ARTICLE

REGISTERED NURSES' EXPERIENCES PERTAINING TO FAMILY INVOLVEMENT IN THE CARE OF HOSPITALISED CHILDREN AT A TERTIARY GOVERNMENT HOSPITAL IN MALAWI

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ABSTRACT

Families need to be involved in the care of hospitalised children because they are custodians of valuable information for the provision of individualised care. Tertiary hospitals need to involve families because they provide specialised care, which may be a source of stress for children. At one of the tertiary government hospitals in Malawi, the average nurse-patient ratio in the paediatric unit is 1:84. Nurses are expected to involve families in care. Evidence shows that nurses' experiences with family involvement shape the way care is delivered. However, little is known about nurses' experiences of family involvement in the care of hospitalised children at this tertiary hospital. The objective of the study was to describe registered nurses' experiences when involving families in the care of hospitalised children. A descriptive qualitative design using a semi-structured interview guide was used. Fourteen full-time registered nurses were recruited and data were analysed using qualitative

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content analysis. The results show that registered nurses were knowledgeable about family involvement but their experiences were mixed. Themes that emerged from the data were registered nurses' knowledge of family involvement, registered nurses' experiences of family involvement and registered nurses' impression of family involvement. The findings reveal that family involvement in the care of hospitalised children by nurses is desirable, but should be regulated. However, the findings reveal that although registered nurses involved family members, the implementation of family involvement was inconsistent and problematic. This status quo may continue unless authorities develop a policy to regulate family involvement in child care.

Keywords: family-centred care; family involvement; hospitalised children; nurses' experiences; registered nurses; policy

INTRODUCTION AND BACKGROUND

Hospitalisation of a child is stressful to both the family members and the child (Shields, Pratt and Hunter 2006, 1319). Evidence has revealed that children's stresses and pain are aggravated by their separation from families (Espezel and Canam, 2003, 35; Paliadelis, Cruickshank, Wainohu, Winskill and Stevens 2005, 32). As such, nurses are encouraged to involve families when caring for hospitalised children. Family involvement entails care being planned around the family because the family is part of the caring team (Stayt 2007, 24). Literature also concludes that for nurses to involve families effectively, nurses and families need to be mutual partners (Soderback and Christensson 2008, 1779; Soderstrom, Benzein and Saveman 2003, 291). With this type of partnership, there is need for respect, information sharing, and collaboration between families and nurses. However, nurses are expected to play a leading role in establishing this type of partnership so as to create a conducive environment, which enables nurses to meet family and children's daily needs in the hospital.

For family involvement to be effective, nurses and families need to share unbiased and timely information. However, the researchers' observations indicated that guardians of hospitalised children knew little about their children's conditions and treatment plans. This observation was in agreement with that of Manji and Reckon (2011,71) who found that in Malawi, 77.2% of guardians did not know medication regimes of their children. This may imply that information sharing challenges exist. This could be attributed to inadequate family participation in child care.

Family involvement is also directed by guidelines and policies. In Malawi, there are guidelines on family involvement in HIV and AIDS services (Betancourt et al., 2010,292). Betancourt et al. (2010,294) suggested that a combination of a patient and family-centred approach to the prevention of mother to child transmission of HIV has the potential to enhance health outcomes in Malawi for members within the household. This could be true for clinical care. However, a review of policy documents such as the health sector strategic plan at national level, directions on family involvement are not

clearly evident. This needs to be subjected to further inquiry because a lack of policy means that nurses lack the basis for implementing family participation in care in Malawi. Furthermore, in Malawi, studies have focused on patients' perceptions of nurses and nursing care. This implies that the experiences of nurses, which form a critical part in the family nurse-partnership remain silent.

Family Involvement in the Context of the Hospitalised Child

It is now accepted that parental involvement in child care is beneficial for the family. Stress and anxiety may be reduced if a care giver is involved in care (Coyne 2006, 327; Coyne and Cowley 2007, 894). Family involvement is a concept within family-centred care, where patients and their families are encouraged and supported by healthcare workers. This also includes family members participating in care and decision-making at the level they choose. Literature revealed that the family is central to child care because hospitalisation of the child is stressful (Espe-Sherwindt, 2008,137; Harrison, 2011,335). This implies that involving the families in the care is important within the nursing care services.

Nurses' Experiences regarding Family Involvement in the Context of Hospitalised Children

Nurses' experiences depend on nursing care settings and are country specific. For instance, in Mozambique, a study on nurses' beliefs and practices regarding family involvement by Soderback and Christensen (2008) revealed that due to cultural hierarchy, nurses' experiences were based on social status, communism and poverty. The study also found that cultural orientation and belief regarding communism were central to family involvement (2008,1781). Zaman (2004,2023) in his Bangladeshi study argued that in a society where cultural hierarchy predominates, the social interactions are also affected. Zaman further argued that such experiences are common in societies stricken by social and cultural inequality of power. It may be concluded that some nurses' experiences are influenced by beliefs in cultural hierarchy and communism. However, this is not well-known in Malawi.

Negative and difficult situations of involvement of families in the care of sick children in critical care units from the perspective of nurses exist (Mackay, 2009,158). This may be true for nurses at this tertiary hospital in Malawi. In 2014, in the paediatric section, the nurse-patient ratio was 1:84. Despite this poor ratio in patient care, nurses are expected to involve families in child care (Soderstrom et al. 2003, 183). Nevertheless, nurses' willingness, experiences and commitment when working with families in such an environment are paramount. Evidence from elsewhere shows that nurses' experiences with regard to interventions with families of sick children are key to care delivery. One may assume that at the tertiary hospital where this study was

conducted, family involvement in child care by nurses may be complex. However, no studies have highlighted the nurses' experiences when involving families in child health care in Malawi. Thus, assumptions may exist in the manner in which registered nurses involve families in the care of children. This study sought to describe registered nurses' experiences of family involvement in the care of hospitalised children at a tertiary hospital in Malawi.

Significance of the Study

In Malawi, little is known about registered nurses' experiences of family involvement in care of hospitalised children. Findings on this topic would influence policy makers to formulate policies and guidelines on family involvement in child care. The findings would also provide an understanding that would guide the implementation of family involvement in the care of children.

Broad Study Objective

To describe registered nurses' experiences when involving families in the care of hospitalised children at a tertiary hospital in Malawi.

Key Research Questions

This study sought to answer the following questions:

What do registered nurses know about family involvement in the care of hospitalised children?

What are the registered nurses' experiences of family involvement in the care of hospitalised children?

THE RESEARCH DESIGN

A qualitative approach using descriptive methods was employed. One assumption about qualitative descriptive studies is that for any human experience, there are essential structures that make up that phenomenon regardless of the person who experiences it (Lincoln and Guba 2004, 184–85). This approach was considered appropriate because it has the ability to reveal experiences of the participants in-depth (Burns and Grove 2009, 281). This means that the researcher was intensely involved and engaged with the respondents in the data collection process.

Study Population, Sampling and Sample Size

This study was conducted at a government tertiary hospital in Blantyre, southern Malawi. The study's target population comprised 16 registered nurses in the paediatric

section. A purposive sampling method was used to recruit participants based on the inclusion criteria, which included the following: being a registered nurse working full-time in the paediatric unit and having at least one year or more working experience in paediatric wards. Fourteen registered nurses participated after reaching data saturation with the fourteenth interviewee.

Data Collection Methods

In-depth interviews were conducted to collect data from individual participants using an interview guide. The data collection tool contained demographic information as shown in table 1, and open-ended questions, which sought information on the meaning of family involvement and the description of nurses' experiences regarding family involvement. Data were collected between July and August 2014. Each interview lasted 50 to 60 minutes.

Data Analysis

Demographic data were analysed using descriptive statistics (frequencies, percentages and means). Qualitative audio recorded data were first transcribed verbatim and analysed using Qualitative Content Analysis (QCA). Graneheim and Lundman (2004, 108) indicate that QCA ensures that data collected is related, appropriate and value bound, and meaningful patterns emerge. QCA has four components for analysing qualitative data, namely transcription of raw data, grouping of data into codes, creation of categories and the development of sub-themes and themes.

Trustworthiness

Trustworthiness was achieved by adhering to credibility, dependability, confirmability and transferability standards. Credibility was achieved by following methodological design during recruitment, data collection and analysis. Information was collected from nurses who were experienced and knowledgeable about family involvement. Dependability was achieved by paying attention to data being collected. The researcher followed the methodology in a step-by-step manner. According to Graneheim and Lundman (2004, 110), a step-by-step presentation of the methodology prevents instability and design-induced changes that may also impact on consistency. Piloting was done to validate the data collection instrument. Confirmability and transferability were achieved by observing and documenting personal biases, correctly selecting participants, adhering to the study design and data collection methods.

Ethical Considerations

The study was approved by the College of Medicine Research and Ethics Committee. The reference number is P.04/14/1562 dated 24 June 2014. This was to ensure that the

study complied with ethical standards regarding the protection of human subjects from exploitation. Permission was also sought from the Hospital Director. Participants were informed of their right to voluntary participation or withdrawal. Identification was kept confidential during data collection, analysis and presentation. The participants signed the consent form voluntarily before participating in the data collection process, thus giving permission for their involvement in the study.

RESULTS

Demographic Characteristics of the Participants

Fourteen full-time registered nurses participated in the study. Their ages ranged from 22 to 48 years, with a mean age of 26.8 years. Of the participants, 78.5% ($n = 11$) had more than one year but less than two years' working experience, 85.7% ($n = 12$) had a first degree in nursing, while14.3% ($n = 2$) had specialised in child nursing.

Table 1: Participants' demographic data

No	Age (Years)	Sex	Religion	Qualification	Cadre	Specialisation	Experience
1	25	F	Christian	BSc Nursing	RN	None	2 years 5 months
2	22	F	Christian	BSc Nursing	RNM	None	1 year 3 months
3	27	F	Christian	BSc Nursing	RN	None	2 year 3 months
4	33	F	Christian	BSc Nursing	RN	None	1 year 4 months
5	28	F	Christian	BSc Nursing	RNM	None	1 year 11 months
6	32	M	Christian	BSc Nursing	RN	None	1 year 5 months
7	25	F	Christian	BSc Nursing	RN	None	1 year 3 months
8	26	F	Christian	BSc Nursing	RNM	None	1 year 3 months
9	27	F	Christian	BSc Nursing	RN	None	1 year 7months
10	23	F	Christian	BSc Nursing	RN	Critical Care	1 year 3 months
11	30	M	Christian	Dip Nursing	RNM	None	2 years 7 months
12	48	F	Christian	BSc Nursing	RN	Child Nursing	5 years 10 months
13	31	M	Christian	Dip Nursing	RN	None	1 year 3 months
14	24	F	Christian	BSc Nursing	RNM	None	1 year 9 months

Key
BSc – Bachelor of Science
F – Female
M – Male
PW – Paediatric ward
RN – Registered nurse
RNM – Registered nurse midwife

Content Analysis

Three main themes emerged from the responses: registered nurses' knowledge of family involvement, registered nurses' experiences of family involvement and registered nurses' impressions of family involvement. Under registered nurses' knowledge, two sub-themes were meaning of family involvement and rationale for family involvement. The latter theme had three sub-themes: rewarding experiences, demanding experiences and encounters with multiple realities.

Registered Nurses' Knowledge of Family Involvement

Two sub-themes emerged from this theme: meaning of family involvement and rationale for family involvement.

Meaning of family involvement

Participants described family involvement as various ways of incorporating members of the family into the care of the hospitalised child from the time of admission, during nursing care and evaluation, through to the discharge or death of their child. One participant said that involvement included siblings and members of the extended family or significant others.

> "It means involving family members in the care of the child. It has different forms; it may mean the physical contact even the input on what to do on the child. The parents can be there or at home but be contacted on the decision on their child."

Rationale for family involvement

The reasons for involving families included sharing responsibilities with families, social support, the family being an expert entity in care and for partnership on decision-making. Nurses reported that they had their own clinical roles and responsibilities but they shared these responsibilities with families during involvement.

> "It helps in care of the child because in cases where you look at the number of nurses and the amount of work that you do, you cannot commit yourself to everything so they take on other responsibilities. Family involvement is also important to us because it is a social support to children. It helps to share the burden of sickness and reduces workload for nurses. Sometimes there are difficult decisions to be made so you need to involve them."

Registered Nurses' Experiences of Family Involvement

Three sub-themes emerged from this theme: rewarding encounters, demanding encounters and encounters with multiple realities.

Rewarding encounters

Some registered nurses regarded working with the family members as a good and fruitful experience. They reported that it was better to work with family members because they brought variety to the care, family members cooperated with nurses and if family members were properly utilised by the nurses, nurses benefited a lot from them. Others reported that due to a shortage of nurses, nurses realised that working with family members was a reality and not an option. One participant said:

> "To be frank with you, it has been a good experience. I have been able to do other things because mothers have assisted me on things that would have been done by me as a nurse such as feeding a child on nasogastric tube; I have given this to mothers and it has lessened my work."

Interestingly, some registered nurses felt that they wanted to work with family members because they deserved to take part.

> "So far so good – we work together with the families because they need to know what is going on. We cannot run away from them because treatment takes time so they need to be there, it is their right."

Demanding encounters

Some participants felt that involving family members was a taxing experience and an obstacle to the accomplishment of daily nursing plans. They cited issues such as negative attitudes regarding nurses and certain family members, family members taking time to gain skills and family members having difficulties following nurses' instructions. Some registered nurses reported that some family members were very demanding, while others brought their children late to the hospital after the condition had worsened. This made nurses' experiences taxing.

> "It has been a challenging experience because the family brings the child very late when critically ill. This is a big challenge because they are bringing the child when the condition is worse. They do not follow instructions either. Some nurses also do not give handover. It is difficult here. This makes working with family members a challenge and you are forced to shout at them and this spoils your relationship and they do not trust you even if they are wrong. Some also have political connections. You feel they will report you."

Encounters with multiple realities

Some registered nurses felt that their experiences were sometimes demanding, but also good and bad at other times. They reported that they could not tell whether it was absolutely good or bad, while others stated that it was a mixture of both good and bad times. Others also felt that ethically, it was their duty to provide care to family members and their children in hospital and that in acting to the contrary, they could be sued. Thus these nurses could not absolutely indicate how their experiences had been.

> "It had been fair, but not all of the nurses do that. It depends on the attitude of the nurse or the guardians. Some even do not want, some want … so it is fair or it is fifty-fifty. Some involve families because they know them or understand the issues. Of course here and there, there have been problems and good things. You see, due to our ethics, it is wrong to give your responsibility to family members as a nurse. You feel you are guilty when you delegate tasks that are nursing in nature to parents or guardians so you may not be comfortable at times."

Registered Nurses' Impressions of Family Involvement

The majority of registered nurses (*n* = *11*) were of the opinion that family involvement was a good idea because it could improve quality of care, although it must be regulated. Some participants said:

> "Family involvement is really important. If it is done properly, it can promote quality care. It should have regulation and direction; that is what I think."

> "In fact it is a good concept, it helps them to cooperate with you and share information in the process so that you can engage with them. In that way, you can be doing other procedures. This promotes good care for the child."

> "It is a good concept and should be implemented fully. Sometimes it helps to make choices according to patient's needs. In that way you are able to make the way forward on the delivery of care."

Discussion

The demographic statistics show that registered nurses had generic degrees in nursing and relatively little working experience in children's wards. However, they were able to give information regarding their experiences and how they involved family members in care. This may imply that registered nurses in this study used their generic paediatric nursing knowledge as a foundation for the acquisition of further skills and experience in child nursing. This generic educational preparation formed the basis for their nursing practice. McHugh and Lake (2010, 277–78) argue that without background knowledge, professionals may risk using poor judgement and may lack the tools necessary to learn from and build on their previous experiences.

Based on the narratives as reported, the findings reveal that registered nurses were knowledgeable on family involvement. According to Espe-Sherwindt (2008, 138), the nurse should recognise, among other things, that the family should be constant in the child's life at all levels of care. This may substantiate why some nurses allowed family members to be treated as partners and respected both the child and family's choices and cultural perspectives. McHugh and Lake (2010, 278) further indicate that knowledge of a phenomenon is important because it enhances acquisition and application of nursing expertise, which is fundamental to quality nursing care.

The narrative on the rationale for family involvement is consistent with some western studies, which have concluded that some nurses rely on parents and guardians to provide care (Coyne 2006, 3154; Coyne and Cowley 2007, 893–894). Evidence shows that nurses involve family members to lessen workload, save time and share responsibilities (Coyne 2006, 3152). Coyne, O'Neill, Murphy, Costello and O'Shea (2011, 2569) conclude that although nurses are aware of the need to work with families, they sometimes involved parents in the care of hospitalised children for administrative efficiency, and not for the empowerment of the family members. This may be the case in Malawian tertiary hospitals, where there has been a chronic shortage of nurses. However, this is contrary to the guiding principles of the Patient and Family Centred Care Model, which stipulates that the reasons for family involvement in care are empowerment, shared decision-making and timely disclosure of adverse effects on the child. Nonetheless, these findings are in line with the growing body of knowledge which indicates that the family is central to the social and psychological wellbeing of the child (Harrison 2011, 335–36; Shields et al. 2006, 1318).

Registered nurses claimed to involve families in the care. However, it was clear that this was for administrative efficiency. This is because involvement of these family members by nurses was an option, thus benefitting nurses considerably if family members were involved appropriately. The major benefit was a reduction in their workload, thereby enabling them to concentrate on important nursing roles such as carrying out orders on ward rounds, drug administration, attending to new admissions and wound dressings. A shortage of nurses and other healthcare workers at this tertiary hospital may explain why registered nurses in this study found the family members' contributions rewarding. These findings are consistent with those of Zaman (2004, 2033) who found that in Bangladesh, due to a shortage of nurses, nurses relied on parents to deliver care. However, this may adversely affect the quality of care provided to the children because family members may be overwhelmed and may provide substandard care. Furthermore, this aspect of involvement is not consistent with the values of family-centred care practice, which entails that families as partners should be encouraged and supported to participate in the care of their children at a level they choose (Uhl, Fisher, Docherty and Brandon 2013, 123). As such, nurses need to assess capabilities of family members before allocating tasks so that children can receive quality care.

There is increasing concern that registered nurses who experience frustration fail to cope with the demands of involving families in the care of their children (Coyne 2006, 3156–57). This could be due to inconsistent availability of resources to support nurses. Apart from shortages of nurses, shortage of supplies and huge workloads are also known to disrupt continuity of tasks and roles of family members as given by and agreed upon with nurses (First Coyne 2006 then Coyne et al. 2011; Zaman 2004, 2027). This, coupled with demanding and politically linked families, may have placed registered nurses in this study under pressure and made them shun families. Shunning demanding parents is widely recognised as a sign of inadequate coping on the part

of nurses (Coyne 2006, 3155; Espezel and Canam 2003, 38–39). This may explain why the process of family involvement in the care of sick children was on an ad hoc basis. Soderback and Christensson (2008, 1783) assert that nurses shun difficult and demanding parents because they experience problems maintaining communication with these family members.

Multiple realities imply that uncertainties and dilemmas exist in the way family involvement is implemented. Gondwe, Bhengu and Bultemeier (2010, 97) found that in Malawi, there are no written policies to support involvement of family members. This may have contributed to the nurses' uncertainty when involving families in the care of hospitalised children, as they had no basis for their practice, which led to frustration and friction within their professional roles. Ford and Turner (2001,293) found that in Australia, nurses experienced friction between their present role in family involvement and their expected professional role, as there was no policy on which to base their practice. This led to disturbances with handovers from fellow nurses and made it difficult for others to describe their real experiences. This may not make the environment conducive to family participation in child care. Multiple dimensions of nurses' experiences and the role of nursing ethics on family involvement have received little attention in family-centred care literature. Thus, further research is needed in this area.

Registered nurses surveyed indicated that family involvement is desired but should be regulated. This implies that these registered nurses valued family involvement in the care of the hospitalised children. This finding is consistent with Western studies, which have concluded that although nurses are constrained in many ways, they are proponents of family participation in child care (Shields et al. 2006, 1321). This explains nurses' positive attitudes towards family involvement at the hospital. Those studies also revealed that although family involvement is a good idea, it should be regulated. Coyne et al. (2011, 2567) found that nurses in Ireland felt they provided substandard care because there was no policy to guide family participation in care. Thus, some registered nurses at this institution seemed aware that the manner in which family involvement as a concept was being implemented had no standard for current practice and this affected the way nurses involved families in care.

Recommendation

The study reveals that there is a lack of direction regarding family involvement. Evidence shows that guidelines act as standards against which current performance is measured (Paliadelis et al., 2005, 35). These study findings provide healthcare managers with an opportunity to develop a policy upon which nurses and families can base their future practice and decisions.

Study limitations

The limitations were time and financial constraints for the researcher. This is because the study was done for academic purposes and time and financial considerations became paramount in limiting the number of study settings and the scope of the study.

CONCLUSION

The study shows that registered nurses are knowledgeable regarding family involvement and that family involvement in child care is desirable, but needs to be supported and regulated. Registered nurses' experiences were mixed and were constrained by negative attitudes from nurses and family members, and an absence of a policy on family involvement. This status quo could continue unless authorities provide support to nurses by developing a policy to regulate family involvement in children's care.

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