

**SCHOOL OF PUBLIC HEALTH
COLLEGE OF HEALTH SCIENCES
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**PSYCHOSOCIAL FACTORS AFFECTING FAMILIES WITH HOSPITALIZED
CHILDREN AND THEIR COPING STRATEGIES AT THE UNIVERSITY
HOSPITAL -LEGON**

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AWARD OF MASTER OF PUBLIC HEALTH DEGREE**

JULY, 2018

DECLARATION

I, PHILOMINA OTI DUAH hereby declare that this dissertation is a result of my independent work. References made to other works have been duly acknowledged. I further declare that this work has not been submitted for award of any degree in this institution and other universities elsewhere.

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(Principal Investigator)

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DATE.....

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(Academic Supervisor)

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DATE.....

DEDICATION

I dedicate this work to the Almighty God for his grace and favour towards me throughout my stay in this school especially giving me the courage to complete this work. I also dedicate this work to my family for their support and encouragement, and to Dr Agnes M. Kotoh my supervisor for her academic direction.

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TABLE OF CONTENTS

DECLARATION	i
DEDICATION	ii
TABLE OF CONTENTS	iv
LIST OF TABLES	vii
LIST OF FIGURES	viii
ACRONYMS	ix
DEFINITION OF TERMS.....	x
ABSTRACT.....	xi
CHAPTER ONE	1
1.0 INTRODUCTION	1
1.1 Background of the Study	1
1.2 Problem Statement	4
1.3 Justification	5
1.4 Research Objectives	6
1.4.1 General Objective	6
1.4.2 Specific Objectives.....	6
1.5 Research Questions	7
1.6 Conceptual Framework	8
1.6.1 Explanation of the conceptual framework	9
1.6.2. The Resiliency Model of Family Stress Adjustment and Adaptation	9
CHAPTER TWO	12
2.0 LITERATURE REVIEW	12
2.1 Introduction	12
2.2 Psychological Effects	12
2.2.1 Social Effects	15
2.2.2 Effects of a Child’s Admission on Siblings.....	21
2.2.3 Economic Effects of Child’s Hospitalization	22

CHAPTER THREE.....	25
3.0 METHODOLOGY.....	25
3.1 Research Design.....	25
3.2 Research Setting.....	25
3.3 Selection of Participants.....	26
3.4 Inclusion Criteria.....	27
3.5 Exclusion Criteria.....	27
3.6 Data Collection.....	27
3.7 Pre-test of Interview Guide.....	28
3.8 Data Quality Control.....	28
3.9 Data Management and Analysis.....	29
3.10 Ethical Consideration.....	29
CHAPTER FOUR.....	31
4.0 RESULTS.....	31
4.1 Introduction.....	31
4.2 Socio- demographic Characteristics of Participants.....	31
4.3 Major Themes and Sub- Themes.....	32
4.4 Psychological Effects on Families.....	33
4.4.1 Anxiety.....	33
4.4.2 Fear.....	35
4.4.3 Helplessness.....	35
4.4.4 Guilt.....	36
4.4.5 Depression.....	36
4.2 Social Effects.....	37
4.2.1 Disruption of Family Functions.....	37
4.2.2 Sleep Deprivation.....	38
4.2.3 Loss of autonomy and control.....	39
4.3 Caregivers' Expectation.....	40
4.3.1 Support from health care staff.....	40
4.4 Economic Effect.....	41
4.4.1 Payment of bills.....	41
4.4.2 Loss of Working Hours.....	42

4.5 Coping Strategies	43
4.5.1 Soliciting Family Support	43
4.5.2 Reliance on God.....	44
4.5.3 Self-motivation	45
4.6 Summary	46
CHAPTER FIVE.....	48
5.0 DISCUSSION	48
5.1 Introduction	48
5.2 Socio-demographic Characteristics	48
5.3 Psychological Effects	49
5.4 Social Effects.....	52
5.5 Economic Effects	53
5.6 Caregiver’s expectation of health care staff	54
5.7 Coping Strategies	55
5.8 Study Limitation.....	56
CHAPTER SIX	57
6.0 CONCLUSION	57
6.1 Introduction	57
6.2 Implications for Policy, Research and Public Health.....	58
6.3 Recommendations	59
6.3.1 Ministry of Health.....	59
6.3.2 The University Hospital.....	60
REFERENCES.....	61
APPENDICES	64
Appendix I - Respondent Information Sheet	64
Appendix II: Informant Consent	66
Appendix III: Interview Guide for Mothers	67

LIST OF TABLES

Table 4.1: Socio-demographic characteristics of participants	32
Table 4.2: Themes and Sub-Themes	33

LIST OF FIGURES

Figure 1.1: Psychosocial and Economic Factors Affecting Families with Hospitalized
Children 8

LIST OF ACRONYMS

ADL	Activity of Daily Living
ANC	Antenatal Care
CHIM	Centre for Health Information Management
COPE	Creating Opportunities for Parent Empowerment
C/S	Caesarean Section
GHS	Ghana Health Service
NHIS	National Health Insurance Scheme
PICU	Paediatric Intensive Care Unit
PPME	Policy Planning Monitoring and Evaluation
WHO	World Health Organization

DEFINITION OF TERMS

Children: Refers to a child between the ages of 0-12 years

Coping: To deal successfully with a difficult or challenging situation

Elective Admission: When one has a known medical condition or complaint that requires further workup, treatment or surgery.

Emergency Admission: This happens when you are admitted through the emergency department and from there you are sent to a medical, surgical or a short stay ward for admission.

Family: It is normally blood relations which include mother, father, siblings, and grandparents within a household

Financial factors: Include payment of hospital bills, loss of earnings, travel cost and purchase of food.

Hospitalization: It is a situation whereby an individual is confined to a hospital to undertake medical/surgical treatment or diagnostic test for an illness.

Psychosocial factors: Refers to social, psychological and economic experiences the family members go through when their child is on admission at the hospital.

Psychological factors: In terms of anxiety, stress and uncertainties regarding the outcome of child's diagnosis and the length of stay in hospital.

Social factors: loss of privacy and autonomy, lack of proper sleep and rest on the ward, alternate arrangement for care of other children and dependants at home.

ABSTRACT

INTRODUCTION: This is an exploratory qualitative study to determine the psychosocial factors affecting families with hospitalized children and their coping strategies at the University Hospital – Legon. Children in some cases of reporting to the hospital will need to be admitted during their recovery period for a short or long period. In such cases, a family member can be on the ward with the child to keep them company and also make them feel secured in the unfamiliar environment. The study was to find out the psychosocial and economic challenges family members encounter during a child’s hospitalization.

Interventions to lower levels of anxiety, fear, uncertainty and depression include support from health care professionals and other members of the multidisciplinary team will be put in place to enable the families to cope better with the situation.

METHODS: A qualitative study of fifteen (15) family members who are staying on the ward was conducted using in-depth interview at the Paediatric Ward of the University Hospital, Legon to explore the psychosocial factors affecting families with hospitalized children and their coping strategies. Interviews with the participants was audio taped and transcribed verbatim. Content analysis of the data based on emerging themes and subthemes in line with the study objectives was carried out.

RESULTS: Study findings revealed that family members with hospitalized children are affected by psychosocial and economic factors which need to be addressed by health care workers and other stakeholders. Family members themselves therefore adopt coping strategies; the dominant ones being soliciting family support, reliance on God and self-motivation.

CONCLUSION: Families with hospitalized children go through psychosocial and economic problems which can be intervened by health care professionals on the ward. These problems must be anticipated immediately a child is admitted to the ward whether for short or long stay and caregivers helped to cope. It is recommended that the NHIS be accepted in all health facilities that take care of hospitalized children to minimise the financial burden on parents. The Ministry of Health in conjunction with other key stakeholders should make available mothers' hostels in all health facilities to provide accommodation for mothers staying on the wards. Information to help mothers cope with the burden of child care during their child's admission should be provided by hospital administration.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of the Study

Regardless of how slight or severe, acute or chronic, a child's illness, their admission to the ward affects the functioning of the family. Children are particularly prone to the adverse effects of being ill, and their hospitalization is a stressful event with potential untoward consequences for children and their families (Kennedy, Kools, Kong, Chen, Frank et al., 2004).

Hospitalization is placing a patient in a hospital for diagnostic study and treatment (Medical Dictionary for Health Professions and Nursing, 2012). There are two major classifications of hospital admissions:

Elective Admission- when one has a known medical condition or complaint that requires further workup, treatment or surgery.

Emergency Admission – this happens when you are admitted through the emergency department and from there you are sent to a medical, surgical or a short stay ward for admission.

Studies have found profound stress in families during a child's hospitalization which is attributed to their diagnosis, number of days the child spends on the ward and also the disruption of the family functioning. The psychosocial functioning of parents affects the child's physical and mental outcomes. Families present with a wide range of emotions and

how they are able to cope depends on how well they are supported both by health care staff and family members. Homer, et al., (1999) noticed the stresses and roles of families in paediatric hospitalizations indicating that “there are dual patients in paediatric care: that is the child and the family members. Thus excellent paediatric care must be family – centred.

Hospitalization separates a child from a familiar and predictable environment and places him /her in an unfamiliar environment dominated by strange people and unknown equipment. The child therefore needs a familiar person to be with him in hospital to feel secure and safe. A family member is often allowed to stay on the ward to attend to the child’s physical and emotional needs. The causes of stress in family members especially mothers of hospitalized children can be environmental factors, social and economic factors that are related to the child’s circumstances (Little, 2002).

In Ghana, family is normally blood relations which includes mother, father, grandparents, uncles, aunties, siblings and cousins. Family, in this study looks at parents (mother and father), siblings and grandparents who reside in a household. When a child is admitted to the hospital any of the family members can stay on the ward with the child but most of the time, it is the mother who stays and other family members assist her either by looking after the siblings at home, looking after the mother’s business or bringing food to her and the sick child at the hospital. The family member who stays on the ward assist with the child’s activities of daily living which includes feeding, bathing, changing of diapers, and accompanying and holding child’s hands for invasive procedures. Given the importance of family-centred care, the family, often the mother stays at the child’s bedside for the entire time of hospitalization (Kritensson- Hallstrom & Commadari, 2010).

Family members of the hospitalized child go through a lot of challenges such as coping with the diagnosis (especially if the child has a chronic condition) which requires repeated hospital admissions, anxiety, stress, fear, anger, resentment and feeling that life has been unfair (Roldan,2013). Family members mostly affected are the parents who are torn between being a family and also struggling with their emotions (Journal of Clinical Nursing). A study done by Kritensson –Hallstrom (2000) in Sweden, stated that most mothers recognized that illness and hospitalization of their children had overwhelming psychological and emotional impact on their own behaviour. In developed countries, special attention is given to identify stressors in nursing care planning and family members’ education and interventions for solutions are also provided.

Caregivers on the ward express emotions through verbal and non-verbal cues such as facial expressions, behaviours and actions show that they are facing pertinent problems which healthcare workers and other stakeholders have to appreciate and address. A child’s illness and admission to the hospital are often crucial events that both the child and family members are faced with. As revealed in literature, the interface of everyday support, patterns of family interactions, relationships with health workers are crucial for family members to come into terms with child’s diagnosis and subsequent care on the ward.

The current study explored the psychosocial and economic factors that affect families during a child’s hospitalization and the coping strategies instituted to alleviate such psychosocial and economic stressors to help families cope effectively with their care giving role outside their homes.

1.2 Problem Statement

Globally, approximately 33% of children experience hospitalization before they reach adulthood. In Ghana, the total admissions of under-fives in 2011 was 160,938. The ten most common causes for children under five years to be admitted to the hospital are malaria (57.17%), Gastro Enteritis and Colitis (6.11%), anaemia (3.19%), diarrhoeal disease (4.2%), pneumonia (2.2%), malnutrition (1.1%), neonatal sepsis (2.0%), typhoid fever (0.7%), upper respiratory tract infections (1.0%), HIV/AIDS related diseases (0.05%), febrile convulsion (0.7%), all other related diseases (14.9%) The Health Sector in Ghana, Facts and Figures-2014.

Family centred care is a health care delivery framework consisting of interrelated principles and practices that recognise the importance of family and well-being in hospital (Committee on Hospital Care and Institute for Patient and Family Centred Care 2012, Johnson 2000, Johnson et al., 2008, Kuo et al., 2012). Though in the Ghanaian context, a family member is allowed to stay and participate in the child care, their needs are not holistically met. Sometimes where to sleep during the night is a challenge unlike in developed countries where special sleeping arrangements are made for family members. In developed countries, systems are put in place to help family members who stay on the ward cope better with any psychosocial stressors they encounter. For example in the U.S.A, a programme called COPE (Creating Opportunities for Parent Empowerment) helps to improve maternal functional and emotional coping outcomes. However, in developing countries including Ghana, not much has been done to help family members who have hospitalized children cope with the social, psychological and economic challenges they experience which can have long term effects post discharge.

In Ghana, family members of the hospitalized child go through a lot of challenges some of these are coping with the diagnosis (especially if the child has a chronic condition) which requires repeated hospital admissions, anxiety, stress, fear, anger, resentment and feeling that life has been unfair (Roldan,2013). Most family members staying on the ward are unsure about acceptable behaviour and how well they are participating in the child's care needs.

Families members mostly affected are the parents who are torn between being a family and also struggling with their emotions. Another effect is how to cope financially with medical bills including purchasing medications, paying for requested laboratory investigations and other diagnostic procedures. The National Health Insurance Scheme (NHIS) is not accepted in some hospitals in Ghana so the family with most hospitalized children will have to pay their medical bills upfront.

This study sought to find out the psychosocial and economic factors that affect families during their child's hospitalization and to make recommendations to alleviate such impacts so families will be even more strengthened to cope effectively.

1.3 Justification

The purpose of the study is to find out the psychosocial and economic factors affecting families with hospitalized children and their coping strategies. It seeks to inform paediatric units, opinion leaders and others to assist health care professionals to plan more comprehensive and effective care delivery services in order to reduce the stress on families during their stay with their children in hospital. Data from this study will also illuminate

factors affecting families and increase awareness of family issues that can stimulate efforts to develop family policies to help family members cope very well when a child is hospitalized.

Literature review showed that most studies done involved family members from other cultures and environment. There is little attention paid to the psychosocial stress that families go through both internationally and locally as revealed in the literature search. There are no recent studies done on the psychosocial factors affecting families with hospitalized children and therefore this study will seek to find out the stress families in Ghana go through as they are also allowed to stay in with the hospitalized child. The research findings will also contribute to literature and generate interest in the topic for further research. It will also inform policy on care of families of hospitalized children and improve health system guidelines.

1.4 Research Objectives

1.4.1 General Objective

To explore the psychosocial and economic factors affecting families with hospitalized children and their coping strategies.

1.4.2 Specific Objectives

- a) To explore the experiences of family members during a child/ ward's hospitalization
- b) To explore the psychosocial factors that affect families during a child/ ward's hospitalization

- c) To examine the economic factors affecting families during a child/ ward's hospitalization
- d) To explore coping strategies used to adapt to the challenges care givers go through during a child/ ward's hospitalization.

1.5 Research Questions

- a) What are the experiences of family members of a hospitalized child?
- b) What psychosocial factors affect the sick child's family members?
- c) How do the family members cope with the stressors that they face during a child's hospitalization?

1.6 Conceptual Framework

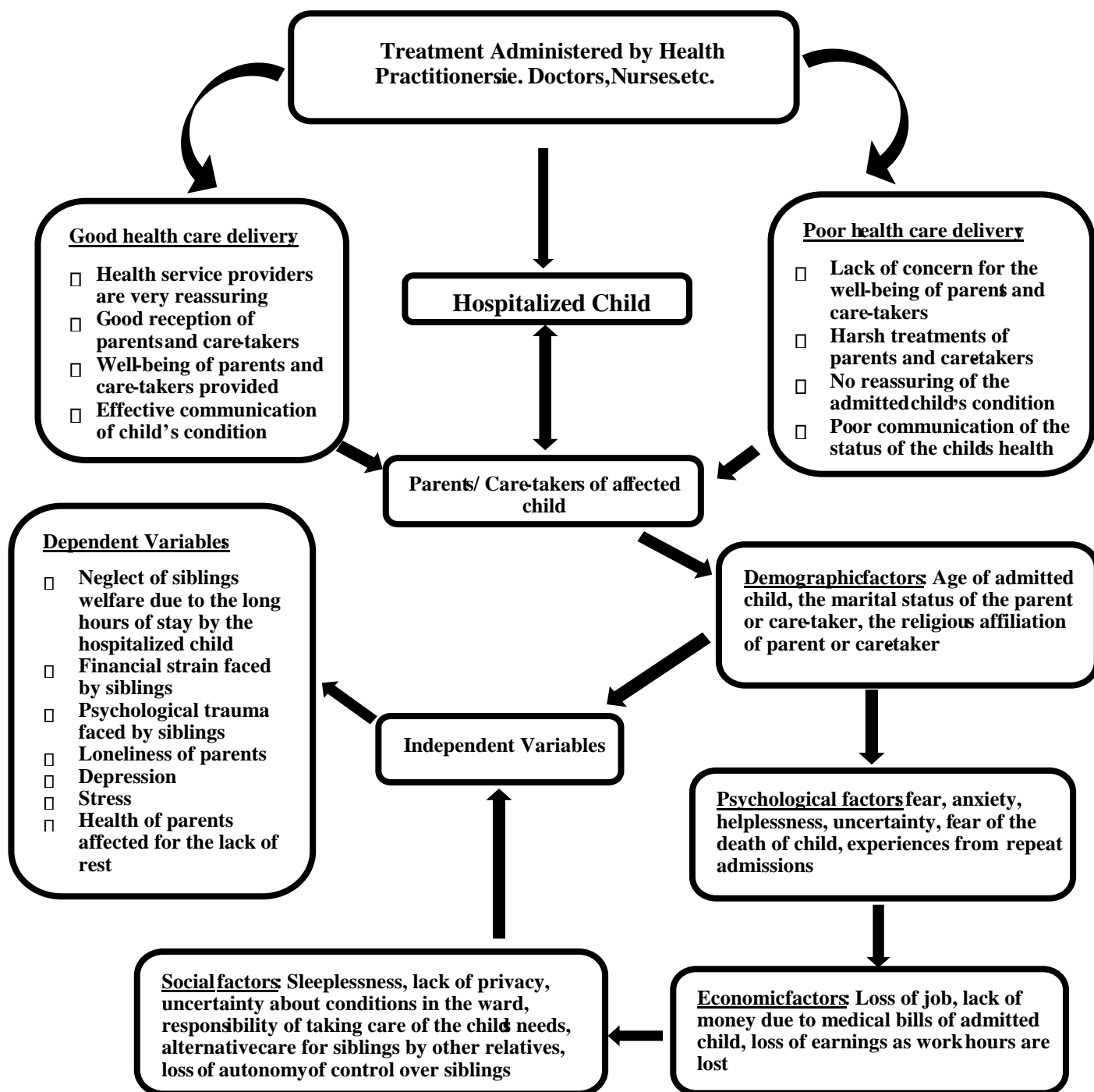


Figure 1.1: Psychosocial and Economic Factors Affecting Families with Hospitalized Children

Source: Adapted from the Resiliency Model of Family Stress and Adaptation

1.6.1 Explanation of the conceptual framework

The conceptual framework seeks to provide the linkages that exist during health care delivery to children admitted to the wards and its resultant effect on parents or caregivers who would have to stay and participate in the care needs of the child. The framework starts from the child being admitted. Aside these conditions of treatment, there are factors that account for the level of commitment and the availability of the parents or caregivers in taking care of the child's welfare. These are categorised as the Demographic factors, the Social factors, the Economic factors and the Psychological factors. These four factors affect the welfare of the parent or caregivers in such situations and vary from the breakdown in the health of the parent or caregiver, depression, financial strain on siblings and the neglect of siblings among others.

1.6.2. The Resiliency Model of Family Stress Adjustment and Adaptation

The resiliency Model of Family Stress, Adjustment, and Adaptation by McCubbin and McCubbin is rooted on Hill's Family Stress Theory. It expatiated the work of Reuben Hill, the Double ABCX Model (McCubbin & Patterson, 1981), and the Typology Model of Family Adjustment and Adaptation (McCubbin, Thompson, Pirner, & McCubbin, 1988). Marilyn McCubbin and Hamilton McCubbin (1993), the Resiliency Model indicated the post crisis, adaptation phase. It tried to explain why some families are "resilient" and recover from crises while others stay cannot and are vulnerable or even deteriorate after crises (McCubbin & Patterson, 1981).

The model uses a method to assess family functioning and the coping mechanisms used to promote adjustment and adapting to medically stressful hospitalizations and diagnosis. It

provides the means to assess stressors, family coping strategies, and how the crisis has interrupted the family functioning. The model emphasises on family resiliency and their strength to recover from adverse effects. It defines the family strengths and the family's response to health stressors. It also help the health care team to define areas that interventions can be developed to better assist families to achieve positive readjustment to illness.

In this study, resilience is defined as the positive behavioural patterns and functional competencies individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by regaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and also maintaining the family unit as a whole (McCubbin & McCubbin, 1996). Assumptions of the model consist of:

- Families experience stress and hardships as aa inevitable aspect of family life over the life cycle;
- Families also have strengths and mobilise competencies to cushion them and help them to recover from both expected and unexpected stressors and strains and to foster the family's recovery, after a family crises;
- Families benefit from the contribution of network of relationships in the community, especially during periods of family stress and crises;
- Families will seek and establish a view that will enhance the family and shared perspectives that the family can move forward as a group.

In a Ghanaian setting, the extended family system is of great assistance as they contribute in various ways to help each other cope especially the parents of the hospitalized child by opting to take care of healthy siblings and other dependents at home. Most often they contribute financially towards the payment of medical bills including purchase of medications investigations and procedures. Some family members look after the business of the caregiver with the child in hospital to help alleviate the loss of earnings. During visitation times, their presence on the ward alleviates the resident family members' anxiety, reassure and support them. Health professionals' support on the ward also alleviate fears and anxiety expressed by care-givers who stay on the ward to participate in the care needs of the hospitalized child. The affected family members therefore mobilise their strength as indicated in the resiliency model to deal with the child's hospitalization.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter looks at various studies done on the psychosocial factors affecting families with hospitalized children and their coping strategies. These studies were mostly done in the developed countries but scarcely in the developing countries. The effects to be looked at include social, psychological and economic and their coping strategies.

2.2 Psychological Effects

It is a stressful event for family members when one of the members is admitted to the hospital. The stress is also worsened by the medical diagnosis, how long the child will need to stay in hospital and the family dynamics. Studies have found profound stress in families with children affected by various conditions, and analysed variables that produce stress. The aspects of stress in the family member's life that will change during hospital stay, include their natural needs, social and economic needs that can cause stress and anxiety for the parents (Shields & Kritensson- Hallstrom, 2000).

A study by Tiedmann (1997) in the U.S.A examined the anxiety expressed by 52 parents of 5 year -11year old children during and after their hospitalization. The study found out the intensity of the parents' anxiety and how long it would last for following the child's discharge from the hospital. The results of the study showed that mothers who had an intervention had positive coping outcomes as compared to those who did not. A similar research done by Hayes and Knox (1984) concerning parental anxiety and stress with

hospitalized children in Britain, discussed parental perceptions especially when the children have long term disabilities and required repeated admissions with 40 parents through in-depth interviews to illicit their experiences and their roles as caregivers on the ward. The results indicated that the parents were worried about their changing roles. The changes needed included how to understand the child's condition, familiarity of the ward environment, disruption in family function and how to assist the health care staff in rendering care to the sick child.

On the contrary, because of hospital staff familiarity with the hospital environment, they do not assume that the hospital environment and setting can be a stress causing factor for mothers of hospitalized children. (Hasan Tehrani, Haghhighui, et al., 2012). However, if the needs of the family member staying with the sick child in hospital are met, they are able to cope better. The American Psychological Association suggests a meeting initially with mothers to let them know what is expected of them during their stay with the sick child on the ward and also who to go to when they have questions to be answered to allay their anxiety. There are similarities of psychosocial effects of child's hospitalization on caregivers in other countries.

Further research was conducted by Melynk, Feinstein, Johnson, and Fairbanks in the U.S. on coping outcomes of mothers with critically ill neonates. One hundred and seventy four (174) mothers were selected with and their 2-7 year old children who were admitted to the paediatric care units (PICU) of 2 children's hospitals as emergency. The findings included maternal anxiety, negative emotions, the care and the child's adaptation which was assessed with the Behavioural Assessment Systems for children parent forms. The findings of this

study showed that mothers who received the COPE (Creating Opportunities for Parent Empowerment) programme experienced improved maternal functional and emotional coping outcomes in comparison with those who did not. COPE is a preventive educational – behavioural intervention programme initiated in early PICU hospitalization on critically ill young children and their mothers on mental/ health psychosocial outcomes.

It is apparent that mothers /parents of hospitalized children go through a lot of psychological problems which health professionals need to help them with as observed by Darbyshire (1994) and Callery (1997). To reiterate further, stressors could include parents missing work, siblings and ill children missing school, painful ongoing procedures or treatments, uncertainty related to prognosis, too much or too little social support, financial constraints related to paying medical bills. Most studies done on the psychosocial factors affecting families with hospitalized children were done in developing countries and not in Sub Saharan Africa so the current study will seek to find out what pertains in Ghana.

Family systems theory and bio psychosocial perspective (McCubbin 2001) align with the assumption that illness is a family experience. When there is a health crisis, it often impacts other domains of life. This is true for parents and their children. Family stress is influenced by particular conditions such as characteristics of family structure. Adoptive mothers perceived increasing levels of stress during their child's hospitalization as compared to biological mothers of the hospitalized children. (Smith et al; 1997).

2.2.1 Social Effects

As parents are allowed to stay with the sick child in hospital, then much attention must be paid to them to prevent any adverse feelings. However, the effects on parents of their involvement in the care of their hospitalized children have received little attention. It is reported that the family, together with service providers, is able to make informed decisions about the services and supports the child and family shall receive. In order to develop a family-centered care practice, it is imperative to understand and address the psychosocial problems experienced by the caregivers of the affected children. (Davis et al; 2010) .Several studies of this kind have been undertaken in western countries but very few are reported in Ghana. During a child's hospitalization, his /her family is the mediator in the hospital and continues to provide care. In this context, the child goes beyond the need of daily care; they need more specific care related to their new demands regarding the cause of his/ her hospitalization. The family needs to be considered by health professionals as a co-participant in the child's care. For this they need to be aided and that their views and wishes taken into account. In Africa and Ghana in particular, the family, especially females play an immense role in the life of a sick person. (Nukunya, 2003). A family member most often mothers of children with a chronic illness experience loss of autonomy and control with repeated hospital admissions.

Family members are often allowed too much than they can bargain for as nurses are always too busy to notice this. In the U.S.A, opportunities are created for parental empowerment during hospitalization where mothers are allowed into the anaesthetic room to see how their children are put to sleep prior to surgery. However, according to Callery (1997) parents described feelings of upset by involvement in some aspects of care for example staying with

the child during painful procedures. Some family members would rather be present during such procedures for they believe the sick child stays calm when there is a familiar face.

Another research done by Hayes and Knox (1984) concerning parental stress in hospitalized children in Britain discussed their perceptions especially when their children have long term disabilities and will be requiring repeated admissions. The study used a qualitative method. Data were collected with 40 mothers through in- hospital interviews and were analysed using the method of constant comparative analysis. Parents own interpretation of their stress experienced is considered in relation to their perception of their role. The data suggests that the hospitalization of a child requires parents to make changes in their usual parenting roles. In describing the nature of the changes required, parents identified the need to understand the illness experience, become familiar with the hospital environment, adapt to their changing relationships with the child and other family members, and negotiate with health professionals about their child's care. Parents see their role in the child's care differently than health professionals do, and it seems much parental stress is due to the 'space between health care workers' comprehension of parents experience and parents' own understanding.

How much agreement have to be done regarding parental participation during a child's hospitalization has not been studied. It is noted that parental participation now has become an accepted norm of the care of a hospitalized child, however, the effects to parents of their involvement in the care of their hospitalized children has received little or no attention especially in Ghana where some hospitals even lack space for the mothers to feel comfortable to perform such roles. From the discussed studies on parental control and participation, parents view themselves as performing the role of advocates and protectors. However, those parents were uncertain as to what is expected of them in relation to both

their children's care and their own behaviour. This uncertainty in addition to lack of information and conflicting advice create considerable anxiety which hampers their ability to cope and perform.

Parents want to be involved in information sharing and technical care areas. This observation was in a research done by Balling and McCubbin (2001) in Britain by using the family systems theory as the underlying framework. It sought the amount of control that parents of children with chronic illness wanted over their hospitalized child's care and how health care professionals valued their expertise using a rational sample of 50 parents. It rated attending physicians and nurses highest in valuing parental expertise. Questions on parental control revealed that parents felt a higher quality care was given at home than in the hospital as nurses are too busy or understaffed to provide optimal care and also in decision making. Robinson (1972) and Tomlinson (1996) conducted studies on parental participation of hospitalized children using 40 mothers. The findings indicated that the mothers' presence provided support for their children however; their absence from home adversely affected other members of the family that is their husbands, siblings and other dependants.

Strategies for feeling secure have been found to influence parent's participation in Sweden. Kristensson –Hallstrom (1999) investigated factors that make parents of hospitalized children feel secure and also factors that affect their level of participation. Questionnaires were distributed to parents whose children were discharged from two paediatric surgical wards and one paediatric medical ward at two hospitals in Sweden. Parental security is almost equally distributed among three given alternatives:

- a) Security derived from being the one who knows the child best.

- b) Security derived from having control over what is happening to the child.
- c) Security derived from trusting that professionals know how to take care of the child.

Depending upon the strategy chosen, parents want to participate at different levels in their care. The results indicate a relationship between parental participation and the estimation of their child's pain. Some parents who wanted to participate in more aspects of their child's care seemed to think their child had less pain than parents who preferred more limited participation. How much negotiations have to be done concerning parental participation during a child's hospitalization has not been researched into. From the discussed studies much need to be done to support mothers with their children in hospital to allay their fears and anxiety. Nurses therefore have to give the parents role cues and information to help them learn how they are expected to act in a hospital. However, with the child's repeated admissions, parents eventually become confident in participating in their child's care. This has been reaffirmed by a study of 613 mothers.

Robinson (1972) found an inverse relationship between the number of hospitalizations the mother experienced herself and her willingness to suggest that mothers become more assertive with hospital and this familiarity with hospital influence parents participation in care. Parents experience surveys are widely used by hospitals across the US, Canada, UK and Australia to collect data on patient and family experiences of inpatient and outpatient healthcare. These surveys commonly probe multiple dimensions of patient and family experience, such as nurse and doctor communication, responsiveness of staff, respect for parents' preferences, emotional support, physical comfort, information and education, continuity and transition, coordination of care access to care and involvement of family and friends.

A study explored the lived experiences of 6 mothers with children afflicted with cancer and needing repeated hospital admissions and how this affected their daily lives at the Children's Haematology Oncology Clinics (CHOC) in Kwazulu Natal, South Africa. The study outlined the socio-emotional and occupational effects of having a child with cancer. The results show the need for improved communication between medical staff and mothers, together with creating an environment that will provide support to the mothers and create opportunities that will help them to gain insight into cancer through shared experiences (South Africa Journal of occupational Therapy, 2016).

According to Shields and O'Callaghan (2003) who examined the need of hospitalized children in Ireland comparing parents and staff perceptions revealed that in a 150 bed paediatric hospital where 132 staff nurses, doctors and allied health staff and 115 parents of children admitted to all the wards except PICU, showed significant difference in perceptions of the importance of different needs of parents of how well they were being met in the hospital and how much help the parents needed to have them filled. Difference between parents and staffs perception of the importance of parental needs were found in areas relating to psychosocial needs, but in general, in that hospital these needs were being adequately met. The main differences between staffs and parents results were in degree of independence shown by parents requiring help to have their needs met. This demonstrated that either the parents were much more independent than appraised by staff or that parents are sometimes unaware of the assistance available.

During a child's admission, health care professionals particularly nurses should view the child as a member of a family unit and as a result other members of this family also present

problems that should not be ignored. A research was conducted by Stratton (2004) in Denver, Colorado, U.S.A. to explore parents' experiences they received for their hospitalized children. The study applied qualitative descriptive theory that is informed by grounded theory for a convenience sample of 6 parent participants. This study finds that parents experience child care in a hospital setting in terms of 4 interconnecting circular processes:

- Facing boundaries
- Trying to understand
- Dealing with uncertainty
- Seeking reassurance from care givers

The experiences shared by parent participants in this study convey new meaning to the interaction nature of the parent- caregiver relationship. In particular the researcher found that the parents use the parent- caregiver relationship to help cope with their child's condition and this in turn influences the parents' sense that their child's needs are being met. Parents sometimes perceive themselves more capable and independent than what the health care workers think of them. Such findings will however, facilitate improvements in communication between parents and staff and can be recommended to be included in education programmes for both. An admission pack on the mother's first day on the ward can be of great benefit where ward activities and routine are spelt out to assist the mother to know what is expected of her and who her child's "named nurse" is so she can go to her for any information she wants to know.

In Ghana, paediatric wards that practise family centred care model do not normally allocate a staying mother with a “named nurse” so when the mother needs information she obtains this from any nurse on duty at the time. About 80% of mothers complain they get conflicting information which does not normally help them. Good communication between hospital staff and family members of the hospitalized child is very essential as both parties will be able to support and understand each other.

Common parental stressors identified include the hospital environment, inconsistent communication, alterations in a child’s appearance and parental role, and uncertainty relating to a child’s illness and future prognosis (Board & Ryan-Wenger, 2003, Colville et al., 2009; Jee et al., 2012). Both groups of the study were identified as good communication with the medical team and opportunities for participation as helpful in reducing stress (Board, Ryan-Wenger, 2003).

2.2.2 Effects of a Child’s Admission on Siblings

It is asserted that during hospitalization of a child, the healthy siblings’ roles in the family are also altered. Traditionally, paediatric wards in Ghana restrict siblings from visiting with a belief that they will carry whatever infection their ill sibling has back home. During a child’s hospitalization, many siblings will be in the ‘magical thinking’ stage in which they view external events to be the result of their own actions or thoughts. Thus a sibling’s illness may be perceived as the fulfilment of any ‘I- wish-you-were-dead’ remarks and result in strong attendant feelings of guilt. In addition, the chronic illness absorbs large amount of parental energy, robbing the other dependant siblings of the support they need to fulfil their own developmental needs successfully. Sometimes siblings are not transported to school

because of the child's hospitalization; however, no relevant studies have been conducted to measure the extent to which siblings suffer during such times emotionally, physically and socially.

It can be said that much research has been done in the developed countries on the psychosocial factors affecting families with hospitalized children but not much in developing countries including Ghana. It is apparent that similar reactions are felt by parents in both developed and developing countries where systems are not even available to help one cope. Several studies indicate parents of hospitalized children experience reduced sleep duration, increased night time awakening and difficult falling asleep (Mathews, Neu, Cook & King 2014; McCann 2008; McLooree, Wakefield, Yoong & Gohn, 2013). Even one night of sleep deprivation has been found to compromise advanced cognitive thinking and decision making ability (Harrison & Horne, 1999). During their child's hospitalization, parents are required to understand complex medical information and participate in decision making. However, the consequences of poor sleep quality on parents' psychological well-being and decision making are not well-understood.

2.2.3 Economic Effects of Child's Hospitalization

Empirical studies demonstrate that regardless of gender, age and ethnicity, care givers that is family members with the sick child are at risk for major stress, anxiety and depression and are vulnerable to possible physical and financial repercussions (Rhee, Yun et al., (2008). A study done by Bareness and Azzaraton (1998) of family expenses caused by paediatric hospitalization in Niamey (Niger). It found out that in Niger, 54.4% of the population live below the poverty level. The study was done in 1994 -1995 of 80 children randomly selected, who had been admitted to the paediatric ward of the Niamey National Hospital.

The total expenses of their families, was recorded and analysed. The total cost (total family expenditure and hospital expenditure) to stay in a paediatric unit was 316.5-350.4 French francs which is equivalent to about 8 to 10 times the mean annual individual expenditure on health in urban areas of Niger. Travel expenses in and out of hospital are also to be considered. Not all hospitals accept the NHIS payment and also provide food for the sick child but as a result, the family member staying with the child will have to eat from outside at an extra cost. Where the mother has to leave her job and come to stay with the sick child in hospital, family income is diminished.

Financial burden is also mostly felt by family members with children with chronic illnesses who demand repeated hospital admissions, also on so many medications that the family members will have to provide and also cater for the needs of the sick child's well siblings. The caregiver can even lose a job if working for someone when they keep on requiring excuse duties to be with the child on admission. It has been asserted that in Ghana, some families will have to sell their properties in order to meet the cost of their children's hospital bills which later on become a taboo in the family when this child eventually dies. Difazo & Vessey (2013) indicated that families often face logistical and financial challenges in achieving proximity to their child because of difficulties with transportation, food and lodging, care of other children or family members and loss of wages due to absence from employment. Families are constantly challenged by unpredictable course of a child's illness and find themselves in a fragile balance between becoming a family and struggling with their emotional burden.

A cross-sectional controlled study was done at the University of Ilorin Teaching Hospital in Nigeria of 100 mothers of children with Sickle Cell Disease (SCD), 75 mothers of children with Asthma and 75 mothers of children with other acute medical illness, show that mothers of children with SCD were more likely to report financial burden, time consumption and hindrance from social engagements. This reveals that repeated hospital admissions of a chronically ill child is stressful as the children themselves experience psychosocial problems concurrently with their mothers.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Research Design

This study is a descriptive, exploratory research. Qualitative research is closely linked to interpretative epistemology and demonstrate the strength of “sensitive, lauded, detailed and contextual data that provides a comprehensive basis for understanding reality”. (Connelly 2009). Qualitative data approach will provide a better understanding and deeper insight into the nature of factors affecting families and the coping strategies they will adopt.

3.2 Research Setting

The study was conducted in the paediatric ward of the University Hospital, Legon .The University Hospital is located at the Ayawaso East Wugon sub-metro of Greater Accra Region of Ghana .It is bounded by the Legon Police Station on the south-west and a taxi and trotro station. The Staff village Primary and Junior Secondary School (JSS) to the south and the Staff Village quarters to the east. The hospital has a bed capacity of 130 and was primarily built to provide care for the university population but later extended to provide care to people from Madina, Adenta, Aburi and Abokobi. The hospital offers the following services; medical and surgical, maternal and child health, reproductive health, dental, dietetics and physiotherapy, specialist eye care, orthopaedics, urology and dermatology.

The Paediatric Unit was constructed in 1996 and officially opened in March 1997. It has a bed/cot capacity of twenty five (25) including an isolation unit. The ward admits children from newly born to 12 years of age. The average daily inpatient admissions is between 48

patients. The commonest case admitted to the ward is malaria which is about 33 cases per month. Other cases are meningitis, bronchiolitis, urinary tract infection, neonatal jaundice, birth asphyxia, pneumonia, sickle cell disease, asthma and occasionally burns. The unit has been designed to give a homely outlook with some Walt- Disney characters painted on the walls. There are two toilets and bathrooms for the children and their resident mothers.

The hospital provides meals for the children three times a day but not their mothers. There is open visitation for parents. Other relatives are allowed visiting between 3.30pm and 5pm each day. Mothers are allowed to stay to take care of their children's needs. Some toys are provided for recreation but the child on admission is allowed to bring in their own from home. Two television sets have been provided for the children and their caregivers. The ward has a playroom for the children when they feel well enough to play. The University Hospital was chosen because it meets the basic criteria of a standard children's ward that will help answer the research questions.

3.3 Selection of Participants

Family members who have stayed with the sick child on the ward for more than one week were purposively selected to participate in this study. In selecting the respondents, care was taken to ensure participants fairly represent the target population. Due to the nature of the study, it was imperative to take into consideration the age, parity, educational background, marital status of participants to assess if these variables had any effect on how they perceived and also did cope with the challenges of a child's hospitalization. . It was realised that after interviewing the 12th participant, the same responses were being given so a total number of fifteen (15) participants were recruited. It was anticipated that interviews with

this number of people could be fully completed within the time limit available for the data collection.

3.4 Inclusion Criteria

The following were the inclusion criteria:

- Being a family member who is staying with the sick child on the ward for one week or more
- Being between eighteen years of age or more
- Being able to provide voluntary consent to participate in the study

3.5 Exclusion Criteria

The following criteria was used to classify participants as not eligible for the interview.

- A family member who does not stay on the ward to participate with the care needs of the child during the period of the child's hospitalization.
- Mothers or family members who had stayed with the sick child for less than 7 days on the ward.

3.6 Data Collection

In-depth interview, is a qualitative research method which involves conducting individual interviews with participants to explore their ideas on a particular perspective (Boyce & Neale 2006). The interviews were conducted in English and Twi at a place convenient to the interviewee. A tape recorder was used alongside field note book .An interview guide was used to conduct the interview which allowed the participants to recount their experiences in-depth. It also helped the researcher to redirect participant's responses when

out of context (Creswell, 2014). The interview guide was in two sections A and B. Section A covered the socio-demographic characteristics of the participants and section B had questions including: “what are the experiences of family members of a hospitalized child?, what psychosocial factors affect the sick’s family members and how do the family members cope with the stressors that they face during a child’s hospitalization?”

The interview was conducted at a place convenient for the participants. Each participant determined the language for their interview and each were not distracting the session .Each participant determined the language for their interview and each interview lasted between 20-30 minutes. After rapport has been established and the purpose of the study explained to the participants, they felt comfortable to share their experiences openly. In order to ensure every caregiver is coping well during the interview sessions referrals were made appropriately for those who could not cope to the social worker.

3.7 Pre-test of Interview Guide

Pretesting was done using the interview guide on four family members with their children on admission at the Achimota Hospital. This was to help fine-tune the questions for the interview and observe all aspects of the study. Unclear questions were restructured and analysis of the responses obtained to improve the interview guide.

3.8 Data Quality Control

Four research assistants with minimum qualification of a University Degree were trained to assist with the data collection. The interview guide was translated from English to Twi and other dialects back to English for dependability and accuracy.

3.9 Data Management and Analysis

All audio taped interviews were transcribed verbatim and rechecked for accuracy. Field notes were recorded during each interview. The interview guide was read at least three times to gain meaning and overview of the family member's experience. The transcripts were read and audio taped interviews listened to several times noting down initial ideas. Thematic content analysis was done by developing specific expressions, ideas and concepts. Similar themes were merged to form categories. The broad themes were psychological, social, economic effects of child's hospitalization and coping strategies. The materials used for the data collection that is digital recorder and transcripts were kept under lock and key in the researcher's possession and were only accessible to the researcher and the supervisor. The transcripts would be kept for five (5) years after the completion of the study.

3.10 Ethical Consideration

The study protocol was approved by the Ghana Health Service Ethical Review Board (GHS-ERC018/02/18) prior to data collection. A letter was obtained from the School of Public Health to introduce the investigator and the purpose of the study to the Director of the University Hospital, Legon. The objectives and benefits of the study were clearly explained to the participants. Participants were asked to sign consent forms and they were assured that whatever they said would be confidential and are free to decide at any point in time to stop the interview if they did not want to continue. Some responses required further probes and the participants who sounded upset were reassured for them to gain back their confidence to continue. Participants were assigned alphabetical letters for proper identification from A-Z. Copies of the transcripts were kept in a folder on a computer with a password for safety and security.

They were informed that they could withdraw at any time during the study without any coercion or punishment. The materials used for the data collection that is digital recorder and transcripts were kept under lock and key in the researcher's possession and were only accessible to the researcher and the supervisor. The transcripts would be kept for five (5) years after the completion of the study.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents findings from the analysis of the data collected in the study: Psychosocial factors affecting families with hospitalized children and their coping strategies at the Children's Ward of the University Hospital Legon, Accra. Fifteen participants were interviewed. Themes and subthemes that were generated, were based on the construct of the Resiliency and adaptation model and the research objectives. The five main themes included: psychological, social, financial effects on the family members and their coping strategies. A new theme that also emerged was family's expectation of health care staff. In total, five (5) themes and sixteen (16) sub-themes were identified.

4.2 Socio- demographic Characteristics of Participants

Fifteen participants were used in the current study. The participants were between the ages of 24-43 years. Regarding their educational level, three had no formal education, one had basic education, seven completed senior secondary school and four had tertiary education. In relation to their occupation, six of them were self-employed, six were civil servants, and three were unemployed. All the 15 participants were the biological mothers of the hospitalized children and they were all married. Six were first time mothers and the remaining nine had children between 2- 7 children. There were fourteen Christians and one was a Muslim .None of the children had been previously admitted to hospital.

Table 4.1: Socio-demographic characteristics of participants

Participants	Age (yrs.)	Marital Status	Occupation	Educational Level	Religion	Parity	Gender
P1	34	Married	Unemployed	SHS	Christian	1	Female
P2	24	Married	Teacher	Tertiary	Christian	1	Female
P3	43	Married	Self employed	No formal education	Christian	4	Female
P4	41	Married	Caterer	SHS	Christian	5	Female
P5	30	Married	Teacher	Tertiary	Christian	1	Female
P6	25	Married	Health Care Assistant	SHS	Christian	1	Female
P7	37	Married	Trader	No formal education	Christian	6	Female
P8	40	Married	Unemployed	SHS	Christian	4	
P9	32	Married	Health Care Assistant	SHS	Christian	2	Female
P10	35	Married	Unemployed	Tertiary	Christian	2	Female
P11	30	Married	Trader	SHS	Christian	1	Female
P12	25	Married	Teacher	SHS	Christian	1	Female
P13	33	Married	Dental Assistant	Tertiary	Christian	4 (3 alive)	Female
P14	42	Married	Trader	No formal education	Christian	2	Female
P15	31	Married	Trader	JHS	Muslim	3	Female

4.3 Major Themes and Sub- Themes

Thematic content analysis of the data of the study produced five major themes and eighteen sub-themes. The major themes comprised (a) psychological effects experienced by family members, (b) social effects, (c) caregivers expectation, (d) economic effects and (e) coping strategies. The sub- themes identified were: (a) anxiety, (b) fear (c) helplessness, (d) guilt, (e) isolation and depression, (f) disruption of family functions, (g) sleep deprivation, (h) loss of autonomy and control, (i) alternate care for other siblings and dependants at home, (j) communication, (k) support from health care staff, (l) caregivers perception, (m) family support, (n) reliance on God and prayer and (o) self- motivation.

Table 4.2: Themes and Sub-Themes

Themes	Subthemes
Psychological effects	<ul style="list-style-type: none"> • Anxiety • Fear • Helplessness • Guilt • Isolation and depression
Social effects	<ul style="list-style-type: none"> • Disruption of family functions • Sleep deprivation • Loss of autonomy and control • Alternate care for other siblings and dependants at home
Caregivers expectation	<ul style="list-style-type: none"> • Communication • Support from health care staff • Caregivers perception
Economic effects	<ul style="list-style-type: none"> • Payment of bills • Loss of working hours
Coping strategy	<ul style="list-style-type: none"> • Family support • Reliance on God • Self-motivation

The results are presented according to themes, their marching sub-themes, and appropriate quotes from the participants to explain the themes.

4.4 Psychological Effects on Families

The psychological effect of child's hospitalization was identified to answer the research question "What are the psychological factors affecting the sick child's family members? The data showed that anxiety, fear, helplessness, feeling of guilt and depression are the sub themes found which the family members experienced due to the sick child's admission to the ward. The subthemes are depicted with verbatim quotes from the mothers. The results show that both participants with formal education and no formal education expressed the same psychological effects.

4.4.1 Anxiety

Caregivers expressed anxiety due to being in an unfamiliar environment, the child's diagnosis and subsequent treatment and management, care of other siblings and dependants

at home. The following comments show how anxious caregivers were when taking care of a child in hospital.

I am far away from my normal and familiar environment and my baby is also not well. It is not comfortable to be in a hospital environment with seeing all these children unwell. (P7, 37 years)

I feel free to ask questions and also get clarifications but I am still worried because my child came with a fever and he is on treatment but the fever is still not settled. I have done all the laboratory tests. (P1, 34 years)

I, husband and mother are all worried and anxious as the doctors were not able to tell us what is wrong with our child. But we hope a diagnosis will be arrived at to make the treatment easy. (P1, 34 years)

I have been very anxious about the whole sickness and worried that a little girl can have an operation just like an adult. She is only 8 months old. (P4, 41 years)

Because of my previous experience, I am hyper- anxious (sounded upset and was reassured), I lost my baby on this same ward last year. (P13, 33years)

My husband does not work in Accra so I had to call him to ask permission from work and come. My land lady has been taking care of him and I was worried and about him because he is only 2 years old. (P10, 35 years)

Some participants believed they were in safe hands and therefore not anxious about their child's admission.

When my children are not well, the hospital is the best place for them to be. Where else can I take them except to bring them to the hospital? (P2, 24 years)

4.4.2 Fear

Some mothers on the ward reported being afraid of their child's condition or the outcome of the sickness. One participant indicated she had lost a baby on the same ward not long ago and was therefore afraid.

On the first day at the emergency ward, I was told my child had something wrong with her intestine and was going to be operated on. (P4, 41 years)

Because of my previous experience, I am hyper- anxious (sounded upset and was reassured), I lost my baby on this same ward last year. You are here thinking is it going to happen again? (P13, 33years)

I am far away from my normal environment and my baby is also not feeling well. The ward environment is very scary .You're sitting here worried and do not know what can happen to your child. (P7, 37 years)

4.1.3 Helplessness

Delay in diagnosis and poor improvement in child's condition were cited as some of the feeling of helplessness on the ward. One mother indicated that she did not know what to do next when the nurses failed to reassure her whilst waiting for her child to be sent to theatre.

I feel free to ask questions and also get clarifications but I am still worried because my child came with a fever and is on treatment but the fever is still not settled. I have done all my labs. (P1, 34 years)

But on the ward, whilst waiting to go to theatre, the nurses changed shift and I was expecting the afternoon nurses to come to me occasionally to reassure me but nobody came. (P4, 41 years)

The doctor told me my baby needs one laboratory test before discharge so I wanted them to do it then I can go home and leave my phone number so they can contact me to come back if there was any problem with the results.(Sounded upset). "Since I delivered, I have not taken proper care of myself and I am feeling sore. (P10, 35 years)

So much since I am not in my usual environment and also did not anticipate to have an operation to get my baby delivered because my

blood pressure was too high the doctor told me. Wish I was home with my well baby. (P7, 37 years)

Madam it is not easy, the way my baby has to be brought here for me to breastfeed and he is taken home. My breast pains me at night. (P7, 37 years)

4.1.4 Guilt

Some mothers reported feeling guilty as their child was hospitalized due to their poor care at home that they did not look after their children's needs of protection properly.

We were told at the antenatal clinic to breastfeed the babies very well to prevent the development of jaundice. I am now worried that the poor feeding might have caused the jaundice but the doctor said the baby has an infection which rather caused the jaundice. (P5, 30 years)

Yes it was a home accident. My child fell in a bowl of hot soup so I think I have been careless and I blame myself. Whenever the nurses are dressing her wound and she is in pain, I feel guilty. (P3, 43 years)

4.1.5 Depression

A few (3) of total (15) participants indicated feeling depressed as they have had Caesarean Section (C/S) and could not rest well due to their baby's hospitalization. Another participant expressed feeling depressed as no one gave her reassurance whilst waiting for her child to be sent to theatre for a procedure.

But on the ward, whilst waiting to go to theatre, the nurses changed shift and I was expecting the afternoon nurses to come to me occasionally to reassure me but nobody came. (P4, 41years)

Hmmm, I thought I was bringing the children just to see the doctor and go home. I did not anticipate an admission but it is okay my children's health is more important than anything else. (P14, 42 years)

I have had a C/S so I feel uncomfortable sitting up to feed the baby. The wound site is ever so painful although I have been offered some painkillers. I wish I could lie down to relieve the pain but I have to sit up and feed the baby. (P6, 25 years).

I normally live at Nsawam and had my Antenatal Care (ANC) there but came to Accra to trade. I felt ill and was rushed here. I was operated on and my baby has been admitted to the ward. (P7, 37 years)

4.2 Social Effects

The social effects of child's hospitalization as stated in the research questions was elicited by participants during the interview. Analysis of the data revealed that family members experienced disruption of family functions, sleep deprivation, loss of autonomy and control over the sick child, alternative care for siblings and other dependants at home.

4.2.1 Disruption of Family Functions

Most of the participants reported that there has been no disruption in their family functions as other family members were taking care of their home but few indicated there was disruption.

Our child has been sick on and off for quite some time now and we have spent a lot of money at other facilities. We hope she will get better here. (P12, 25 years)

My sister has to cook for my other children and my husband. I feel very uncomfortable leaving my home for my sister alone to take care of but I have to keep my sick child company until he gets better. (P 15, 31 years).

I know I am supposed to be home with my baby by now but the baby needs treatment for her infection so I have to manage for my baby. (P5, 30 years)

They serve meals from the kitchen but I prefer to buy food from outside because their food is also expensive and not enough to satisfy me. (P10, 35 years)

However, some participants indicated that their homes were adequately catered for.

My younger sister takes care of the child's siblings at home and my husband. She cooks for them and send them to school. (P4, 41 years)

My husband is my only direct dependant and he visits me mostly daily. (P1, 35 years).

4.2.2 Sleep Deprivation

All participants except one were not happy with the sleeping arrangements on the ward especially those who were recovering from C/S. Those that indicated that they were offered beds to sleep on could not sleep properly as the beds were too far away from where their babies/ children were sleeping. Some participants indicated that the ward activities during the night interrupted their sleep or they had to be awake to assist the nurses with their child's care needs including feeding, changing of diapers and tepid sponging intermittently when the child felt warm to touch.

Honestly, sleeping arrangements here is not the best. Either you sleep in an empty bed far away from your baby or sit in a chair all night if you want to be close to your baby which every mother wants to. I do not get enough sleep. I am even feeling sleepy as I am talking to you. (P10, 35 years)

I sleep in the same bed with my son and I do not get enough sleep because I think about the baby at home. (P8, 40 years)

I have not slept properly since we came on admission and this is making me tired but the nurses help to sit with them so I can rest a little. (P5, 30 years)

I sit on a chair in between their 2 cots. Sometimes I put my head on one of the cots and sleep. I wish I can have a bigger bed to sleep on. (P14, 42 years)

Because I am pregnant, the nurses gave me an empty bed to sleep on both at night and during the day to rest but because of my child's condition my

sleep was disturbed as I have to be checking on her and also to be sponging her intermittently. The nurses do it but she cries and prefers I rather do it. (P12, 25 years).

I sleep on a mat on the floor or sit in a chair during the night. Not comfortable at all. The floor is so hard and cannot sleep for longer periods even when my son is fast asleep. (P1, 34 years)

Unlike the others, one participant said she was happy with her sleeping arrangement.

I was given an empty bed close to my babies (twins) to sleep on so that is where I rest and sleep and my mother stays during the night to give me a hand with their needs so I do get enough sleep. (P2, 24 years)

4.2.3 Loss of autonomy and control

Some mothers expressed losing autonomy and control as far as the child's care was concerned. They had to be assisted in taking care of their own children by the nurses because of the child's condition.

Yes. When my child was on a drip and she was crying on the bed, I did not know how to pick her up but the nurses came to help me pick her up. (P4, 41 years)

I do participate in my child's care needs and being a first time mother, the nurses supervise me to do so or do it for me. I am yet learning every day. (P6, 25 years)

I had a C/S so I feel uncomfortable sitting down and feeding the baby although the nurses help me to put the baby to breast. When you have not prepared your mind to have surgery when you come to have your baby but you have an emergency C/S it is not easy. (P6, 25 years)

The nurses supervise me to take care of the baby because of the gadgets they are using to monitor the baby. I am normally unsure how to even lift the baby up. (P6, 25 years)

4.3 Caregivers' Expectation

Majority of the mothers indicated that they had their expectations met by the health care staff and this was a buffer for them to feel confident in the care that they received from them and also appreciated their presence on the ward.

I am able to ask questions during routine ward rounds and also get answers for questions and doubts expressed from both nurses and doctors. When I have any other doubts, I can still go to the doctors or nurses to ask. (P2, 24 years)

I am expecting them to inform me about my baby's progress all the time. Also to support me to take care of the baby especially when I am out of the ward for a short time. (P10, 35 years)

I am expecting them to tell me what will be done for my baby who has jaundice and they did so. I mean both doctors and nurses. (P5, 30 years)

I expect them to tell me about whatever they do in terms that I will understand and also support me to cope with any fears and anxieties. (P8, 40 years)

I expected them to involve me in every decision they take concerning my child and also to encourage and assist me to look after my sick child. (P10, 35 years)

4.3.1 Support from health care staff

Participants narratives show that they were supported by the health care staff either by giving them a hand in meeting their child's daily living needs or also cuddling the child in their short absence from the ward or when baby is crying. This support from the health care staff made the mothers feel at ease and also have confidence in their care. Majority of the participants indicated that the support given by the health care staff was a great inspiration for them to carry on with their care giving on the ward.

Most of the time, they give me a hand to attend to my baby's needs and encourage me to take care of baby's needs. In fact the nurse here are very supportive. (P6, 25 years)

I do participate in meeting the needs of my child and being a first time mother, the nurses supervise me to do so or do it for me. The staff here show concern. (P6, 25years)

Yes. I am very happy about the way the staff supported me. My family members only did what was beyond the nurses. The nurses pick my baby up when he is crying in my absence. (P9, 32 years)

Very much. The nurses and doctors are very supportive and give you the information you want to know. (P2, 24 years)

However, one participant narrated that she did not feel so supported by the health care staff.

My baby had a problem and needed a paediatrician to see him but was told the doctor was not around but there are paediatric nurses and other general doctors I can talk to. I was not very happy with this answer. (P13, 33 years)

4.4 Economic Effect

Different views and means of payment of hospital bills during their child's hospitalization were reported by the participants. They indicated that the bills were rather expensive and the facility does not accept the NHIS.

4.4.1 Payment of bills

Some of the participants did not have problems with the payment of the hospital expenses since they themselves were either University staff or staff dependants and therefore

exempted from paying. Others had private insurance which the hospital accepted however, those that had to pay expressed difficulty in paying. The hospital also does not accept the NHIS and other modes of payment for example by cheque or mobile money which one participant indicated was so inconveniencing.

Fortunately, we contribute to a private insurance which the hospital accepts so we do not pay any bills upfront. (P5 30 years)

My husband is a staff of the University so we do not pay bills. However, the medicines we are not able to get here, we buy from an outside pharmacy but I will later be reimbursed. (P8, 40 years)

My husband and the little savings I have. We also have the other children to take care of (she sounded very upset and was reassured. (P7, 37 years)

The bills here are very expensive. If you do not prepare well financially before coming then it will definitely be a problem. They do not accept the NHIS here. I hope something can be done about this. (P10, 35 years)

One time I had to pay for some services and I did not have physical cash on me so I asked for a mobile number to transfer the money into and was told the hospital had no such services. I had to struggle a bit before I got money to pay. I was not very happy about this. (P 11, 30 years)

We have problems with paying the bills now. We spent so much at the other hospital and this facility does not accept the NHIS. But my mother and husband have been of immense help. I am also using my savings and we have to prepare for the new baby as well. (P15, 25 years)

4.4.2 Loss of Working Hours

Some participants who are self-employed, had to close down their businesses in order to be with their sick child. They revealed that,

I have closed the place (my shop) temporarily as I cannot trust anyone to operate it in my absence. You see I could have assisted my husband with the payment of bills if I was working. (P3, 43 years)

I am supposed to be helping him (my husband) with some money but I have not been to the market for more than 9 days since I have been on the ward with the child. (P 15, 31 years)

I normally live at Nsawam and I attend ANC there but I came to Accra to trade but I had to be rushed to the hospital because I was not feeling well and I ended up having a caesarean section to deliver my baby. (P7, 37 years)

When I am not around at home, I do not take orders in my absence as a caterer. I am afraid they may not do a good job to satisfy the customer and I can lose my customers. (P4, 41 years).

However, one participant indicated that her business is being managed in her absence

I am a twin so my twin sister looks after my business in my absence. We both sell “slippers” at the Achimota market. (P14, 42 years)

4.5 Coping Strategies

To answer the third research question, “How do the family members cope with the effects of their child’s hospitalization?” The sub –themes family support, reliance on God / prayers and self- motivation were identified as their coping strategies.

4.5.1 Soliciting Family Support

Family support is one of the important coping strategies that majority of the participants indicated enabled them to cope. Two major sources of family support mentioned were support from immediate family members mostly the mother or spouse of the care giver. Support offered by the family members included care of other siblings at home , visiting the sick child and mother in the hospital, bringing food to the care giver in the hospital and also taking care of their business in their absence. Some participants indicated that relatives at home were taking excellent care of dependants at home which gave them a peace of mind

to concentrate on the care of the sick child in hospital .One of the participant who is a first time mother and had her twin babies on admission, had her mother staying on the ward with her assisting her with meeting the care needs of the babies which she reported gave her a lot of confidence and hope.

My sister-in-law takes care of other children at home with my husband and she sleeps with the sick child on the ward at night then I go home .Come back in the morning to take over from her. (P3 43 years)

My mother has been allowed to stay with me and she gives me a hand with the babies because they are twins. (P2, 24 years)

Though my husband is my only dependant at home, I still miss home so my husband visits us two times a day. (P1 34years)

My younger sister takes care of the child's siblings at home and my husband. She normally lives with us so the children are used to her so I feel satisfied and not worried. (P4, 41 years)

My relatives bring food from home every day so I do not have to buy food from outside. (P15, 31 years)

My husband would have taken time off work to look after the baby at home but my mother is doing this. I had to send for my mother from the village to come and help. (P5, 30 years)

My sister brings my baby over during the day and I breastfeed him and he is taken back home. My baby is a good baby and only cries when he is hungry. (P15, 31years)

4.5.2 Reliance on God

Majority of the family members sought religion and prayers as a means of reassurance and hope. They mentioned that numerous religious practices such as prayers, having, faith in God as their child's healer and health provider gives them peace of mind and also assist them to endure the caregiving situation. Some also reassured themselves knowing the

ultimate health provider is God. They believed that praying was likely to reduce the suffering of their hospitalized child thus making faith indispensable to continue looking after sick child.

I believe so much in prayer. Though, the doctors and nurses will do their part but God gives them the knowledge they have so I know my daughter will be well. (P4, 41 years)

Religion is very important to me. We turn to God first when we have any problem including sickness. Whilst here, I pray and read my bible every day. (P8, 40 years)

I normally seek God first, my family members and also church members when in trouble. I have been praying myself and my church members came to visit us and prayed for us. (P5, 30 years)

Religion is our panacea in all our troubles. I have been praying a lot since I came with my baby on admission (P13, 33 years)

Whenever we are in any difficulty, we pray to God first then turn to other family members for assistance like the situation I am in now. (P1, 34 years)

We believe whatever happens is in in the hands of Allah. (P15, 31 years)

Religion is very important to me. I pray with my husband when I am in need of help. Our trust is always in the Lord. (P 8, 40 years)

4.5.3 Self-motivation

Participants in general encouraged and motivated themselves in order to cope with their stay with the hospitalized child. They saw it as a personal duty to contribute to the progress of the child's health, keeping in mind that whatever experience they go through on the ward is for the betterment of the sick child. Self – motivation indicated as:

I speak to siblings on phone (hearing their voices is reassuring that they are ok at home". (P7, 37 years)

I miss him so I speak to him often on phone and I also requested for him to come and visit us on the ward one day which he did. (P9, 32 years)

I know whatever I am going through now is for my baby's sake to get him better so I am ok. (P5, 30 years)

I know I am supposed to be home with my baby by now but the baby needs treatment for her infection so I have to manage for my baby" (P5, 30 years)

I have to leave home to come and stay here when I have so many things to do at home. I am doing so for my sick boy to get better. (P8, 40 years)

It's not very comfortable but I am doing this for my baby's survival. Reassures self that whatever I am doing is for my child's sake. (P1, 34 years)

4.6 Summary

The findings of the study revealed the various aspects of the factors affecting family members with hospitalized children at the Children's Ward of the University Hospital-Legon, Accra. The findings showed that, family members had psychological, social and financial challenges during their child's hospitalization. In order to cope with these effects, the strategies they employed was applied to the resilience and adaptation model where resilience strengthens the family members to adapt positively to the situation and overcome the worst impact of it and also mobilise assistance from family and sometimes community members to cope.

Psychologically, they experienced anxiety, fear, guilt, depression and helplessness during the stay of the family member in hospital. Socially, they encountered disruption of family function, sleep deprivation, loss of autonomy and control. They also experienced financial effects in the form of payment of bills and also loss of working hours. The coping strategies

that most participants used were the reliance on God, prayer, family support and self-motivation.

Finally, a new theme that emerged was the support and expectation from health care staff. The expectations from health care staff in this study was realised as an effective coping strategy. It included effective communication, support and active involvement of family members in the sick child's care.

CHAPTER FIVE

5.0 DISCUSSION

5.1 Introduction

This study explored the psychosocial factors affecting families with hospitalized children and their coping strategies at the Paediatric Ward of the University Hospital, Legon. The chapter discusses the findings of the study in relation to the proposed framework given its relation to existing literature. The discussion is organized on the socio-demographic characteristics of participants, economic, social, psychological effects, family members' expectation of health care personnel and the coping strategies which emerged in the study.

5.2 Socio-demographic Characteristics

The participants in this study were all females who were biological mothers of the hospitalized children. Adoptive mothers perceived significantly higher levels of stress during their child's hospitalization compared to mothers whose biological children were hospitalized (Smith et al., 1997). Although, the caregivers in this study were all biological mothers of the hospitalized children, they still expressed feelings of stress during the interview.

The care giver's role is seen as the preserve of females (Nukunya, 2003). Whereas caretakers could in some cases be males or fathers, in this study no males were identified as caregivers. In Ghana, there is the cultural belief that women are care givers at home as well as during a family member's hospitalization. In the absence of a sister or mother, it is expected that other extended family members will offer to take care of sick relatives. However, the

extended family system is gradually losing its significance (Motha, 2017). Therefore, that expectation is now waning and the task now rests solely on the nuclear family.

Age and parity had no effect on the experiences expressed by the participants. Both multiparous women and first time mothers all expressed feeling of anxiety during their stay in hospital as indicated by the participants in the current study. Participants who had formal education (87%), and those (13%) who had no formal education had similar expectations and also needed answers from the health care team to understand their child's diagnosis and subsequent management to allay their fears and anxieties.

5.3 Psychological Effects

The psychological effects of the participants dwelt on anxiety, fear of death of the child, helplessness, guilt and depression. Beyond the obvious stress and anxiety, parents may also have feelings of insecurity, guilt and fear. Repeat admission as observed in some cases was extremely affecting the wellbeing of the mothers or caregivers. Psychologically, the health impacts were high as some mothers had to share experiences with the social work staff. The participants in this study thus expressed anxiety due to being in an unfamiliar environment (Hayes & Knox, 1984). A study in Britain concerning parental anxiety and stress in families with hospitalized children yielded the same response. However, in Britain, measures are put in place for the family members to cope better on the ward.

The participants expressed anxiety due to being in an unfamiliar environment, delay in diagnosis and subsequent treatment and management, slow progress of the child's condition, alternate care of siblings and other dependants at home as well as the length of stay of the

child in hospital. Anxiety responses examined by Tiedman (1997), of parents of children during and after the hospitalization of their child revealed a positive relationship between parental anxiety and the length of stay of the child in hospital. No interventions are put in place on paediatric wards in developing countries to help mothers to cope as reported by the participants as compared to developed countries.

Parental anxiety and stress with hospitalized children in Britain, discussed the perceptions of parents especially children with long term disabilities and required repeated admissions. On the contrary, in this study, there were no children with long term disabilities and majority of the children have not been admitted to a ward before but parents still expressed anxiety. The caregivers indicated the need to understand the child's illness, become familiar with the hospital environment and also negotiate care with the health care staff (Hayes & Knox, 1984).

The current study, showed as in other studies, that most mothers need more communication and explanation from nursing staff about different procedures, their role, and contribution in medical procedures, to provide better care for their children (Lam, Chang, & Morrissey 2006). Some participants reported they would rather prefer to be with their sick child during invasive procedures as the presence of a familiar face will make them less frightened. Contrary to this, in a study by Callery (1997), parents described feelings of upset by involvement in some aspects of care for example staying with the child during painful procedures.

The participants reported that their source of fear was attributed to being unable to pick and hold their child due to the various gadgets attached to the child contrary to what mothers reported as fear of their child dying in a study by Tehrani (2012) in Iran. In addition, they expressed fear because they were unsure how to meet their child's activities of daily living (ADL) needs unless assisted by a nurse to do so. As well, the feeling of helplessness was expressed by majority of the participants in the current study. This was experienced when there was delay with the diagnosis of the child's condition, not being reassured enough whilst waiting for child to go to theatre and also when child's admission was not anticipated.

Beyond the obvious stress and anxiety, parents may also have feelings of insecurity and guilt and fear (Hopia et al., 2005). Another psychological effect the participants experienced in this study was the feeling of guilt, similar to what was found by Hopia et al., (2005). However, the authors reported insecurity and fear as psychological effects on caregivers. Some of the family members blamed themselves for being the cause of their child's illness. Another also indicated her inability to feed her new born properly which caused baby to develop jaundice from dehydration.

The participants indicated they would appreciate daily information on the child's progress from the health care staff to allay their fears and anxieties. Callery (1997), reported that parents of hospitalized children go through a lot of emotional and psychological problems which health care professionals need to help them with including keeping them informed about the child's progress of health to reduce their anxiety, fear and helplessness.

5.4 Social Effects

Participants reported the disruption of family functions, sleep deprivation, loss of autonomy and control, alternative care of sick child's siblings, responsibility of taking care of the sick child on the ward as the social effects of the hospitalized child on the family. Shields & O'Callaghan (2003), indicated that during a child's admission, health care professionals particularly nurses should view the child as a member of a family unit and as a result other members of this family also present with problems that should not be ignored.

The phenomenon of disruption of family functions stemmed from mother leaving home to stay with the sick child in hospital for the entire duration of their admission therefore another family member needed to look after other dependants at home including siblings and spouses. Allowing the mother to stay at the hospital with the sick child, is a strategy that makes it possible to strengthen the emotional bonds, reduce the emotional stress of both child and the family, consequently contributing to a shorter time of hospitalization (Hopia et al., 2005). Though participants reported that other family members were taking care of siblings and dependants at home, they were not too happy with this arrangements and wanted to do it themselves. Others missed their children so much that they spoke with them on phone on a daily basis. Participants whose were those on admission were calmer and more relaxed than their counter parts with other children at home. This was because the caretaker or mother could concentrate on the affected child without feeling a sense of having neglected the other children.

Another social effect that was reported was sleep deprivation. Participants attributed lack of sleep to poor sleeping arrangements, taking care of their child's needs during the night and

also noise from the usual ward activities. This finding agrees with (Mathews, Neu, Cook & King 2014; McCann 2008; McLooree, Wakefield, Yoong, & Gohn, 2013) parents of hospitalized children experience reduced sleep duration increased night time awakening and difficulty falling asleep. Mostly, the participants that have had C/S complained about their lack of sleeping and how this was making them tired and their wound sites painful. However, reports of poor sleep quality in hospital suggest that family members may experience negative mood and difficulty in making decisions under such circumstances (Harrison & Horne, 1999). Sleep deprivation has significant impact on the health of parents due to the stress involved in taking care of the sick child.

The participants indicated that they felt supported when they were involved in every decision making concerning their hospitalized child and as such had no problems with their moods. Additionally, where there was a relief for parents by other relatives coming in to sleep with child or admitted ward, sleep deprivation was less and child care more bearable.

5.5 Economic Effects

With regards to the economic effects of child's hospitalization on the family through the payment of bills and loss of working hours; the non-acceptance of the NHIS at the health facility was reported. Families often face financial challenges in achieving proximity to their child because of difficulties with transportation, food and lodging, care of other children and dependants and loss of wages due to absence from work (Dzifazio & Vessey, 2013). Though the participants in the current study were resident on the ward and therefore did not have to travel to visit their sick child, the purchase of food was still a burden for them as they lamented food outside was expensive. Personal articles bought for the upkeep of caretaker and the hospitalized child did affect the purses of the family leading to high

indebtedness in some cases to the extent of default in loans. Some workplaces had allowances for staff with hospitalized wards. Support from employer in some cases was not present and could lead to loss of work. The loss of work hours economically affected productive for self-employed caretakers who had to bear the cost of child care all in the best interest of their child.

In this study, economic support did come for some participants who indicated that their immediate family members (mostly husbands) did help shoulder the cost burden. Such contributions not only relieved them economically but also psychologically. Additionally, some participants reported that they were University staff and therefore were exempted from paying bills as well as those with private insurance schemes who would be assisted by their insurers and help get a solid arm to lean on. This finding supports Tehrani et al., (2012) observation that mothers with no medical insurance had problems settling hospital bills in a study done in Iran.

5.6 Caregiver's expectation of health care staff

One that emerged was the expectations of family members which included: involving them in decision making, good communication and support of family members by the nursing staff. In this study, participants were more than happy to participate in their child's care when they were supported to do so. On the other hand, some caretakers and mothers were likely to move their wards to other health facility for factors they considered as poor health care delivery. Some of the factors mentioned was the harsh treatment meted to caretakers by health care providers be it nurses, ward assistants and doctors. Some pointed out how they detested the apathy exhibited by some health care providers in those hard times of caring for the hospitalized child. Thus, such mothers and caretakers dreaded visits to the

health facilities and repeated visits were not frequent as they would naturally be drawn to where quality health service delivery was guaranteed.

Good communication with the medical team and opportunities for participation are thus helpful in reducing stress (Board & Ryan-Wenger, 2003). For this case study, the participants indicated in this study that their expectations were met by the health care staff. Most of their questions about the sick child were answered and clarifications given to make them less anxious. The participants indicated that they felt supported when they were involved in every decision making concerning their hospitalized child and as such had no problems with their moods. A study done in Iran reported that the mothers' source of worry and stress was due to staff being unfriendly and they were therefore afraid to ask questions different from what was indicated in the current study (Tehrani et al., 2012).

5.7 Coping Strategies

The coping strategies in this study included family support, reliance on God and self-motivation and the key theme was family support. Participants reported they were being supported to cope by family members opting to take care of other siblings and dependants at home, bringing them food from home, assisting them to settle hospital bills and also looking after their businesses in their absence. Reports from some participants indicated that family members assisted them in the performance of domestic activities (Fennell et al., 2016).

Members of the extended family are expected to assist members of the family during sickness and in times of need but because we live far away from our extended family members nowadays, the participants indicated they were assisted by members of the nuclear family. Families have strengths, resources and expertise that can be mobilised to deal successfully with the effects of a child's hospitalization (McCubbin & Patterson, 1981). One of such strengths is the support of family members in times of crises.

Findings from the study indicated that, reliance on God was an adopted mechanism by the participants (Nukunya, 2003). Majority of the participants relied on God, both Muslims and Christians for the healing process of their sick child. Reliance on God was characterized by increased frequency in prayer which brings family members closer to God. Some participants also motivated themselves that whatever situation they were going through was for their child's sake and this reassured them.

5.8 Study Limitation

The study was conducted in a general ward. The participants in this study were all females and also married. Thus, the applicability of the results is limited to married women and females. Additionally, the results cannot be generalized since the study was done in one facility only and the sample size is small and cannot be said to be representative of the target population.

CHAPTER SIX

6.0 CONCLUSION

6.1 Introduction

This chapter outlines the conclusion and recommendations of the study. This study set out to explore the psychosocial and economic factors affecting families of hospitalized children and their coping strategies. The study employed a qualitative exploratory descriptive design. A semi-structured interview guide was used based on the objectives of the study which was conducted at the University Hospital, Legon. Ethical approval was obtained from the Ethical Approval Committee of the Ghana Health Service prior to the collection of data. Pre-testing of the interview guide was done at the Achimota Hospital to ensure clarity of the questions and also to ascertain if they will answer the research questions. Participants who were ready to take part in the study were consented and they were interviewed.

The key findings revealed that majority of the family members especially those staying on the ward with the hospitalized children, experienced psychological effects such as anxiety, fear, guilt, helplessness and depression which was attributed to the unfamiliar environment, uncertainty with child's diagnosis and the outcome, lack of information from health care staff. Another major concern to most participants was sleep deprivation due to poor sleeping arrangements as the mothers had to sit on a chair during the night if they desired to be close to their child otherwise they could sleep in a bed so far away from their child. This was expressed by fourteen out of the fifteen participants.

Financial burden was indicated as one of the factors that affected the family due to payment of medical bills, mothers not having the NHIS and had to pay for medical bills and also loss of working hours. Disruption of family functions consisted of relying on other family members to take care of their homes and their dependants in their absence and also their businesses. Support systems expressed for coping included support from family members, reliance on God and prayer and most importantly support from family members which helped most participants to adjust as reported in the resilience and adaptation model.

It was revealed in the study that both Muslims and Christians rely on God and prayers in time of family crises. Lastly, another theme that emerged was expectations from health care staff which included involving the care givers (family members) in decision making and also adequate information on the progress of the child. Hospitalization of a child remains a stressful phenomenon for family members especially the one staying with the sick child at the hospital to help the nurses with the care needs and also to keep them company. However, most health facilities do not even have enough space to accommodate these family members on the ward including sleeping arrangements for the night. It is the dual responsibility of the health care staff to look after the sick child and necessary for the other members to be provided with adequate information about the progress of the child and also involve them actively in the care needs of the child to allay any anxieties that may be expressed by the family member staying on the ward.

6.2 Implications for Policy, Research and Public Health

The findings of the current study have implications for policy, research and public health. With regards to policy, the government of Ghana through the MOH, NGOs and other stakeholders must ensure that mothers are properly accommodated by providing hostels and

extra beds on paediatric wards throughout the country to enable caregivers have a reasonable resting place and perform the needed roles during a child's admission without stress. The NHIS must also be accepted in all facilities that offer treatment to sick children especially those on admission. Research is needed to document further the exact requirements of children and their families in health care settings especially in Sub-Saharan Africa as evidenced by literature review. There is evidence that some mothers with babies/ wards admitted to PICU suffer Post-Traumatic Stress Disorder (PTSD) long after their babies/ wards are discharged from hospital.

Public health education on children must be strengthened in order to control the admission of children to the hospital by health care providers especially Community Health Nurses at Child Welfare Clinics as the mothers bring the children for their routine immunizations. Families with hospitalized children go through psychosocial problems which can be intervened by health care professionals when they are on the ward whether short or long stay. These problems must be anticipated immediately a child is admitted to the ward and not compromised to escalate them.

6.3 Recommendations

The following recommendations have been made to the Ministry of Health and the University Hospital, Legon.

6.3.1 Ministry of Health

1. The NHIS must be accepted in all health facilities that take care of hospitalized children.

2. The Ministry of Health, NGOs and other stakeholders should provide mothers' hostel in all health facilities to accommodate family members or caregivers during their stay with their hospitalized children so that they will not have to travel far from their homes to access specialized children's care.
3. Public education for families on child care should be provided by the Ghana Health Service through television and radio programmes on how to cope with the stress of caring for hospitalized children.

6.3.2 The University Hospital

1. Hospital management must provide an "admission pack" on the ward for every family member indicating what to expect during your child's admission and who and where to go to for assistance on the ward.
2. Family members must be part of all decision making concerning the care of the hospitalized child.
3. Arrangements of schemes like pre-admission visit must be instituted in elective paediatric admissions to make the hospital environment less frightening for both child and care givers.
4. Provision of supporting social services for example a social worker should be attached to each facility to provide counselling and social support to families during a child's hospitalization.
5. Proper comprehensive nursing care planning must be instituted and maintained to reduce the hospitalized child's length of stay in the hospital.
6. The hospital should accept the NHIS so that the payment of bills can be affordable by the families.

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APPENDICES

Appendix I - Respondent Information Sheet

General Information

Project Title: Psychosocial factors affecting families with hospitalized children at the University Hospital, Legon.

I am Philomina Oti Dua (Interviewer). A student of the Department of Population, Family and Reproductive Health in the School of Public Health master's programme. I am here with my research assistants to carry out a survey to find out the effects of hospitalization of children on the family. This is purely for academic purposes and forms part of the requirement for the award of masters of Public Health Degree. The researcher has no conflict of interest in their study.

Procedure

The study will involve answering questions from an interview guide to the effects of hospitalization of children on the family. The information provide will add to knowledge and inform stakeholders about the effects of hospitalization of children on the family and propose some interventions.

Benefits and Risks

There will be no monetary or material compensation for the study. There are also no known risks associated with this study and I am always available to assist with any questions.

Confidentiality

No name will be recorded. Your name and identity are not needed in the study. However the information. However the information you are going to provide will be coded treated as strictly confidential. You are assured of total confidentiality to information you will give. Apart from the researcher and supervisor of this research, no one else will have access to information whether in part or in whole. Data collected will be stored under lock and key and then destroyed after a minimum of three years as per protocol.

Right to Refuse

Participation in this study is voluntary. You are free to stop the interview at any time you want. You can also choose not to answer any question(s) you find uncomfortable. Should you choose not to participate, it will not affect you in anyway. However, you are encouraged to participate fully in this study to help find out the effects of Hospitalization of children on the family in Accra, Ghana and beyond.

Dissemination of Results

Findings and recommendations would be available at the school of public health and it will also be disseminated through a meeting with different stakeholders at the end of the study.

Before Taking Consent

Do you have any questions you wish to ask about the study? Yes/No.

If you have any question(s) or further clarification concerning this study and/or the conduct of the researcher and research assistants, please do not hesitate to contact the following;

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Ethical Review Secretariat

Accra-Ghana

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Appendix II: Informant Consent

I have read the information given above and I understand. I have been given this study and questions have been answered to my satisfaction. I now voluntarily agree to participate in this study knowing that I have the right to withdraw at any time without it affecting my current or future use of health care services.

Signature/Thumbprint

Date.....

Contact detail.....

I, the undersigned, have explained this consent to the respondent in English/Twi and that she/he understands the purpose of the study, procedures to be followed as well as the risks and benefits of the study. The participant has fully agreed to participate in the study.

Signature/ of Interviewer

Date.....

Appendix III: Interview Guide for Mothers

Greet! Introduce yourself and the purpose of the study being undertaken. This study is primarily interested in your opinions about how you feel staying with your hospitalized child. What I mean is how your stay is affecting your psychological, social and personal needs and your coping strategies.

A. Background Characteristics

1. Demography age, sex, marital status, occupation, level of education, religion and parity.
2. How important is religion to you and your family?
3. How old is your child on admission?
4. How many times has your child been admitted to the hospital in the past?
5. How many children do you have apart from the one on admission?
6. What is the position of the sick child within your children?

B. Health Care Professionals Support

1. What kind of support do you expect from the healthcare staff during your stay?
2. Do you participate in your child's care and are you encouraged to do so?
3. Are you allowed to ask questions during routine ward rounds?
4. Were you asked before being allowed to participate in your child's care?
5. How do you access information about your child's condition on the ward apart from during ward round?
6. How do you cope with your stay in hospital?

C. Care of siblings and other dependants at home

1. Who takes care of your husband and other dependants while you are here?
2. How are you able to speak with them?
3. How worried are you about their welfare?

D. Psychological Impact of your stay in hospital

1. Where do you sleep during the night on the ward?
2. Do you get enough sleep?
3. How do you rest during the day after attending to your child's needs?
4. How has your child's admission affected you and the family?

E. Financial impact of child's hospitalization

1. Who pays the hospital bills?
2. How has the payment of medical bills affected you and your family?
3. How do you eat on the ward?
4. If you are self-employed, how is your business managed in your absence?
5. Do your employers know about your child's admission?
6. How do your employers react to your absence?