Original Research Study

Parental Perceptions: The Psychosocial Impact of Hospitalisation of Young Children with Special Needs

Sarah McDonald
Starship Children’s Hospital, Auckland

Abstract

This paper reports on a study undertaken to examine parents’ perceptions of the psychosocial impact of hospitalisation on their children with special needs. A grounded theory approach was employed to understand the way in which families were affected by their child’s hospitalisation. Four parents whose children with special needs were aged six years or under participated in the study. Parents participated in an initial focus group interview followed by individual interviews. Stress was identified as the most significant impact on families of hospitalisation of the child with special needs. Cognitive pressure and social disharmony were also identified as major challenges that families experienced around the time of their child's hospitalisation. The findings of this study are discussed in relation to the literature. Implications from this research indicate the importance of commitment to, and implementation of, family centred care within healthcare organisations.

Key Words: Special needs children, hospitalisation, family centred care

Introduction

Research demonstrates that hospitalisation is often a stressful time for children and their families due to factors such as unfamiliarity of environment, unpredictability of events, and experiencing frightening or painful procedures (Gaynard, Wolfer, Goldberger, Thompson, & Laidley, 1998; Petrillo & Sanger, 1980; Thompson 1985; Wright, 1995; Youngblut & Brooten, 1999). It has been suggested that the psychosocial impact of such experiences may be greater for children with special needs and their families, as they are often faced with extra challenges in relation to hospitalisation (Burke, Costello & Handley-Derry, 1989; Department of Health, 1991; Kayes, 1998; McDonald, 2005). According to Kayes (1998) children with special needs may be even more at risk – the hospital environment may be unsupportive of their special needs, staff may have no specific training and the children may have a more limited ability to communicate and to interpret correctly what is happening to them.

Despite calls for further research (Burke et al., 1989; Finn, 1982; Perkins, 1993), current literature about the psychosocial impact of hospitalisation for children with special
needs and their families is limited. What is available tends to focus specifically upon children with the same type of special need. There is a need for research that examines experiences common to children with a range of special needs and their families. Information from such research could be useful for the professional learning of health care professionals (Darling, 1983) and to support more effective practice (Hall, 1997).

The purpose of the study reported here was to gain insight into parents’ perspectives of their social and emotional experiences during and after the hospitalisation of their child with special needs, and to identify the range of strategies that families used to manage these experiences.

Methodology

Research Question

The question this study addressed was “what are parents’ perspectives of the impact of hospitalisation of children with special needs upon the family or whanau?”.

Participants and Participant Selection

For the purpose of this study, children with special needs was defined as including those with intellectual, learning, behavioural, emotional, or physical impairments and children with ongoing medical needs such as cancer. To initiate the research process, the researcher telephoned administrators from eight disability organisations. Six of these agencies agreed to participate in the selection of participants for the research project. The researcher explained the purpose of the research and asked administrators whether they would be willing to approach three current parent members who may be suitable to participate in this study, using the following criteria:

- Their family needed to include a child with special needs.
- Their child with special needs must have been admitted to a hospital in New Zealand for a period of no less than five consecutive days within the previous two years.
- The parent needed to have a good understanding of English.
- The parent needed to be prepared to take part in a preliminary focus group meeting to be held in Auckland, and needed also to be willing, if selected, to participate in a face to face interview.
- The parent needed to be accessible by telephone.

Administrators explained the purpose and criteria of this research to parents, and sought permission for their contact phone number to be given to the researcher. The researcher then contacted interested parents to restate the aim of the research, check that parents fitted the criteria, and to answer any questions. An information sheet outlining the purpose and structure of the study, and a consent form were then posted to parents, along with an invitation to participate in a focus group in Auckland to help identify the issues relating to their child’s experiences.
Nine parents whose children with special needs had been hospitalised in New Zealand for five or more consecutive days within the previous two years (2003-2004) participated in an initial focus group. Six of these parents had children with special needs who were aged six years or under. Of these six parents, four parents of children aged six or under from different disability-specific organisations were invited and agreed to individual interviews. This paper focuses on the perspectives of these four parents.

Participants’ families lived in or around the Auckland area and represented a range of cultures such as Pacific Island, Maori, Asian and Pakeha. Parents, aged between 25 and 55, had between one and six children whose ages ranged from 14 months to 30 years. The ages of children with special needs ranged from 14 months to six years. Children’s special needs were varied, including blindness, cerebral palsy, developmental delay, epilepsy, chronic lung disease, hydrocephalus, cancer, and cardiopulmonary valve stenosis. Some children had more than one special need as well as additional long-term healthcare requirements such as a gastrostomy for feeding. These children had experienced between three and 14 hospital admissions in the previous two years; during this time, they, and one of their parents, had spent between 30 and 90 nights in hospital.

Data Collection

Data was initially generated using focus group methodology. This was useful to gain specific qualitative information from a predetermined and limited number of participants (Knight, 2002; Krueger, 1994) and attain a primary source of data during the exploratory stage of the research project (Litosseliti, 2003). Data obtained from the focus group was used to develop interview questions for individual interviews.

The questions for the face-to-face interviews drew on six primary themes identified in the focus group interview: family organisation, change, coping, preparation, conflict and stress, and stress management. These themes were developed into descriptive statements in a summary of the findings. Open and closed questions were developed after each descriptive statement as a means of verification as well as providing an opportunity to gain additional information about each category (Strauss & Corbin, 1998). For example, the descriptive statement relating to preparation acknowledged the forward planning which families of children with special needs appeared to do ‘just in case’ their child was hospitalised. Interviewees were subsequently asked if they, or other family members, prepared for such instances, and if so, how this was done.

Validity and Reliability

Before the face-to-face interviews took place, participants were sent a written summary of the focus group findings. Face to face interviews ranged in duration from 45 minutes to three hours and were carried out in participants’ homes. During each interview, the individual summary statements were read to participants, followed by probes to verify their accuracy. Probes were also employed as a means of stimulating, extending, or gaining clarity of information (Keats, 1988).
Following the interviews, audiotapes were transcribed and transcriptions sent to participants for verification of accuracy. Some participants chose to delete or amend certain information from the transcripts such as details they had repeated.

**Analysis**

A grounded theory approach was taken in this study. This approach is useful for generating theory systematically from a process of data collection, coding and analysis and does not require the existence of previous research to work from (Glaser & Strauss, 1967). The benefit of this approach is that it not only generates theory, but also grounds that theory in data, therefore preventing researchers from trying to force data to fit a preconceived theory (Ezzy, 2002; Glaser & Strauss, 1967).

Analysis of face-to-face interview transcripts was undertaken following similar coding processes and techniques used to analyse the focus group data. Open coding involved identifying words or phrases that were frequently repeated in the data. Words with similar meanings were colour coded and assigned common categories (Strauss & Corbin, 1998). For example, words such as scared and dread were categorised as fear, while words such as chaos and disarray were categorised as disorganisation. Categories were then explored in terms of their specific properties or dimensions so that patterns, variations and subcategories could be identified (Strauss & Corbin, 1998).

Axial coding involved a variety of analytical processes that occurred concurrently. For example, comparative techniques were employed to find patterns and variation in the data, and to identify other properties that may have been overlooked. Some methods, such as the Flip-Flop technique (Strauss & Corbin, 1998) were used to gain a different perspective on events by looking at occurrences from different angles, while others focused on analysing specific words or phrases in order to consider the range of possible meanings attributed to them and to discern which interpretation was most accurate. Literature was also utilised to inform the process of analysis and foster conceptualisation (Strauss & Corbin, 1998). This enabled the researcher to examine data using a different lens or perspective; however this analytic technique was employed carefully by the researcher in order to enhance sensitivity to subtle nuances in data rather than hinder creativity.

Selective coding was applied to the data to further refine and integrate categories by grouping them according to the type of impact they had upon individuals. For example, fear was categorised as an emotional impact; mental pressure was defined as a cognitive impact; disorganisation was categorised as a social impact. Further analysis of these three key areas of impact (emotional, cognitive and social) enabled the researcher to identify the core category (stress) and two major categories (cognitive pressure and social disharmony), and to develop a theory grounded in the data.

**Ethical Considerations**

Consideration was given to ethical and cultural issues prior to, and during the research. As the researcher was a healthcare employee, recommended practice was followed by
gaining approval for this research from the Auckland Ethics Committee (Ministry of Health).

Participants were asked to select pseudonyms for themselves and other members of their families to protect their identity. Names of healthcare professionals were replaced with their occupational title. No specific details of treatment, medical services, facilities or individual hospitals were included in this study.

Before completion of this study, two families experienced the death of their children with special needs. One child died soon after the focus group was held, while the second child died a few weeks after the interview process had been completed. As the first child died before a face-to-face interview was undertaken with her parent, the researcher sought guidance from her supervisors in regard to the appropriateness of this parent’s continued involvement in the study. As the child’s parent was still willing to participate in the study, and this person’s experiences and perceptions were still valid and important, the interview proceeded.

To address the question often asked who is to benefit from studies regarding people with special needs (Mitchell & Snyder, 1997; Turnbull, Blue-Banning, Behr & Kerns, 1986), the researcher chose a research approach that would support findings to be structured in a way that achieved three main goals. These were (a) to provide an accurate voice for parents about the impact upon their families of hospitalisation of their child with special needs, (b) to provide useful information for other parents and families of children with special needs that would help them prepare for and manage similar experiences, and (c) to enhance professional awareness and practice in regard to working with children with special needs and their families around the time of the child’s hospitalisation.

Participants’ differing cultural backgrounds and experiences were taken into account by the researcher whose own culture was New Zealand Pakeha. Questions asked by the researcher were carefully constructed and occasionally reframed using different terms to ensure participants understood their meanings and were thus able to actively contribute their thoughts and ideas during the focus group discussion and face to face interviews (Ray, 1997). For more discussion of ethical procedures and considerations please see the full report (McDonald, 2005).

**Results and Discussion**

It was a major shock to us. When we heard about it my husband thought they must have given us the wrong results – that they must be wrong. We [wondered] how we were going to handle this… We don’t have anybody here – no support, nothing. We were devastated. We just wondered what we were going to do. We didn’t know where to begin - it turned our lives upside down. (Selina)

Stress was identified as the core category because of the overriding emotion that families experienced around the time the child with special needs was hospitalised. This
is similar to other research findings (Burke, Harrison, Kauffman, & Wong, 2001; Warner, 2000; Yantzi, Rosenberg, Burke, & Harrison, 2001). Family members often experienced shock and disbelief when faced with the unexpected. Feelings of helplessness and frustration though lack of information, choice, and loss of control were also common, particularly for parents as they felt a strong sense of responsibility to care for and protect their unwell child, but were often limited by what they could actually do.

Emotions such as guilt and regret were commonly experienced by family members, particularly if they felt they had to make certain choices that might cause difficulty for others such as consenting to painful procedures or taking leave from work. Underlying feelings of grief and anxiety also intensified around this time, as family members often worried that the child with special needs might die. Research suggests the triggering of such emotions can often leave family members feeling inadequate and exhausted (Warner, 2000; Yantzi et al., 2001).

**Cognitive Pressure**

Sometimes the light at the end of the tunnel was so small that we thought we would never get there. (Ginger)

Cognitive pressure was identified as a significant impact of hospitalisation upon the family that was overwhelmingly negative. Many events in hospital were described by parents as being mentally taxing and overwhelming, such as having to learn and understand complex medical information about the child or treatment, and having to manage multiple healthcare teams. The literature suggests that families of children with special needs often face a greater number of cognitive challenges and demands during this time than families of nondisabled children (Burke et al., 1989; Marchetti, Bonati, Marfisi, La Gamba, Biasini & Tognoni, 1995; Perkins, 1988).

We suddenly realised that this time we would have to become involved with a different specialised medical team. We’d learnt a lot about many other areas but now we had a new area that we had to find out about. Having to do that was like going to medical school for 24 hours a day when you’re not really equipped and you haven’t got anyone to tell you what to do. (Gail)

All parents reported at times feeling mentally saturated and no longer able to think or take on any new information. This sometimes led to loss of confidence in oneself. Parents, who perceived their child’s care or treatment options as being threatened by factors such as lack of professional knowledge, staff errors, or budgetary constraints of the hospital, also reported loss of confidence in the hospital system or in health professionals. In keeping with these findings, Burke et al (1989) suggest that as parents experience successive hospitalisations of their child with special needs and become more knowledgeable, their heightened awareness of potential weaknesses and failings of the hospital system can further increase their levels of stress and fear.
Social Disharmony

My baby had never even spent one night away from me and when Vicki ended up being in hospital for weeks and weeks, he (younger sibling) got shoved from pillar to post - and he hadn’t stayed one night with anyone before that - that was hard. (Aroha)

Social disharmony was identified as another major category that impacted upon the family. Home, school and work environments were often negatively affected by the child’s hospitalisation, as people were required to change roles, rearrange schedules, relinquish certain tasks and often manage without the main caregiver in the home environment. Yantzi et al (2001) suggest disruption to family functioning is not uncommon for families of children with special needs.

The last time he was in hospital… there was even less help to have a break from him – I was ready to jump out the nearest window. He needed to have someone with him all the time. That’s why I dread going in – once you’re there, you just can’t get away. (Gail)

All participants who stayed with their child in hospital described feelings of aloneness and isolation due to the decrease in social contact they experienced both within hospital and returning home. These feelings were intensified if parents and children had to be quarantined from others in hospital due to infection control precautions. In addition, most parents continued to be socially isolated after their child’s discharge, either due to their own exhaustion and lack of time, or as the result of other people’s fear about the child’s fragility or discomfort about what to say or do. Research identifies similar difficulties experienced by parents of children with special needs who are isolated and suggests their inability to take time out from their child leads to increased stress and frustration (Burke et al., 2001; Redmond & Richardson, 2003; Warner, 2000).

Influences upon the Impact of Hospitalisation

You’re re-explaining everything that’s already happened, and you know that they probably won’t believe you anyway, and they’ll just think you’re a paranoid parent and that you don’t know what you’re talking about - when actually you know more about your child’s condition than they do. (Ginger)

The literature suggests that a range of variables such as parent’s prior experiences and level of confidence, skill and understanding about their child with special needs influences the impact of the child’s hospitalisation (Hayes & Knox, 1984; Perkins, 1993). This study identified a wide range of influencing factors associated with children’s hospitalisation. Relationships between parents and healthcare professionals greatly influenced parents’ experiences. Parents identified four main issues that caused strain upon their relationships with healthcare professionals, including not being listened to, having their concerns minimised, feeling excluded from decision making processes about their child, and having negative or incorrect assumptions made about
them. Other literature highlights similar challenges for children with special needs and their parents (Crawford & Raven, 2002; National Fathers Network, 1996). Burke et al. (2001) and Warner (2000) suggest parents of children with special needs can be perceived as experts of the hospital system and subsequently provided with little support, despite the fact that each hospitalisation can be more stressful, present additional unexpected and unfamiliar challenges and have the potential to cause long term problems for the family. Crawford and Raven (2002) suggest assumptions made by healthcare professionals in regard to the abilities and understanding of children with special needs can be particularly disadvantageous for these children, causing them to be ill-informed and left feeling powerless and unconfident.

Literature suggests a variety of additional reasons for difficulties between families and healthcare professionals. Hayes and Knox (1984) suggest strained relationships between parents of disabled children and healthcare professionals are largely the result of differences in beliefs and perceptions about parental roles and responsibilities in regard to the child’s care in hospital. Ygge and Arnetz (2004) assert difficulties may arise between families and healthcare professionals if service providers feel threatened by a parent whose expertise exceeds their own. Hostler (1991) suggests families of children with special needs can experience conflict with healthcare professionals over roles, which can worsen when interaction is prolonged. In addition, Perkins (1988) suggests strained relationships between children, families and healthcare professionals may also be triggered by healthcare professionals’ feelings of frustration that can arise when children with special needs are repeatedly hospitalised.

You look at the doctors for answers because they are the ones who should know, and when they turn to you and are unable to answer the ‘why’, it’s like, as parents, you are already on unstable ground. You are catapulted into uncharted territory. (Ginger)

Family members also experienced heightened feelings of fear and anxiety if they regarded the acuity of the child’s illness and level of risk to his or her survival as high. In addition, parents whose children with special needs had illnesses or medical conditions that were relatively unknown to medical professionals reported heightened levels of anxiety and frustration.

The level of stress and sense of urgency experienced by family members significantly affected their ability to process and apply information. Parents who were aware of the emotional state of their child tended to be affected by transference of those emotions and reported often feeling the same way. The more stressed parents felt, the more difficulty they appeared to have processing and applying information especially in terms of maintaining daily responsibilities, dealing with multiple information and recalling and utilising appropriate supports. Burke et al (1989) report similar findings and suggest parents under high levels of stress are more likely to experience a form of immobilisation that inhibits them from providing positive support to their hospitalised children.
I felt they looked at me as if I was a bad parent. And that thought also can leave you very shaken even with a healthy child let alone a sick one. I felt like a failure as a parent - I just felt blamed and labelled as a bad mum, and I’m trying to do everything I can… (Ginger)

Parents’ self-confidence was influenced by the amount of familiarity they had in regard to the hospital environment, and by the level of trust they had with medical professionals. Participants also emphasized that having prior knowledge about the ward their child was admitted to provided them with a great sense of relief and comfort as the roles and responsibilities of parents and healthcare professionals were already known. Literature supports these findings, suggesting familiarity of environment plays an important role in enabling people to meet their needs, as those who know how a system works are more able to utilise components of that system effectively (Hostler, 1991; Rubin & Quinn-Curran, 1983).

Because the family knew what had happened last time in hospital, they were all as scared as I was. (Gail)

Memories of the child’s previous hospitalisations had a strong influence upon family members’ emotional responses to the child’s current admission, including the level of mental preparation they undertook. If previous experiences during admissions had been particularly difficult, family members often felt more anxious about their child’s current or impending admission, and tended to subsequently become more vigilant or assertive. Hayes and Knox (1984) report similar findings and suggest first time hospitalisations of children with special needs most strongly influence parents’ impressions of subsequent admissions, as these are used to compare and interpret successive hospital experiences.

This last [admission] was massively stressful; my husband being made redundant; [my other child’s] behavioural programme going out the window… Financial ones were – yes… The stress with the medical staff – not knowing whether I was going to be listened to, the family coming out of the woodwork… My own medical needs… so it’s just stress, stress, stress, stress, stress, stress, stress. (Betty)

The number and intensity of concurrent stressors experienced by family members impacted upon their stress levels around the time of the child’s hospitalisation. Family members who had to deal with a number of additional stresses often felt overwhelmed and exhausted during this time, particularly if they did not have access to appropriate support. Societal beliefs and values influenced whether some parents sought or accepted external support, as some parents suggested that accessing support might indicate to others that they were failing in their role as parents. It has been suggested that societal attitudes and assumptions about children with special needs play an important part in determining the amount of support that these children and their families receive and subsequently the level of stress they experience (Darling, 1983; Kalyanpur, 1999; Mentro, 2003; Rempel, 2004; Rubin & Quinn-Curran, 1983).
[My other son] is just coming right after Michael’s last admission to hospital three weeks ago. He’s been very clingy and he’s cried every day at kindy when we’ve dropped him off. He’s very jealous of Michael now – he’ll say ‘I don’t like Michael – I don’t want to play with him – he’s naughty’. They used to be best mates. (Gail)

The impact upon relationships between the child with special needs and his or her siblings was largely determined by the children’s ages and level of understanding. Participants noted that preschool children sometimes felt jealous or angry with the child with special needs, blaming him or her for causing disruption to the family. Older children were described as being more understanding of their brother or sister’s predicament, although parents noticed they too at times felt jealous and resentful about the amount of attention their hospitalised brother or sister was getting. Literature suggests such responses by children are typical, and can result in an increase of parental stress (Cook, 1999; Gaynard et al., 1998; Perkins, 1993; Thompson, 1985).

Coping Strategies used to Manage Stress

Because the trip to hospital before this one was such a bad experience when people wouldn’t listen to me, this time I was even more determined that I was going to fight for his rights. So I suppose that helped me cope, knowing that I’m not going through this again. (Betty)

Family members used both emotion-focussed strategies and problem-solving strategies to maintain a sense of control and assist decision making during their child’s hospitalisation. Emotion focussed strategies (such as functioning in an automatic manner and reprioritisation) tended to be used by family members when they were unable to change or control certain stressors (such as deterioration in the child’s health). Problem solving strategies (such as anticipating challenges and increasing one’s medical knowledge) were often employed by family members in situations where they had some control and ability to reduce or avoid certain stressors. Literature reports the use of these techniques by family members when children with special needs are hospitalised (Burke et al., 1989; Gaynard et al., 1998; Perkins, 1993; Thompson, 1985).

Time out seemed to be regarded as the most necessary and effective approach to coping for parents who stayed with their child in hospital. All participants utilised this strategy, either by taking a physical break away from their child and the hospital environment, or by taking a break from tasks that required ongoing concentration and focus (such as documenting their child’s seizure activity).

Most participants sought emotional and practical support from their partners, whom they generally described as their greatest source of help. Other sources of support utilised by family members included extended families, friends, healthcare professionals (such as social workers, hospital play specialists, and hospital grandparents), disability agencies, church and other community groups.
We just – we dealt with day by day – hour by hour - we didn’t look forward to tomorrow because tomorrow was far, far away. We were just very tunnelled visioned – “Right, he made it through this hour – he drained more fluid off – well that’s really good”. We took very much a medical approach even though it was really emotional. (Ginger)

Some family members found it helpful to manage stress by functioning in an automatic manner and repressing their emotions. This enabled individuals to carry out and complete necessary tasks as well as provide a sense of reassurance and guidance for others. Parents often did this by directing their attention to specific and measurable aspects of the child’s medical condition or treatment. This form of disassociation was most often used by parents as a temporary measure and regarded as an effective way of functioning when feeling highly stressed or overwhelmed.

Distractive activities, such as cleaning the house or returning to work, were also used by some family members to temporarily shift their focus from the child’s hospitalisation or illness. Such activities provided people with a sense of control, routine and normalcy, and gave them a much needed break from worrying about their child.

Mum goes into a bit of “I can’t handle it any more”, and then she leaves…she’s had a lot of pressure put on her… she’s an exhausted grandparent - she’s at the stage of ‘grandparent overload’. (Gail)

Some parents and extended family members who found changes in the environment too difficult to deal with, responded by physically withdrawing from or avoiding that environment as much as possible. Others contained their thoughts of not coping by using ‘self talk’, a form of psychological preparation, either to tell themselves they had no choice but to deal with the situation, or to reassure themselves that with the support of others, or guidance from God, they would be able to manage.

Changes in priorities were often made by parents when children with special needs were hospitalised, as the child’s wellbeing became their main focus. Decisions to postpone or relinquish certain activities were influenced by the level of disruption to family life that parents expected might occur during or after their child’s discharge. For example, in situations where parents realised children with special needs would require repeated hospitalisations or long term post-hospital care, it was not uncommon for one parent to resign from paid employment in order to take on such responsibilities.

We took the approach of being very open with [our other son]. We didn’t hide anything. He always knew what was going on. We explained everything and kept the communication channels open. He was always in the scene, right from the start. We even told him of the possibility of Ashley dying. (Selina)

Family members sought information about their child’s condition from a range of sources in order to increase knowledge, make meaning of their situation and gain confidence in being able to participate actively in their child’s care. Parents who found
themselves overwhelmed or inundated by well meaning people wanting to offer opinions or advice on aspects of their child’s care or treatment managed these situations by screening information and disregarding that which was confusing or conflicting with their own beliefs.

Comments that other people would make were sometimes very hard, like someone told us, “Why don’t you have another baby?” and that hurt very badly. It’s like saying, “You might as well give up and have another child”. (Selina)

In turn, to protect their privacy and maintain a sense of control, family members sometimes limited the amount of information they provided to others. Well developed skills in tolerance and patience were also used by some family members to deal with people’s misguided or hurtful comments so as to minimise feelings of anger or frustration that otherwise might negatively impact upon their relationships with others.

Adapting or relinquishing roles was a strategy employed mainly by parents to manage or prevent stress. For example, some parents in hospital withdrew from actively participating in their child’s care in order to avoid a potential conflict of roles with healthcare professionals. In addition, parents often mentally prepared themselves by predicting unpleasant events and planning for these.

**Summary and Discussion**

Stress was the major impact of hospitalisation of the child with special needs upon the family, and was experienced no matter how many times the child had previously been hospitalised. A number of factors such as uncertainty, loss of control, and lack of information triggered this phenomenon. Around the time of the child’s hospitalisation, family members experienced increased cognitive pressure from having to assimilate and accommodate new information while under stress. Families also experienced social disharmony due to changes in family functioning brought about by factors such as separation of family members and disruption to roles and routines.

The way in which families coped during this time was largely dependent upon their ability to change or control their circumstances. Problem solving strategies were generally used by family members when they felt they had some ability to change or influence their circumstances, while emotion focussed strategies were employed as a means of minimising the level of stress associated with an event over which they had no control.

Findings from this study and others suggest family members’ ability to cope during their child’s hospitalisation is largely dependent upon their perceptions and understanding of the situation, their relationships with healthcare professionals, and their ability to access support and resources (Darbyshire, 1994; Leff, Chan & Walizer, 1991; Rempel, 2004; Stein-Parbury, 2000; Thomas & Pollio, 2002; Wondrak, 1998). Literature suggests that healthcare professionals and others can lessen the negative impact of hospitalisation of children with special needs for families by being aware of
potential stressors in the hospital and home environment, and by using a family centred approach to minimise these (Perkins, 1993; Rubin & Quinn-Curran, 1983; Shelton & Stepanek, 1994; Ygge & Arnetz, 2004).

Healthcare systems and those working within them therefore have a crucial role in minimising the negative impact of hospitalisation for families of children with special needs. Family stress, cognitive pressure, and social disharmony can be significantly reduced by implementation of genuine family centred care that acknowledges and utilises the strengths of families while meeting their needs. This requires healthcare professionals to remain constantly aware of the many stressors that families are exposed to during the child’s hospitalisation, and be proactive in eliminating, or at least minimising these. Such commitment will not only benefit children with special needs and their families, but healthcare professionals alike (Crawford & Raven, 2002; Mentro, 2003; Rubin & Quinn-Curran, 1983; Shandor Miles, Burchinal, Holditch-Davis, Brunssen & Wilson, 2002; Shelton & Stepanek, 1995).

This was a small study with a small number of participants. It is not representative of the views and experiences of parents in general with children who have special needs; therefore care should be taken in the use of the findings. An important aim of this study, which was achieved, was to provide an authentic interpretation of four parents’ perceptions and experiences, as the validity of grounded theory is said to be achieved if it is recognisable to participants, and if others can relate their own experiences to its content (Strauss & Corbin, 1998). Issues raised by participants but not relevant to the purpose of this study such as funding, have not been included, and thus remain embedded in the raw data awaiting attention within another forum as well as a catalyst for further research.

**Recommendations**

Further research is required about this topic, particularly from the perspective of the child, his or her siblings, and extended family members. Findings of the current study suggest reduction of stress, cognitive pressure and social disharmony are key areas that need to be addressed by healthcare professionals in order to lessen the negative impact that families experience when their children with special needs are hospitalised. Thus further research on the perspectives of both families and healthcare professionals regarding the quality of family centred care in New Zealand hospitals is needed.

It became evident during the study that family members of frequently hospitalised children with special needs were at risk of post-traumatic stress. Boss (2002, p.6) describes this phenomenon as “a chronic crisis that immobilises” and one that can be instigated by intense emotional experiences, uncertainty, helplessness and unpreparedness (Colville, 2001; McFarlane & de Girolamo, 1996) such as witnessing children’s physical and psychological distress during hospitalisation. As similar experiences have been identified in the current study, it is recommended that further research be undertaken in this area. This may increase awareness of the potential risks that family members face, and encourage development of effective services and supports.
Immediately after the focus group finished, an informal discussion took place between some focus group participants about discrepancies in the level and availability of support offered to families of children with differing types of special needs during and after their child’s hospitalisation. Further research in this area is suggested as it may generate valuable information and lead to enhanced and more equitable provision of appropriate support and services for all children with special needs and their families.

References


Acknowledgements

I would like to thank my thesis supervisors Dr Patricia O’Brien and Maureen Corby for their support, encouragement and advice throughout my research project. I would also like to thank the families who participated in this study.

ABOUT THE AUTHOR

Sarah McDonald was a kindergarten teacher in Taumaruanui, Ngaruawahia and Auckland. In 1996 she completed the Diploma of Early Intervention, and in 1997, took up an early childhood position as a hospital play specialist at Starship Children’s Hospital. In 2005 she completed her Master’s Degree in Education (Special Education).