

# Managerial guidelines to support parents during the hospitalisation of their children in a private paediatric unit

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## **Key words**

*Managerial guidelines; support; parents; hospitalisation; private paediatric unit*

## **Abstract: Curationis 32 (3): 47-59**

*The purpose of this article is to describe managerial guidelines to support parents with the hospitalisation of their child in a private paediatric unit. The hospitalisation of a child is regarded as a major stressor for both parents and child. The role of the family in participating in a child's illness is slowly being recognised (Kibel & Wagstaff, 2001:544), but the South African government per se has not yet issued any formal reports on parental participation in the hospitalisation process.*

*The study explored and described*

- *the nursing care experiences of parents regarding the hospitalisation of their child in a paediatric unit;*
- *managerial guidelines to support parents with their lived experiences of their child's hospitalisation in a paediatric unit.*

*To achieve the purpose and the objectives of the research, an interpretive-phenomenological qualitative approach was used in the research design and methods. Research was conducted through unstructured individual interviews, narrative diaries and field notes and data were analysed through open-coding (Tesch, 1990). Parents were asked to respond to the question "How did you experience your child's hospitalisation in the paediatric ward", followed by probing when the responses of the parents were ambiguous.*

*Purposive sampling was used to achieve saturation of data and seven parents were interviewed and fifteen parents completed narrative diaries. The model of Lincoln and Guba (1985) was used to ensure trustworthiness.*

*Ethical considerations were maintained throughout the study and consent was obtained from the respondents. The recommendations of the research were that attention should be given to 1) empowering parents to participate in their child's care; 2) guiding nursing personnel to plan the discharge process; 3) including parents in the unit routine; 4) fostering a trusting relationship with parents; 5) promoting the communication of information; and 6) creating a therapeutic environment for parents.*

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## Introduction and rationale

When a child is hospitalised, parents' priorities, roles and values change. The concept of parental participation in the care of the child has become a central tenet of paediatric nursing for the 21<sup>st</sup> century. To this effect, nursing care interventions, such as in-hospital and home-based care, have shifted to recognise families' involvement in care as central to a child's care. Parents' involvement with the care of their child not only contributes to positive feelings within parents, as has been shown by this research, but Hallström (2004:n.p) indicates that strengthening parents' involvement in the provision of care to their child, enables parents to take on greater responsibility and increases their sense of being in control.

Nursing care personnel have a medical knowledge and background, whilst parents have a comprehensive knowledge about their child, their environment, and family dynamics, and understand the role that the child plays in the family and the family's role in the child's life. Both types of knowledge described above are imperative for treating the child, and should be viewed as equally important (Strober, 2005:204). Also, parents' role in participating in their child's care is not always clarified. Darbyshire noted in his study that parents were often confused and uncertain as to exactly what they were allowed and expected to do during their child's hospitalisation (Benner, 1994:190).

Parental involvement in the care of hospitalised children has been encouraged by the governments of the United Kingdom, Brazil and America (de Lima, Rocha, Schochi & Callery, 2001:599), with many reports being issued to the effect of including parents in the care of their children during a hospitalisation episode. The role of the family in a child's illness is slowly being recognised in South Africa (Kibel & Wagstaff 2001:544), but this is by individual authors and the South African government per se has not issued any formal reports on parental participation in the hospitalisation process.

A child's hospitalisation is particularly difficult, and parents who are already

sad and worried about their child's condition, are likely to also feel frightened and agitated when hospitalisation is needed (McCollum, 1975:55). Despite the regular occurrence of children being hospitalised for varying degrees of illness and surgery, there is no consensus regarding how parents should be supported by nurses during the possible stressful period of hospitalisation of their child.

Parents naturally wish that they could spare their children from suffering. McCollum (1975:5) notes that parents expect it from themselves to keep their children safe, and therefore experience feelings of guilt, verbalised and manifested in many ways, for example "Is it my fault? Could I have prevented it if I'd cared for my child in a different way, or if I'd been a different person"?

During a child's hospitalisation, parents have a unique perspective from which to report their experiences of their child's hospitalisation to the paediatric nursing unit manager. From the researcher's unstructured observations of parents within the paediatric unit, the researcher expected this perspective to be one of caring for, providing for and making decisions in the best interest of their child. Parents ultimately know what their child's specific needs are and how they can be met.

The discrepancy between the nursing practice and nursing theory emphasises the need for a study to describe and explore parents' reality. It can be deduced that if there are few or no studies about parents' lived experiences of their child's hospitalisation, there were no managerial actions or strategies in place to facilitate the findings of such a study. Indeed, in South Africa there are no known strategies in place to facilitate parents' experiences within a paediatric unit.

## Overview of the literature

In qualitative research the full literature review is done only after the data have been collected, to minimise the prejudging of the data. Thus a brief overview is presented. Few recent literature sources could be found on the topic.

The reliance of parents on the parent-caregiver relationship highlights the

need for a supportive relationship between parents and nursing personnel within the paediatric unit. Various emotions are at play during a child hospitalisation, and parents feel relatively disempowered when dealing with illness in their children. They struggle to make sense of their child's illness. Any illness, no matter how minor in the eyes of trained nursing care professionals, is perceived as a crisis by parents – an event that upsets their everyday living and generates anxiety (Kibel & Wagstaff, 2001:544). The stress is further increased when the child is admitted to a paediatric unit in a hospital. Their experiences of seeking advice from professionals could leave them feeling uncertain and uninformed.

Parents tend to be troubled by their negative feelings. These troubling feelings, together with feelings of anger, grief, bitterness and helplessness could be vented on unsuspecting, well-meaning nursing personnel. Parents may find themselves feeling critical of almost everything done by the professional personnel. Without intending to, parents can become blinded to any actions that reveal competence, concern and compassion by nurses. The sense of angry protest that parents could experience seeks a target; in the hospital setting, that target is often the nursing personnel.

Parents are also under the impression that no one could know their child better than they do, and as such they want to do everything for their child, in the manner that they feel is best for their child. When the child is admitted to a paediatric unit, this care is often taken over by the nursing personnel, especially during the initial admission period, where personnel members examine the child, do blood tests, take x-rays, make measurements made, engage in hushed conversations, or exchange worried glances. Parents may feel that they are pushed aside during this time (McCollum, 1975:6).

Through his study of parents' as well as the nursing personnel's perception of parental participation Darbyshire (in Benner, 1994:185-209) concluded that the term parental participation seemed to have a meaning for nurses and parents that implied an arrangement whereby one party, the parents, would

be allowed by the other party, the nurses, to help with their child's care. However, the impression gained seemed to imply that the nurses perceived the parents as being able to only do the work of an unqualified member of the personnel, namely the parental work. A previous study by Stratton, (2004:10) found that parents could experience their child's hospitalisation in a paediatric unit in terms of; *-facing boundaries* which includes parents feeling helpless and parents questioning the skills of personnel, as well as the way in which certain procedures are carried out; *-coping with uncertainty*, highlighted by dealing with fear that parents have as well as the parents' need to create a comfort zone. Parents expressed the desire for caregivers to recognise and comfort the child, as well as the parents. A third aspect of coping with uncertainty was parents' attempts to try and protect their child.

McCullum (1975:56) advocates that parents should be encouraged to help care for their children, especially by feeding, bathing, changing, dressing and playing with them. Parents however, may feel emotionally torn about visiting. They wish to be with their child to comfort and reassure them, and to observe their condition and progress directly, but on the other hand, visiting or living in may be difficult and upsetting. Parents' discomfort may be intensified because they lack the familiar, organising influence of their usual routine of daily work.

In order to accommodate the parents' need to continue performing their parenting tasks, family-centred care has been introduced to nursing units over a period of time, and in varying degrees. One aspect important to this study is the concept of parent participation. A narrow definition of parent participation in hospitalisation is "to include performance of routine physical care and extended visiting" (Knafl et al., 1988:109). An extreme form of parent participation is the establishment of care-by-parent units, wherein nursing personnel are only minimally involved and parents provide all physical and emotional care for their child (Knafl et al., 1988:99).

Acutely ill children require special

equipment and special nursing care. However, as the child's condition improves, so the scope of care that parents can deliver increases, so that by the time the child is well enough, the parents are able to perform all parenting tasks in totality (Passero, 1988: 3-4).

When a child is hospitalised, parents' priorities, roles and values change. Parents are characterised by placing high levels of trust in professionals, relinquishing control over decision-making to physicians and nurses, and receiving information rather than seeking information and care. Also, parents' role in participating in their child's care is not always clarified. Darbyshire noted in his study that parents were often confused and uncertain as to exactly what they were allowed and expected to do during their child's hospitalisation (Benner, 1994:109, 190).

## Research problem

As mentioned in the background and rationale (point 1.1) the lack of role clarification and the change in parents' priorities and values during the hospitalisation of their child are all sources of conflict. Ambiguity and uncertainty as to the boundaries of acceptable behaviour of parents in the paediatric unit can cause conflict. The disruption of the balance of power between a nurse and parent may also be an aggravator of conflict. Conflict exists in a relationship when parties believe that their aspirations cannot be achieved simultaneously, or perceive a divergence in the values and needs (Anstey, 1997:6, 13). This conflict often manifests itself in the responses obtained in patient opinion surveys which parents are requested to complete.

Patient opinion surveys completed by parents in a paediatric unit within a private hospital (Vereeniging Medi Clinic, 2004) indicated that parents are experiencing their child's hospitalisation negatively. Comments made included that "personnel are not friendly", "too few personnel for the number of patients", "day personnel more competent than night – more helpful", and "medication not given as prescribed". No follow-ups had been done on these comments, and no investigations had been instigated by management, to document parents' lived experiences

and how these can be effectively managed within a paediatric unit. Dissatisfaction of next of kin with patient care is one of the five categories that Booyens (ed) (1998:593) recognises as a high-risk area. It was also noted that nursing personnel are involved in this area.

The study raises the following questions:

- What are the lived nursing care experiences of parents regarding the hospitalisation of their child in the private paediatric unit?
- How can parents lived nursing care experience of their child's hospitalisation in a private paediatric unit be managed in a supportive manner?

## Purpose and objectives of the study

The purpose of this study was to describe managerial guidelines to support parents with the hospitalisation of their child in a private paediatric unit.

To research the purpose, the following objectives were formulated:

- explore and describe the nursing care experiences of parents regarding hospitalisation of their child in a paediatric unit;
- describe managerial guidelines to support parents with their lived experiences of their child's hospitalisation in a private paediatric unit.

## Concepts

Child as defined by the Child Care Act (No 74 of 1983) is "any person under the age of 18 years". For the purposes of this study a child is a person aged between 6 weeks to 12 years (of either sex), suffering from no major physical or mental impairments other than the one for which hospitalisation was required, and who is expected to make a total recovery following treatment. The patients included both medical and surgical patients, and only parents of children who were admitted in the unit (i.e. this excluded all out-patients) were used for data collection purposes.

Paediatric unit is a unit within a hospi-

tal accredited for the treatment and care of ill children within a private hospital. As the study focused on typical paediatric hospitalisations, the paediatric unit used for data collection was a typical private hospital paediatric unit, thus excluding ones which specialise in certain conditions or purport to have experimental or especially innovative paediatric programmes.

**Parent** (including adoptive parent) for the purposes of this study, is defined as a mother or father (including step-parents as well as single parents) who are raising the child. Parenting is defined by the Oxford Dictionary (Thompson (ed) 1996:674) as the "bringing up of children". Thus, for the purposes of this study, a parent is defined as a mother or father (including step-parents as well as single parents) who are raising the child. For data collection purposes the mothers and/or fathers (including step-parents and single parents) who were involved with the paediatric unit routine were approached.

**Lived experience** is defined by Benner (1994: xi) as being engaged in practices as a being who acts in and on the world. Lived experience is understood to be the ways in which people encounter situations in relation to their interests, purposes, personal concerns, and background understanding (Benner, 1994:186).

**Manage** is defined by the Oxford Dictionary (Thompson (ed) 1996:538) as "organise, regulate or be in charge of". In a nursing context, **management** is described by Yura et al., (in Mackenzie, 1998:178) as the use of delegated authority within a formal organisation to organise, direct and control.

**Guidelines** refer to standards or principles by which to determine and direct policies or actions (Collins Pocket Dictionary, 2003:377; Thompson (ed), 1996:332). **Managerial guidelines** therefore are actions that are implemented from management downwards, during the phases of planning, organisation, delegation and controlling. In this study management was defined as the planning, organising, guiding and evaluating of parents' lived nursing care experiences which had to be effectively addressed in the paediatric unit routine.

**Hospitalisation** as defined by the Oxford dictionary (Thompson (ed) 1996:424) is to "send or admit to hospital". In this study the term hospitalisation refers to all the management processes (nursing activities and functions) that occur within the paediatric unit once the child is physically placed in a bed within the unit.

## Research design and method

### Research design

This was an interpretive-phenomenological qualitative study whereby the lived nursing care experiences of parents were explored and described within a context, within an interpretive-phenomenological approach. An interpretive approach allows for a specific way to interpret the captured lived experience, whilst phenomenology allows for the capturing of the lived experience of the parents (Svenaeus, 2000:126).

A qualitative design enabled the researcher to explore and describe the parents' experiences in an in-depth and holistic manner. When a study is explorative (Talbot, 1994:90) it attempts to uncover relationships and dimensions of a phenomenon. The design was exploratory and thus suitable for gaining insight into the experience of the parents in this context. The understanding of parents' lived nursing care experiences contributed to the formulation of managerial actions to be implemented to support parents during the hospitalisation of their child.

When a study is descriptive, it is similar to the explorative type of study, but more structured (Talbot, 1994:90). In this study, the lived nursing care experiences of parents were explored and described.

When an interpretive approach is going to be used, it is important to note that it relies heavily on the particular context of the situation, that is the timing, meanings and intention of the particular situation (Benner, 1985:40). This study was contextual in that it dealt with the experiences of parents whose children were hospitalised for three days or longer in a typical private paediatric unit.

### Research method

Various questioning methods were used during this study. In interpretive studies, the primary source of knowledge is everyday practical activity. Individual interviews, narrative studies, field notes and a conceptualisation of the data allowed for parents' experiences of their child's hospitalisation in a private paediatric unit to become a text analogue, which could then be interpreted (Benner, 1994:59).

### Population, sampling and selection criteria

Parents whose child was at that stage being hospitalised in a private paediatric unit were used for the data gathering phase of the research. The study was conducted in one of the private hospitals in the Vaal Triangle region of Gauteng, South Africa. Criterion-based purposeful sampling was conducted. Purposeful sampling chooses subjects who are judged to be typical of the population in question, or who are particularly knowledgeable about the issue under study (Polit & Hungler, 1997:229). Thoughtful planning was required for appropriate participant selection. Purposeful sampling was used to achieve saturation of data and seven parents were interviewed and fifteen parents completed narrative diaries. The criteria for parents' selection were as follows:

- Parents able to communicate in English or Afrikaans;
- Biological parents (mother or father), adoptive parents, single parents or step-parents;
- The parents' child was formally admitted in a paediatric unit within a private hospital;
- The hospitalised child was aged between six weeks and 12 years of age;
- The child was hospitalised in the paediatric unit for a minimum of three days (three days being the shortest duration of antimicrobial treatment);
- The parents visited their child at least once a day in order for them to be able to actively participate in their child's care;
- The parents were willing to reflect freely on their lived nursing care experiences and con-

vey it to the researcher (using the questioning method of their choice, i.e. interview and/or narrative diary).

## Data collection

In interpretive studies, the primary source of knowledge is everyday practical activity. Human experience becomes a text analogue that is studied and interpreted in order to discover the hidden or obscured deeper meaning of a phenomenon. Given that our everyday lived experience is often so taken for granted as to go unnoticed, it is frequently through the dissemination of the text analogue that the researcher achieves flashes of insight into the lived world (Benner, 1994:59). Interviews, narrative studies, field notes and a conceptualisation of the data allowed for parents' experiences of their child's hospitalisation in a private paediatric unit to become a text analogue, which could then be interpreted.

An unstructured, individual interview was used as the primary data collection method. Interview questions, commencing with an opening question and followed by probing, explored parents' experiences and probed into their thoughts, feelings, concerns and worries during the hospitalisation of their child.

As a secondary data collection method, narrative diaries were handed out on admission to parents whose child was expected to remain in the unit for at least three days, and who gave consent.

The conceptualisation phase was conducted in order to merge the findings of this research study into the already existing body of knowledge that was relevant to parents' experiences of their child's hospitalisation in a private paediatric unit. The merger of new knowledge and existing knowledge served as the conceptualisation of parents' experiences of their child's hospitalisation and gave the findings deeper, more meaningful significance.

## Data analysis

Making use of Tesch's method of open-coding, as described in Cresswell (1994:155), the transcribed interviews, narrative diaries and the researcher's field notes during the individual inter-

view were analysed. The inclusion of the researcher's field notes was important for the enrichment of the data.

Steps included in this method were:

- reading carefully through all transcripts in order to get a general overall feeling for the transcripts;
- randomly choosing one transcript and reading through it, jotting down ideas in the margins on the transcript as they come to mind and answering the following questions: "What is it about" and "What is the underlying meaning?";
- repeating the previous step for all transcripts, and then making a list of all topics listed in the margins, clustering similar ones together, and then drawing up three columns marked 1) major topics, 2) unique topics and 3) leftovers;
- finding the most descriptive wording for topics and turning them into categories;
- making a final abbreviation for each category and alphabetising these codes;
- assembling the data material belonging to each category in one place and performing a preliminary analysis.;
- re-coding the existing data.

The four main underlying processes identified during the empirical data, which led to the formulation of guidelines, were:

- parental participation in the care of their child,
- the unit management dimensions in the paediatric unit
- communication between parents and nursing care personnel.
- creating a therapeutic environment for parents.

## Trustworthiness

Measures to ensure trustworthiness were applied. Guba's (Guba & Lincoln, 1985:290-327) strategies of credibility, transferability, dependability and confirmability were implemented.

## Credibility/truth-value

Prolonged engagement of at least three

days, during which the child was hospitalised, allowed the respondents (parents) to become used to and familiar with the researcher. When the researcher had prolonged engagement with participants, it allowed the researcher to identify inconsistencies in the respondents' responses (Burns & Grove, 2001:41). These inaccurate responses could be based on social expectations rather than on personal experience.

Reflexivity refers to the assessment of the influence that the researcher's own background, perceptions and interests have on the study (Krefting, 1991:218). In order to counteract the possible over-involvement, a field journal was kept by the researcher. Making use of the field journal, the researcher kept a record of her own behaviour, experiences and reflections on her thoughts, feelings, and ideas.

Multiple data sources and contexts (triangulation) were preferred in order to create a more naturalistic account and to prevent an overly narrow perspective of the situation (Benner, 1994:119). In this study, field notes, narrative diaries and unstructured individual interviews were methods used to achieve data triangulation.

The interviewing technique also enhanced the credibility of the study (Kvale, 1983:171). Precision in description and stringency in meaning interpretation were important for credibility. The rephrasing of questions, repetition of questions, or expansion of questions on different occasions were ways in which credibility was increased (May in Krefting, 1991:220).

## Transferability/applicability

Transferability is the criteria against which applicability is measured in a qualitative study. It is the ability to transfer findings to another similar situation. Transferability was achieved by a dense description of the data and purposive sampling (Guba & Lincoln, 1985:301).

## Dependability/consistency

In assessing whether or not similar results would be obtained if the study were done again with the same people or in a similar situation, consistency

was proven. As qualitative research does not control the variables, but emphasises the uniqueness of individuals' perceptions, variations in experience, rather than identical results are expected (Krefting, 1991:216). In this study the data was sent to an independent coder and the findings compared for similarities and differences.

#### **Confirmability/neutrality**

Confirmability in this study was achieved by ensuring reflexive analysis and data analysis triangulation (both methods have been previously described) (Krefting, 1991:221).

### **Ethical considerations**

Ethical clearance was obtained from the ethical committee of the residential university where the researcher was registered for the postgraduate study as well as the private hospital authority. Parents also signed a letter of consent before being interviewed or completing the narrative diary. The parents were given a covering letter, explaining the reasons and importance of the research. Confidentiality was assured and the respondents could choose whether to participate or withdraw during the study. The respondents were also assured of anonymity. The researcher respected the individual parent's right to privacy, confidentiality and anonymity by not allowing any form of identification on the transcriptions or narrative diaries. The researcher planned and executed the research in such a way that it was to the parents' benefit, and that there were no harmful, physical or psychological experiences for the parent or child. Interviews were held at a time convenient for the parents, during their child's admission. The child was cared for by nursing personnel for the duration of the interview. The researcher maintained the highest standards of research planning, implementing and reporting.

### **Interpretation of data**

The findings regarding parents' experiences of their child's hospitalisation related to **two main categories** namely 1) experiences related to various interactive processes in the paediatric unit and 2) experiences related to the environment within the paediatric unit.

Four subcategories were identified. **Three subcategories** related to the interactive processes in the paediatric unit are *parental participation in the care of their child, unit management dimensions in the paediatric unit and communication between parents and nursing care personnel*. The **one subcategory** related to the environment of the paediatric unit is *to create a therapeutic environment for parents* (Table 1).

Table 2 only indicates examples of raw data that was interpreted and lead to certain findings. The raw data given by parents that lead to the interpretation of certain **categories** related to their lived experiences of the hospitalization of their child is outlined in table 1. The same process was followed for interpretation of all the raw data towards identifying guidelines to support parents with the hospitalization of their child in a paediatric unit in a private hospital.

### **Findings**

Parents described the following experiences with the hospitalisation of their child in a paediatric unit in a private hospital (transcribed raw data from the individual interviews and narratives given by participants in table 3):

From the empirical data and the literature study, the following guidelines were formulated to support parents during their child's hospitalisation in a private paediatric unit.

Guidelines can be implemented to effectively support parents during their child's hospitalisation in a private paediatric unit. Possible managerial actions that could be taken are by no means limited to the selection below.

#### **Guidelines related to the interactive processes in the private paediatric unit**

Based on the narratives of parents during this study, the following guidelines were developed to address the themes raised by parents. This will ensure that parents whose children are admitted to the private paediatric unit in future will be supported in an appropriate manner with regard to their participation in their child's care. Unit management dimensions will address incorporating par-

ents into the unit routine as well as managing resources in a cost containing manner. The guidelines should also ensure that effective communication takes place in the unit between all parents and nursing care personnel.

#### **Guideline 1: The unit manager in charge of the private paediatric unit should encourage parental participation in the unit**

The South African Patient's Right Charter (1999) states that the patient (in this study the parent is inherently also entitled to all patient's rights) has the right to participate actively on any decisions regarding their healthcare. Whilst the Department of Health has made this decision at National level and is implementing it through the Patient's Right Charter, it is important that it filter down to the lower levels of healthcare as it ultimately affects the user of the healthcare services.

The unit manager of the private paediatric unit should focus her nursing personnel on empowering parents to participate in certain aspects of their child's care to the extent and intensity that they feel comfortable with, recognising parent's strengths and intrinsic characteristics and minimising feelings of parental guilt created by social roles.

The following are managerial actions that could be implemented by the unit manager through means of an appropriate strategy:

- In decision-making, parents should be consulted regarding the level of care that they would like to give their child. It is also important for nursing care personnel to consult with parents on a daily basis as the child's condition improves or deteriorates. This consultation could be facilitated by the most senior nursing personnel on the shift, or allocated to work with the parent and their child, to meet at least daily with parents. This meeting could take place at set times (for example, following the doctor's rounds or at a specified family meeting) or it could be an impromptu, informal meeting that takes place.
- Solicitation of parents input into their child's nursing care

**TABLE 1: Nursing care experiences of parents regarding their child's hospitalisation**

MAIN CATEGORY	SUBCATEGORY	THEME	SUBTHEME
1. Experiences related to the interactive processes in the paediatric unit	1.1 Parental participation	<ul style="list-style-type: none"> <li>Parents willingness to participate in their child's care</li> <li>Barriers on the extent and intensity of parental participation in their child's care</li> </ul>	<ul style="list-style-type: none"> <li>Empowerment of parents to participate in certain aspects of care</li> <li>Parents' feelings of guilt as a barrier in parental participation in child's care</li> <li>Challenges caused by parents' social roles</li> </ul>
	1.2 Unit management dimensions: Planning and organising	<ul style="list-style-type: none"> <li>Experiences related to family education activities in discharge planning</li> <li>Experiences related to aspects of organising the paediatric unit routine</li> <li>Experiences related to organising of resources in the paediatric unit</li> </ul>	<ul style="list-style-type: none"> <li>Preparedness of parents for discharge</li> <li>Provision of quality nursing care</li> <li>Stock availability</li> <li>Cost containment</li> </ul>
	1.3 Communication in the paediatric unit	<ul style="list-style-type: none"> <li>Experiences related to interpersonal relationships</li> <li>Experiences related to caring in the paediatric unit</li> <li>Experiences related to information management in the paediatric unit</li> </ul>	<ul style="list-style-type: none"> <li>Parents – nursing care professional relationship</li> <li>A trusting relationship</li> <li>Physical gestures of affection and sensitivity</li> <li>Lack of basic nursing actions</li> <li>Communication flow in the paediatric unit</li> <li>Relevant information</li> <li>Communication style</li> </ul>
2. Experiences related to the environment of the paediatric unit	2.1 Creating a therapeutic environment for parents	<ul style="list-style-type: none"> <li>Experiences related to facilities available</li> <li>Creating a safe environment for parents</li> </ul>	<ul style="list-style-type: none"> <li>Rooming in facilities</li> <li>Nutritional needs of parents</li> <li>Parental general comfort</li> <li>General hygiene</li> </ul>

**Table 2: Examples of raw data that were interpreted as experiences relating to Category 1: Experiences related to the interactive processes in the paediatric unit Subcategory 1.1: Parental participation**

<b>Theme: Parent's willingness to participate in their child's care</b>	
<i>"...Your baby knows you better than the nurses. So if you are with your baby then the baby doesn't have much problems, so to be with your baby I think it is a fine thing""I watched her getting better all the time, and that makes it all worthwhile for me". "...they didn't wake him up for his medicine... and then I gave it when he woke up"</i>	<b>Subtheme:</b> <i>Empowerment of parents to participate in certain aspects of care</i>
<b>Theme: Barriers on the extent and intensity of parental participation in their child's care</b>	
<i>"The worst was when they told me I wasn't allowed to go with her when they put the drip in. Said I should go have a cup of coffee. That was really silly, I thought. What mother can leave her child while they hold her down and hurt her?" "One morning the sister said she was just going to inject straight out of the syringe, one, two, three and it was over. He screamed and she held him down with her one arm and injected with the other. He is so small, he couldn't move, so he just screamed. I feel that was terrible."</i>	<b>Subtheme:</b> <i>Parents' feelings of guilt as a barrier in parental participation in child's care</i>
<i>"take a break" from it all, "... You need to get out of here too, you can't just sit in these four walls, and it gets a bit too much.... And life goes on out there"</i>	<b>Subtheme:</b> <i>Challenges caused by parents' social roles</i>

delivery needs to be an ongoing and dynamic process, and not just a "once-off". This is because circumstances, priorities and needs may change over the duration of the child's hospitalisation (Pogoloff, 2004: 118). Parents should be asked at least daily, if they would like to take part, or assist the personnel in any way. When the nursing care personnel allocated to care for the child go and introduce themselves to the parents, they could enquire if there are any particular tasks that the parents assist with or would like to assist with. By enquiring and asking the parents themselves, the nursing care given can be continued and parents also have an opportunity to increase their input into the child's care. Parents should also be taken into consideration in the decision-making process regarding their child's care. Where parents are not present during the doctor's rounds, nursing care personnel could phone the parents and inform them of changes in treatment and improvement in the child's condition. This is a practical way of getting parent's "buy-in" into the care being

given to the child, as well as emphasizing parent's importance in the treatment of the hospitalised child. Should the decisions taken by parents not be implemented, it is the responsibility of the 'responsible person', be it the doctor or the nursing care personnel who vetoed the decision to phone the parents and explain the reasons for their actions as soon as possible.

- In the routine management of the unit, the role of open visiting hours for parents and patient's siblings should also be considered. Open visiting hours could place less stress on parents to balance their inherent need to be with their hospitalised child and their need to spend time with other children at home. Open visiting hours could also allow for parents to be supported from external social networks during the trying time of their child's hospitalisation. Open visiting hours will need to be discussed with hospital management and in some private hospital groups, group management. The nursing unit manager could suggest open visiting hours be trialed at their hospital and a parent satisfaction survey conducted before

provincial or national roll out of open visiting hours.

It is important that the unit manager of the private paediatric ward realizes that there are certain barriers on the extent and intensity of parental participation in child's care. The unit manager should guide the nursing personnel in overcoming these barriers so that patient care is not jeopardized in any way. This could be facilitated through the following:

- Parents who choose to not be actively involved in their child's care should not be victimised or made to feel inferior, and their decision should be respected at all times. Parents should not be made to feel as though their motives are being questioned, and all nursing care personnel should be guided in not being judgmental. This implies that nursing personnel must be cautioned regarding their body language, tone of voice and non verbal communication patterns, that could lead to parent's feeling victimised.
- It is important to clarify parental and nursing roles, thus ensuring that no misunderstandings occur which will impact the quality of care received by the child. This could also be done



**Table 3: Experiences described by parents related to the interactive processes and the environment of the pediatric unit in the pediatric unit**

INTERACTIVE PROCESSES IN THE PAEDIATRIC UNIT
<b>Experiences related to parental participation</b>
<i>Parents willingness to participate in their child's care</i>
<i>Barriers on the extent and intensity of parental participation in their child's care</i>
<b>Experiences related to unit management dimensions: Planning and organising</b>
<i>Family education activities in discharge planning</i>
<i>Aspects of organising the paediatric unit routine</i>
<i>Organising of resources in the paediatric unit</i>
<b>Experiences related to communication in the paediatric unit</b>
<i>Interpersonal relationships</i>
<i>Caring in the paediatric unit</i>
<i>Information management in the paediatric unit</i>
<b>Experiences related to communication in the paediatric unit</b>
THE ENVIRONMENT OF THE PAEDIATRIC UNIT
<b>Experiences related to creating a therapeutic environment for parents</b>
<i>Facilities available</i>
<i>Creating a safe environment for parents</i>

*at a scheduled family meeting early in the child's admission or impromptu throughout the child's hospitalisation.*

**Guideline 2: The unit manager should have the ability and expertise to be able to manage the private paediatric unit through detailed planning and organising of nursing care activities in the unit**

*The Batho Pele principles as set out in the White Paper on Transforming Public Service Delivery (South Africa: 1997) promotes the rights of the patient (parent) with regard to what service standards can be expected from the nursing units. Thus standards set should be of the highest, and this requires that the unit manager has Quality Improvement Programmes in place to facilitate the setting and maintaining of such standards (Muller 2002:9).*

*The unit manager should guide nursing personnel to plan the discharge process effectively, to include parents in the unit routine and to manage resources whilst promoting cost containment.*

*Experiences related to family education activities in discharge planning can have an adverse effect on parent's perceptions of their stay in the private paediatric unit. It is therefore very important that the unit manager, together with the multidisciplinary team compile action plans and strategies that directly address the discharge process. Managerial actions that could be included in such a strategy include:*

- Parents should be informed at admission and during the child's hospitalisation of possible discharge dates. Once again, this emphasizes the usefulness of a family meeting that could be held with members of the multi disciplinary team, who would be treating the child. Doctors, nursing care personnel and physiotherapists are examples of team members who could attend such meetings, and provide relevant information to parents.*
- Other members of the community should be contacted prior to discharge, if any areas of need have been identified dur-*

*ing the assessment or hospitalisation process (e.g. dietician, physiotherapist, etc.). By contacting team members prior to discharge, the discharge process does not have to be delayed by parents waiting for other healthcare professionals to consult with them.*

- Effective communication between doctors, nursing personnel and the parents should be ensured. This could be facilitated by the nursing care personnel phoning parents on at least a daily basis to inform them of developments in their child's condition and treatment.*
- Where possible, nursing personnel should consider logistics, such as transport and parents who may have to be at work during the planned discharge time, while doing their discharge planning. Discharge planning could be discussed at the family meetings that are held during the child's admission to the paediatric unit. This would allow parents to partake in the discharge planning and any time constraints or requests that they may have, can be raised and taken into consideration.*

*A unit routine needs to be flexible enough to accommodate the varied needs of the parents and children in the paediatric unit. Thus the unit manager needs to coordinate all therapeutic services, the provision of a safe environment, the physical care of the child in respect of their hygiene, feeding requirements, and even recreation (Mellish, Brink & Paton 2001:4). This implies an enormous amount of planning and consultation together with parents in accordance with the Batho Pele principle of consultation (Muller, 2002:9). The process of consultation can be promoted by the following:*

- All personnel of the private paediatric unit should participate in the setting of a unit specific vision and mission, as well as appropriate goals for the unit. The paediatric unit manager could use open, two-way communication whilst compiling the vision and mission for the unit. The individual nursing person-*

nel's, and nursing unit's aspirations, expectations, intentions and opinions must be considered. The unit manager should encourage nursing personnel to rise above personal interests and work as a team during the setting of the vision and mission (Naudé, Meyer & van Niekerk, 2001:138)

- A hard copy of the vision and mission could be handed out to all nursing personnel, and should be communicated clearly and consistently. This can be achieved by explaining the vision and mission in such a way that it becomes practical and understandable for all categories of nursing personnel in the paediatric unit (Naudé et al., 2001:138). The vision and mission could also be displayed in the unit so that parent's can also be made aware of the intentions and aspiration of the unit in which their child has been admitted.
- The type of delegation used should be dependent on the needs of the patient and should be dynamic so as to facilitate the needs of patients and parents in the unit. When functional allocation is used, the unit manager should rotate the personnel so that personnel do not become bored with tasks allocated to them. Boredom could lead to nursing personnel becoming complacent, and the quality of the nursing care received may be adversely affected.
- In order to increase the nursing care personnel's attention to their daily tasks and responsibilities, it may be useful for personnel to sign a delegation book on a daily basis, whereby they accept responsibility for the correct execution of the tasks delegated to them (Naudé et al., 2001:154).

All resources and services impacting on the private paediatric unit should be optimally organised to promote patient satisfaction. The unit manager could implement the following managerial actions to promote organised re-

sources:

- Service contracts should be drawn up between the private paediatric unit and the pharmacy, as well as other departments that are in interaction with the unit (pharmacy, technical department, kitchen, house-keeping services, etc.) to ensure that the patients receive timely treatment and quality care.
- Nursing care should be evaluated continuously to ensure quality patient care at all times. This can be accomplished by instituting a risk management team or clinical governance team, who would be responsible for the auditing of nursing care, as well as the investigation of any "failure of care" incidents, which could have any form of negative repercussion for the healthcare service. It could also be very useful for all nursing care personnel to audit nursing documents on a monthly basis in order to identify possible "failure of care" areas. This will draw nursing care personnel's attention to their own shortcomings in the delivery of quality patient care.

**Guideline 3: The manager in charge of the private paediatric unit should promote meaningful communication between all role players in the unit**

Nursing in South Africa is largely governed by the South African Nursing Council (SANC). In accordance with the Nursing Act No 33 of 2005, the SANC could set out regulations that must be followed or there could be disciplinary repercussions. Professional confidentiality is an important aspect of professional conduct and is supported by the Patient's right Charter as well (Department of Health, 1999:3).

The unit manager of the private paediatric ward should promote interpersonal relationships in the paediatric unit, with special emphasis on fostering a trusting, caring parent-nursing care professional relationship that promotes the communication of information by using a communication network that ensures parents receive adequate information.

Interpersonal relationships should form

part of continuous personnel development. This could be facilitated through the following actions:

- Nursing personnel should respect and guard confidentiality at all times. They should not discuss any other child or use other children as comparisons, even favourable ones. If parents hear nursing care personnel discussing other children with anyone other than his/hers parents, it may open the door for distrust (Pogoloff, 2004:116)
- Each conversation with parents should start with a positive statement about their child. When nursing care personnel provide parents with positive feedback, parents will look forward to speaking with them (Pogoloff, 2004:116).
- Nursing personnel should allow parents to be part of the decision-making process regarding their child's care, and they should respect informed decisions that have been made.

Caring actions should be an inherent part of nursing; however, when they are lacking it is possible to encourage and motivate nursing personnel through the following:

- Nursing personnel should be friendly at all times and basic actions such as smiling when greeting a patient should be encouraged. If necessary nursing care personnel should receive coaching regarding their demeanor when dealing with parents and patients.
- Nursing personnel should be gentle and praising, and encourage children, which will allow parents to feel at ease and which will facilitate a trusting relationship between parents and personnel, as well as children and personnel.
- Nursing personnel should pay attention to parents' emotional state rather than ignoring it. Nursing care personnel should be sensitive to the emotions of parents. Topics or comments that may seem insignificant to nursing personnel may sound harsh or negative to parents (Pogoloff, 2004:117). An area

should be allocated within the unit where parents and nursing personnel can discuss sensitive matters. It is also important that parents are reassured that while they are in another part of the unit or hospital, that their child is being taken care of by the nursing personnel in the unit.

- Nursing personnel should be available during their working times to respond immediately to parents' queries. This could facilitate parent's trust in the personnel as well as build open communication networks. The nursing unit manager should ensure that the number of nursing personnel that she has scheduled to be on duty will be able provide safe and adequate care to both child and parent (Swansburg & Swansburg, 2002:101). The nursing unit manager should ensure that tea times are scheduled in such way that the ward will still be covered with sufficient nursing personnel during tea and lunch times.

Facilitating effective communication networks is an integral part of the nursing unit manager's responsibility. Not only is courteous towards the parent, but it is also important that parents are provided with appropriate information regarding the services available to themselves as well as their child's treatment (South Africa; 1997:9)

- The child and his/her parents should be informed about procedures to be done prior to it being done. According to the Health Act, 2004, of South Africa, doctors are responsible for explaining the procedure to be performed. It is no longer the responsibility of the nursing care personnel.
- Nursing personnel should respond immediately when the bell call/ button is pressed. By implementing hourly unit rounds, nursing personnel would be able to anticipate potential problems as well as decrease noise in the unit (Hunter, 2006:4)

- Personnel should be encouraged to communicate honestly with parents and provide them with sufficient information to make informed decisions.
- Communication break-downs should be avoided and it may be necessary to consult with all departments interacting with the paediatric unit (technical, kitchen, pharmacy, theatre, etc.) regarding acceptable communication channels to be used with the unit.
- Information should be obtained from parents using various forms. Provide parents with an opportunity to communicate about their child in writing, by phone, and with face-to-face interactions. Parents may prefer to use one or more forms of information. It may also be more convenient for parents to take a phone call, rather than having to read pages of information.
- Nursing care personnel should be encouraged to communicate using the parents' preferred mode of communication, rather than always using nursing care personnel's most convenient form of communication. This could be noted during the admission assessment, or parents could be asked to complete a short questionnaire regarding their communication preferences.
- Various forms of communication should be provided throughout the unit, such as verbal communication, pamphlets on admission, posters on the walls and access to additional information (e.g. paediatric textbooks and other relevant reading material).
- The use of a computer-based information center should also be considered. This would make information easily accessible at all times, and not only when it suits nursing care personnel. Parents may find it more convenient to "surf the web" for information while their child is sleeping, rather than when their child is awake and demanding attention.

## Guidelines related to the environment of the private paediatric unit

Based on the interviews and narratives of parents as well as the observations of the researcher, the following guidelines were developed to address the themes raised by parents. This will ensure that parents whose children are admitted to the private paediatric unit in future will experience a therapeutic environment for themselves which has sufficient facilities, is safe and comfortable for parents who choose to participate in their child's care.

### Guideline 4: Unit managers should motivate and budget for facilities that could contribute to creating a therapeutic environment for parents within the private paediatric unit

The creation of a therapeutic environment includes the creation of a warm, caring, aesthetically pleasing physical environment. Unit managers are responsible for the establishment and maintenance of a therapeutic environment that will facilitate a parent's physical, mental and spiritual health. The creation of the above described environment is seen as a basic patient (parent) right as set out in the Patient's Right Charter (Department of Health; 1999:3).

The unit manager of the private paediatric unit should facilitate the creation of a safe, therapeutic environment for parents, where parents can be comfortable with adequate facilities and minimal external stimuli.

Practical means for creating should an environment could include:

- Allowance should be made for privacy for child and parents. This will provide parents for an area that they can retreat to, where they can spend quiet time with their child as well as possibly maintaining, where parents can, their own routine, to a certain degree.
- A protected and safe outdoor play area should be provided. This will allow for the children to play and socialise with other children, as well as providing parents with an opportunity to socialise with other adults and "break free" from the four walls that they may find themselves

enclosed by.

- The quantity and quality of stimulation should be controlled, by enhancing therapeutic stimulation and minimising harmful stimulation. This can be facilitated through the use of "Silence" boards displayed prominently, the playing of calming background music or nature sounds, as well as the use of curtains and, where appropriate, carpets, to act as a buffer for the noise.
- Social interactions should be enhanced and parents allowed a space where they can comfortably interact with other parents or family members. This could be a visitor's lounge or a dedicated parent's room where comfortable chairs and refreshment facilities are provided for parents use.

## Limitations of the study

Only seven parents took part in the study, which may be too small a group to obtain accurate information. Parents who declined to take part in the study cited anxiety and concern for their child as their overriding reasons.

Despite parents fulfilling the selection requirements, they were at times unable to "grasp" the intended meaning of the term 'experience' and were thus unable to give dense descriptions of their lived experience during their child's hospitalisation in a private paediatric unit.

The study was conducted in a private paediatric unit, therefore generalisation outside of this environment may be difficult to justify.

## Recommendations

Recommendations for nursing practice, education and research will now be set out.

### Recommendations for nursing practice

Parental participation should be encouraged in all paediatric nursing units with units becoming more "parent friendly". This can be done by implementing the guidelines set out in Chapter 5 of this study.

Policies to promote parental participation should be written by the unit manager and nursing personnel must be made aware of the policies, and where they can be located for easy reference. The policies can then be revised as more information becomes available with regards to effectively supporting parents during the hospitalisation of their child in a paediatric unit.

To ensure optimal implementation of the policies and guidelines, in-service training should be given to all member of the multi-disciplinary team, who partake in the hospitalised child's care. This will ensure that there is continuity of care for child and parents.

### Recommendations for nursing education

Parents need to receive accurate information regarding their participation in their child's care during hospitalisation. This information should preferably be presented in various forms at appropriate intervals.

Nursing personnel should receive in-service training (both formal and on-the-spot) regarding the importance of parental participation, as well as the benefits thereof for the parents and the nursing personnel.

### Recommendations for nursing research

Research on parental participation in their child's nursing care is very limited in South Africa and the following could be future research topics:

- Factors influencing parents' participation in their child's care;
- Nursing personnel's attitude towards parental participation;
- The extent to which parent's can be effectively coached to continue with home care in terminally ill children
- Comparison between parental participation in a Paediatric Intensive Care Unit setting and a paediatric unit, as well as comparative studies between parental participation in acutely ill children and terminally ill children.

## Conclusion

This study has shown that there is a

demand for parental participation at various levels during the hospitalisation of a paediatric patient. Whilst some parents experience it positively, other parents appear to be resistant towards it. Regardless of this, parents' participation in the care of their hospitalised child is becoming an increasingly popular phenomenon and further research needs to be conducted around this wide field of study of which we, in South Africa, have limited knowledge.

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