



**EXPLORING PARENTS' PARTICIPATION IN THE CARE OF THEIR
HOSPITALISED CHILDREN IN A GENERAL PAEDIATRIC WARD AT
ZOMBA CENTRAL HOSPITAL, MALAWI.**

MASTER OF SCIENCE (CHILD HEALTH NURSING) THESIS

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OCTOBER, 2018

Declaration

I, George Yotam Nsitu, hereby declare that this thesis is my own original work and has not been submitted to any institution for similar purposes. Where other people's work has been used, acknowledgements have been made accordingly.

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Signature

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Certificate of approval

We hereby declare that this thesis is the student's original work and where any additional information has been used, this has been acknowledged. It is therefore submitted with our approval.

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Dedication

I dedicate this thesis to my lovely wife Titha, parents, my brother Brian and all close friends for their support and perseverance throughout my study period.

Acknowledgements

I would like to express my sincere gratitude to my supervisors, Dr Ezereth Kabuluzi and Mrs Tiwonge Munkhondya, for their immeasurable support and guidance towards the completion of this work. In a special way, I would like to acknowledge the ELMA Foundation for the financial support provided for the completion of this study. I also acknowledge the contributions of Mr Ian Kapira, Mr Isaac Mphande, Mrs Maryeuster Kalawa Bisika, the staff in paediatric ward (Zomba Central Hospital) and all my masters' classmates in Blantyre for the assistance they provided.

Abstract

Parental participation is regarded as an essential element of the quality of care for hospitalised children, and is the main element of Family Centered Care (FCC). Parental participation has been perceived significant in the reduction of adverse effects of hospitalisation and anxiety, and improvement of satisfaction. Parents in Malawi are allowed to stay with their sick children and participate in the provision of care in the ward. Their participation extends to the performance of almost all tasks related to care due to shortage of staff, which is critical in most public health facilities. The parents' perspective of their participation in the care of the sick children in a paediatric context had not been explored in Malawi. This study therefore, aimed at exploring parents' participation in the care of their hospitalised children. The study used a descriptive qualitative design, and it involved parents of children hospitalised for more than forty-eight (48) hours in a general paediatric ward at Zomba Central Hospital, Malawi. Purposive sampling method was used, and twenty three (23) parents who met the inclusion criteria and gave consent participated. Collection of data involved the use of an interview guide through face to face interviews and all responses were audio recorded.

Findings showed that parents participate in care through roles which are not different from roles performed at home. The roles include mainly providing physical care and emotional care. There were various reasons also for the parents to participate in care that the study revealed. Parents' participation is not without challenges. Challenges included limited support and guidance in care provision, and limited family support and needs. The study has highlighted other significant areas also that need the health worker's attention if parental participation is to assist in improving the care outcomes of the hospitalised children. It was therefore recommended that policies and guidelines be formulated in the department, to guide parental participation in care.

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List of Abbreviations

COMREC	College of Medicine Research and Ethics Committee
FCC	Family Centred Care
HMIS	Health Management Information System
ZCH	Zomba Central Hospital

CHAPTER 1

Introduction and Background

Introduction

Family centred care (FCC) as a model of care delivery, has been considered the standard of paediatric care, and the best choice in paediatrics (Kuo et al., 2012). It is “a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients” (Shields, Pratt, & Hunter, 2006). FCC advances and expands the concern to include in the gaps of care those persons who are important in a patient's life (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009). Providing FCC in the clinical setting means incorporating into care giving the knowledge and conviction that family is a constant in children's lives, and that children are affected by and affect those with whom they have relationships (Harrison, 2010). Therefore, by including families in the care processes, ensures that children will receive higher quality care.

Family centred care is a move from a practice where care for children was exclusively provided by health professionals and visitation by parents was either limited or completely not allowed (Harrison, 2010; Saleeba, 2008; Zhou et al., 2012), to a practice of allowing parents to participate in the provision of care to their hospitalised children. The shift in approach is a result of evidence that revealed the effects of separation of a child from a mother, leading to change of mind-set of health professionals on the role of parents in the care of their sick child (Lam, Chang, & Morrissey, 2006). The family centred approach has been suggested as one way to alleviate potential problems while respecting the child and parent relationship (Hallstrom & Elander, 2007).

Family centred care has several elements, but its main element is the involvement of parents in a child's care (Shields, Mamun, Pereira, O'Nions, & Chaney, 2011) and arranging for family involvement is thus an essential element (Soderback & Christensson, 2008). The concept of parental participation has always been integral to the family centred model of care (Corlett & Twycross, 2006) and has been increasingly been emphasised in paediatric nursing practice (Coyne & Cowley, 2007). There is an agreement by those implementing family centred care that involving parents in the care is an essential element of the quality of care for hospitalised children (Jolley & Shields, 2009). During care provision, parents should clearly be involved in the decision-making process and be able to negotiate on the level of participation they wish to have in caring for their children (Corlett & Twycross, 2006).

In the care of a hospitalised child, parent participation has been perceived significant in the reduction of adverse effects of hospitalization and anxiety, promoting parent-child bond and improved satisfaction (Coyne, 2015). Apart from that, parents' presence alone, makes the parents representatives and advocates for children, and they may also assist in identifying shortcomings in the care provision processes in the hospital (Patrick, Ferris, Marino, Homer, & Perrin, 2003).

In Malawi, separation between parents and sick children has not been a main cause of concern in the general paediatric wards. Parents or family members are allowed to be with their sick children throughout the hospitalisation period. Concerns often are on the workload and tasks that parents of the sick children perform during hospitalisation of their children. Parents perform almost all activities related to care in the wards including some medical tasks, mainly due to shortage of staff. In Malawi the shortage of human resource for health is severe, with vacancy rates still remaining high (Bradley et al., 2015). The ratio of the health personnel to patients is so high (2 physicians/10000 and 3.4 nurses/midwives /10000 people)

(World Health Organisation, 2013). Most public hospitals are also characterised by overcrowding and scarcity of supplies (Hoffman et al., 2012).

The child population in Malawi, which is a majority, is mainly faced with a burden of diseases, such as malaria, pneumonia, HIV and AIDS, and malnutrition, complicated by poverty with one in five children likely to die before their fifth birthday as a result of disease (UNICEF, 2010). The parents or significant others to the sick children play a vital role in care provision during hospitalisation. They participate in care through the provision of basic care activities such as feeding, bodily maintenance, advocacy (such as reporting child needs, suggesting different times for interventions) and in other instances, cook food for the patient (Hoffman et al., 2012), and they are mainly female.

In order to stay with their hospitalised children, they have to stay away from home which affects household life and the care of other siblings if there are some. For these parents, what does participation in care mean to them and through which roles do they achieve it? What are the challenges faced by these parents as they are participating in care through various roles? These parents' understanding and perspectives of the concept of participation in care in the paediatric context, had not been studied, as evidenced by the dearth of literature. This study sought to address such a gap. In the care of sick children, the views of parents take on increased importance as parents have both the legal, emotional responsibility for the child's welfare (Ygge & Arnetz, 2004).

Background

Family centred care has been accepted as a model by many organisations dealing with sick children and embraced by many child nurses (Coyne, 2015). As noted by Lam et al. (2006) among the Chinese population, the increase in acceptance of parents to be with their sick children, through the implementation of family centred care, has provided an opportunity for parents to participate in care. For most families, hospitalisation of a child in a paediatric

ward is a stress in the family and brings disturbance in family routines. Parental roles and responsibilities alter significantly (Aein, Alhani, Mohammadi, & Kazemnejad, 2009). This affects how parents can participate in the care, and it can only be reasonable to believe that the parents need time to adjust to their child's hospitalisation before they can participate actively in their children's care (Lam et al., 2006). Each family is unique in relation to parenting style, family structure, ability to share emotions and needs (Corllett & Twycross, 2006), therefore it is important for health professionals to understand and appreciate issues surrounding parental participation, as it can be a demanding and challenging experience (Aein et al., 2009).

In the hospital setting, parent participation refers to the activities that are done by the parents for their children in hospital (Vasli & Salsali, 2014). The recognition of the importance of parental participation, has been another further step in family centred care. It has raised issues for discussion and research related to parents' willingness and readiness to participate in their hospitalised children's care and the influence of culture (Lam et al., 2006). Thus, the knowledge of parents' views of their own participation has been necessary for the development of clinical routines for parent participation (Ygge & Arnetz, 2004). Studies have highlighted significant areas in relation to the concept of parent participation within the paediatric context, which include; parental roles and negotiation of roles, participation, and partnership (Corllett & Twycross 2006; Coyne & Cowley, 2007; Shields, Pratt & Hunter, 2006).

It has to be appreciated that parental roles and responsibilities alter when a child is admitted to hospital (Aein et al., 2009). The roles of parents change from parenting a well-child to parenting a sick one. For parents to perform their usual and newly acquired roles due to the hospitalisation, there has to be a negotiation of roles with the staff. Lack of negotiation about these parents' roles has often been a source of conflict, and affects delivery of family

centred care (Corllett & Twycross, 2006; Shields et al., 2006). Negotiation involves a process of discussion resulting in a mutual agreement, but expectations and assumptions nurses have, are often a stumbling block to this process (Aein, 2009; Coyne & Cowley, 2007).

Parents' perspective of their participation has been explored through studies also. From the previous studies done in the western countries and the East, it is clear that parents are willing to be included in the care of their hospitalised children. The parents appreciate being allowed to participate in the care of their children during hospitalisation (Lam et al., 2006; Shields et al., 2006; Hallstrom and Elander, 2007). Despite that similarity, their understanding of participation has been different, ranging from being available for the child, being able to carry out basic care, being informed, continuing home practices and working with health care professionals (Pongjaturawit et al., 2006). These parents also differed in their reasons for participating in the care of their sick children during hospitalisation. The reasons included that participation enables parents to provide individualised care, ensure adequate child monitoring and meeting the children's and parents' own emotional needs (Lam et al., 2006).

Partnership has also been significant in the process of parent participation. It offers parents opportunities as partners, to solve parenting problems and to build on existing strengths and expertise (Fowler et al., 2012). Partnership implies equality among partners, information sharing, and negotiation of care and shared responsibility (Coyne & Cowley, 2007). Through this partnership, the health workers support the parents as they participate, which results in empowerment. Empowerment allows the family to assume a sense of control over their affairs.

In the Malawian paediatric context, the perspective of parents of their participation in care had not been explored, as there is lack of literature on the same, therefore there was a

gap in information. The knowledge of the parents' perspective is significant in the delivery of care considering that parents provide almost all the care of the sick children in the hospital. Due to high admission numbers and a critical shortage of staff in the wards, parents provide most of the care, ranging from the provision of basic to the performance of some medical tasks. For example, Zomba Central Hospital, in the period beginning July 2015 to June 2016, registered 6,854 paediatric admissions, with the in-stay number of patients averaging 115 per day. The top causes of admission were malaria and pneumonia (Zomba Central Hospital, 2016). Parents are tasked to administer medications (oral and topical medications), dressing of wounds in some cases, tepid sponging in children with fever, tube feeding of critically ill children and continuously observing for any changes in condition. The nurses usually take and perform orders after a ward round, administer the intravenous medications, and attend to emergencies in the ward. The tasks are shifted to the parents without proper psychological preparation and resources to use in the caring (Hoffman et al., 2012). Furthermore, the parents' capability and literacy levels are not considered before shifting the tasks. In addition to this shortfall, there are no guidelines in the wards for parent participation. As a result there is no clear direction and uniformity on how parents should participate in care of their sick children and the type of basic support the health workers should provide to the parents as they participate.

Problem statement

In Malawi, the child population is faced with a high burden of diseases. This burden leads to increased admissions and congestions in paediatric wards. For example, Zomba central hospital paediatric ward had 6,854 admission against a bed capacity of 92 for the paediatric ward. Parents in these paediatric wards are allowed to stay with their sick children and participate in the provision of care as health professionals cannot cope with the workload. The shortage of staff is critical, that parents provide basic care including performance of

medical related tasks in care without adequate physical and psychological preparation, resources, knowledge and skills. However, despite their presence and participation in the care, there is insufficient information on the parents' perspective of their participation in the care of their hospitalised children, which can be used to effectively facilitate parent participation in the hospital setting. Therefore, in order to facilitate effective and meaningful parent participation to benefit the hospitalised children here in Malawi, there was a need to explore and gain an understanding of the parents' understanding and perspective on the concept of participation in care, as they care for their sick children in the ward.

Justification of the study

The successful implementation of family centred care, which encompasses parent participation, is a result of good collaboration between the health care professionals and the parents of the children under care. Conducting this study has several advantages to the paediatric clinical practice. The study will increase awareness and sensitivity on issues surrounding parent participation in the paediatric wards and elicit an appropriate response from those involved. The results of the study will also strengthen the existing strategies or initiatives that are directed towards parents' welfare, involvement and participation. The facility where the study has been conducted, and others, may use the results to formulate policies and guidelines that can be used in the clinical area, to promote parent participation in the care of their sick children during hospitalisation. Such developed guidelines may bring consistency to clinical nursing practice, simplify processes, resulting in improved practice standards and care outcomes. Furthermore, the study has identified gaps in relation to parent participation, thereby revealing more areas requiring further research. In this absence of published evidence, these results when peer reviewed and published, will add to the knowledge and evidence base that can be used in nursing practice, management and education to improve paediatric nursing in Malawi.

Objectives of the study

Broad objective

To explore parents' participation in the care of their hospitalised children in a general paediatric ward at Zomba Central Hospital

Specific objectives

1. To describe parents' understanding of their role in the care of a hospitalised children.
2. To describe roles parents play as they participate in the care of their hospitalised children.
3. To describe how parents negotiate roles during hospitalisation of their sick children.
4. To identify challenges to parents' participation in the care of their hospitalised children.

CHAPTER 2

Literature Review

Introduction

This chapter presents a review of literature on parents' participation in the care of their hospitalised children. Review of literature provides an understanding of what is known about the topic and the knowledge gaps that exist (Burns & Groove, 2009). This literature review has a focus on the concept of parent participation, the parents' understanding of their role in the care of their hospitalised child, negotiation of roles during care and limitations to parent participation in the care of their hospitalised child. The review was guided by the study objectives to find what is known about the subject and identify gaps.

Literature Search Strategy

The following sources were used to access the research articles for the literature review: Pub Med, MEDLINE, and EBSCO HOST. Using Boolean search, the following terms were used in the searching: family, family centred care OR family centered care, family/parent involvement in child care, roles of parents in sick child care, history of family centred care, and parent participation in care. Articles used were all in English.

Parents' participation in care of their sick children

Parent participation, being the main element of family centred care (Shields et al., 2011), has been an integral part of the family centred model of care (Corllett & Twycross, 2006). For a hospitalised child's care, it has been increasingly promoted in paediatric nursing for many years. It ameliorates the adverse effects of hospitalisation, avoids parental separation and contributes to quality care for sick children (Coyne, 2007). On a day-to-day basis, the act of being a parent is synonymous with participation in their child's care, as the

parents are charged with the responsibility of making decisions that they feel are in the best interest of the children (Just, 2005).

Study findings have already demonstrated that parents appreciate being allowed to participate in the care of their hospitalised care of their sick children (Lam et al., 2006; Shields et al., 2006; Hallstrom and Elander, 2007). In addition to these findings, other studies revealed that not only are the parents willing to participate, but they want to be able to determine what this participation will involve (Coyne, 2013). How parents determine the extent of their participation in care can be influenced by their perceptions of the assumptions and expectations of nurses (Aein et al., 2009; Coyne & Cowley, 2007). Parents in Malawi have always been allowed to stay with their sick children and have been significant in care through the performance of various hospital care tasks.

Further reports suggest that the parents are also comfortable providing care related to activities of daily living, but are less eager to be taught and participate in more technical aspects of care, such as treating wounds and giving injections (Soderback & Christensson, 2008). In paediatric wards in Malawi, parents provide the basic care (Hoffman et al., 2012) including the performance of medical tasks such as administering medications; wound dressing, feeding the critically ill with limited support from health workers. Their views on how comfortable they are in the performance of these medical tasks have not been explored. Generally, differences may exist during parent participation between parents of an acutely ill child and those of a chronically ill child. For those that take care of the chronically ill child, the technical care is part of the daily routine as most of these children are nursed at home. The findings that parents are less eager to participate in technical aspects of care, also relate to other research findings that suggest further that parents are not always participating in their children's care in the way they would like (Romaniuk, O'Mara, & Akhtar-Danesh, 2014) but cannot openly express these views. Sousa, Antunes and Casey (2013) reported that

about one third of the parents in their study reported feeling discomfort at the prospect of telling the nurses they preferred not to participate in care. At Queen Elizabeth Central Hospital, Malawi, Israel et al. (2008), made a similar observation. Parents were not able to express their views or seek clarification. This was due to fear that they will be told off and shyness. The inability of the parents to choose their level of participation in care should be of concern to health workers working with sick children in paediatric wards.

Despite having similar attitudes towards participation in care, Pongjaturawit et al. (2006) from their study in Thailand, noted that parents had various understandings of participation. This ranged from being available for the child, being able to carry out basic care, continuing home practices, and working with health professionals. Participation in care, for some parents is not an option as the society expects it (Pongjaturawit et al., 2006; Soderback & Christenson 2008), unlike parents in China, whose participation is by choice and they can leave the rest of the care to the nurses (Lam et al. 2006).

Parents' understanding of their role in the care of their sick children

Roles that parents play during hospitalisation may not differ from normal parenting roles when they are given an opportunity to participate in care. They can participate in the provision of basic care such as feeding the patient, and bodily maintenance (Hoffman et al., 2012). For some parents, they have generally perceived their roles as to provide individualised care, ensure adequate child monitoring, and meet the child's emotional needs (Lam et al., 2006). The parents in Shields and Cowley's (2007) study, were specific to highlight that their primary motive and role of being there for the children was to provide emotional support for their children rather than to be involved in giving physical care. Generally, parents lose many of their normal parenting roles, although they are still regarded as experts in their child's care when their child is admitted to hospital. They have to negotiate their new roles in the new setting.

Negotiation of roles in care

The hospital is an unfamiliar setting for both the child and parent, and the stress that comes with it makes them vulnerable (Ygge, 2004). Parents undergo various changes, and these changes can occur in both the general paediatric and intensive care units. Disruption of parental roles has been identified also as the greatest source of stress in parents within a paediatric intensive unit (Meert, Clark, & Eggly, 2013). For parents to effectively participate in this strange, unfamiliar environment, they need to negotiate with the health workers and clarify roles during the process. Generally, most parents face challenges in negotiating care.

Negotiation involves a process of discussion resulting in a mutual agreement. Negotiation between the parents and the nurses is often the key element to the success of interactions during a child's hospitalisation (Corlett & Twycross, 2006; Espezel & Canam, 2003). However, it is suggested to date that negotiation is not routinely planned or conducted (Power & Franck, 2008; Ygge & Arnetz, 2004). Negotiation, allows parents to feel that they still retain control over what their participation in the care would be. The ability of parents to negotiate their roles is constrained by health professionals' expectations (Aein, 2009; Coyne & Cowley, 2007) and the absence of individualised assessment. Many parents are willing and eager to participate in their hospitalised children's care (Ygge & Arnetz, 2004), but this is not possible because of health professionals' expectations. This concurs with the findings of several other studies that later found that lack of negotiation about parent's roles was often a source of conflict and affected delivery of family centred care (Corlett & Twycross, 2006; Shields et al., 2006).

Literature on expectations, suggests that most parents are not sure what is expected of them while the nursing staff have clear views of what they wanted parents to do. Parents are uncertain on how their roles fitted with the nurses roles, forcing other parents to gradually

learn by observing and asking advice from other parents (Coyne, 2013). In reality, parents and children come with different expectations to the clinical setting and have to be socialised in the hospital culture to minimise this conflict (Coyne, 2007). Hoffman et al. (2012) noted in a Malawian context, that conflict has been inevitable with parents, often resulting from lack of understanding of hospital regulations and lack of respect for the parent's role, compounded by health workers' lack of time for effective communication due to increased pressure of work. An open negotiation with continued communication with parents allows nurses to determine how much assistance parents need in providing care (Just, 2005).

Limitations to parents' participation in care

Results of studies from the Western and Eastern countries have demonstrated that parent participation during child hospitalisation is not without problems (Soderback & Christensson, 2008). Limitations to parental participation in the care of their hospitalised children exist.

Parents bemoan lack information related to their children's condition, course of treatment and the expected prognosis and roles. They have often been uncertain of how their role fitted in the nurses' roles (Coyne, 2013). This lack of information, often has led to parents learning their role through difficult ways. In most African contexts, there is a lack of information before and after admission as well as during care process, leading to a feeling of neglect as noted by Soderback and Christensson (2008) in Mozambique. In this Mozambican study, parents had expectations that nurses would take more initiative to report the child's progress despite their presence at the bedside. Israëls et al., (2008) found that parents in Malawi had fear and shyness which contributed to parents not seeking more information regarding prognosis and medical procedures being done on their children. This limited their ability to participate in the decision making process. Access to understandable and consistent

information, assurance that the best care is being delivered to the patient, support, and being part of care, reduces feelings of powerlessness in parents (Al-Mutair, Plummer, Clerehan, & O'Brien, 2013).

Disruption of social responsibilities has also emerged as a limitation to parents' participation in care. Parents experience difficulty finding a balance between being there in the hospital for the children and competing needs of other family members, occupational role, personal needs and house work (Coyne & Cowley, 2007). The effort of being there for the children is potentially stressful for parents with minimal resources, resulting in neglect of their own needs such as food and rest. This situation demands significant support from both health care professionals and family. In Mozambique, nurses witnessed mothers leaving the ward due to lack of support from family, which could have affected the child's chances of survival (Soderback & Christensson, 2007). Supporting parents' social conditions and participation in the care process are important not only for survival but also for the sick child's recovery (Grantham-McGregor et al., 2007).

Conclusion

The literature has shown that parental participation is a concept that has been embraced by many institutions and organisation in paediatric care for a long period of time. It is the main concept of the philosophy of family centred care. Studies done have shown the benefits of parent participation in care. They have also highlighted how parents from various regions understand participation, their roles in care and limitations to their participation.

There are few studies from Africa and Malawi. Parents in Malawi participate in the care of the sick children, but there is a gap in information, especially from the parents' perspective of their participation. The findings from the other studies cannot be transferred to the Malawian

context, hence the need for an assessment of parents' participation in the care of their hospitalised children here in Malawi.

CHAPTER 3

Methodology

Introduction

This chapter presents a detailed description of the design, setting, and sampling technique, criteria used to include and exclude participants for the study, participant selection process, data management, trustworthiness and ethical considerations.

Study design

This was a descriptive qualitative study. A qualitative approach to research facilitates exploration of relationships and human experiences within the research setting and enable face-to-face, personal contact in data collection (Moule & Goodman, 2014). It allows the researcher to describe existing phenomena and current situations through immersion in a situation and as a result of direct interaction with them. Reality is created by individuals and needs to be interpreted. The researcher aimed at understanding the reality as it is understood by the parents regarding participation in care hence the qualitative approach was more suitable for the study.

Setting

The study was conducted at Zomba Central Hospital, which is a tertiary level hospital, providing care to both adults and children. It is one of the four tertiary hospitals in Malawi, located in the Eastern region. Zomba Central Hospital is a teaching centre for students doing health related studies, i.e. nursing, midwifery. It is a referral centre for 42 health facilities within Zomba, the district in which it is located, and other four districts in the Eastern region. The total bed capacity of the hospital is 665.

The hospital's general paediatric ward has a capacity of 90 beds. When the admission rate of sick children is high, total number of children in the ward can reach 300 per day,

which is three times more than the bed capacity. This results in congestion resulting in more than two children occupying a single bed. There are 3-4 nurses during the day shift and 2-3 during the night with one clinical officer to examine the inpatients. In the period from July 2015 to June 2016 there were 6,854 admissions that were registered in the ward (Zomba Central Hospital, 2016). The site admits people of different backgrounds (cultural or socioeconomic) which diversified the data collected for the study (though they did not influence the participant selection, inclusion criteria). Different backgrounds may influence perception of issues of caring for sick children.

Population

The targeted population for the current study were parents of children admitted in the general paediatric ward for not less 48 hours.

Inclusion criteria

Parents that participated in the study were the ones who had a child admitted to the ward, and that the child had stayed in the ward for not less than 48 hours from the time of admission. The parents also had the ability to communicate well in either Chichewa or English. These were parents who were mostly spending time with the child and could give an account of their understanding of participation in care. Despite Zomba Central Hospital serving people of the eastern region which the majority are of Yao background, Yao language was left out because it is rarely used in the clinical area as a local language compared to Chichewa.

Exclusion criteria

Parents whose children had been admitted in the ward for less than 48 hours, and those that were not able to communicate well either in Chichewa or English and did not give consent were excluded.

Sampling

The study used purposive sampling method. Purposive sampling aims to sample a group of people with a specific set of experience or characteristics (Moule & Goodman, 2014). This method of sampling was more specific and time saving in this study as the parents with the required information were involved.

Sample size

The sample size was guided by the need to obtain sufficient information to address the research problem, (Moule & Goodman, 2014). The Initial proposed sample size was 20 participants though it is difficult to specify at the beginning of the research how many people the researcher will interview. Guest, Bunce, and Johnson (2006), suggest that at least 12 interviews would suffice and enable the development of meaningful themes and useful explanations. During data collection, by the twenty third interview, no new data was being generated from the interview and data saturation was declared. Therefore, a total of 23 parents were interviewed in the general paediatric ward. Data saturation refers to repetition of discovered information and confirmation of previously collected data (Burns & Groove, 2009). There are no rules for sample size in qualitative research. It is dependent on the aim of the study, sample specificity, quality of dialogue and analysis strategy (Malterud, Siersma, & Guassora, 2015) .

Participant recruitment process

Screening was done on each day of data collection to identify the parents meeting the inclusion criteria from review of admission records. Thereafter, the parents meeting the criteria were approached for possible participation in the study. The parents were briefed on the aim of the study, and that the interviews would be recorded. The participants were also informed of the risks and benefits of participating in the study and the rights that they had

while participating in the study, like the right to withdraw participation at any time. After the parents' informed written consent, face to face interviews followed.

Data collection procedures

In-depth interviews were conducted using an interview guide. All interviews were conducted in Chichewa. In-depth interviews allow a researcher to have a rich description of phenomena, and they also provide a more relaxed atmosphere in which to collect information and assists in elaborating ideas (Boyce, 2006). All interviews were audio-taped with a digital recorder, and field notes were taken to enrich the recorded information. The interviews were conducted in a private room within the department. No parent withdrew during data collection, and no modifications were done to the tool during data collection. Data was collected over a period of two weeks between March and May 2017.

Data collection tool

An interview guide, which was developed by the researcher, was the tool for data collection in this study. It was developed after a literature review on parents' participation in care and in line with the study objectives. The tool was initially developed in English then translated to Chichewa (**Appendix 4**). The translation was verified by another person to ensure the meaning of the questions remained the same. To ensure credibility of data, the tool was reviewed by others experienced in qualitative research and child health issues for appropriateness and applicability. The tool had a focus on the parents' demographic and socioeconomic data and their views on participation in the care of their hospitalised children (**Appendix 1**).

Data analysis

After the in-depth interviews, data were transcribed verbatim, and then translated to English. To ensure transcripts contained the original meaning of the audiotaped data,

proofreading of all transcriptions was done against the audio tape and revision of the transcript files followed accordingly. Data were analysed manually using thematic analysis. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). The process begun with familiarisation with the data by reading and re-reading the transcripts to understand the depth of the content. This was followed by the isolation of codes. Codes identify a feature of a theme that appears interesting to the analyst and refer to the most basic elements of segments of raw data that can be assessed in a meaningful way regarding the phenomenon (Braun & Clarke, 2006). Searching for themes was the next step after the coding process. The codes were categorised and then further condensed to form potential themes. These potential themes were reviewed, refined to form main themes and subthemes.

Trustworthiness of the study

Trustworthiness refers to the process of evaluating the quality of data and findings (Speziale & Carpenter, 2007). The study used Lincoln and Guba (1985) criteria for establishing trustworthiness in qualitative research. Four key components were used in the study to ensure data trustworthiness; credibility, dependability, confirmability and transferability (Moule & Goodman, 2014).

Credibility

Credibility refers to confidence in the truth of the data and interpretations of them (Polit & Beck, 2010). This was achieved through prolonged engagement which involved the use of open ended questions which granted participants freedom to express themselves. It also included description of phenomena, building good rapport and trust with the participants, and taking field notes. Responses were validated through member checking, where clarification were sought from participants when answers given were not clear, including

verification of responses with participant, in order to have a clear understanding of the participants' ideas on the subject under investigation.

Dependability

To achieve dependability, which is the stability of the data over time and other conditions (Polit & Beck, 2010), the research process was recorded and reported in detail from the design, data collection and analysis. This will allow future researchers to repeat the work. It will also enable the reader to develop a thorough understanding of the methods used and their effectiveness and be able to assess the extent to which research processes have been followed (Shenton, 2004).

Confirmability

The methods used in the research process have been presented in detail. This has been done to prove that the results are experiences and ideas of the informants (Shenton, 2004). In this study, audio recording of the participants' responses enhanced confirmability, and made it easier to distinguish participants' views from interviewer's views. Before the conclusion of this study, results that have been obtained will be presented to examiners both internal and external for scrutiny.

Transferability

In qualitative research, transferability refers to the extent to which findings from the study can be transferred to other settings (Speziale & Carpenter, 2007). Sufficient descriptive data in the research report, including the research methods and context in which this study was conducted has been given. This can help the reader to relate properly and make a sound judgement on the transferability of the findings to their contexts which might be similar to the one in which this study was done or different.

Ethical considerations

Ethical clearance was sought from the College of Medicine Research and Ethics Committee (COMREC) (**Appendix 7**) and site approval from the Hospital Director of Zomba Central Hospital (**Appendix 8**) before conducting the study. A clear explanation was given to the participants about the purpose and the possible benefits and consequences of participating in the study (**Appendix 2**) to obtain consent and ensure that the rights of participants were protected. Furthermore, participants were reminded and allowed to exercise their right to withdraw from the study without any consequences. A written consent was sought from participants (**Appendix 3**). To ensure confidentiality, names were not used, instead a code was assigned to each participant. All information collected was kept safe by the researcher, in a password protected computer.

Summary

A detailed and clear description of the study plan, and other related processes in this chapter assisted in maintaining a systematic approach. The data collected was significant, as it has added new information to the body of knowledge on parent participation in Malawi and will influence current clinical practice.

CHAPTER 4

Findings

Introduction

This chapter presents the findings of the study. The broad objective of the study was to explore parents' participation in the care of their hospitalised children in a general paediatric ward. The main findings have been presented starting with the demographic characteristics of the participants followed by themes and subthemes. The following are the main themes: Perception of their own role in care, Parents' care roles, Parents' perspective of participation in care and Challenges to participation in care.

Demographic characteristics of participants

There were 23 parents that were interviewed in this study, with the majority being mothers (twenty one), and two fathers. All participants were from the general paediatric ward at the hospital. The age of parents ranged from 18 to 45 years. No one among the participants had a full time job, but were involved in a small scale business (nine), farming (eleven) and three were not involved in anything.

The number of siblings ranged from one, with the highest being nine. Among these families, three were divorced. Most of the parents had dropped school at primary level, and few at secondary school level. The minimum duration of stay in the ward was three days, with others staying up to more than a week depending on health condition the child was having. Twelve parents had more than one admission with the child since birth (Table 1).

Table 1. Demographic characteristics of participants

Variable	Number of participants
Age (years)	
16-24	1
25-35	19
≥35	3
Marital status	
Married	20
Divorced	3
Number of children	
1	4
2	5
≥3	14
Occupation	
Farming	11
Business	9
None	3
Relationship to child	
Father	2
Mother	21
Duration of stay in the ward	
2-5 days	10
≥5 days	13
No. of previous admissions	
0	11
1	8
≥2	4

Below, the themes have presented with their subthemes in a more detailed and elaborate way.

Perception of their own role in care

One subtheme emerged from the findings under this theme: unconditional responsibility

Unconditional responsibility

In this study, parents acknowledged that they had a role to play and that it was really necessary for them to be present and assist in the care of their sick children. This was because the children could not do it on their own, regardless of the sickness or the general condition. The parents felt that, being parents it was their responsibility to take care of the sick children and ensure their well-being. Some parents thought it is something that every parent should do when their child is sick. One participant, a mother, said;

“It is the responsibility of every mother to take care of her child. It cannot be possible for me to stay home and leave the care to someone...that will not give me a peace of mind” (Participant 5)

Parents’ care roles

This themes captures and illustrates real roles through which the parents participate in care of their hospitalised children. The following two subthemes emerged from the findings: physical care, and emotional care. The performance of these roles was either with external support or without.

Physical care

Parents indicated that they were there to provide basic care. This basic care ranged from bathing, feeding, giving medications, washing clothes for the sick child and turning the

sick child. The parents were ready to provide this type of care as it was almost similar to what they were doing when the child was not sick. This is illustrated by the following statement:

“My role is that of taking care of the child. Like bathing, feeding” (participant 15).

In addition to providing basic care, the parents were also monitoring the sick children. The parents were providing adequate monitoring of the children as the health workers rarely did it due to a shortage of staff. The parents were observing the child for any changes in condition and report accordingly to health workers on duty for urgent interventions.

“My role is taking care of the child, checking how he is fairing and the current problems and report” (participant 14).

“My role now that he is sick is that of taking care of him to get better. I need to rush to inform the doctor whenever I feel he is not feeling well, to get assistance for his comfort” (participant 13).

Furthermore, parents indicated that they were there to stay close to the sick child and provide security and protection to the children. The parents were there to protect the child from sustaining any form of injuries whilst in the ward since they thought the children were too young to care for themselves.

Emotional care

The parents were present to talk to the sick children and play with them to reduce anxiety and stress resulting from hospitalisation. Through this, the parents were able to provide emotional support, offer reassurance and assist the sick children cope with the situation and it strengthened their awareness of their children’s needs through increased bonding. Two parents had to explain this:

“My role is that of talking to the child so frequently so that he should not be anxious, while am also providing care such bathing, feeding even though the child is refusing” (participant 7).

“My role is that of showing love so that the child should know he is better. The love has increased than in the past. I am able to understand the pain he is in, everything am doing is for him” (participant 11).

Parents’ perspective of participation in care

Under this theme, there are three subthemes that are capturing the parents’ perspective of participation from different angles. The subthemes are: meaning of participation, reasons for participating in care, and role negotiation and communication.

Meaning of participation

Parents had difficulties in defining the term ‘participation in care’. However, several definitions emerged and these included; being there for the child, doing things that promote child wellness, the ability of the mother to take care of the sick child, and doing the actual care as advised or with the doctor.

Reasons for participating in care of their sick children

The parents had their own reasons for participating in care. The first reason is that of being a parent to the sick child. Parenting was associated with the participation in the care activities.

“Am participating in care because the child is mine. It is the responsibility of every mother to take care of her child...” (Participant 5)

Secondly, it was the desire to go home quickly. Parents felt their participation would contribute positively and facilitate the quick recovery of the children so that they could go

home quickly and resume their domestic activities which were disturbed because of the admission. In all these reasons, wishing to see the health and wellbeing of their sick children was at the heart of all parents that participated in the study.

“The reason is that I want the child to recover quickly, so that we go back home to resume our activities” (participant 14).

The third reason is that the parents did not have a choice as of whether to participate in the care or not because of the situation in the ward, shortage of staff. The parents were doing almost all the activities related to care of the sick children from the time of admission up to discharge.

“I just have to participate, as here the doctors have their own time to give medications and care, but the rest of the care is left to you as a parent to take care of the child. You agree to do everything for your child since he is sick” (Participant 5).

Role negotiation and Communication

The study findings showed that some parents were able to discuss the care of the sick child, as part of the negotiation of roles with the health worker. For these parents, the dialogue with health workers was an opportunity to discuss the care of the child. For the majority of parents, there was no discussion of care or negotiation of care roles during an encounter with a health worker during the course of care. The health workers were there to give instructions regarding care which parents should follow, thereby deciding the parents' roles.

“It's them who find us. They tell us what to do. Like, ‘This child has a new medication to apply three times a day’. So if I will not cooperate, it means I have failed to do the task I was assigned” (Participant 3).

This was a one way communication. During this one way communication also, general information was not being presented well in the ward. This resulted in parents missing some vital information which later created a bad impression about the parents.

“... We sometimes cannot hear properly and eventually we miss the information. This makes us look as reluctant people not following care properly and we do not want to be assisted” (participant 14).

Challenges to participation in care

The study findings also highlighted the parents’ challenges encountered in the course of participating in care. These limitation are presented under these two subthemes: doing things ignorantly and limited family support and needs.

Doing things ignorantly

Parents noted that they lacked guidance in relation to taking care of their sick children. This included how to feed the child in critical cases, how to lift the patient and other necessary measures needed during care, even though they were reluctant to approach the health workers for assistance. Some admitted having less basic skills in caring for a sick child. A huge responsibility related to care is put on the parents when the child is admitted, which causes stress on the parent. One mother and a father elaborated:

“My wife and I are still young and it’s our first time to be admitted... skills in care is a challenge. I cannot care him like home, the caring skill is lacking....I want to ask if there can be that chance to explain to us how to take care of a small baby because we are just doing it ignorantly” (Participant 11).

Limited family support and needs

Parents also cited lack of support from family. This was a challenge for parents who were not getting support or being visited by family members. Family members could not visit

due to long distances from home and lack of adequate finances for transport fare. This limited support from family members made the meeting of the child's needs and theirs difficult, creating stress in the parents. This was in addition to other sources of concerns such as disturbances in routines and activities, concerns over the care of other siblings left at home, and limited finances. Parents who had family members visiting them while in the wards were mainly from areas around the hospital.

"Since I came alone, it has been difficult. I have to leave him alone to do other things like cooking. Sometimes other people are assisting me with food to give the child, for me to be close" (participant 15).

"... Since I came here my relatives are not coming including the father of the child. Am trying to make his life comfortable, though am struggling....because absconding from the hospital because my relatives and husband are not coming is not possible. I will try till the day the doctors will instruct us to go home" (Participant 5).

In addition to limited support from family members, parents also indicated scarcity of basic resources to support their stay in the hospital as another challenge which affects their participation in care.

Conclusion

The chapter has presented findings of the study on parents' participation in the care of their hospitalized child. The findings have demonstrated that parents do participate in the care of their sick children and they know their roles. The various roles include providing physical care and providing emotional care. The parents had difficulties in explaining their understanding of participation in care, but several definitions were identified. There are challenges encountered during participation. These include limited support and guidance which leads to doing things ignorantly during care and lack of family support and needs.

CHAPTER 5

Discussion of findings

Introduction

This chapter presents a discussion of the findings of a study on parents' participation in the care of their hospitalised children in a general paediatric ward. The study aimed at exploring the parents' understanding of the concept of their participation in care, roles assumed and challenges faced. The discussion has been done under the following significant areas: Parents' roles in the care of their sick children, understanding participation in care, role negotiation and communication and challenges to parents' participation in care of their sick children.

Parents' roles in the care of their sick children

All children had a parent to take care of them regardless of the health condition and duration of hospitalisation. Staying with the sick children was of significance to the parents and they felt the need for them to be present and assist in the care of the sick children. In this study, parents were providing most of the care. The parents understood their role as that of providing care for the sick children through various roles. The roles performed by parents were either related to physical care and emotional care. These roles assumed by parents during hospitalisation of their children were not much different from the ones performed at home when the child was not sick. This was due to parental expectations and also due to the situation in the ward where the staffing levels are low. The performance of these roles by the parents was achieved with the support of family members, other parents in the ward and in limited cases, health workers.

Provision of basic care is a common phenomenon across many studies focused on parents' participation in the care of hospitalised children. The parents are comfortable with it and health workers (especially nurses and doctors) also are dependent on these parents to provide this basic care (Coyne, 2013; Hoffman et al., 2012). Parents, apart from the basic care provision which falls under physical care, were also administering medications and monitoring of the sick children in the ward. Their role of monitoring could be of benefit to the parents. It can alleviate the parents' own anxiety as they could witness their child's progress and current condition (Lam et al., 2006). Parents took this role as their sole responsibility, as the health workers were hardly performing it. Guardians to patients in a study by Hoffman et al. (2012), emphasised that it was their role and that without diligence their patients could have been going unobserved for a large portion of the day or many days. Further to that, in another study among Chinese parents (Lam et al., 2006), parents understood that nurses were busy and committed themselves to monitor vigilantly the sick child's progress. Other parents cited in that study to being the first to notice their child's problems such cyanosis, febrile convulsions.

Much as the parents' efforts in monitoring can be appreciated, there is a disadvantage to it. Most parents have limited knowledge in recognising danger signs and early signs of complications (Al-Ayed, 2010). This is compounded by lack of supervision and limited interaction that occurs between parents, which later also affects decision making and compliance to treatment (Majamanda, Munkhondya, Simbota, & Chikalipo, 2015).

Understanding participation in care

Taking care of the sick child is part of a social responsibility that goes together with being a parent within the society. The performance of various roles in the care of their sick children strongly suggests that parents participate in the care of their hospitalised children. However, the findings have revealed that parents have difficulties in defining the term

‘participation in care’, but they were able to explain daily activities and responsibilities they were performing to assist their sick children. Several meanings of participating in care were revealed. These meanings included being there for the child, doing things that promote child wellness, the ability of the mother to take care of the sick child, and doing the actual care as advised or with the doctor. The definitions are similar to what Pongjaturawit et al. (2006) described as how Thai parents understood parental participation in care. The Thai parents’ definitions included; continuing home practices, learning new things in hospital and working together with health workers taking care of the child. This is suggestive that the understanding of the parents in relation to participation is almost the same regardless of the continental boundaries, socioeconomic status and culture.

Participation in care through the various roles was due to various reasons. Parents participated mainly because of being a parent to the sick children, and the wish for the sick children to get better and the desire to go home. It was the wish of the parents to see their children get better and were reluctant to leave the children alone unattended to. Parents felt their participation will contribute positively and facilitate a quick recovery, so that they can go home and resume their stalled social and economic activities.

The participation of these parents was not a choice. Being a parent was strongly associated with caring of a child, sick or healthy. Parents emphasised on the link between being a parent and caring for the children. This was also noted among Thai parents, who similarly had no choice but to participate and play a role in the care of their hospitalised children because of society's expectations (Pongjaturawit et al., 2006). Thai parents were there to do anything for the sick child. Soderback and Christensson (2008) in a cross-sectional study involving family care givers in a paediatric clinic at a central hospital in Maputo, made a similar observation. Parents did not have a choice but to participate in care, though they did not want to be involved in frightening procedures and decision making. They preferred to leave that to the

professionals. This Mozambican study was aimed at articulating Mozambican family caregivers' expressed needs, expectations and experiences.

Contrary to the observation that parents were not participating in care by choice (Pongjaturawit et al., 2006; Soderback & Christensson, 2008), Lam et al. (2006) in a study involving Chinese parents in four paediatric wards of a regional acute general hospital in New Territories, Hong Kong, made a different observation. The study was designed to explore Chinese parents' experiences of their participation in taking care of their hospitalised child. The authors observed that Chinese parents were choosing to participate and they could leave the rest of the care to the nurses.

In this study, it was also not possible for the parents to just leave the sick children in the hospital to the nurses, because of social responsibility attached to parenthood and limited support from family members. Parents felt that there was always a need for them to be present and take care of the sick children, and leaving the sick children to someone for care was not a better option. It was necessary, though for someone to be present to relieve the mothers temporarily for them to rest and address their physical needs. Presence of extended family members prevents exhaustion as they take turns in managing the patient (Majamanda et al., 2015). For resource limited contexts, situations like shortage of staff and a heavy workload can further limit parent choices of participation (Soderback & Christensson, 2007).

Role negotiation and communication

In this study, parents had already assumed the role of caring for the sick child as their responsibility. Their discussion with the health worker, for the majority of parents, could not be easily regarded as a process of negotiating care, rather a dialogue for receiving instructions. The health worker delivers the instructions for the parents to follow with minimal room for discussion on issues that are of significance to the parents. Given the fact

that parents were performing almost all the roles, it was important that the health workers should discuss the care with parents. As observed in other studies (Corlett & Twycross, 2006), discussion of roles and the demarcation of care activities for the majority of parents is minimal. Negotiation of roles has often been a source of conflict mainly between parents and health workers in the clinical setting (Corlett & Twycross, 2006). Findings from a study by Shields, Pratt and Hunter (2006), as they were reviewing qualitative studies on use of family centred care in children's hospital demonstrated that parents felt imposed when an assumption was used that they would do basic care on their children while in hospital without discussing it with them first.

The lack of negotiation in this Malawian context could be explained by the shortage of staff in the wards mostly, leading to less availability of time for proper interaction and communication with the parents (Hoffman et al., 2012) and also due to lack of initiative by the parents to ask the health workers (Israëls, Chirambo, Caron, de Kraker, Molyneux and Reis 2008). It is also possible that there were no negotiations of care because the parents were already performing all the tasks related to the care of the sick children, hence making the health worker to have nothing to bargain with during negotiations.

Shortage of staff is a chronic problem crippling the health sector in Malawi. Most facilities have few health workers across all cadres (Bradley et al., 2015). The country is in dire need of health personnel and recruiting trained staff remains a challenge. The country's shortage of health sector staff has led to low capacity to meet a minimal level of health care. A part from the low numbers, uneven distribution of the available staff between urban and rural areas is another big challenge (Bradley et al., 2015).

This situation has limited parents' choices in care, role negotiation, leading to most tasks being shifted to parents in the wards as the health workers cannot cope with the work load. In a study by Hoffman (2012) done at Kamuzu Central Hospital, Malawi, with an aim of

exploring the roles and also characterising the patient guardian population in the health system at the hospital, made a similar important observation. They observed that due to a nurse and physician shortage, more tasks were shifted to the guardians of the patients. The results of that study further revealed that most guardians were the ones providing a wide range of daily tasks for the patient and conflict was often arising from lack of understanding of hospital rules, lack of recognition for the role of the guardian. In addition to the observation that tasks are being shifted to parents, Aeni et al., (2009) in Iran earlier, observed that these trends of shifting care responsibilities were slowly turning parents into trainee nurses as direct child care responsibilities were being shifted from staff to the parents. Parents in that study complained of informal delegation of care without sufficient and planned parental training on how to perform medical tasks.

Parents' participation in some aspects of care is important, but what causes concern in this Malawian context is the nature of tasks being left to parents of the sick children to perform. As observed at the study site and most hospital paediatric settings in Malawi, dependence on parents is high, and that these parents are not well prepared psychologically and are not provided with the necessary material resources to use during care provision (Hoffman et al. 2012). This puts the life of the patients at risk of adverse events from preventable errors and acts of omission. Complications from errors in medical care are already on the increase. In the United States of America (USA), a study pointed to medical errors as being the third leading cause of death (www.npr.org). Another study involving review of records from six paediatric hospitals in the USA indicated that forty percent of admitted children were exposed to harmful events from medical errors (McCann, 2015). These alarming levels of errors are made by trained professionals. The situation in Malawi might be more alarming as the care is mostly provided by the parents, unfortunately such errors and their complications are hardly reported (as observed from the study site), and dearth of literature.

It was observed during the study that parents were made to participate with the aim of reducing the workload for the health workers. This was also noted by Phiri (2015) in his study involving registered nurses at QECH, in which he was exploring their experiences on family involvement. This situation is similar in most facilities in Malawi. It is surprising to note however, that when the work load is lighter in the hospital setting, the health workers do not assume the assigned tasks back, contrary to the initial reason for involving parents in care. This is strongly suggestive that currently the use of parents is no longer a temporary measure to alleviate workload. The shifting of tasks to parents has led to over involvement of parents in care and has also created over dependency in clinical setting. This trend has to be monitored and regulated, as it is a threat to nursing practice and efforts to improve quality of care.

Communication between health workers and parents is so significant in care of the sick children. It is highly accepted that parents lose their normal parenting roles during admission and often parental anxiety and uncertainty is present which can significantly reduce further the confidence of the parents to negotiate care. It is important that the health workers communicate with the parents and sick children to clarify roles and expectations during the course of admission. The lack of skills to negotiate, lack of initiative to seek assistance and clarification in the process of care delivery, are somehow suggestive of lack of empowerment. Empowerment allows parents to assume a sense of control over their affairs. Imparting knowledge and creating opportunities helps the parents to make informed choices. There is an increase in percentage of women involved in decision making about their health, from 55% in 2010 to 68% in 2015-2016 period (National Statistical Office, 2017). Similar trends in empowerment levels are strongly desirable in the clinical setting, for the women to be involved in decision making about their sick children, since they form majority of the parents that stay with the sick children during hospitalisation.

Challenges to parents' participation in the care of their sick children

Parents outlined challenges encountered during care of their hospitalised children in the general paediatric ward. Lack of support for parents from relatives was a common challenge as the patients are referred from very distant health facilities, which are situated in the rural areas, away from their homes. Health facilities in the district are far from the central hospital. The commonly used means of transport during referrals are government ambulances, which usually accommodate the sick child and the parent, as there are usually many patients to be referred from the health centres. This situation further limits the amount of resources that they can use during the hospitalisation period, which often they are uncertain of. Other relatives have to find their own means of transport if they wish to accompany the sick child. In reality, due to socio-economic challenges they cannot manage to follow the pair to the central hospital, leaving the mother with the sick child without adequate support. This was building pressure as the mothers had to take care of the needs of the sick children and also theirs. Malawi is one of the poorest countries in the world with 50.7 percent of the population living below the poverty line and 25 percent living in extreme poverty. The majority of these poor people live in the rural areas (International Monetary Fund, 2017).

Parents were also concerned with limited support and guidance in care provision from health workers. They admitted having shortfalls in caring skills and were doing things ignorantly. Despite having the task of keeping children healthy and caring for them during illness, most parents have little formal education for health care of children (Vivian, Nielsen, Heims, & Frances, 2010). However, it is surprising that most parents in this study were not forthcoming to seek that assistance from the nurses in the ward, for reasons not known. Israëls et al. (2008) in a study conducted at Queen Elizabeth Central Hospital (QECH) among guardians of cancer patients in the paediatric ward, found that parents in Malawi had fear and shyness which contributed to parents not seeking more information regarding prognosis and

medical procedures being done on their children. This limited their ability to participate in the decision making process. This study was done to explore guardians' perspective of cancer treatment and factors that affect adherence to treatment following a background of abandonment of paediatric cancer patients in many developing countries.

Lam et al. (2006) had found an explanation for a similar observation in their study. Parents often avoided taking initiative to seek help because they perceived nurses to be too busy to be approached.

Generally, staying with the sick children in hospital, though it seems natural for parents, creates practical problems in the household (Soderback & Christensson, 2008), and necessitates the need for extra support. This limited support from family members made the meeting of the child's needs and theirs difficult, creating stress in the parents. Leaving the care of the sick child to one parent is stressful and exhaustive. Stress and exhaustion come from inadequate rest and other unmet physical needs, anxiety arising from the severity of the child's illness and the overall strange hospital environment. This is an important aspect that needs the health worker's attention as it may affect the type of care the child can receive, nature of mother child interaction, treatment compliance, thereby affecting care outcomes.

Recommendations

From the study findings, recommendations have been drawn for the following areas: clinical practice, clinical research and nursing education.

Clinical practice

With the evidence from these findings, the paediatric department should develop and pilot policies and guidelines for management of parent participation in the paediatric wards. The management of Zomba Central Hospital should support and facilitate the process. These guidelines should be available and accessible to parents and health workers in the paediatric ward. The guidelines should also have a focus on giving information that empowers the parents in the care of their sick child. This information may include common hospital regulations, schedules to ward routines and links to support groups or organisations. These guidelines may bring consistency to clinical practice, simplify processes, resulting in improved practice standards and care outcomes.

Clinical research

This study has demonstrated that parents do participate in the care of their sick children during their child's hospitalisation. However, some areas still need to be pursued further through research. These areas include: needs of the parents during a child's hospitalisation, factors that hinder parents from seeking relevant information from health workers in the clinical area, levels of participation which parents wish, the nature of support parents need during their child's hospitalisation.

Nursing education

The study findings have brought evidence on parent's participation in the care of their hospitalised children, which can be used to teach nursing students on how best to embrace the parents' participation and include the parents in care.

Conclusion

Parents participate in the care of their hospitalised children through various roles and it is a social responsibility that goes together with being a parent, but they are over involved. They perform nursing roles without being involved in the planning of care. As the findings suggest, parents have difficulties in defining the term ‘participation in care’. Parents’ participation in care is not without challenges. It is marred by lack of opportunities to discuss care roles, pressure from stalled economic activities and social responsibilities and limited support from health workers.

The positive attitude, dedication and commitment the parents have is something that the health workers need to embrace if the care outcomes of the sick children admitted in the ward are to improve. The implementation of family centred care principles, formulation of guidelines for parental participation and valuing the presence of the parent in care can assist in limiting the challenges highlighted by the study findings.

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Appendices

Appendix 1: Interview guide

Code Number: _____

Name of interviewer: _____

Date of interview: _____

SECTION A: Demographic data

I am going to ask for information about yourself

1. Age
2. What is your marital status?
 - a. Married []
 - b. Single []
 - c. Divorced []
 - d. Other (specify).....
3. How far did you go with your education?
 - a. Tertiary []
 - b. Secondary []
 - c. Primary []
 - d. Did not attend school []
4. How many children do you have []
5. What type of work do you do? _____
6. How related are you to the child?
 - a. Mother []
 - b. Father []
7. How long have you been in this ward? []

8. How many times have you been admitted to a hospital before? []

SECTION B: Understanding roles in participation

9. What are your roles as a parent?

SECTION C: Negotiation of roles

10. How do you negotiate the roles?

SECTION D: Participation in care

11. What is your understanding of the term participation in care?

SECTION E: Challenges during participation in care

12. What challenges are you encountering during participation in care?

Thank you for taking part

Appendix 2: Client information

Study Title: EXPLORING PARENTS' PARTICIPATION IN THE CARE OF THEIR
HOSPITALISED CHILD IN A GENERAL PAEDIATRIC WARD AT
ZOMBA CENTRAL HOSPITAL

SECTION A: Study information

My name is George Yotam Nsitu and I am a student at Kamuzu College of Nursing, currently pursuing a Master of Science Degree in Child Health Nursing. As a requirement for the completion of my program, I am conducting a research titled "Exploring parents' participation in the care of their hospitalised child in a general paediatric ward at Zomba Central Hospital". This letter seeks to ask you to take part in this study, which aims to add voice to parents' perspective on participation during their child's hospitalisation period.

Section B: Participant's information

It is important for you to note, firstly, that your participation in this study is completely voluntary, and should you at any point in time feel that you cannot continue participating, please be free to do so and there shall be no any consequence that will follow. Secondly, there will be no financial benefits from participating in this study, however your participation is highly valued as the information you shall give shall help in improving clinical practice. In this study, no risks have been anticipated.

This study has been approved by the College of Medicine Research and Ethic Committee (COMREC), which is responsible protection of subjects, and the hospital management of Zomba Central Hospital.

But, if you would like to know more information or you have any concerns that need to be clarified about the study, please contact

Physical Address: University of Malawi College of Medicine

Mahatma Ghandi Campus

Postgraduate Room Ground Floor

Room 822.

Postal Address: College of Medicine Ethics Review Committee

P/Bag 360,

Chichiri,

Blantyre 3.

Email address: comrec@medcol.mw

The Study Investigator: Mr George Yotam Nsitu

Kamuzu College of Nursing

P.O. Box 415, Blantyre.

Email address: nsituphiri@gmail.com Phone: 0995422780

Appendix 3: Informed consent for participants

PLEASE READ AND SIGN THE FORM IF YOU ARE TAKING PART IN THIS STUDY

I _____ (Name/ Thumb print) voluntarily give consent to participate in this study. I have read or have had someone read the contents of the information letter to me and I have fully understood. I have understood that the information I will give will only be used for purposes of research by the researcher and the people directly concerned with the research.

Participants Signature: _____ Date: _____

Researchers Signature: _____ Date: _____

For more information you can contact:

The Chairperson

College of Medicine Ethics Review Committee

P/Bag 360,

Chichiri,

Blantyre 3.

Physical Address:

University of Malawi College of Medicine

Mahatma Ghandi Campus

Postgraduate Room Ground Floor

Room 822.

Email address: comrec@medcol.mw

Appendix 4: Chichewa version of the interview guide

Mlozo wa mafunso a kafukufuku

Nambala ya chinsinsi:_____

Dzina la ofunsa mafunso:_____

Tsiku:_____

Gawo A: Mbili yanu

Ndikufunsani mafunso okhudzana mbili yanu

1. Muli ndi zaka zingati? []
2. Muli pa banja?
 - a. Okwatiwa []
 - b. Osakwatiwa []
 - c. Tinasiyana []
 - d. Zina (fotokozani).....
3. Mudapita patali bwanji ndi maphunziro?
 - a. Koleji []
 - b. Sekondale []
 - c. Pulaimale []
 - d. Sindinapiteko ku sukulu []
4. Muli ndi ana angati? []
5. Tchulani ntchito yomwe mumagwira.....
6. Inu ndi ndani ake a mwanayu? a. Bambo [] b. mayi []
7. Mwakhala nthawi yaitali bwanji muno mu wodi?.....
8. Munayamba mwagonekedwapo ndi mwana mchipatala?.....

Gawo B: Ntchito yanu pa chisamaliro

9. Kodi ntchito yanu ndiyotani ngati kholo la mwanayu?

Gawo C: Kukambirana za ntchito yoti mugwire pa chisamaliro

10. Mukumakambirana bwanji pa ntchito zoti mugwire muno mu wodi?

Gawo D: Kutengapo gawo pa chisamaliro cha mwana amene akudwala

11. Maganizo anu ndi otani pa zakutengapo gawo pa chisamaliro cha mwana pamene wadwala?

Gawo E: Mavuto amene mukukumana nawo pamene mukutengapo gawo pa chisamaliro cha mwana wodwala

12. Ndi mavuto anji amene mukukumana nawo pamene mukutengapo gawo pa chisamaliro cha mwana wodwalayu?

Zikomo kwambiri potenga gawo mkafukufukuyu

Appendix 5: Chichewa version for participant information

Kalata yofotokoza kafukufuku

Gawo A: Kufotokoza kafukufuku

Ine dzina langa ndi George Yotam Nsitu ophunzira wa pa sukulu ya ukachenjede ya Kamuzu, imene imaphunzitsa anamwino ndi azamba muno mmalawi. Ndili mu chaka chomaliza cha maphunziro anga ozama okhudza umoyo wa ana (Master's Degree in Child Health Nursing). Ngati gawo lina la maphuzirowa, ndikuchita kafukufuku yemwe ndi “Kutengapo gawo kwa makolo pa chisamaliro cha mwana pamene wadwala mchipatala”. Kafukufukuyu akufuna kuunika mozama pa nkhani ya kutengapo gawo pa chisamaliro chamwana pamene wadwala ndipo ali mchipatala kudzera mu liwu la kholo. Cholinga cha kalatayi ndi kufuna kukupemphani kuti mutengapo mbali pa kafukufuku amaneyi.

Gawo B: Zoyenera kuti mudziwe

Mukudziwitsidwa kuti kutengapo mbali pa kafukufuku amaneyu sikokakamiza ayi, ndipo muli ndi ufulu osiya panthawi ina iliyonse ngakhale mutalowa kale popanda zovuta zili zonse. Dziwaninso kuti simudzalandira mphatso ya mtundu wina uliwonse chifukwa chotenga mbali pa kafukufuku ameneyi.

Kafukufuku ameneyi wavomelezedwa ndi komiti yoteteza anthu amene akutenga nawo gawo mu kafukufuku (COMREC), komanso mkulu oyendetsa chipatala chachikulu chino cha Zomba.

Ngati muli ndi mafunso kapena nkhwawa mutha kufunsa zambiri ku malo kapena anthu awa:

Komwe amapezeka: University of Malawi College of Medicine

Mahatma Ghandi Campus

Postgraduate Room Ground Floor

Room 822.

Keyala yawo: College of Medicine Ethics Review Committee

P/Bag 360,

Chichiri,

Blantyre 3.

Email: comrec@medcol.mw

Kapena

Mwini kafukufuku: Mr George Yotam Nsitu

Kamuzu College of Nursing

P.O. Box 415, Blantyre.

Email address: nsituphiri@gmail.com Phone: 0995422780

Appendix 6: Informed consent (Chichewa version)

Kalata yovomeleza kulowa mu kafukufuku

CHONDE WERENGANI NDI KUSAYINILA KALATAYI NGATI MWAVOMERA KULOWA MU KAFUKUFUKU

Ine _____ (dzina kapena chidindo cha chala) ndavomeleza kulowa mu kafukufuku. Ndawelenga/munthu wandiwerengela ndipo ndamvetsetsa zonse zokhudza kafukufukuyu. Ndamvetsetsanso kuti zimene ndipereke mkafukufukuyu zidzagwiritsidwa ntchito yokhayo yogwirizana ndi kafukufukuyu ndi anthu amene akupanga.

Posayinila otenga mbali _____ Tsiku _____

Posayinila mwini kafukufuku _____ Tsiku: _____

Ngati mungafune kudziwa zambiri, mutha kufunsa Kwa:

Wapampando

College of Medicine Ethics Review Committee

P/Bag 360,

Chichiri,

Blantyre 3

Nambala ya foni: +265 187 4377

Komwe amapezeka:

University of Malawi College of Medicine

Mahatma Ghandi Campus

Postgraduate Room Ground Floor

Room 822.

Email address: comrec@medcol.mw

Appendix 7: COMREC Approval Certificate



CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

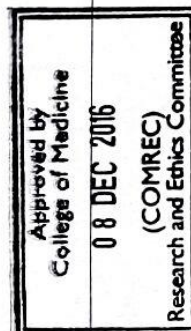
P.11/16/2056 – Parents' participation in the care of their hospitalized child in a general paediatric ward at Zomba Central Hospital by Mr. G. Nsitu

On 8th December 2016

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

A handwritten signature in black ink, likely belonging to Dr. C. Dzamalala.

Dr. C. Dzamalala- Chairperson (COMREC)



8th December, 2016

Date

Appendix 8: Letter of permission from Zomba Central Hospital

Telephone No.: 01 526266/01525195

Telefax No.: (265) 1 524 538

Telex No.:

E-Mail: medzch@malawi.net

Please address correspondence to:
The Hospital Director



MINISTRY OF HEALTH
ZOMBA CENTRAL HOSPITAL
P.O BOX 21
ZOMBA
MALAWI

29th September, 2016

GEORGE NSITU,
ZOMBA CENTRAL HOSPITAL,
P.O. BOX 21,
ZOMBA.

Dear Sir,

RE: AUTHORITY TO CONDUCT STUDY AT ZOMBA CENTRAL HOSPITAL

Reference is made to your request to carry out a Study titled: " **Parents participation in the care of their hospitalized child in a general paediatric ward at Zomba Central Hospital**". We wish to convey management's approval for study.

You are therefore requested to adhere to all study ethical considerations and to seek permission from the Hospital Director prior to publication.

I wish you all the best in your study.

Yours faithfully,

A. Kamanga

**THE PRINCIPAL HOSPITAL ADMINISTRATOR
FOR: THE HOSPITAL DIRECTOR**

