mode were that participants did not use their own words to express their perceptions and due to the nature of the collection of data procedure and time constraints, the researcher did not have direct access to many participants for questions or further discussion. This might explain some of the missing data.

4.3 CONCLUSIONS

The study set out to examine possible contributory factors to the experiences and emotional responses of parents with hospitalised children. The findings have shown how parents of children in hospital experience some aspects of hospitalisation. Generally parents are satisfied with hospital procedures; staff communication and their role at hospital, although parents of children with first time admissions were less satisfied with some aspects of communication and parental role. This may be due to lack of experience and knowledge. These findings support earlier literature on this subject.

The study also found that parents in hospital generally, were a highly anxious group of people (even compared to early diagnosed cancer patients). However, one of the study's main hypotheses which stated that parents of children with first time admissions would have higher levels of distress than parents of children with repeated admissions, was not supported. One way of explaining this may be due to the most substantive finding, which highlights the way in which parents perceive the seriousness of their child's illness (rather than medical indices of the illness) to be a contributory
factor to their emotional responses, regardless of whether they have a first time or repeated admission. Therefore, the interventions designed to meet the needs of parents in hospital can be articulated for both groups.

While these findings go some way towards understanding what factors contribute to parents' experiences and emotional responses with their hospitalised children, it is worth bearing in mind that there may be other, less obvious or visible factors which may effect response to stressful situations. For example, according to the theoretical framework of Folkman and Lazarus (1984), it is an individual's personality and biological constitutions, as well as their perceptions that substantially influence how a person responds to stress. These were variables which remain unknown in the present study, which has attempted to examine possible contributory factors to the experiences and emotional responses of parents with hospitalised children.

A report of the main findings has been prepared to disseminate to the health care professionals and for the clinical psychologist to utilise in working on the ward. Suggestions on how to improve and enhance the findings together with the clinical implications are discussed below.

4.4 DIRECTIONS FOR FUTURE WORK

As there appear to be some flaws with the present constructed questionnaires as mentioned above, perhaps more consideration needs to go into 'fine-tuning' the questionnaire pack and re-testing some of the hypotheses in view of the current
findings. Alternatively, additional questionnaires could be devised but these would need to consider parents’ views on content, concepts, format and language and more clearly defined constructs.

As the findings did not support the implied model that different levels of distress would be correlated with whether parents were attending for the first time or for a repeated admission, but found that the perceived seriousness of their child’s condition was correlated with high levels of anxiety, there would be no need to divide parents into two different groups for further study of this phenomenon. Therefore, one possible way to take this study forward would be to repeat the study, using a larger, more representative single group of parents, perhaps employing the use of more widely used questionnaires which show satisfactory levels of reliability and validity, such as the Client Satisfaction Questionnaire, (CSQ-8) (Nguygen, Attkisson & Stegner, 1983).

In addition to quantitative methodology which can limit the scope of a study, one could add depth and breadth by combining qualitative and quantitative methodology as a means of gathering additional information. This would enable certain issues to be explored in-depth, such as the quality and nature of staff communication, and the quality of care provided not only for children but for parents too. In addition, Zigmond and Snaith, (1983) suggest that the HADS could be supplemented by a brief interview when used with clients other than out-patients. This approach would add complexity to the design and uses the advantages of both the qualitative and the quantitative paradigms.
This study, which supports earlier research, has shown that parents experience considerable anxiety during their child’s hospitalisation, but it could be that the relatively simple measure, and the limitations imposed by using the adapted version of the HADS in this study (as discussed earlier), failed to assess some aspects of the distress. Therefore, in future studies, it might be more valuable to use multidimensional measures of anxiety (e.g. assessments of intensity and duration) to assess a wider variety of hospital stressors and to monitor it over time from initial admission.

The results of the present study show that there is still some confusion around parental role in hospital, especially for first time parents with no prior knowledge and experience. This study supports earlier findings in that clearly, there still remains a need for roles to be defined. One way to address this, could be for staff to provide parents with written information at admission. This could take the form of a pilot study, to see what changes were needed as well as taking pre and post measures of confusion and satisfaction. Alternatively, someone, either a psychologist or staff informed by a psychologist, could explain roles, procedures and answer questions either prior to the admission where feasible, or at admission.

The results of the present study show that parents’ perceived seriousness of their child’s condition are correlated with high levels of anxiety at the hospital. This study also acknowledges that parental distress may be related to other external variables which were recorded but not part of the analyses of this study. For example, Marais (1996) found that younger parents had higher levels of distress, while Bradford (1991) suggested that parents from ethnic minorities found it difficult to cope at hospital. As only one of the variables (perceived seriousness) measured in the current study
Clinical psychologists offering opportunities for parents and health care professionals to work as partners, either in clinical activities around individual children, or in educational programmes designed to increase professional understanding, also provides an arena in which professionals and parents could share their experiences with one another. Recognition of individual coping styles as well as ethnic, cultural and religious contributions to attitudes and beliefs are important components of this work. Often serving as a link between the families and health care professionals, clinical psychologists on a paediatric ward hold a strategic position. They may also play an important role in helping parents understand and manage their intense emotions and help empower them to obtain answers to their questions on the ward.

Whilst there are often problems with attempting to integrate psychological approaches into hospital settings (Nichols, 1995) the amelioration of parental distress in caring for a child at hospital is essential in promoting successful adjustment not just for the child and/or parent but for the whole family.
parents' experiences. From the findings of this study, this should be paramount for all clinical psychologists who have a role either working or offering a liaison service to paediatrics. Unfortunately, it seems that any staff education programmes currently being offered are mostly attended by and directed towards nursing staff, but in order to bring about a change in understanding, attitudes and belief, doctors need to be included in any training being offered.

Furthermore, clinical psychologists need to provide and/or increase awareness with health care professionals about the need to be sensitive to the variety of coping strategies parents use in parenting their child while in hospital. While health care professionals' main focus is that of the patient, clinical psychologists could provide an on-going education to help them identify those parents with increased anxiety and who appear to be unable to cope, whether this is due to their perceived seriousness of their child's condition or other factors. Bradford (1991) found that staff significantly underestimated the magnitude of emotional problems experienced by parents, whilst significantly overestimating the opportunities available for parents to discuss their concerns.

With increased understanding of the parents' experiences and attempts to cope, professionals would be better prepared to acknowledge the parents' efforts, as opposed to avoiding or resisting their coping strategies. However, health care professionals should also be able to discuss and negotiate the possibility and necessity of referring a parent to a clinical psychologist.
correlated with parents' psychological distress, it was not possible to complete a multiple regression. However, perhaps the next, and rather ambitious step could be to complete a larger study, using a wider more representative sample, to examine correlations between several, clearly identified variables and complete a multiple regression, the aim of which would be to examine what proportion of variance in parental distress can be accounted for by each of the predictor variables. This may go some way further to identifying the contributory factors to the experiences and emotional responses of parents with hospitalised children.

4.4 CLINICAL IMPLICATIONS

Despite the limitations of this study, which have been outlined above, the study's findings indicated that there is still room for improvement in some of the areas that parents experience while in hospital. However, with the advent of clinical psychologists taking up posts in physical health departments, including paediatrics, it should be possible to address some of the issues that concern parents in hospital with their children.

Whilst it has been shown in this study that some aspects of hospital staff communication with parents can be difficult, other research has confirmed that it can be facilitated by staff who are aware of the difficulties (Hughes & Lieberman, 1990). Although some health care professionals appear to have an understanding of the stressors parents experience when their child is hospitalised, there is a need to continue to provide an increased awareness and educate new health care professionals about
5. REFERENCES


Dare, J. & Hemsley, R. (1986). Design and evaluation of a questionnaire to identify emotional distress and its causes in parents of children with liver disorders. (Paper available from the authors; Presented at 58th British Paediatric Association meeting, York)


APPENDIX 1: Staff Communication Questionnaire
Please read the following 15 statements and tick whether you strongly agree, agree, disagree or strongly disagree with any of the statements which may apply while in hospital with your child.

Please think about the doctors and the nurses

SA = Strongly agree
A = Agree
D = Disagree
SD = Strongly disagree

1. The staff did not fully discuss with me what was causing my child’s problem
2. The staff showed a genuine interest in my child’s health
3. The staff encouraged me to express my concerns and worries
4. The staff made me feel completely at ease
5. The staff did not treat me as an equal
6. The staff thoroughly explained everything to me
7. The staff asked for my opinion on what to do
8. The staff were very informative about my child’s health
9. The staff asked for my thoughts about my child’s health
10. The staff reassured me about how I have been caring for my child.
11. The staff gave me quite a bit of responsibility regarding how to deal with my child’s medical condition
12. The staff’s explanations and recommendations were clear and easy to understand
13. The staff seemed to care about my child’s feelings
14. The staff identified themselves clearly
15. The staff used simple to understand language
APPENDIX 2: Parental Role Questionnaire
PARENTAL ROLE

Please read the following list of statements that parents or staff may possibly do while a child is in hospital and tick which of the answers most applies to you. Remember there are no ‘wrong’ and ‘right’ answers, this is simply trying to find out what parents think they should or would like to do while in hospital with their children.

Please underline which of the tasks you actually did

<table>
<thead>
<tr>
<th>Task</th>
<th>Definitely appropriate for parent to do</th>
<th>Appropriate for parent to do</th>
<th>Uncertain who would do this</th>
<th>Appropriate for staff to do</th>
<th>Definitely appropriate for staff to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraged child to drink fluids and recorded</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Changed child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Obtained urine specimen</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Placed child on bedpan</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Kept record of amount of urination</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Emptied bedpan</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Gave enema</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Kept record of number of bowel movements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Took temperature and reported to staff</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Took pulse and reported to staff</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Took blood pressure and reported to staff</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Gave pills or liquid medication</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Did physical therapy on child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Changed dressings</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Went with child to X-Ray</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Held child for examination</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Stayed with child during painful procedure</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Restrained child for painful procedures</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Accompanied child to operating theatre</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Comforted child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Fed child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Got items from canteen/snacks machine</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Bathed child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Obtained linen and changed bed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Entertained child/played with</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Escorted to playroom and stayed to play</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

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APPENDIX 3: Hospital Procedures Questionnaire
HOSPITAL PROCEDURES

Please read the following statements, and circle which number applies to your experience while in hospital with your child.

1 = Very Dissatisfied
2 = Dissatisfied
3 = Satisfied
4 = Very Satisfied

How satisfied were you with:

<table>
<thead>
<tr>
<th>Service</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff's welcome on to the ward</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Appearance and comfort of child's bed space</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>The ward's general appearance</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Length of time to complete admission procedure</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Diagnostic tests completed quickly and results reported promptly</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Medication treatment</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Other health care your child received</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Quality of care provided by ward staff</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Handling of transfer from ward to theatre (if applicable)</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Post operative care provided (if applicable)</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Speed and efficiency of discharge procedure</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Advice/information on what to do at home</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Provision of post hospitalization medication</td>
<td>1 2 3 4</td>
</tr>
</tbody>
</table>
APPENDIX 4: Support While in Hospital Questionnaire
SUPPORT WHILE IN HOSPITAL

Listed below are various people who may be important in your life while you are at the hospital with your child. For each group of people, please circle a number from 1 to 5 to show how well they provide the type of help that is listed.

<table>
<thead>
<tr>
<th>Medical Staff i.e. doctors/nurses</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you trust, talk frankly and share feelings with the staff?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you lean on, and turn to them to discuss any worries you may have?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you get practical help from the medical staff?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do they give you practical advice?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Parents on the Ward</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you trust, talk frankly and share feelings with other parents?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you lean on, and turn to them to discuss any worries you may have?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you get practical help from other parents?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do they give you practical advice?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Partner/Family/Friends</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you trust, talk frankly and share feelings?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you lean on, and turn to someone to discuss any worries you may have?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you get practical help?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do they give you practical advice?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Who out of this last group, do you feel is offering you support while you are at the hospital with your child

........................................
APPENDIX 5: The Adapted HADS
A number of statements which people have used to describe themselves are given below. Please read each statement and then tick the box to indicate how you feel while in hospital with your child. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you feel now.

<table>
<thead>
<tr>
<th>I feel tense or 'wound up':</th>
<th>I feel as if I am slowed down:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>Time to time, occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling as if something awful is about to happen:</th>
<th>I get a sort of frightened feeling like 'butterflies' in my stomach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>Not at all</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>Occasionally</td>
</tr>
<tr>
<td>A little, but it does not worry me</td>
<td>Quite often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things:</th>
<th>I feel restless as if I have to be on the move:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Time to time, occasionally</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind:</th>
<th>I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
<td>Very often indeed</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Quite often</td>
</tr>
<tr>
<td>From time to time but not too often</td>
<td>Not very often</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful:</th>
<th>I can enjoy a good book or radio or TV programme:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Often</td>
</tr>
<tr>
<td>Not often</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Not often</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can sit at ease and feel relaxed:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td></td>
</tr>
<tr>
<td>Not often</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
</tr>
</tbody>
</table>
BACKGROUND INFORMATION

Age:
Marital Status:
Gender:
Ethnicity:

Is this your first time in hospital as parent? Yes/No

Do you work outside the home? Yes/No
Have you needed to have time off to come to the hospital? Yes/No
If so, how difficult was it to get time off?

How many children do you have?
What are their ages?
Have you needed to make childcare arrangements while at the hospital? Yes/No
What is your relationship to this child in hospital? i.e. mother/father etc.

Why is this child in hospital?
How serious do you think his/her condition is?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all serious</td>
<td>slightly serious</td>
<td>not sure serious</td>
<td>extremely serious</td>
<td></td>
</tr>
</tbody>
</table>

Thank you.
APPENDIX 7: Inclusion/Exclusion Criteria List for Staff
CRITERIA FOR INCLUSION/EXCLUSION

Parents of children who are attending the hospital for the first time:

- whose child stays longer than 24 hours
- who may have been involved in an accident, or
- who may have an acute medical condition (i.e. meningitis), or
- who is about to undergo surgery (elective or otherwise)
- or other similar cases.

Parents of children who have had at least one previous admission, either with the child who is currently here, or another child in the family:

- whose child stays for longer than 24 hours
- who may have a chronic condition, or
- who may need ongoing treatment or surgery, or
- who may return again at some time in the future.

Only parents of children aged 3 - 14 will be included.

Children who are fostered and those who arrive at the hospital with suspected non-accidental injuries, will be excluded.
APPENDIX 8: Written Information for Participants and Consent Form
Dear Participant,

I am completing a doctorate in Clinical Psychology on the South Thames (Salomons) Training Course, Canterbury Christ Church University College. A requirement of my course is to carry out a piece of research.

I am interested in finding out about parents' experiences while in hospital with their children. Although quite a long time ago, I have personal experience of being a parent in hospital. Two years ago, I completed a small study on parents of first time attenders in hospital with their children, which identified the most stressful aspects of the experience. In order to strengthen the results of that study, it is necessary to survey a much larger sample of parents.

If you are interested in helping me with this piece of research, it will be necessary for you to complete five short questionnaires by reading a list of statements and placing a ‘tick’ in a box for the most appropriate answer that applies to you. There are no ‘right’ or ‘wrong’ answers. It should take approximately fifteen minutes to complete all the questionnaires.

The questionnaires will be kept strictly confidential and will be available only to myself and my research tutor. No individual results will be used, but overall results will be made part of the final research report. Under no circumstances will your name or any identifying characteristics be included in the report.

If you agree to take part in this study, I would like to emphasise that:

- your participation is entirely voluntary;
- you are free to refuse to answer any question;
- you are free to withdraw at any time without giving a reason;
- or without affecting your own or your family’s future medical care.

PTO....
Please sign below to show that you have read and understood the contents of this letter and you agree to take part. (This letter and your signature does not form part of the questionnaire pack).

If for any reason, you have any questions, worries or concerns that filling in the questionnaires have highlighted for you, please let me know when you return the pack, and I will be happy to spend some time in a private area discussing these. If at the end of this time, you are still concerned and need support, a referral can be made for you to speak to the appropriate member of staff.

Thanking you in anticipation,

Yours sincerely,

June O'Dwyer, BA. MSc
Psychologist in Clinical Training

Signed: ........................................... Date: ...........................................
APPENDIX 9: Ethical Approval
Ms J O'Dwyer  
Clinical Psychology Training Scheme  
Salomons Centre, Broomhill Road  
Southborough  
Tunbridge Wells  
TN3 OTG.

Dear Ms O'Dwyer

EC99/203 Parental anxiety in hospital - what contributes to psychological distress experienced by parents while in hospital with their children? A correlational study  
*June O'Dwyer*

The above project was considered at the Research Ethics Committee meeting on 30/11/1999. The Committee required the following:

*The following amendments were required:*

1) parents should not be approached on day of child's admission  
2) in pl of questionnaire - Staff Communication - question no. 8, change 'was' to 'were'  
3) letter to parent to be on headed notepaper

Once I have received written confirmation that the above have been addressed (including copies of any amended documents), a final letter of approval will be issued.

Please note that this study carries a reference number, noted above, which must be quoted in any future correspondence.

Yours sincerely,

Chairman  
Research Ethics Committee
Dear Ms O'Dwyer

EC99/203  Parental anxiety in hospital - what contributes to psychological distress experienced by parents while in hospital with their children? A correlational study

Thank you for your correspondence dated 16.12.99 and for addressing the queries raised by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

The LREC is compliant with the ICH GCP requirements.

Yours sincerely

Chairman
Research Ethics Committee

Encl.