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# Caregivers' Experiences and Needs During Participation in Care of their

Hospitalised Children at a Tertiary Government Hospital in Blantyre, Malawi-A

**Preliminary Qualitative Exploratory Study** 

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# Original Research Article

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**Abstract:** Parental participation is one of the cornerstones of pediatric practice. Queen Elizabeth Central Hospital (QECH) is the major referral hospital in Malawi and caregivers stay with their children in the hospital and participate in the care. However, little was known about the perception of these caregivers regarding their participation in care of their hospitalised children. The aim of the study was to explore caregivers' perceptions regarding parental participation in the care of their hospitalised child. A descriptive qualitative study was done using semi structured interview guide to collect data from 20 caregivers in the pediatric department. Thematic analysis was done guided by Collaizzi method. Seven main themes emerged from the data and these were lack of role negotiation by health care workers, inadequate role preparation for caregivers, perception of caregivers on care they provided to their hospitalised children, poor HCWs- caregivers' communication, benefits of caregivers' participation in care of hospitalised children, needs of caregivers participating in care of hospitalised children and overall impression of caregiver's participation. The study findings showed that caregivers view their participation in the care of hospitalised children as appropriate, important and satisfying. However, gaps exist in the way caregivers participate in the care of their hospitalised children due to inadequate role negotiation, role preparation for caregivers and inadequate information for caregivers. The researcher recommends that management should develop protocols and guidelines for the implementation of parental participation in care of hospitalised children to promote best practices.

Keywords: Parental participation, Caregivers, Experiences, Needs, Hospitalised Children Care.

# INTRODUCTION AND BACKGROUND OF THE **STUDY**

Parental participation (PP) in care of hospitalized children has become one of the cornerstones of pediatric nursing practice [1]. It is viewed in terms of partnership between health care professionals and caregivers in the care of children in hospital setting [2]. Parental participation is one of the core concepts of family centered care (FCC) which forms the framework for pediatric nursing care. As such allowing caregivers to participate in care activities alleviate anxiety for both caregivers and children, promotes the emotional welfare of children and caregivers experience the continuity of parental role and enhanced coping skills [3]. In addition, competence of the caregiver in dealing with the child illness is strengthened and caregivers experience continuity in their role as care giver [2]. However, some HCWs find it difficult to integrate caregivers in the care process.

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Studies have shown that caregivers often experience inadequate information leading to feeling of anxiety, loneliness and lack of support [4]. Caregivers involved in the care of hospitalised child require negotiation of caring roles. Literature has shown that parental participation is based on the assumption that all caregivers are willing to participate in care of their hospitalised children [5, 6]. However, in order for PP to be effective, it depends on caregiver's preparedness to participate in care and HCWs can communicate and negotiate the caring roles for the hospitalised children [7, 1]. In Malawi, caregivers stay with their children in the hospital. However, observations showed that they knew little about their children's treatment plan and This study aimed at describing disease condition.

Copyright @ 2018: This is an open-access article distributed under the terms of the Creative Commons Attribution license which permits unrestricted use, distribution, and reproduction in any medium for non commercial use (NonCommercial, or CC-BY-NC) provided the original author and source experiences and needs of caregivers and how information is shared between HCWs and caregivers in care of hospitalised children at a tertiary hospital in Malawi.

### Significance of the study

The study findings may influence policy makers to formulate policies and guidelines on parental involvement in child health care in Malawi. Secondly, the findings may provide knowledge and understanding that can guide the implementation of parental involvement in care of hospitalised children. Thirdly, the study findings may serve as a basis for future research.

#### STUDY OBJECTIVES

The specific objectives were to describe how information is shared between HCWs and caregivers in care of hospitalised children and secondly, to explore experiences and views of caregivers towards their participation in the care of hospitalised children at a tertiary government hospital in Malawi.

# LITERATURE REVIEW

Parental participation is seen as most critical in care of hospitalised children. Parents view their children's' hospitalisation as most critical event regardless of the child condition and period of hospital stay [8]. Researchers have described how caregivers participate in care of their hospitalised children [6]. Roden [9] reported that mothers felt that their role was to do the mothering tasks. Similarly, Tourigny *et al.*, [10] found that in Canada, parents' activities largely consisted of basic mothering tasks like bathing, feeding, changing them when soiled leaving more technical tasks to nurses. Mothers viewed technical care as solely the responsibility of the HCWs. This is because HCWs have knowledge and expertise from their training [6].

# Communication between HCW and caregivers during parental participation

Communication is crucial to effective parental participation in care of patients in the hospital. Hoffman et al., [11] found that presence and participation of parents in the care provided to hospitalised children enabled them to draw closer to HCWs, a situation in which communication was the key. Evidence shows that when communication between HCWs and caregivers is good, caregivers experience less anxiety and become more involved. Conversely, poor communication had been a common theme in many studies [11, 12]. Roden [9] in a study involvement of parents and nurses in the care of acutely ill children in non-specialist paediatric setting reported that mothers were not happy with hospital doctors communication which was attributed to talking down to the mothers and not providing adequate information. Further to this the nurses were insensitive, unsympathetic and rude to

them. This led to mothers feeling as being nuisance. Similarly, Lam et al., [2] found that there were a few HCWs who were perceived as rude. Literature also shows that parents lack adequate information about their child condition, treatment plan and what to expect [3, 13]. Soderback and Christenson [12] reported that parents were unable to participate effectively due to inadequate information or unsatisfactory communication. Similarly, Pongjaturawit and Harrigan [14] found that caregivers lacked information especially related to child condition, treatment and care needs. Studies have shown that parents need information about their children illnesses, treatment plan on going basis [15]. It can be argued that parents need for information and detailed instruction is paramount.

# Views of caregivers regarding their participation in care of hospitalised children

Studies have confirmed that parents desire to participate in care of their hospitalised children. Parents felt the need to be with their children in the hospital because of the concern for the child's welfare [3]. Literature has shown that parents feel that their participation in child's care is very important and beneficial to the child, to HCWs and to themselves [8, 16]. As such sharing that expertise with the HCWs is an important parental role. Thus, without parental participation HCWs may not be able to deliver custom made care that truly makes a difference. Although most studies show positive views on parental participation, some literature shows that parents have negative attitude towards parental participation in care of hospitalised children. Power and Franck [1] found that parents felt unhappy when they thought that nurses expected them to participate in the painful procedures without their choice and adequate information.

In summary, literature has shown that parental participation is considered a practice by the caregivers. Parents' views on parental participation seem to be positive in most of the studies. Parents feel compelled to be with their children at the hospital because children want their parents near them. In addition, parents feel that their presence as means of providing comfort to the child. Conversely there were other studies in which caregivers had feelings of stress, anxiety and afraid of making mistakes as they were providing the care. Literature showed that communication and perceptual problems exist in parental participation. However, this is specific and depends on the settings.

# Study design and setting

This study used descriptive qualitative design to explore perceptions of caregivers on parental participation in care of hospitalised children. The study was done at Queen Elizabeth Central Hospital, a tertiary government referral hospital in Southern Malawi. The setting has specialized pediatric services. The setting

was chosen because it is a place where children with complicated conditions are admitted and they stay in the hospital for more than one day.

# Study population sampling method

The target population in this study was all caregivers who were taking care of children admitted to all sections of pediatric department to have a broader understanding of caregivers' perceptions regarding their participation in care of hospitalised children. Purposive sampling was used to recruit participants for this study based on the inclusion criteria. The participants were selected because they were knowledgeable and had experience of the phenomena under study.

### Sample Size

Twenty caregivers were recruited and interviewed. Holloway and Wheeler [17] indicate that in qualitative studies a sample of ten or less is adequate especially when the researcher is using homogenous participants. Nevertheless, the sample may increase or decrease depending on data saturation. In this study, data saturation was reached during an interview with  $20^{\rm th}$  participant.

#### **Inclusion Criteria**

The study included the caregivers who spent more than 48 hours in the hospital with the child and the child condition was stable and the participants volunteering to participate in the study and who were able to communicate in Chichewa which is the national local language in Malawi.

#### **Data collection methods**

Data was collected using face to face in-depth interviews with the aid of a semi structured interview guide. The interview guide contained demographic information and qualitative information guided by the study objectives. The interview guide sought information on how the caring roles were negotiated between the HCWs and caregivers and how the caregivers were prepared for their role. Data was tape recorded using the voice recorder. Each interview took 45 minutes.

#### Data analysis

Demographic data were analysed using descriptive statistics. Qualitative data were analysed using Collaizi method of analyzing data. Collaizi method [18] has seven steps which are reviewing the data, extracting significant statements, spelling out of the meaning of each significant statement, organizing the formulated meanings into the cluster of themes, integrating results into an exhaustive description of the phenomenon under study, extraction of fundamental structures and member checking.

#### Trustworthiness of data

Trustworthiness was measured by adhering to credibility, dependability, confirmability and transferability as standards for measuring trustworthiness. Additionally, the researcher has provided sufficient descriptive information of the participants and their perception to reflect what is happening on the ground.

### **Ethical Consideration**

The researchers ensured that participants' human rights were respected throughout the research process: the right to self-determination, anonymity, privacy, confidentiality and protection from harm. The research protocol was approved by College of Medicine Research and Ethics Committee (COMREC). Permission to conduct a study at pediatric department was obtained from hospital director. The consent was obtained from each participant.

#### **FINDINGS**

# Demographic characteristics of participants

The table shows that most of the caregivers were female with the age ranging from 21 to 43 years. Table-1 presents demographic information of 20 caregivers who participated in this study.

### **Qualitative findings**

The qualitative data were analysed using thematic content analysis (TCA) which was guided by Colaizzi method and the main themes that emerged were:

- Poor HCWs-Caregivers communication,
- Needs of caregivers participating in care of hospitalised children
- Impression of caregivers towards their participation in care of hospitalised children.

## **HCW-Caregivers communication**

Under this theme, three sub themes emerged namely: Mode of communication, inadequate information from HCWs and manner of communication.

# **Mode of communication**

Majority of respondents (n=19) indicated that communication was largely verbal and was done in Chichewa. Some caregivers needed written information concerning their children illnesses but were not available. One participant said:

When they want to give us information they do explain to us. They have never given us any written materials on disease conditions so that we can read. This would have helped us to understand what is happening to our children that because sometimes when we are seeing them face to face we fail to ask them questions because we are shy or they are in a hurry (Participant # 6).

**Table-1: Demographic characteristics of participants** 

Characteristic	n	% (n/N)
Age in Years		
20-24	4	20.00
25-29	6	30.00
30-34	3	15.00
35-39	4	20.00
40-44	3	<u>15.00</u>
Total	20	100.00
Gender		
Male	3	30.00
Female	<u>17</u>	70.00
Total	20	100.00
Level of Education		
None	1	5.00
Primary	8	40.00
Secondary Education	10	50.00
College Education	<u>1</u>	<u>5.00</u>
Total	20	100.00
Relationship to the sick child		
Mother	16	80.00
Father	3	15.00
Aunt	<u>1</u>	<u>5.00</u>
Total	20	100.00
Religion		
Christian	19	95.00
Moslem	1	5.00
Total	20	100.00

### **Inadequate information from HCWs**

Two categories emerged from this subtheme namely: Incomplete information about child diagnosis and incomplete information about child treatment plan.

# Incomplete information about child diagnosis

The majority (n=17) of the participants reported that they were given incomplete information about their children's illness. They were told by the HCW diagnosis of the child but the HCWs did not explain to them what it was, the cause of the illness and the possible complications. For example, one participant said "I was told that the child has cancer but they did not explain to me what cancer is" (Participant # 3).

A few participants (n=3) complained that they were never told about their children's diagnosis. One participant said: "We did not discuss my child's illness because when they come they do not spend much time. They do ward round and do things in a hurry so that they should also see other patients" (Participant # 6).

# Incomplete information about the child treatment plan

All participants (n=20) reported that they received incomplete information about their children treatment. One participant said:

I was not told the names of drugs that the child is on, the times for the medication. I go every time the nurse is calling caregivers to receive their children's medication only to be told that the child has no medication at that particular time and that will receive medication at another time (Participant # 10).

The only exception was for caregivers from oncology department who were told the frequency, duration and side effects. One participant said:

I was told that the child will be receiving the medication. They did not tell me the names but they said that will be taking three times a day another one five times and will take them for the whole year. They said that the medication that the child is taking are very powerful and the child may fall very sick, may develop alopecia and these are the things that are happening to my child. That is all but they did not tell me what to do

if the child develops this. I hope I should be coming to the hospital (Participant # 2).

# Manner of communication by HCWs

Three categories emerged under this subtheme. These were: appropriate communication, inappropriate communication and communication without privacy.

# **Appropriate communication**

The majority of participants (n=13) said that some HCWs talked to them calmly, nicely with respect. They said that these HCWs did not shout at them. One participant said:

"These "nurses" or the "doctors" were not insulting. HCWs talked to us peacefully and calmly realizing that they are talking to other human beings" (Participant # 12).

# **Inappropriate communication**

The other participants (n=7) said that there were some HCWs who talked to caregivers inappropriately. These HCWs were insulting such that when the caregivers had made a mistake they shouted at them. In addition these HCWs talked rudely to caregivers which made the caregivers to fear them. "He said:

I was called a mad man who does not think properly by the nurse. She was shouting that everyone heard her. This made me to feel shy because she was talking in front of many caregivers both male and female" (Participant # 9).

Nevertheless, one participant tried to justify why HCWs shouted at them. She said these HCWs only shouted when they saw that there was a problem. She said this:

Other HCWs do shout yes but one cannot just shout without any problem. If one does not understand what they are saying you can see them as if they are shouting because some are difficult. If you don't understand what they are saying when they tell you to give the child medication at such a time and you give at your own time, when they call you to receive medication you are not going at that time you see them as difficult and bad if they shout at you (Participant # 19).

# **Communication without privacy**

Almost all the participants (n=19) indicated that the HCWs communicated information to them during ward rounds at the bed side where there was no privacy. They said that at times caregivers failed to ask questions because they did not want other caregivers to know their problem. One participant said: "a doctor explained to me concerning my child after they had examined him but there was no privacy. He was just

explaining to me about what they had found on the child" (Participant # 1).

# Benefits of caregivers participating in the care of hospitalised children

Five subthemes emerged under this theme. These were: caregiver's knowledge of child condition, meeting the medical and physical needs of the child, meeting psychosocial needs of the child, relieving the HCWs of their tasks and provision of information to the HCWs.

# Caregiver's knowledge of child's condition

A few participants (n=4) indicated that when they participated in the care, they knew their child illness better although it was not detailed except for those who had asked the HCWs for details. One participant said:

I learnt a lot from the HCWs about my child illness since I was able to ask them question and were answered. This enabled me to understand what was happening to my child when the HCWs were giving treatment to him (Participant # 12).

These participants felt that knowledge of their children's' illness would help them after the child is discharged from the hospital. One participant said,

I came to the hospital for assistance and the HCWs cannot follow me home after discharge. With the knowledge I have gained I will not have problems to care for my child at home. I learnt a lot from the HCWs during my participation....For example, I was taught how to give medication to the child which I might also do at home (Participant # 16).

#### Meeting medical and physical needs of the child

Under this subtheme, two categories emerged. These were provision of comprehensive care and provision of attention to the child.

# Provision of comprehensive and individualised care to children

Some participants (n=10) said that their participation ensured that children received comprehensive and individualised care. One participant said:

"When the HCWs had forgotten to give the child medication, I would remind him or her (Participant 17).

Secondly, they made sure that their children basic needs have been met like bathing, eating, elimination and making sure that children slept at the good place. One participant said:

The HCWs do not do most of the basic things for the children. These things are done mostly by the caregivers. For example the child may have diarrhea so it is the caregiver who cleans the child and washes for him or her, the HCWs do not clean them (Participant # 15).

#### Provision of attention to the child

Two participants said that the HCWs did not pay attention to the children. If they wanted to give children medication they did not take time to make sure that children had taken the medication. One participant said:

If I give the child medication myself, am able to know whether the child has taken the medication or not while them (HCWs) they just come giving the child medication forcefully. It is good that they should take the medication I should give him myself because they can take and give him violently or they may just leave it on the bedside without knowing whether the child has taken the medication or not. Yet if I take the medication to give him I will take my time till the child takes the medication ... HCWs don't have time for the children (Participant # 18).

# Needs of the Caregivers in Regard to their Participation in Care of their Hospitalised Children

This theme was characterised by participants describing the needs which they expected to be met during their stay in the hospital. Three subthemes came out under this theme which were need for information, need for supervision and need for material support.

#### **Need for information**

Two categories emerged under this subtheme namely: Information about child condition and information about how to care for children.

# Information about child condition

Some participants (n=3) reported that they needed the HCWs to give them comprehensive information about their children illness for them to participate in the care of their children effectively. They explained that the HCWs were supposed to tell them everything that was happening to their children. One participant said:

"They should give us information about our children illness now and then" (Participant 13). Another participant said: "When there is a problem there should be nothing to hide they are supposed to reveal everything that is happening to my child...I do not see them being free sometimes" (Participant # 12).

# Information about how to take care of children

Other participants (n=5) said that HCWs should give them proper information so that they should

participate effectively. For example one participant said:

"I needed information on what I was supposed to be doing as was taking care of my hospitalised child from the time I arrived. This could have enabled me to take care of my child properly" (Participant 1).

## Another participant said:

I needed to be prepared on my role as the caregiver. The HCWs gave me some of the tasks to do which I did not have knowledge on how to do it. It is the HCWs who have the knowledge through their training. They needed to transfer that knowledge to me so that I should have carried out the task that they gave me properly like collecting the urine specimen (Participant # 4).

### **Need for supervision**

Some participants (n=6) said that they wanted to be supervised by the HCWs on the task and the care they were providing to their children. The participants said that most of the care was done by the caregiver so they expected the HCWs to be coming and see how the care was being provided to the children to prevent or correct mistakes at the same time giving correct instruction. One participant said:

When the HCW has given me tasks they should have come to see if what I am doing is right. When the HCWs gave me task to do they did not come back to see how I have done it. I expected them to come and see how I have done it" (Participant # 4).

In addition, the participants said that they needed the HCWs to supervise them because they had observed some caregivers who could not provide some of the care to their children. One participant said:

They should come to see how we are caring for our children...they do not come visiting us that they should see how we are carrying out the tasks like has the child taken medication because other mothers keep the medication at the side when the child is refusing. They should supervise and instruct us so that we should be able to do the way they want us to do it (Participant # 11).

# Need for material support

Majority of the participants (16) indicated that the HCWs did not provide them with the materials for use when caring for their children. They indicated that it could have been appropriate if they were provided with the necessary materials (resources) that they could have used when caring for their children. One participant illustrated this way:

They should have the cups that the children should use when taking the medication. Some of the people come here referred from far hospitals so it may be possible that they come to hospital with nothing even money they don't have to buy cups for example. If you don't have one feels like a fool to be borrowing from friends now and then the friends also get tired. They should give us everything that we are supposed to use because it is not everyone who can manage to buy, others people are poor like myself. When I do not have money I send massage home so that they should sell things at home like maize for me to have money to buy the necessary things like soap (Participant # 11).

# Overall impression of caregivers Appropriateness of caregivers' participation in care of hospitalised children

Majority of the participants (n=19) viewed their participation in the care of their hospitalized children as appropriate. These participants said it could not take somebody's parent to come and care for their children. It takes his or her own parent to care for the child. These participants said that it could have been possible for them to leave everything for the HCWs that they should be taking care of the child and not participate. One participant said:

It is proper that I should participate because this is my child. It cannot be possible for somebody's parent to come from there to take care of my child. It requires me as the owner who gave birth to this child like the parent to be the first to take part. It is right and proper that the first care should come from me so that other people who are helping should just be helping but the first care should come from me the owner. I am not feeling any pain when caring for my child and I know that the child is mine (Participant # 12)

# DISCUSSION

The results showed that communication was largely verbal and to some extent written. Verbal communication was in form of HCWs telling caregivers about the diagnosis, treatment plan and in other cases and sometimes prognosis of the condition. Some participants reported that HCWs wrote child's information in the case note. The caregivers had to ask for it in order for the HCWs explain to them. The findings of this study are consistent with these earlier assertions. This could be one of the reasons why verbal communication is commonly used at this hospital. The study findings showed that caregivers were given inadequate information regarding their children's condition and the treatment. Makaryus and Friedman [19] indicated that during hospitalisation, patients and caregivers need more information especially on the diagnosis, the condition, treatment plan, side effects of medications and the duration such medications must be taken. Makaryus and Friedman further stated that lack

of awareness on these factors affects caregivers' ability to comply with treatment plan. It is revealed that some HCWs were talking to them nicely and calmly. Participants reported that HCWs did not shout at the caregivers when they made a mistake instead they corrected them and advised them. Literature shows that the key aspect of appropriate communication is when HCWs demonstrate interest and willingness to talk to family caregivers [20]. This willingness of HCWs may have enabled them to establish rapport with caregivers. Further, findings showed that caregivers needed comprehensive information from HCWs for them to participate effectively. Literature has shown that parents need information about their children illness and treatment plan on ongoing basis [15]. However, it is evident from the findings of this study that HCWs provided inadequate information which is contrary to the values of FCC in which PP is core concept. This explains why caregivers reported that they needed more information.

Lam et al., [2] stated that nurses gave caregivers the tasks and the resources without coming back to see how they were fairing. This suggests that it may be common for HCWs to give tasks to caregivers without following up especially in busy settings. The caregivers also reported that they needed the HCWs to provide them with material resources for caring for their children but every caregiver used his or her own resources such as cups, basin and soap which they used when caring for their children. Studies have shown that providing material support to caregivers is important and can enhance parental participation in care [21]. However, at QECH, is the scarcity of resources at this institution may have acted as a barrier. Caregivers explained that their participation in the care of their hospitalised children was important and appropriate. This concurs with the findings of Shields *et al.*, [22] who found that in Australia parents served as the link between the child and staff. Parents also assisted in relieving the child's anxiety and provided a sense of security. Further to this, caregivers reported that the HCWs relied on them for information, physical and psychological comfort of the child. This is what made their participation appropriate in that study. This may mean that caregivers know the importance of being present and their participation in care [8].

# CONCLUSION

In conclusion, the findings of this study showed that caregivers experiences and view their view on participation in child care is positive, appropriate, important and satisfying. However, gaps exist in the way caregivers are communicated to by nurses. Further, more gaps exist on meeting their needs when in the hospital. There is a great need to review the manner HCW communicate with care givers of hospitalised

children at this hospital so that adequate information is shared between HCWs and caregivers.

### RECOMMENDATIONS

The study findings have shown that caregivers experiences and views are positive. However, they were given inadequate information concerning their children's diagnosis and plan of treatment. To enhance communication and information sharing, there is need for the managers to develop the leaflets on common disease conditions in local language. Furthermore, the HCWs need to supervise the caregivers whenever they have delegated a task to them to check if they needed support.

#### Limitations of the study

HCWs views regarding their experiences with parental participation were not sought. Seeking nurses' views would have enriched the findings and conclusion of this study.

### **Authorship credits**

LS Phiri was the principal investigator and did data collection, analysis and finalized writing the thesis report. AC was supervisor and methodologically supervised the execution of this research at all stages. PGMC Phiri assisted in data collection and analysis, edited the research and led the development of this manuscript. All the listed authors conceptualised the study.

# Conflict of interest: None

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