

**FACTORS CONTRIBUTING TO PRIMARY CARE GIVERS' DELAY IN  
PRESENTING CHILDREN WITH CHRONIC KIDNEY DISEASE FOR MEDICAL  
CARE IN GHANA**

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## **ABSTRACT**

Chronic kidney disease (CKD) in children has become a public health problem in Ghana. The researcher observed that children are presented late for medical care by their primary care givers. This ignited the researcher to conduct this study to identify the factors that contribute to primary care givers' delay in seeking early medical care for children with CKD.

The purpose of the study was to explore and describe the factors that contribute to primary care givers' delay in presenting children who suffer from CKD for medical care in Ghana.

A descriptive qualitative design was used to answer the research question: What factors contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana? Convenience sampling was used to recruit ten primary care givers of children admitted for CKD at the Paediatric Renal Unit of Komfo Anokye Teaching Hospital in Kumasi, Ghana, to participate in the study. Semi-structured interviews and field notes were used to collect data.

The thematic data analysis approach of Colaizzi (1978) cited by Polit and Beck (2014:309) was used, and the ecological model of Schneider (2017) assisted in organising themes and subthemes. The themes which emerged are: intrapersonal-related factors contributing to delay; interpersonal-related factors contributing to delay; community-related factors contributing to delay; and public policy-related factors contributing to delay. These were directly related to the research question. A fifth theme which emerged serendipitously is the need for a community awareness campaign.

The findings revealed that intrapersonal, interpersonal, community and political level factors influence primary care givers' decisions in seeking medical care for their children. At intrapersonal level factors that played a role were personal attitudes and

beliefs; primary care givers' beliefs in traditional medicine as a cure for CKD; their lack of knowledge on CKD and its management; primary care givers' financial constraints; and their beliefs in ancestral spiritual powers for healing. At interpersonal level factors included primary care givers' lack of family support and marital conflicts. At community level factors included primary care givers' delayed referral from the local health facility; incorrect advice received from family and neighbours on management; mismanagement of the disease at the local health facility; and misdiagnosis by neighbours. At political level the distance of the primary care givers' homes from the hospital can contribute to delays.

One of the recommendations of the study is development and implementation of a national referral policy for CKD patients, to guide health practitioners at the districts. Early referral for appropriate treatment of children with CKD can slow progression of the disease and prevent early mortality.

Awareness campaigns need to be developed and implemented by the Ghana Kidney Association to provide health educational programmes for health professionals and communities. Further research using a larger sample or quantitative research methods is also recommended, to gain a better understanding of the factors contributing to delays in presentation of children with CKD in Ghana.

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## LIST OF ABBREVIATIONS

ACEI	Angiotensin-converting enzyme inhibitor
AKI	Acute kidney injury
ARB	Angiotensin-receptor blocker
CKD	Chronic kidney disease
GFR	Glomerular filtration rate
KATH	Komfo Anokye Teaching Hospital
PD	Peritoneal dialysis
rhGH	Recombinant growth hormone
RRT	Renal replacement therapy
UCT	University of Cape Town
WMA	World Medical Association

## CHAPTER ONE

### OVERVIEW OF THE STUDY

#### 1.1 Introduction

Chronic kidney disease (CKD) is the universal term for heterogeneous disorders which affect the kidney's structure and function (Levey & Coresh, 2012:165). It is a clinical term that is used when the damage to the kidney has reached an irreversible state, or where there is a reduction of kidney function which persists for three months or longer, with or without a decreased glomerular filtration rate (GFR) (Harambat et al., 2012:364; Amr et al., 2013:67; Lowth, 2013:34).

CKD is rising in developed and developing countries, in both adults and children, and has become a major public health problem (Warady & Chadha, 2007:1999; Harambat et al., 2012:363). Marsenic and Baluarte (2011:401) suggest that the incidence and prevalence of CKD, including its early stages, is 12.1 per million children and adolescents in the United States of America, while the yearly incidence and prevalence of late-stage CKD is reported as ranging from 5.7 to 14.8 per million children in different countries.

In Africa CKD has been attributed to occupational and environmental exposure to chemicals which include lead, mercury and cadmium (James, Hemmelgarn & Tonelli, 2010:1297-1298). According to James and partners (2010:1298), the increasing problem of chronic non-communicable diseases seen in many developing countries will possibly lead to striking corresponding rises in prevalence of CKD and kidney failure in Africa over the next two decades. The prevailing causes of CKD in adults are hypertension and diabetic nephropathy, but approximately 60-70% of children affected with CKD have congenital or inherited kidney disorders (Staples et al., 2010:2172).

## **1.2 Rationale**

Evidence from developed countries shows that the progression and complications of CKD can be slowed, delayed or even prevented (Mathew & Corso, 2009:367; Crockell, 2012:230). However, the general observation by the researcher, who is a registered nurse in a Renal Unit in one of the teaching hospitals in Ghana, is that children with CKD are brought to hospitals with late-stage CKD, when the child's condition has deteriorated and very little can be done medically to alleviate their suffering. This observation is unique to children with CKD, because children with other health conditions, such as diarrhoeal disease, are brought in early for medical care. This triggered a need in the researcher to investigate the primary care givers' views on the factors that contribute to delays in presenting children with CKD for medical care.

## **1.3 Problem statement**

Evidence shows that if detected early, the progress of CKD in children can be slowed down and the complications, including early death, can be prevented (Mathew & Corso, 2009:367; Crockell, 2012:236). However, in Ghana it has been observed that primary care givers delay in presenting their children who suffer from CKD for medical care. These children are brought to hospitals with severe complications which are difficult to treat or manage, and result in increased deaths among these patients. Managing these severe complications of CKD increases medical care and is a huge burden on the health system of the country. Exploring and describing care givers' perspectives on the factors that contribute to the delay in presenting children with CKD to hospital is important in order to inform health education programmes on how to educate primary care givers and the public about CKD in children for the prevention of early death.

## **1.4 Purpose of the study**

The purpose of this study is to explore and describe the factors that contribute to primary care givers' delay in presenting children with CKD for medical care.

## **1.5 Objectives of the study**

1. To explore and describe the factors that contribute to primary care givers' delay in presenting children with CKD for medical care.

## **1.6 Research question**

The following is the research question that was addressed by this study: What factors contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana?

## **1.7 Definition of terms**

**Child:** A child in this study is anyone between the ages of 4 months and 18 years old who has been diagnosed with CKD after the required investigations. However, according to the 1992 Constitution of the Republic Ghana, a child refers to someone from birth to the age of 18 years.

**Chronic kidney disease (CKD):** This is the universal term for heterogeneous disorders which affect the kidney's structure and function, where damage to the kidney has reached an irreversible state.

**Delay in presenting to hospital:** For the purpose of this study delay in presenting the child to hospital means presenting the child with CKD to the hospital for medical care more than a month after the initial observation of signs and symptoms of CKD. The latter include oedema, oliguria, anorexia, fatigue, weakness and persistent headache.

**Primary care givers:** This refers to anyone who has a primary responsibility to nurture and care for a child who suffers from CKD. This could be a biological parent or a guardian/care giver.

## **1.8 Outline of the study**

### **Chapter 1**

This chapter provides an introduction to the background of the study, the rationale and the problem statement. It also outlines the purpose, objectives and research question of the study. It ends with the definition of terms related to the study. The main aim is to give a broad picture of the study and motivate for the need for it to be carried out.

### **Chapter 2**

This chapter outlines the literature pertaining to the factors that contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana.

### **Chapter 3**

This chapter discusses the research design and research methods used throughout the study as well as the ethical considerations, and concludes with the limitations of the study.

### **Chapter 4**

This chapter provides a detailed description of the data management and data analysis methods used in the study. It further elaborates on how trustworthiness was ensured in this study.

### **Chapter 5**

This chapter describes the characteristics of the study participants and provides details on the themes identified as findings of the study.

## **Chapter 6**

This is the final chapter, which discusses the findings, recommendations and conclusions of the study. The references and the appendices are found at the end of the dissertation.

### **1.9 Conclusion**

This chapter provided an introduction to the study, the rationale for the study, problem statement, purpose, objectives and research question of the study. It concluded with a definition of terms of the study and an outline of the structure of the dissertation.

## CHAPTER TWO

### LITERATURE REVIEW

#### **2.1 Introduction**

This chapter outlines the results of a literature review conducted prior to development of the study proposal. The reviewed literature was used to develop the proposal for the study and also served as the baseline information to start the research process. This is supported by Grove, Gray and Burns (2015:163), who state that the benefits of reviewing the literature lie in the description of current knowledge about the study and identification of gaps in that knowledge, as well as contributing towards development of the study proposal.

The literature reviewed prior to development of the study proposal revealed a lack of literature on the factors that contribute to primary care givers' delay in seeking medical care for children with CKD in Ghana.

Further review of the literature was conducted during the research process to guide the researcher in interpreting and analysing data. This literature also assisted the researcher to avoid the prospect of research errors that could have influenced the data collection, data analysis and findings of the study (Grove, Gray & Burns, 2015:164). The literature reviewed during data analysis was used to confirm the themes that emerged as findings of the study and to allow for discussion of findings.

The search engines that were used to search for literature were CINAHL, MEDLINE, Africa-wide information, Google Scholar and eBook collection (EBSCOhost). Literature from 1991 to 2016 was included, including both African and international literature. The search terms used included epidemiology of CKD, factors contributing to delay in reporting, impact of CKD on children, outcome of early recognition, outcome of delay referral, early referral, management of CKD, and experience of primary care givers of CKD.

## 2.2 CKD in children

Literature reviewed revealed that CKD has now become a serious, common and high-priority public health problem. Its incidence is increasing across the world and children with CKD impose a great burden on society, which is rising regardless of ongoing efforts to control the disease (Assadi, 2012:61). Harambat and Ekulu (2016:355) assert that CKD prevalence is higher in individuals from low- and middle-income countries. According to Assadi (2012:61) the global prevalence of children with CKD below stage 2 is reported to be between 18.5 and 58.3 per million. The author emphasised that children who are at risk of CKD are those with congenital anomalies of the kidney and urinary tract, hereditary disorders such as medullary cystic disease and polycystic kidney disease, prematurity and low birth weight, or a family history of CKD.

Literature reviewed further revealed that the incidence and prevalence of CKD are greater in boys than girls due to the higher incidence of male congenital anomalies of the kidney and urinary tract, such as renal hypoplasia, obstructive uropathy, prune belly syndrome and renal dysplasia (Marsenic & Baluarte, 2011:401). Jayaraman and Van der Voort (2010:291) suggest that CKD in children may be due to congenital, inherited, acquired or metabolic renal disease. They also reported that the underlying cause correlates with the age of the patient at the time that CKD is first detected. For instance, children less than five years of age are commonly affected as a result of congenital abnormalities such as obstructive uropathy, renal hypoplasia or dysplasia (Jayaraman & Van der Voort, 2010:291; Lowth, 2013:35). On the other hand, children above five years of age may be affected by the disease through various forms of glomerulonephritis, including lupus nephritis, and inherited disorders including familial juvenile nephronophthisis (Sreedharan & Avner, 2016:2543-2544). Harambat and Ekulu (2016:355) posit that besides genetic causes of CKD, infectious diseases like recurrent urinary tract infection, low birth weight, poor sanitation, early malnutrition and traditional medications may result in CKD.

Crockell (2012:228-229) suggests that CKD can be detected by proteinuria, which is an early and sensitive marker of kidney damage. It is essential to monitor proteinuria because increased levels can lead to fast progression of CKD, and are also an indicator of patient risk for cardiovascular disease. The author further states that the presence of protein in the urine may assist in establishing the prime cause of CKD. Marsenic and Baluarte (2011:401) state that the stages of CKD for children older than two years are based on estimated glomerular filtration rate (GFR) using the Schwartz equation, which aims at promoting early detection and treatment of CKD.

CKD in children is manifested in oliguria or polyuria, oedema, hypertension, proteinuria and haematuria (Marsenic & Baluarte, 2011:402; Sreedharan & Avner, 2016:2544), but the clinical manifestations depend on the severity of the renal disease and the underlying cause. In the early stages of CKD glomerular diseases frequently present with hypertension, oedema, haematuria and proteinuria. Polyuria may be an early symptom of congenital anomalies of the kidney and urinary tract, for example, obstructive uropathy, inherited disorder (e.g. nephronophthisis) and tubulo-interstitial disorders caused by impairment in renal concentrating ability, which precede a significant reduction in GFR. Poor growth is a common manifestation in CKD children. More severe symptoms and signs like weakness, vomiting, anorexia, fatigue, fever, arthralgia and rash begin to appear with CKD stage 3, and worsen in stages 4 and 5 (Marsenic & Baluarte, 2011:402; Kennedy, Bailey & Kainer, 2012:256).

### **2.3 Management of CKD in children**

Literature reviewed show that the principal management of CKD aims at controlling reversible factors such as vomiting, diarrhoea, infections, nephrotoxic drugs and inflammation, in the belief that this will slow down and prevent the progression of further damage to kidney function (Jayaraman & Van der Voort, 2010:292). Slowing the progression of CKD is attained by controlling hypertension and decreasing proteinuria, as these are known to hasten the progression of CKD. Principally angiotensin-

converting enzyme inhibitors (ACEIs) and angiotensin-receptor blockers (ARBs) are used as treatment in this regard. However, children with renal failure and polyuria do not generally tolerate such drugs, as a result of a decrease in perfusion pressure, causing further reduction in GFR (Jayaraman & Van der Voort, 2010:292). Therefore the dosages of these drugs should be adjusted against the GFR.

Further studies suggested that oral alkali therapy not only slows down the progression of CKD (Watnick & Dirkx, 2013:915) but is also used to prevent muscle wasting and bone disease and to improve nutritional status (Sahni, Rosa & Batlle, 2010:1065). Magnesium-containing medications such as laxatives and antacids should be avoided, as well as phosphorus-containing medicines, particularly cathartics (Watnick & Dirkx, 2013:915). The administration of supra-physiological recombinant growth hormone (rhGH) is used to overcome stunted growth, a common problem in children with CKD (Seikaly et al., 2009:1712).

## **2.4 Management of complications**

According to Sreedharan and Avner (2016:2545) the complications of CKD can be managed through appropriate nutrition. This confirms what Rees and Mak (2011:615) assert: children with CKD have a high mortality rate as compared with healthy children of the same age because of inadequate nutrition. They further states that it is not only inadequate nutrition that can result in poor growth, but also other contributing factors such as metabolic derangement, cachexia, anaemia and growth hormone resistance, which may result from the impaired kidney function and worsen as the disease progresses (Rees & Mak, 2011:615). Managing CKD children with nutritional complications is essential when they are referred early to a paediatric nephrologist, in order to assist in preventing the growth retardation which might result in death if not well managed. This includes addition of iron-containing foods and folate supplementation to manage anaemia, a common problem among children suffering

from CKD (Koshy & Geary, 2008:209). Managing anaemia and nutrition improve the cognitive outcome of children (Jayaraman & Van der Voort, 2010:294).

Children with CKD often die from cardiovascular complications like hypertension and infections rather than the kidney impairment (Assadi, 2012:61). Hypertension is among the most common complications of CKD in children and is a crucial determinant of CKD progression resulting in cardiovascular death. The preferred antihypertensive medication for CKD children, if tolerated, can be either ACEIs or ARBs, and they should be closely monitored (Hadtstein & Schaefer, 2008; Dionne, 2015:1923). Dionne (2015:1920) suggests that their blood pressure should also be monitored with the appropriate equipment whilst on medication to detect any abnormality. CKD also has a detrimental effect on bone, and in children management is by both medication and a phosphate-lowering diet (Swolin-Eide, Hansson & Magnusson, 2009:367; Bacchetta et al., 2011:594).

Evidence shows that if detected early, the progress of CKD in children can be slowed down and complications can be prevented (Mathew & Corso, 2009:371; Jayaraman & Van der Voort, 2010:292; Crockell, 2012:230; Wilson et al., 2012:326). Additionally, early presentation of patients with CKD is essential so that treatment can be implemented to reduce the risk of complications like cardiovascular events and progression of the kidneys' function to failure (James, Hemmelgarn & Tonelli, 2010:2172).

## **2.5 Management of CKD in African countries**

Although CKD patients in some parts of Africa, including South Africa and Tanzania, have access to dialysis and other forms of management for CKD, in Ghana this is not the case. In South Africa there is a formalised set of guidelines by the Department of Health for renal replacement therapy (RRT). Candidates are selected based on specific criteria. Those who do not meet the criteria for renal therapy in the Government institutions may either go to private dialysis centres or be on conservative treatment until they die (Etheredge & Paget, 2015:234).

A study conducted in Nigeria by Odubanjo, Oluwasola and Kadiri (2011:790) revealed that in Nigeria RRT is available in four teaching hospitals. However there is limited access due to inadequate funding, negative cultural beliefs towards organ donation, frequent breakdown of dialysis machines, and lack of appropriate health policies based on data derived from the renal registry. These authors also assert that RRT centres are based in the urban areas, with limited accessibility to people in the rural areas. This means that those who cannot afford RRT are left to die on conservative treatment, since there are either no government funds or no insurance to cover the cost of treatment.

The peritoneal dialysis (PD) programme was initiated in 2009 at Kilimanjaro Christian Medical Centre, Moshi. The initial focus of the programme was to treat women of childbearing age and children with acute kidney injury (AKI). The programme has been extended to men with AKI and a few children with AKI (Callegari et al., 2012:331; 333).

In Ghana only two teaching hospitals offer PD for children with AKI: KATH and Korle Bu Teaching Hospital, but there are currently no haemodialysis or PD options for children with CKD. These children receive conservative treatment until they die. Nevertheless, there are treatment modalities for children with other renal problems such as nephrotic or nephritic syndrome.

## **2.6 Factors that contribute to delay in seeking medical care**

A study conducted in Ghana revealed that factors that contribute to delay in presentation of chronic diseases, for example breast cancer, include poverty, traditional and spiritual beliefs and lack of knowledge (Asoogo & Duma, 2015:4-5). Furthermore, Kennedy, Bailey and Kainer (2012:253) posit that in Australia delayed presentation was due to the time of referral by a physician, where primary renal disease was not considered significant, which tends to have intense effects on children's total quality of life.

A study conducted in Brazil on children with CKD and their access to the RRT by Harambat and Ekulu (2016:353) revealed the inequality of access of children from low-income areas as well as health-related organisational structures, are deprived from accessing kidney transplantation, which attributed to factors that delay seeking health care by their primary care givers. Hidalgo and others (2013:1087) confirm that financial and societal burdens on low-income families with children suffering from CKD means these households may have limited resources for medication and difficulty in accessing health care. This can lead to decreased kidney function and subsequently disease progression to its end stage.

## **2.7 Conclusion**

The literature reviewed prior to development of the study proposal revealed a lack of literature on the factors that contribute to primary care givers' delay in seeking medical care for children with CKD in Ghana. This identified gap supported the need for the current study.

The literature reviewed during the research process guided and supported data collection and analysis and interpretation of data, which will be highlighted in the following chapters.

## CHAPTER THREE

### METHODOLOGY

#### 3.1 Introduction

This chapter discusses the study design and research methods used to conduct the study and the ethical considerations applied throughout. It also includes the limitations of the study.

The purpose of the study was to explore and describe factors that contribute to care givers' delay in presenting children with CKD for medical care in Ghana.

#### 3.2 Study design

A descriptive qualitative study design was used, since this explores and describes phenomena in real-life situations and provides a true account of characteristics of a particular individual or situation (Grove, Gray & Burns, 2015:33). Descriptive qualitative studies tend to be eclectic in their design and methods and are based on the general premises of constructivist inquiry. They are commonly used in nursing research because of the naturalistic inquiry of the qualitative data (Polit & Beck, 2014:274-275). Qualitative study describes experiences and situations from the perspective of the person involved, such experiences being considered unique to that individual (Grove, Gray & Burns, 2015:67).

A descriptive qualitative study design was regarded as suitable for this study because it assisted the researcher to carefully explore and describe the factors that contribute to primary care givers' delay in presenting their children suffering from CKD to the hospital for medical care, as confirmed by the annual statistics of the Paediatric Renal Unit of the Komfo Anokye Teaching Hospital in Kumasi, Ghana (Komfo Anokye Teaching Hospital, 2016). Polit and Beck (2012:495) assert that descriptive qualitative research designs assist the researchers to carefully describe the ordinary conscious experiences of the participants, such as feelings and beliefs.

The four phases involved in descriptive design were used: bracketing, intuiting, analysing and describing.

Bracketing involves the process of identifying and holding back any preconceived ideas and beliefs about the research question under study (Polit & Beck, 2012:495). The researcher employed this by clarifying any of her personal values and identified areas that could have had an influence on the study.

Intuiting is when researchers remain open to the meanings attributed to the phenomena by those who experience them (Carpenter, 2007:85). This was achieved as the researcher paid strict attention to the research question and interpreted the findings exactly as described by participants.

Data analysis is the organisation and synthesising of data to answer the research question under study and give meaning to the data (Polit & Beck, 2014:374; Grove, Gray & Burns, 2015:502). During this phase the researcher was able to identify significant statements, categorise them and then make essential meaning of them.

Describing is when researchers come to understand and define the phenomenon (Polit & Beck, 2012:496). In this last phase the researcher came to understand and define the meanings as described by the study participants.

The descriptive study design was ideal to answer the research question 'What factors contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana?' and discover participants' perspectives on the factors that caused the delay. Using this design the researcher was able to analyse the words of the participants, discover meaning in their words and provide a description of their experiences which promoted deeper understanding (Grove, Gray & Burns, 2015:67).

### **3.2.1 Study setting**

The study was conducted at the Paediatric Renal Unit of the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana. KATH is the second largest teaching hospital in the country. It serves as a training, clinical and learning facility for sub-specialty training for qualified doctors and nurses, medical students, nursing students and other health professionals.

The hospital is situated in the centre of Kumasi, the capital of the Ashanti region, and the second largest city in Ghana. KATH is a tertiary hospital with a 1000-bed capacity and serves the entire northern sector and some parts of the southern sector of Ghana as well as some neighbouring countries.

According to the Paediatric Renal Unit records there were a total of 704 reported cases of children with CKD between 2010 and 2014. About 30 patients are reviewed every week at the renal clinic, of which at least 5 are new cases. The current statistics indicate that about 252 cases are reviewed in 2016, which indicates that the occurrence of CKD has increased since there were 204 cases in 2015.

A quiet consulting room not frequently used by staff was used to interview the participants.

### **3.2.2 Study population**

A study population is defined by Polit and Beck (2014:387) as the entire group of individuals or subjects who have some common characteristics. The population can comprise the target population, which means the entire population which the researcher is interested in, or the accessible population, which is a portion of the target population which is accessible to the researcher (Polit & Beck, 2014:177).

In this current study the target population was all primary care givers whose children were attending the paediatric renal clinic at KATH in Kumasi. The accessible population was all primary care givers who delayed presenting their children with

CKD for medical care at the paediatric renal unit at KATH seen between August 2016 and January 2017.

### **3.2.3 Sampling method**

Sampling is the process of selecting representatives of the entire population so that inferences can be made about that population (Polit & Beck, 2012:515).

Convenience sampling, which is also known as accidental sampling, is the use of readily accessible and/or available people as study participants (Holloway & Wheeler, 2010:141; Grove, Gray & Burns, 2015:264). In the current study convenience sampling was used to recruit ten (10) primary care givers who were known to have presented their children with CKD late at KATH, and who met the inclusion criteria. The primary care givers were readily accessible in the Paediatric Renal Unit for the researcher to recruit them, as their children had already been enrolled, making convenience sampling the ideal method in this study.

The first two participants were identified for the pilot study after two information sessions were held at the renal clinic to aid the recruitment process. These were carried out by the researcher with assistance from a professional nurse in charge. The study was explained to them and permission to participate was requested. Subsequent information sessions were held with other participants. Those who met the inclusion criteria were recruited for the main study.

### **3.2.4 Inclusion criteria**

Study participants were selected based on the following inclusion criteria:

- Primary care givers who have been responsible for the care and nurturing of the child with CKD for at least six months prior to admission to hospital.

- Primary care givers who presented their children with CKD for medical care at least two months after initially noticing/observing the signs and symptoms of CKD during the first six months of the study.
- Primary care givers whose children with CKD had already been started on the renal programme at KATH.

### **3.2.5 Exclusion criteria**

Potential participants were excluded from the study based on the following criteria:

- Primary care giver who has been responsible for the care and nurturing of the child with CKD for less than six months prior to admission to hospital. These were excluded because it was felt that they would not know the full history of the child or be able to answer questions regarding factors that contributed to the delay in presenting the child for health care.
- Primary care giver whose child with CKD was presented for medical care less than two months after initially noticing/observing the signs and symptoms of CKD.
- Primary care givers whose children with CKD had already been excluded from the renal programme at KATH for conservative management.

### **3.2.6 Sample size**

A sample size of ten (10) participants was used. This includes the first two participants from the pilot study. This sample size was not predetermined but was achieved through data saturation. Data saturation means that recruitment, data collection and analysis continued until no new data were emerging from data analysis and the themes and categories became repetitive (Holmes, 2006:325; Polit & Beck, 2014:55).

A small sample size is acceptable in qualitative research because it allows for an in-depth study of the participants (Holloway & Wheeler, 2010:145). In a qualitative study

the intent is not to generalise the information but to elucidate particular and specific findings of the study (Creswell, 2013:157). Therefore the meaning and depth of data from a small sample size is more important than that required from the large sample size often required in quantitative research (Denscombe, 2010:41).

### **3.2.7 Recruitment**

Recruitment of the participants commenced after ethical clearance was received from the University of Cape Town (UCT) Faculty of Health Sciences Research Ethics Committee and SMS/KATH Committee on Human Research, Publication and Ethics respectively (see Appendices E and F). Information sessions were held in the renal clinic for two week to aid the recruitment process, carried out by the researcher with the assistance of a professional nurse in charge. The study was explained to them by the researcher and permission to participate was requested from those who were interested (see Appendix A). Those who agreed to participate were recruited for the study by signing a consent form (see Appendix I). All participants agreed to be interviewed in the allocated consulting room, which is not frequently used and is quiet and private. All participants were given R125 (GHS 30) towards travel expenses for research purposes. Refreshments and snacks were provided after each interview session.

### **3.2.8 Pilot study**

Two participants were recruited for a pilot study, using the above mentioned recruitment strategy, at the beginning of December 2016. The semi-structured interview guide developed for the main study was used to collect data (see Appendix C). The purpose of the pilot study was to assess whether the semi-structured interview guide would yield relevant data, so that it could be refined if necessary. The pilot study was also conducted to assist the researcher to determine the appropriateness of the interview site and the duration of the interview. It also assisted the researcher in estimating the time required for data collection or the interview session per person for the main study (Creswell, 2013:165-166).

Pilot studies add value and credibility to the researcher's work (Polit & Beck, 2014:346). The results of the pilot study informed the researcher on the preliminary data and competency of the interview guide for the main study. Data from the pilot study were included in analysis of the final results because the same method was used for data collection and analysis in the main study, as proposed by Duma (2006:89). This is allowed in qualitative research (Duma, Khanyile & Daniels, 2009:55).

### **3.2.9 Data collection**

In qualitative research data collection refers to the information derived from participants' thoughts, perceptions and ideas (Grove, Gray & Burns, 2015:82). Data collection was conducted between the second week of December 2016 and the end of January 2017. Interviews with participants took place in consulting room 10 which is a quiet room not frequently used by hospital staff.

#### ***3.2.9.1. Semi-structured interviews with study participants***

A semi-structured interview guide that was developed in line with the research objectives, with open-ended questions and probing questions for use where necessary (see Appendix C). A semi-structured interview guide ensures that the researcher obtains all the essential information needed and also gives the study participants freedom to provide as many illustrations and explanations as they wish in order to express themselves (Polit & Beck, 2012:537).

The researcher established rapport by greetings and self-introductions. The purpose and objectives of the study were explained again. The participants were allowed to ask questions or gain clarity about the study. This allowed participants to either continue with the study or to withdraw and to clarify any misconceptions. An information sheet was given and read with each participant. Consent forms were signed by each participant (see Appendix I). Each participant's permission was sought to use a digital

audio-recorder to record the interview, and the reason for writing down field notes was explained.

Using the semi-structured interview guide, interviews were conducted in Twi (the vernacular language of the region) (see Appendix D). Each interview lasted for approximately an hour and was conducted in the consulting room. Each interview was transcribed verbatim by the researcher within the next 24 hours, to capture the meaning and how things were said, including all of the non-verbal communications/gestures observed during the interviews. This also helped the researcher to return to participants for clarification and additional information where necessary.

The transcribed interviews conducted in Twi were translated into English by a professional language translator who is fluent in both languages. This was further checked against the transcribed data by the researcher, who is competent in both languages and had first-hand knowledge of the transcribed data. Preliminary data analysis occurred parallel to data collection to enhance verification of data and initial member checking as well as to determine data saturation.

### ***3.2.9.2 Field notes***

Field notes are generally notes taken on the observations during an interview. Field notes were recorded in writing by the researcher in her personal journal which was purposed for the study. The field notes included the participants' expressions, changes in positions, and other gestures which could not be captured by the audio recording. These observations are very important in data analysis as they provided validation of relevant points made by participants, and also facilitated appropriate emphasis on emergent themes (Streubert Speziale, 2007:43).

### **3.3 Ethical considerations**

This study was guided by the World Medical Association (WMA) Declaration of Helsinki, which involves the code of ethics for human subjects (WMA, 2015). Ethical

clearance and permission to conduct the study was sought from UCT's Faculty of Health Sciences Research Ethics Committee (reference number 402/2016), and the KATH Committee of Human Research Publication and Ethics (reference number CHRPE/AP/509/16) (see Appendices E and F). Consent for voluntary participation was obtained from the primary care givers before commencement of the study. The following ethical principles were applied throughout the study.

### **3.3.1 Autonomy**

Autonomy is one's ability to think, decide, and act on the basis of a freely made decision without being forced or coerced to do so (Townsend, Cox & Li, 2010:620). The following measures were put in place to ensure participants' autonomy during the study:

- The study was explained to participants verbally using Twi at the information sessions held during recruitment. Participants were given the information sheet to read through and any misconceptions were clarified before they were given the informed consent form to sign for their voluntary participation in the study (see Appendices A and B respectively).
- For participants who were illiterate and could not read, the information sheet was read and explained to them by the researcher with the assistance of a professional nurse before they were given the informed consent form to sign for their voluntary participation, using their thumb print.
- Participants were informed about the right to withdraw or refuse to participate in the study at any point in time and assured of the continued care of their children even if they opted to withdraw.
- Permission to audio-record the interviews and to take field notes on observations was sought and obtained from participants prior to the interview sessions.

- Participants were assured that the information they provided during the interviews would only be used for research purposes and nothing else.

### **3.3.2 Confidentiality**

Confidentiality involves the way a researcher manages the information on and from participants to ensure that it is kept private from others (Grove, Gray & Burns, 2015:107). Confidentiality of the study participants was ensured as follows:

- Information on each participant was kept privately. The researcher stored participants' information electronically using Microsoft Word documents in the researcher's computer, which is accessible only through the researcher's password.
- Each participant was given an individual pseudonym, which was used throughout the study.
- Participants' information was stored individually using their pseudonyms.
- Raw data such as field notes, signed consent forms, the digital voice recorder and other relevant information were stored in a safe box with a pin-coded lock.

This was done to ensure the safety, confidentiality and anonymity of participants' information. The information was only made available to the research supervisor for verification of data during data analysis.

### **3.3.3 Beneficence**

Grove, Gray and Burns (2015:108) assert that beneficence requires researchers to do good and not to harm study participants. The following was observed to ensure beneficence during the study:

- Participants were allowed to express their experiences, feelings and challenges about their children's diseases without the researcher blaming them for the delay in presentation.
- Health education on CKD was given during the course of the study when this was necessary.

### **3.3.4 Non-maleficence**

Non-maleficence is not inflicting evil or harm on participants (Polit & Beck, 2012:152). The researcher ensured that the risks of participating in the study did not exceed the potential humanitarian benefits of the knowledge gained (WMA, 2015:108) through the following strategies/activities:

- The possibility of feeling blamed for not bringing the child for care was anticipated. Therefore participants were assured that the research questions were meant to understand the factors that contribute to primary care givers' delay in presenting children with CKD for medical care for research purposes and future prevention strategies, and not to apportion blame for the delay.
- Participants were informed about their right not to answer any question if they felt it was too personal or if talking about it made them uncomfortable.

### **3.3.5 Justice**

Justice is giving each individual what he/she deserves without partiality, as well as ensuring that procedures carried out in the research study was fair and just (Grove, Gray & Burns 2015:107). This was employed in the study as follows:

- All participants who were selected for the study met the research objectives without any biases.

- Participants' selection was based on the inclusion and exclusion criteria of the study, which were emphasised during the recruitment phase.
- All participants were treated with respect and dignity regardless of their culture, beliefs and socio-economic background.

### **3.4 Limitations of the study**

Limitations of a study are defined as the flaws, restrictions and incompleteness which constrain the research (Holloway & Wheeler, 2010:42-43, 340). The limitation of this study was the fact that the interviews were conducted within the hospital, and the researcher could not confirm other factors that delayed seeking health care, for example the distance between the hospital and the participants' homes.

### **3.5 Conclusion**

This chapter described the research design, its suitability to answer the research question under study and the research process followed to collect data. It also highlighted the ethical considerations that were applied throughout the study, in accordance with the WMA Declaration of Helsinki on the code of ethics for studying human subjects (WMA, 2015). It also described the limitations of the study.

## CHAPTER FOUR

### DATA ANALYSIS

#### 4.1 Introduction

This chapter discusses the management of data collected from the study participants and how data were analysed using Colaizzi's (1978) cited by Polit and Beck (2014:309) approach of data analysis. The chapter further discusses procedures that were employed throughout the study to ensure scientific rigour (trustworthiness).

#### 4.2 Data management

Data are fundamental pieces of information collected and gathered in the course of a study (Holloway & Wheeler, 2010:338; Polit & Beck, 2014:45). Data management is significant and needs attention because it brings structure and order to the mass of data collected and stored for final data analysis (Streubert Spezaile, 2007:43; Holloway & Wheeler, 2010:284). Polit and Beck (2014:304) further posit that data management involves converting large masses of data into more manageable segments.

All transcribed interview documents were stored electronically in the researcher's computer using Microsoft Word documents; the computer is accessible only through the researcher's password. Each participant's transcribed interview document was labelled with their pseudonym. The transcribed interview documents were put in a folder named 'Interviews transcribed' and the digital audio records were saved as 'Interviews'. This aided easy accessibility for the researcher and confidentiality of participants' data. The transcribed interviews and the digitally audio-recorded interviews were all backed up on an external hard drive, a flash drive and in Dropbox. All raw data including field notes were stored in a safe box and secured by the researcher with a pin-coded lock. The data storage protocol for this study was adapted from Creswell (2013:175) to enhance anonymity, prevent permanent loss of data and to be organised and able to retrieve information at all times. The stored data will be kept

safe for five years according to the requirements of UCT's Faculty of Health Sciences Human Research Ethics Committee, and then they will be destroyed.

### **4.3 Data analysis**

Data analysis involves the process of organising, providing structure, coding and organising themes; it elicits meaning from the data and runs concurrently with the data collection process (Polit & Beck, 2014:301). Even though data analysis is a complex, non-linear process, it is systematic, orderly and well-structured (Holloway & Wheeler, 2010:281).

Manual data analysis was conducted. This involved using different colour-coded pens for statements with different meanings in relation to the research question. The ecological model (Schneider, 2017) was used to organise the identified themes under four main levels of factors: intrapersonal factors, which included the individual's attitude; interpersonal factors, including family, friends, co-workers; community factors, including organisations such as hospitals and the church; and political factors including regulatory bodies, and the influence all of these have on one's behaviour in seeking healthcare treatment (Schneider, 2017:211-213).

The Colaizzi (1978) thematic method of data analysis cited by Polit and Beck (2014:309) was applied in this study, and includes the following:

- Read all transcripts to acquire a feeling of them.
- Review each transcript and extract significant statements.
- Spell out the meaning of each significant statement to formulate meanings.
- Organise the formulated meanings into clusters of themes.
  - a. Refer these clusters back to the original transcript to validate them.

- b. Note discrepancies among or between the various clusters, avoiding the temptation of ignoring data or themes that do not fit.
- Integrate results into an exhaustive description of the phenomenon under study.
- Formulate an exhaustive description of the phenomenon under study.
- Ask participants about the findings as a final validating step.

To apply Colaizzi's thematic data analysis, the following was carried out by the researcher:

- (a) Reading all participants' transcripts to acquire a feeling for them: The interviewed transcripts were read separately several times to obtain a feel for them and an overall sense of the content. Thoughts, ideas and feelings that were noticed during the interviews helped the researcher to reveal participants' experiences/expressions.
- (b) Reviewing each transcript to extract significant statements: Each transcript was reviewed again and significant statements from all of them were identified using colour pens. These identified colour-coded significant statements helped the researcher to organise, identify, retrieve and analyse meanings from the data.
- (c) Spelling out the meaning of each significant statement (i.e. formulating meanings): Meanings were formulated from the significant statements coded with different colours to guide the researcher for analysis. The researcher then linked the meanings with the data to ensure that each significant statement was marked correctly.
- (d) Organising the formulated meanings into clusters of themes: In this step all formulated meanings were grouped into categories that reflected a unique structure of clusters of themes using the ecological model. These themes were

grouped and organised under the intrapersonal, interpersonal, community and public policy levels. The grouped clusters of themes that reflect significant statements were incorporated together to form a distinctive theme. Four main clusters of themes with subthemes extracted from the data were then used to describe the factors that contribute to primary care givers' delay in reporting children with CKD for medical care in Ghana. In addition, a fifth theme was identified serendipitously.

Table 4.1: Below shows how the themes and subthemes were organised according to the four levels of the ecological model.

**Table 4.1: Example showing how themes, subthemes and significant statements were organised according to the ecological model**

THEMES	SUBTHEMES	SIGNIFICANT STATEMENTS
Intrapersonal-related factors contributing to delay in presenting children with CKD for medical care	Primary care giver's beliefs in traditional medicine as a cure for CKD	<p>"My daughter said she had read on the internet about CKD and a particular traditional medicine which cures the disease. We believed what she read, so I bought the medicine for her. She drank it like tea every morning and evening for more than a year but it could not cure her. I decided to send her to the hospital."</p> <p>"I sent him to a traditional healer for traditional medicine which he drank and applied on his navel. During that period, [about two years] we tried a lot of traditional medicine but none was able to cure him. I decided to seek medical care since the traditional medicine failed to cure."</p>
Interpersonal-related factors contributing to delay in presenting children with	Primary care giver's lack of family support	<p>"When we asked for financial help, my in-laws told us that we are the ones who have a sick child and must do whatever we can to send her to the hospital, but we should not bother them with our problems."</p> <p>"A child in our village suffered from the same</p>

CKD for medical care		illness and died so my family said they did not want to waste their money getting help for my child because she would die anyway. I had to wait for more than six months to get money before I could to send her to the hospital.”
Community-related factors contributing to delay in presenting children with CKD for medical care	Delayed referral from local health facilities	<p>“The child was sent to SDA Hospital where he was admitted for two weeks and then discharged home. I took the child back to the hospital for a scheduled review after another two weeks. Only then did the doctor give us a referral letter to bring him to KATH. They delayed us.”</p> <p>“When he fell ill, I took him to Dadiese Hospital. There, He spent about three weeks when they tried to treat him. But they could not help him with all the medicines were giving him. Then later they sent us to KATH.”</p>
Political-related factors contributing to delay in presenting children with CKD for medical care	Primary care giver’s distance from home to the hospital	<p>“The distance is discouraging, we have to set off around 4am and will get here around 11am depending on how bad the road has become and the road is bad when it is raining season.”</p> <p>“We waited for more than a week to get a car/ lorry/ taxi because of the bad road and the distance. Taxis/cars don’t come to the village because the distance is long, so it makes getting care to the city very difficult. That is was why we delayed.”</p>
Serendipitous finding	Perceived need for community awareness about CKD	<p>“I would appreciate it if education talks can be given to people of my village so that people will be enlightened about the disease; even health workers in our local health centre need such education. If such education talks were held earlier, I wouldn’t have used traditional medicine to treat my child. I would have sent him to the hospital and maybe the illness would not have worsened so badly.”</p>

- (e) Integrating results into an exhaustive description of the research question under study: The researcher studied the meanings of clustered themes to formulate an in-depth/comprehensive descriptive meaning of the factors which contributed to primary care givers' delay in presenting children with CKD for medical care. These findings are accurate and significant since they were derived from the data from the study.
- (f) Formulating an exhaustive description of the phenomenon under study in unequivocal statements: The researcher examined the descriptions of the meanings of the factors that contribute to primary care givers' delay in presenting children with CKD for medical care to formulate a statement describing the meaning of the phenomenon. The researcher engaged with the research supervisor and they both thoroughly read through the clustered themes and supportive raw data. They were both agreed that the formulated themes were a true reflection of the data describing the factors contributing to primary care givers' delay in seeking medical care for their children.

The five main themes and the subthemes which emerged from the data are as follows:

1. Intrapersonal-related factors contributing to delay in presenting children with CKD for medical care
  - Primary care giver's beliefs in traditional medicine as a cure for CKD
  - Primary care giver's lack of knowledge about CKD and its management
  - Primary care giver's financial constraints

- Primary care giver's beliefs in ancestral and spiritual powers for healing
2. Interpersonal-related factors contributing to delay in presenting children with CKD for medical care
    - Primary care giver's marital conflicts
    - Primary care giver's lack of family support
  3. Community-related factors contributing to delay in presenting children with CKD for medical care
    - Delayed referral from local health facility
    - Incorrect advice from neighbours
    - Mismanagement of disease at the local health facility
    - Misdiagnosis by neighbours
  4. Political-related factor contributing to delay
    - Distance from Primary care giver's home to the hospital
  5. Perceived need for community awareness about CKD

(g) Asking participants about the findings as a final validating step: At this final step of the analysis, as part of member checking, the researcher went back to the study participants with the research findings for validation and confirmation that they were true reflections of their descriptions. Member checking is a technique to validate the credibility of qualitative data through debriefing and discussion with study participants (Polit & Beck, 2014:384).

For member checking, the researcher contacted study participants for their views on the study findings by phone or a physical meeting in January, 2017. Out of the ten participants, five participants were met with and three were contacted by phone. Each participant was presented with the study findings and the researcher explained it to them in Twi (the vernacular language of the region) for proper understanding and expressions. All participants indicated their satisfaction with the researcher's interpretation of their views in the study findings. They all said the findings reflected their descriptions of the factors that contributed to their delay.

#### **4.4 Ensuring scientific rigour (trustworthiness) of the research**

In qualitative research the concepts of credibility, dependability, transferability and confirmability are used in describing various aspects of trustworthiness (Polit & Beck, 2012:584-585; Seale, 1999:43). Polit and Beck (2006:332) further assert that these criteria go beyond the assessment of qualitative data but rather are concerned with evaluation of the interpretation of and conclusions drawn from the data.

##### **4.4.1 Credibility**

Credibility is defined as the truthfulness of the data and how the interpretations are made so that people can believe the findings. This criterion also involves establishing that the results of qualitative research are credible or believable from the participants' perspective (Polit & Beck, 2014:323; Grove, Gray & Burns, 2015:392). Credibility can be ensured through member checking, inter-coding reliability and/or peer debriefing.

Member checking involves going back to the research participants with the findings to verify whether they matches with their descriptions or for clarification (Polit & Beck, 2014:328). To ensure credibility of the findings the researcher contacted participants and presented them with the findings which emerged from data analysis of the transcribed interviews. They were asked if they could confirm that the findings presented to them were a true reflection of their views, and all answered in the affirmative.

Credibility was also ensured through inter-coding reliability, which is when two coders operating independently agree on their coding decisions (Polit & Beck, 2014:383). The researcher and the researcher's supervisor analysed the data individually and later compared their findings, which were in agreement.

Peer debriefing is a review of the research process by a second person who is knowledgeable in the same field (Polit & Beck, 2014:330). The researcher kept in regular contact with her supervisor throughout the data analysis, and the raw data were shared with the supervisor to ensure credibility.

#### **4.4.2 Confirmability**

Confirmability is demonstration of the way in which interpretations have been arrived at throughout the study (Seale 1999:44; Koch, 2006:92). This involves keeping a reflective journal during data collection so that important communication methods such as gestures, emotional outbursts and facial expressions used by the participants are not missed (Polit & Beck, 2014:270). Confirmability can be achieved through keeping an audit trail and decision trail.

The audit trail is where the systematic process whereby data collection and data analysis were carried out is clearly spelled out. The decision trail is how and when the researcher decides to categorise the data and make inferences in the analysis (Polit & Beck, 2014:327; Grove, Gray & Burns, 2015:88). Confirmability was established by sharing with the research supervisor the steps involved in data collection and analysis; the interpretations arrived at by both the supervisor and researcher were in agreement.

#### **4.4.3 Dependability**

Dependability is the degree to which frequent administration of a measure will provide the same data, or the extent to which a measure that is administered once but by different people gives the same results (Krefting, 1991:216). Dependability can be

achieved by an inquiry audit technique which involves scrutinising of the data and relevant supporting data by an external reviewer (Polit & Beck, 2006:335).

To ensure dependability the researcher ensured that methods and procedures were recorded. These serve as a guiding tool during the study in order to ensure that data that were collected and their interpretation were dependable. The researcher also shared the data with her supervisor so that the latter could check the relevant supporting data and the steps followed to reveal findings.

#### **4.4.4 Transferability**

Transferability depends upon the degree to which similarity exists between two contexts; that is, the extent to which findings can be transferred to or are applicable in other settings or groups (Krefting, 1991:216; Koch, 2006:92; Polit & Beck, 2012:525). Transferability involves a thick description being given by the researcher so that someone else may make a transfer in order to reach a conclusion when necessary. A thick description refers to a rich, thorough description of the research setting and the transactions and steps observed during the study (Polit & Beck, 2014:336).

To ensure transferability the researcher provided an audit trail of all steps used in collecting and analysing data, the participants' context and relevant reasons for using specific methods. The audit trail enables readers to follow the process used throughout the study in order to trace the course of the research step-by-step, including how decisions were made and the procedures followed (Shenton, 2004:70). The methodology may be replicated in other sociocultural environmental settings, but the findings may differ from one setting to another.

#### **4.5 Conclusion**

This chapter described in detail how the data obtained in this study were managed and analysed. It also highlighted how the themes which emerged were derived from the researcher's interpretation of the data from the semi-structured interviews, and

consequently revealed factors that contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana. Lastly, it also discussed how trustworthiness was ensured throughout the study.

## CHAPTER FIVE

### FINDINGS

#### 5.1 Introduction

This chapter discusses the findings that emerged from the study, which are organised into themes according to Schneider's (2017) ecological model. The purpose of the study was to explore factors that contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana. The research question was 'What factors contribute to primary care givers' delay in presenting children with CKD for medical care in Ghana?'

#### 5.2 Description of study participants

Ten primary care givers of children with CKD who were admitted to the Paediatric Renal Unit at KATH participated in the study. This included the two participants who were used in the pilot study. Eight of the participants were female primary care givers and identified themselves as the mothers of the children with CKD. Two participants were male primary care givers and identified themselves as the fathers of the children with CKD.

Of the eight female participants, five were married, two were divorced and one was widowed. The two male participants were married.

Table 5.1 summarises the demographic data of the study participants.

**Table 5.1: Demographic data of study participants**

Primary care giver	Gender	Relationship to the child with CKD	Marital status
Female	8	Mother	5 married, 2 divorced, 1 widowed

Male	2	Father	2 married
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The number of women in the study attests to the Ghanaian culture, where women are responsible for rearing children and managing the home; men are responsible for provision of material needs and shelter (Danso et al., 2004:4).

Seven female participants indicated that they were illiterate, while one male had primary school education, one female had secondary education, and one male had tertiary education. The findings on the educational status of the participants are a reflection of the level of education in local communities in the northern sector of Ghana, the area served by KATH. In rural areas most girls do not go to school because it is traditionally believed that their responsibility is to take care of the home when they grow up (Lambert, Perrino & Barreras, 2012:12). A study conducted by Aziato (2016:331) revealed that although the education of the girl child has been promoted over recent years in Ghana, female learners' enrolment in schools continues to be lower than that of male learners.

Two male and five female participants identified their occupation as farming, which is the common form of employment for citizens in the rural areas. Two female participants were unemployed, and another was a street vendor selling locally prepared drinks. The socio-economic status of the country has pushed many of its citizens into farming, in an effort to earn money for their daily upkeep (Appiah et al., 2007:472).

### 5.3 Findings

Thematic data analysis generated five themes, which were organised according to Schneider's (2017) ecological framework. Excerpts from the participants' responses are used to support the themes which emerged. The first four themes are directly related to the research question about factors that contribute to primary care givers' delay in presenting children with CKD for medical care. The fifth theme was discovered serendipitously, as an unexpected finding during data collection and analysis

(Holloway & Wheeler, 2010:341). The fifth theme related to the need for community awareness campaigns in order to educate health professionals and community members about CKD and the necessary interventions, in order to urge them to seek early medical care for sufferers.

The five themes that contribute to primary care givers' delay in presenting children with CKD for medical care that were identified were the following:

1. Intrapersonal-related factors contributing to delay in presenting children with CKD for medical care;
2. Interpersonal-related factors contributing to delay in presenting children with CKD for medical care;
3. Community-related factors contributing to delay in presenting children with CKD for medical care;
4. Political-related factor contributing to delay in presenting children with CKD for medical care; and the
5. Perceived need for community awareness about CKD.

### **5.3.1 Intrapersonal-related factors contributing to delay in presenting children with CKD for medical care**

Intrapersonal-related factors involve the knowledge, skills and attitudes of an individual and the impact these characteristics have on their behaviour in seeking health care (Schneider, 2017:211). This theme emerged from the data in relation to the individuals' personal characteristics, attitudes or abilities which contributed to the delay in presenting their children for medical care. The four subthemes under this theme are:

- Primary care giver's beliefs in traditional medicine as a cure for CKD;

- Primary care giver's lack of knowledge about CKD and its management;
- Primary care giver's financial constraints; and
- Primary care giver's beliefs in ancestral and spiritual powers for healing.

### 5.3.1.1 Primary care giver's beliefs in traditional medicine as a cure for CKD

Belief of primary care givers in the ability of traditional medicine to cure CKD emerged as one of the factors contributing to the delay. Data showed that this belief in traditional healers was entrenched among the community as a whole.

Said one participant:

*"I sent him to a traditional healer for traditional medicine which he drank and applied on his navel. During that period, [about two years] we tried a lot of traditional medicine but none was able to cure him. I decided to seek medical care since the traditional medicine failed to cure." (Afe, female)*

Another participant expressed her belief in using traditional medicine to cure sickle cell disease (which later complicated into CKD) as follows:

*"We used the traditional medicine for more than a year. Actually we went for the traditional medicine to cure the sickle cell not knowing that it would also cause the kidney disease. When we were educated by the renal professionals on the danger of traditional medicine in kidney disease then we stopped." (Age, female)*

One participant confirmed his belief in traditional medicine as a contribution to the delay in presenting his child to hospital as follows:

*"My daughter said she had read on the internet about CKD and a particular traditional medicine which cures the disease. We believed what she read, so I bought the medicine for her. She drank it like tea every morning and evening for more than a year but it could not cure her. I decided to send her to the hospital." (She, male)*

Participants believed traditional healers to have a cure for CKD, as stated in this excerpt:

*“I had no choice and I was scared because he has been taking a lot of traditional medicines from different traditional healers. I sent him to different traditional healers, because I believed they could cure him.”* (Ade, male)

### **5.3.1.2 Primary care giver’s lack of knowledge on CKD and its management**

This theme was developed from data relating to lack of knowledge about the symptoms of and treatment for CKD among primary care givers and other community members as a contributory factor in delay in presenting children for health care.

The following statement attests to lack of knowledge on CKD as a contributory factor to delay in presenting their child for medical care:

*“If I had insight about the disease, I would have sent him to the hospital right away than to send him to the prayer camp. Yes, I believe prayer works but sometimes not being educated can worsen things.”* (Abe, female)

Another participant also stated that they wished they had knowledge of the disease earlier:

*“I have never heard about the disease before. I only got to know of it when we were admitted here. If I have heard about [the] disease before I would have tried my best to send him to the hospital earlier when we were referred, [rather] than to stay home for three years waiting to get money.”* (Ade, male)

Another participant thought that CKD affected only adults and not children, confirming their lack of knowledge on CKD and its management:

*“I used to think that this disease affects adults who drink alcohol; I did not know children get it too. I can say my poor knowledge about the disease made me delay. If I knew that*

*traditional medicine can cause this disease [complications of traditional medicine on the kidneys]; I would not have used it in the first place.” (Age, female)*

The following statement was made by another participant with lack of knowledge about CKD, who also thought it was a disease affecting only adults

*“I thought the disease of swelling affect adults only. If I knew that this disease also exist in children, I wouldn’t have gone around seeking unnecessary help or stay at the prayer camp for two months without seeking medical care.” (Abe, female)*

### **5.3.1.3 Primary care giver’s financial constraints**

This theme emerged from data relating to lack of money as a contributory factor to delays in presenting a child for medical care. As one participant affirmed:

*“My husband didn’t have money. We had a huge debt following the funeral of my father-in-law. During that period, we then tried a lot of traditional medicine because they are cheap, but none was able to cure him. He had to borrow money for us to send the child to the hospital.” (Afe, female)*

This participant explained that financial constraints caused the delay in presenting their child with CKD for medical care:

*“I didn’t have money - that was why it took more than two weeks to return for [the] laboratory investigation results.” (Abe, female)*

Another two participants stated as follows:

*“It was very difficult to get money for transportation, hence the delay.” (Ate, female)*

*“It is because of the financial problems. If I had the money, I would have brought him to the hospital earlier. Money issues have become very challenging for us.” (Ahe, female)*

One participant shared how relocating her family from one village to another caused financial challenges that contributed to the delay in presenting her child for medical care:

*“When he fell ill, we had just relocated from our old village and we didn’t have money to seek treatment for the child. The financial burden was too much. A pastor saw his condition then gave us money to send him to the hospital.”* (Axe, female)

Another participant explained what he had to do to be able to get the money to bring his ill child to hospital, confirming the theme of primary care giver’s financial constraints as follows:

*“I had to get a job. After I worked for one year, I was able to gather enough money, then, I decided to finally bring him to the KATH, where he had been referred more than two years ago.”* (Ade, male)

Another participant felt that CKD drains poor people of their money as if they are rich:

*“Madam, this disease is for the rich but you see they are not suffering from it; it is the poor who are suffering from it. The little money you get, you have to spend it seeking cure of the sick child. [Facial expression sad and worried]. I was always crying and waiting for help to come my way until Sunday school teacher from church came to visit us. He saw the condition of my daughter; he gave me money to send her to the hospital.”*  
(She, male)

#### **5.3.1.4 Primary care giver’s beliefs in ancestral and spiritual powers for healing**

This theme emerged from data describing how participants’ beliefs in ancestral and spiritual powers as causing and healing illnesses contributed to their delay in seeking medical care for their ill children. Under this theme both belief and disbelief in spiritual powers to heal illness emerged as contributory factors in delaying primary care givers in presenting their children with CKD for medical care.

One primary care giver expressed her belief in the ability of spiritual powers to heal CKD as a contributory factor to the delay in presenting the child for medical care as follows:

*“When my child first fell sick, I thought my husband’s family ancestors have conspired with my family ancestors in the spiritual realm to inflict the disease to my child. I sent him to the prayer camp where prayers were offered for him for two months. My husband bought a taxi to work and sustain us financially but it broke down and he could not repair it. He entered into wood business and his machines also broke down. All these challenges made me think that both my husband’s family and my family members have bewitched us and that our ancestors were working against us spiritually. At the prayer camp his condition did not improve so I decided to send him to the hospital to seek treatment.” (Abe, female)*

Another primary care giver’s statement supported this theme:

*“The pastor said it was a spiritual problem so I believed him. I stayed at the prayer camp for two months. An intense prayer was offered to my son. He was given anointing oil to rub on his body. The pastor said he has cast out the disease in the spiritual world and I was happy [said with a smile on her face]. Later, I sent him to the hospital as his condition was worsening.” (Ahe, female)*

The following statements by two other primary care givers also reveal their belief in the ability of spiritual powers to heal CKD, and support emergence of this theme:

*“I believed that this disease was spiritual. My wife told me that a tenant that she had quarrelled with threatened her and said that she purchased this disease in the spiritual world to hurt our daughter. The tenant bought a dress for our daughter as a gift when she was a baby ... A pastor confirmed that the dress the woman gave to my daughter as a gift was a medium for the transfer of the disease. The pastor prayed for her consistently*

*for three months to cast out the spirit behind the disease. I then sent her to the hospital for medical care.” (She, male)*

*“We thought maybe she acquired the disease from school by eating food that has been bewitched. Neighbours advised me to send her to a spiritualist for cleansing but I did not go. I was afraid of losing my child so I sent her to the prayer camp instead. There she was offered prayers for three months; the pastor said he had cast out the spirit behind the disease. It was now left with the physical aspect. I later sent her to the hospital; hence the delay.” (Ate, female)*

*“I strongly believed that there was a spiritual connection with my daughter’s disease and that she acquired her illness from the spiritual world as revenge for something I might have done. I quarrelled with one neighbour. She insulted me ... She also told other neighbours that she purchased this disease for my daughter and that she will do whatever it takes to create problems for me. When she [neighbour] later died, my daughter started to get well. I believed she was healed permanently; then the swelling started again.” (She, male)*

Primary care givers’ *disbelief* in ability of spiritual powers to heal was also a contributory factor in delays in presenting the children for medical care, as revealed in the following statements by one participant:

*“A neighbour told me that my child must have passed urine in a river and angered the gods, who have then cursed him with this illness. The neighbour told us to go to the river with alcoholic drinks (schnapps) to appease the gods in order to reverse the curse, but my husband refused to do this. When the child did not get better, we decided to bring him to hospital.” (Axe, female)*

### **5.3.2 Interpersonal-related factors contributing to delay in presenting children with CKD for medical care**

Interpersonal-related factors that influence an individual's behaviour in decision making related to health care include the opinions and impact of friends, family and neighbours (Schneider, 2017:212). This theme was developed from data that showed how the influence of interpersonal relations among families, friends and neighbours contribute to the primary care giver's delay in seeking medical care for their children suffering from CKD. Two subthemes emerged under this theme: (i) primary care giver's marital conflict; and (ii) primary care giver's lack of family support.

#### ***5.3.2.1 Primary care giver's marital conflict***

This subtheme developed from data relating to women's status in the marriage and marital problems as a contributory factor in the delay in presenting children with CKD for medical care. In particular, this refers to data related to husbands' refusal to listen to their wives' requests or advice to take the children to hospital until it was too late.

As one female participant stated:

*"I delayed because of marital problems in my house. My husband doesn't listen to me when I talk about anything, even talking about our children's wellbeing. He has lost interest in our marriage. Everything I suggest to him, he does not take it seriously. I begged him to allow me bring the child to the hospital, but he refused. The child was at home for two months. When the child's condition deteriorated and he collapsed, then we sent him to the hospital."* (Axe, female)

Another excerpt from participant on how her husband's refusal to take her inputs into raising the children seriously contributed to the delay in presenting the child with CKD for medical care in the following question:

*"How can I seek medical care for the child when my husband refused to listen to my contributions in the marriage?"* (Axe, female)

Another statement from a participant indicated how marital conflict contributes to delay in seeking medical care for the child with CKD:

*"We were advised to go to hospital, but my husband refused to take her to the hospital. I tried hard to convince him, but he was not willing to listen to me because of our marital problems. This caused the delay for one whole year, and I think it also worsened the disease. If I had my own will, I would have sent her to the hospital myself." (Ape, female)*

The following extract shows how the woman's status in the marriage became a contributory factor to delay in presenting the child with CKD for medical care:

*"I cannot understand him. I cry when I think about his attitude, I am his wife, but in my tribe as a woman I cannot challenge my husband's word or decision. His word is final. His friends advised him to give our child traditional medicine for two months, but the disease worsened. I did not know what else to do for her. There was nothing I could do to relieve her of the pain or heal her because my husband had to make all decisions ... She had difficulty in breathing, I was afraid she will die. I rushed her to the hospital without my husband's consent." (Ape, female)*

### **5.3.2.2 Primary care giver's lack of family support**

This subtheme was generated from data related to lack of family support as a discouraging factor which delayed seeking medical care for the child with CKD. The following statement from a participant illustrates this point:

*"I didn't get any support from my family and my husband is dead [crying]. I have to take care of my children. Nobody in my family was willing to help me because they thought my child was going to die. I have to work in someone's farm for six weeks to gather enough money to send my child to the hospital." (Ate, female)*

*“A child in our village suffered from the same illness and died, so my family said they did not want to waste their money getting help for my child because she would die anyway. I had to wait for more than six months to get money before I could to send her to the hospital.” (Ate, female)*

Other participants described lack of support from their in-laws as a contributory factor to the delay in seeking medical care for their child:

*“When we asked for financial help, my in-laws told us that we are the ones who have a sick child and must do whatever we can to send her to the hospital, but we should not bother them with our problems.” (Ace, female)*

*“We did not get any support from my husband’s family. They blame my husband for marrying me, a disabled person [disability of both legs] ... They said that they will never use their money to support us with our ill child. My brother-in-law told me that the child will die so why should they bother themselves. Madam was it my fault to be born with a disability?” (Axe, female)*

### **5.3.3 Community-related factors contributing to delay in presenting children with CKD for medical care**

Community-related factors involve organisations such as churches and hospitals that significantly influence individuals’ behaviour either positively or negatively in seeking health care (Schneider, 2017:213). This theme emerged from data that showed how community-related factors contributed to the delay in presenting children with CKD for medical care. Four subthemes emerged from this theme: (i) delayed referral from local health facility; (ii) incorrect advice from neighbours; (iii) mismanagement of disease at the local health facility; and (iv) misdiagnosis by neighbours.

#### ***5.3.3.1 Delayed referral from local health facility***

This subtheme was developed from data related to factors beyond the primary givers’ ambit, but also contributed to delay in presenting children with CKD for medical care.

Data in this theme show that the primary care givers started seeking medical care at their local health facilities, but the delay was due to either mismanagement or delay in referral. This is reflected in the following four excerpts from participants:

*“When he fell ill, I took him to Dadiese Hospital. There he spent about three weeks when they tried to treat him. But they could not help him with all the medicines they were giving him. Then later they sent us to KATH.”* (Axe, female)

*“The child was sent to SDA Hospital where he was admitted for two weeks and then discharged home. I took the child back to the hospital for a scheduled review after another two weeks. Only then did the doctor give us a referral letter to bring him to KATH. They delayed us.”* (Abe, female)

*“She was admitted in Keta Hospital for three weeks. She was given a drip [intravenous infusion] but she continued to swell up. The doctor then sent us to KATH.”* (Ace, female)

*“I sent him to our local hospital where he was admitted for two weeks and then discharged. We were given a review date in another two weeks’ time. When we got there for the review, they gave us more medicines and sent us back home, but those medicines did not work for him. I took him back to our local hospital, and only then did the doctor write us a referral letter to bring him to KATH.”* (Ade, male)

### **5.3.3.2 Incorrect advice from neighbours**

This theme emerged from data showing how primary care givers were incorrectly advised by neighbours to use an alternate way to cure their children with CKD, which contributed to the delay in seeking medical care.

The following statements from three participants show how they were incorrectly advised by neighbours to use traditional medicine, which contributed to the delay in presenting their child with CKD for medical care:

*“Some neighbours advised us to use traditional medicine, which we used for three weeks ... The medicine seemed to work initially because the swelling around the eyes subsided. Eventually we decided to try the hospital.” (Ace, female)*

*“People advised us to use traditional medicine, which we used, but it couldn’t cure the disease. We sent her to the hospital for medical cure.” (Ape, male)*

*“About two months ago he felt sick again, passing blood in his urine. Neighbours advised us to go back to the traditional healer for more medicine. We went and he gave us oral traditional medicine, which didn’t cure the disease but rather intensified the pain, and the disease progressed badly. We were afraid he was going to die, so we decided to send him to the hospital for cure.” (Afe, female)*

### **5.3.3.3 Mismanagement of disease at the local health facility**

This subtheme indicates how mismanagement of the illness at local health facilities contributed to the delay in primary care givers presenting their children with CKD at the Paediatric Renal Unit at KATH.

The following statements from four participants express how the local health facilities’ health professionals’ mismanagement of the disease contributed to the delay in presenting the child for medical care at KATH:

*“It was a challenge to take my ill child to the hospital again because the health workers could not manage his disease well before. They were just tossing us around and made us pay for expensive medicines to keep him alive, but not to cure the disease completely. Every time we went to the health centre and told them about his symptoms, like not passing enough urine, they did not believe me because they could not see any major signs, but rather said I was exaggerating and the child was okay. This made it difficult for me because my concerns and complains were not addressed early. So we stayed home for almost a year. The disease worsened so I sent him to another hospital, then the doctor gave me a referral letter to send him to KATH.” (Afe, female)*

*“He was admitted at Prestea hospital for about a week and was given drips [intravenous infusion] but the swelling continued. We were then sent to Tarkwa Hospital. There he was admitted for another week and was given injections but he was still swelling up. He was again referred to another hospital but my husband said he knew someone at KATH and so we brought him here.” (Ahe, female)*

*“How can you send a sick child to the hospital and the so called ‘doctors’ cannot cure the child?” [Very angry tone] (Ade, male)*

*“Madam, even the district doctors [physician assistants] don’t know anything about this disease. They used my daughter for practice [trials].” [Nods head] (She, male)*

#### **5.3.3.4 Misdiagnosis by neighbours**

The subtheme emerged from data as a contributing factor to delay as the primary care givers sought advice from their communities, which influenced their decisions in seeking medical care for their children.

One participant expressed how misdiagnosis contributed to the delay in presenting the child for medical care as follows:

*“My daughter is a fat person, so when we noticed the swelling around the eyes neighbours advised us to use traditional medicine because they claimed it was haemorrhoids, which we used for three weeks.” (Ace, female)*

Another participant had this to say:

*“Friends told me to send him to the traditional healer since they can spiritually determine the cause of the disease, which will assist them to cure disease, which we did.” (Afe, female)*

In this case it was a traditional healer who made the misdiagnosis:

*“The traditional healer told us that it might be worms, so he gave us traditional medicine to apply on the abdomen, but it didn’t cure him.” (Ade, male)*

### **5.3.4 Political-related factors contributing to delay in presenting children with CKD for medical care**

Political-related factors encompass the political regulations and limitations that influence one’s behaviour that are beyond the primary care givers’ capabilities to make decisions pertaining to medical care for their children with CKD (Schneider, 2017:213). These factors include things such as distance, poor roads and lack of transport to KATH, all of which contributed to delays in presenting children with CKD for medical care.

One participant attributed bad roads and long distance as a contributing to the delay in presenting her child for medical care:

*“We waited for more than a week to get a car/lorry/taxi because of the bad road and the distance. Taxis/cars don’t come to the village because the distance is long, so it makes getting care in the city very difficult. That is was why we delayed.” (Ace, female)*

Another participant stated that the distance from their home to the hospital was a contributor to the delay in seeking medical care for the child with CKD:

*“The distance is discouraging, we have to set off around 4am and will get here around 11am depending on how bad the road has become, and the road is bad when it is raining season.” (Ahe, female)*

### **5.3.5 Perceived need for community awareness about CKD**

The research question ‘What factors contribute to primary care givers’ delay in presenting children with CKD for medical care in Ghana?’ revealed data from participants which showed a perceived need to raise community awareness of CKD and

its management. This theme emerged from primary care givers' comments on the need for health education on CKD in their various communities.

The following statement by a primary care giver supports the development of this theme:

*"I would appreciate it if education talks can be given to people of my village so that people will be enlightened about the disease; even health workers in our local health centre need such education. If such education talks were held earlier, I wouldn't have used traditional medicine to treat my child. I would have sent him to the hospital and maybe the illness would not have worsened so badly." (Afe, female)*

Here are another three affirming statements regarding this theme from different participants:

*"I want the health workers to create an awareness of this disease to my community by organising education talks to communities. If this is done, any parent whose children suffer from this disease will be able to know when to send them to hospital [rather] than to stay home and seek other alternative treatments that do not help to cure this disease, but just worsen it." (Age, female)*

*"Madam, please come and educate us on this disease. We need to know about the causes of this disease so that we will know. It is killer disease and it is taking away our innocent children from us." [Respondent crying, saying 'I am losing my child'] (Ace, female)*

*"I have never heard about the disease before. I only got to know of it when we were admitted here. If I had heard about the disease before, I would have tried my best to send him to the hospital earlier when we were referred, [rather] than staying home for three years waiting to get money. Please give health educational talks on the disease so that people will be aware of the disease." (Ade, male)*

## **5.4 Conclusion**

This chapter described the four themes and their subthemes which emerged from the analysed data, as guided by the ecological model as a theoretical framework. In addition, a fifth theme was discovered serendipitously and highlighted the need for a community awareness campaign on CKD. Extracts from participants' statements were used to highlight and support the emergence of each theme or subtheme.

## CHAPTER SIX

### Discussion of findings, recommendations and conclusion

#### 6.1 Introduction

This chapter discusses the findings of the study, which are supported by literature, the recommendations and the conclusion. This descriptive qualitative study was intended to explore and describe the factors that contribute to primary care givers' delay in presenting their children with CKD for medical care in Ghana. The findings revealed five themes as factors contributing to the delay in presenting children with CKD for medical care, which are discussed below.

Schneider (2017)'s four levels of the ecological model assisted in organising the discovered themes. Schneider (2017:211-213) asserts that, the individual's health behaviour in seeking medical health is influenced by four levels of factors, including intrapersonal-related factors, interpersonal-related factors, community-related factors and political-related factors, as revealed in Chapter five. The results for each of these types of factors are discussed below.

#### 6.2 Intrapersonal-related factors contributing to delay in presenting children with CKD for medical care

Under the intrapersonal-related factors theme the subtheme of primary care givers' beliefs in traditional medicine as a contributory factor to the delay in seeking medical care for children with CKD was found to be common to all participants. For the participants in this study the use of traditional medicine was thought to be a cure for the CKD and other related symptoms. However, when this was found not to be true as the child's condition worsened, the children were then brought to hospital for medical care. The primary care givers' belief in traditional medicine as a cure for CKD thus contributed to the delay in presenting their children for medical care.

This finding shows how traditional medicine has remained significant in the primary care of many illnesses in many developing countries, especially in sub-Saharan Africa, including Ghana. This finding is confirmed by Gyasi, Mensah and Siaw (2015:314) who reported that traditional medicine is used to diagnose, treat and/or prevent physical or mental illness in most African communities. Truter (2007:56) also confirms the findings, asserting that traditional medicine is regarded as curative or therapeutic and can be used for maintenance or restoration of physical and mental health and/or wellbeing in developing countries.

Traditional medicine has been used in Africa for many years because of the African people's belief system, and Ghana is no exception. In Ghana traditional medicine is recognised as an integral part of the cultural and traditional system of the people (Gyasi et al., 2015:250). This was confirmed by the findings of the current study, which revealed that the belief in and utilisation of traditional medicine was a major contributory factor to the delay of primary care givers in presenting their children with CKD for medical care. The findings of the current study are further supported by Gyasi, Mensah and Siaw (2015:315), who attested that traditional healers take the social contexts of the disease into account and provide holistic and culturally acceptable care for patients.

Gyasi, Siaw and Mensah (2015:139) concluded that even though traditional medicine has a great deal of economic importance among its users, its unscientific use together with lack of regulation are major impediments to its growth and can be harmful. This was found to be the case in the current study, which showed that primary care givers' made prolonged use of traditional medicine due to their belief in it as a cure for CKD - until the disease worsened, at which point the decision was made to present the children with CKD for medical care. Consequently, by the time the children were brought to KATH for proper medical care for CKD, their kidney function has declined

to the point that nothing much could be done to slow down the progression of the decline in kidney function.

This finding was also confirmed by Asoogo and Duma (2015:6) in a study conducted in Ghana on late presentation for medical care of breast cancer. They reported that the prolonged use of traditional medicine to cure breast cancer – even when it was obvious that there was no improvement in the condition – contributed to the delay in presentation of women with breast cancer for medical care. They concluded that the use of traditional medicine is not bad, but traditional healers should encourage users to seek early medical care before the illness worsened. A similar study that confirmed the prolonged use of traditional medicine as contributing to delay in seeking medical care for breast cancer in sub-Saharan African and developing countries was also reported by Memon et al. (2013:7412).

Lack of knowledge of or ignorance about certain illnesses is common and can contribute to a delay in seeking medical care for the illness. The findings of the current study revealed that primary care givers' lack of knowledge about CKD and its management contributed to the delay in presenting children with CKD for medical care. Similar findings have been reported elsewhere, where lack of knowledge about the illness contributed to the delay in seeking appropriate medical care. For instance, a study on factors that contributed to the delay in presenting for medical care for breast cancer in Ghana revealed that lack of knowledge of the disease contributed to delay in seeking early medical care (Asoogo & Duma, 2015:4). That study found that the participants associated the early symptoms of breast cancer with normal changes in the woman's body, such as those related to menopause. In the current study participants associated the early signs of kidney disease with normal body changes in childhood, e.g. being fat, or other common childhood illnesses such as worm infestation, and thus delayed sending their children for medical care while treating them for common childhood illnesses.

Poor health literacy has been linked to higher incidences of diseases and disabilities. For instance, Burns and Dunn (2013:138) reported that children whose care givers have poor health literacy are likely to use more health services as opposed to seeking medical care. In the current study, although there was no direct link between the primary care givers' poor health literacy and an increase in diseases, complications of CKD can be associated with increased disabilities related to poor health literacy. Delay in the primary care givers presenting their children for medical care resulted in CKD, which is a major disability leading to death.

In acknowledging lack of knowledge on CKD and its management as a factor contributing to the delay in presenting children with CKD for medical care, some participants highlighted the need for health education and community awareness on the illness. This finding is supported by Harrington (2015:54), who concluded that addressing literacy among caregivers can lead to improved knowledge on CKD and its management, and thus influence appropriate decision making regarding presenting children early for health care that can yield positive outcomes for these children.

Findings of the current study revealed that financial constraints contributed to the delay among participants in presenting their children with CKD for medical care. Similar findings were reported by Asoogo and Duma (2015:4), who reported that financial constraints due to unemployment contributed to the delay in seeking general medical care among women with breast cancer in Ghana. They attributed the delay in seeking medical care to financial constraints relating to the poor socio-economic status of that country. In a study in three African countries including Ghana, Macha et al. (2012:51) revealed that compared with their wealthier counterparts, poor people do not get access to health services early. High costs associated with seeking health care, especially in relation to laboratory tests and drugs, were a barrier for poor people. The current study revealed that financial constraints contributed to the primary care givers' delay in

bringing the child to hospital for appropriate medical care or investigations, even when referrals had been made early in the course of the illness.

Primary care givers' beliefs in ancestral and spiritual powers for healing influenced their decisions in seeking medical care for their children with CKD. Health-seeking behaviours are characterised by social determinants such as spirituality and religiosity, which are identified as having an impact on health and treatment (either positively or negatively) (Kretchy, Owusu-Daaku & Danquah, 2013:2). These beliefs are related to an individual's internal and emotional expressions of attachment to a Supreme Being for peace and healing; these beliefs are part of their understanding of life through cultural norms.

The findings revealed that primary care givers' beliefs in ancestral and spiritual powers for healing or causing disease contributed to delays in seeking medical care for their children with CKD. They sought help from spiritual and traditional healers, spending months in the hope of attaining healing for their children. Some participants believed that their children's illness was inflicted by ancestral and spiritual powers whilst others thought witchcraft was the cause. This is supported by a number of studies conducted in Ghana on chronic illness and mental illness, where findings revealed an association between such illnesses and spiritual causes (Quinn, 2007:181; Kretchy, Owusu-Daaku & Danquah, 2013:2; Gyasi, Mensah & Siaw, 2015:315). The primary care givers' beliefs in spiritual powers' ability to cause or heal illness resulted in some participants and their ill children staying at prayer camps where they were promised a cure for spiritual causes of CKD. These stays in prayer camps further contributed to the delay in presenting children with CKD for medical care. Belief in spiritual powers for healing and conducting prayer-related activities has been confirmed by Kretchy, Owusu-Daaku and Danquah (2013:2), who reported that rituals and other related symbolic activities like prayers and fasting were practised according to people's specific beliefs and modes of social organisation.

### **6.3 Interpersonal-related factors contributing to delay in presenting children with CKD for medical care**

Primary care givers' experiences of marital conflict and disrespect of women's status in relationships by their male partners were also found to be contributory factors to delay in presenting children with CKD for medical care. This finding was supported by another study conducted in Ghana by Tenkorang et al. (2013:772), where cultural practices and traditional gender roles in Ghana were reported to render women unable to defend their rights (*and that of their children – own conclusion*). A husband's refusal to consider his wife's view in seeking medical care contributed to the delay in presenting the child for medical care, and is a violation of not only the mother's human rights, but also those of the child. This view is confirmed by Tenkorang et al. (2013:771) in their definition of domestic violence as the violation of fundamental human rights and an obstacle to achieving gender equity in sub-Saharan Africa where patriarchy remains dominant.

Findings of the current study revealed that lack of family support contributed to primary care givers' delay in presenting their children for medical care. This is supported by Bair et al. (2009:1287), who found that family support assists the individual in attaining effective health care. The family influences the lifestyle and health status of its members. According to Burns and Dunn (2013:137-138) the role of the family is to serve as a natural support system in planning effective health care for members. In the current study primary care givers who did not receive the necessary support from their families considered this lack of support to be a contributory factor in the delay in seeking medical care for their children with CKD.

In their study on barriers and facilitators to chronic pain self-management, Bair et al. (2009:1285) attest to the devastating effects of not receiving the support needed from the family. This was indirectly confirmed by the current study participants' facial and other

expressions when they related how a lack of family support contributed to the delay in presenting their children with CKD for medical care.

#### **6.4 Community-related factors contributing to delay in presenting children with CKD for medical care**

The current study found delayed referral from the local health facility to be a significant contributory factor in the primary care givers' delay in presenting children with CKD for medical care at KATH. The delayed referral resulted in the progression of CKD, which could lead to early mortality. This is confirmed by Jha et al. (2013:266), who suggest that delayed referrals lead to missed opportunities to implement strategies to slow the progression of CKD and provide cardiovascular protection, recognised as among the main causes of mortality in those who suffer from CKD. The current study's finding of delayed referral from local health facilities as contributing to delay in presenting a child with CKD to KATH meant that this prevented opportunities for treatment of underlying conditions in order to slow progression of the kidney dysfunction (Sreedharan & Avner, 2016:2546). Although there is no definitive treatment to improve kidney function in children with CKD, treating specific underlying disorders may reduce the rate of progression of the kidney dysfunction.

Early management of children with CKD is essential to slow the progression of renal dysfunction and reduce the risk of death from cardiovascular issues (Jha et al., 2013:267; Sreedharan & Avner, 2016:2545). The findings of the current study showed that the delayed referral and mismanagement by various local health facilities contributed to the delay in presenting children for early medical care, thus contributing to the progression of the dysfunction of the kidneys in children with CKD. The delayed referrals could be a sign of the local health practitioners' lack of knowledge about appropriate management of CKD and its benefit in slowing progression of the disease. This was confirmed by one participant who alluded to the fact that the local health facility would not believe her when she told them that her child was not passing enough urine,

because they could not see any major signs. The health staff told this mother that she was exaggerating and her child was okay. Sreedharan and Avner (2016:2545) propose that management of CKD in children should take place at paediatric centres where proficient multidisciplinary services, which include nursing, social services, medical and psychological support, can be provided.

### **6.5 Political-related factors contributing to delay in presenting children with CKD for medical care**

The findings of the current study revealed that the distance of caregivers' homes from KATH was a contributory factor to their delay in presenting their children with CKD for medical care. Nephrology or renal care as a sub-specialty in Ghana's health sectors is limited, with only two teaching hospitals which manage CKD in both adults and children in the whole country: KATH in Kumasi and Korle Bu Teaching Hospital in Accra. Children with CKD from across all of the regions of Ghana are referred to KATH for management. This means that primary care givers have to travel for long distances before they can get access to KATH to care for their children with CKD.

Distance from facilities is the most important factor influencing utilisation of health services in Ghana. Longer travel times and greater distances to health centres from rural areas contribute to the delay in seeking medical care and also reduce the life expectancy of rural inhabitants, increasing child mortality and morbidity (Awoyemi, Obayelu & Opaluwa, 2011:1). This was also found to be a significant contributory factor in the delay in presenting children with CKD for medical care in the current study. This finding is supported by Al-Taiar et al. (2010:1), who emphasised that the distance that people have to travel to access health facilities is a barrier to healthcare services.

Awoyemi<sup>1</sup>, Obayelu and Opaluwa (2011:1) noted that rural people often spend a great deal of time getting access to a health facility. On many occasions they have to walk long distances because they have problems obtaining access to reliable transportation. The same finding was discovered in the current study; one primary care giver had to be

in a queue for more two weeks in order to get a seat on a bus, which contributed to the delay in presenting the child with CKD for medical care. Unfortunately in Ghana there is no formal bus- booking system so the owners operate on a 'first come, first served' system. This is confirmed by the findings of a study conducted in some rural communities in Ghana by Atuoye et al. (2015:4-6), where transportation to the health facilities was reported to be a challenge and thus a contributory factor to the delay in their seeking medical care.

A poor road network is one of the main characteristics of the rural geography of Ghana and is more pronounced in the Northern sectors, the region served by KATH (Atuoye et al., 2015:4). The findings revealed that participants reported the poor road system, especially during the rainy season, as making transportation very difficult for them, and thus contributing to the delay in presenting their children with CKD to KATH for medical care. In addition, some participants reported the high costs involved in transportation as having contributed to the delay.

#### **6.6 Perceived need for community awareness about CKD**

This theme was discovered serendipitously, when primary care givers raised the need to educate their communities and health professionals about CKD. Participants stated that if they had heard about CKD early through education they would not have spent time seeking alternative treatment which contributed to the delay in presenting their children with CKD for medical care. The need for community awareness about CKD was therefore identified as important for the benefit of both the health professionals in local health facilities and the community as a whole. This is supported by a study conducted by Morton et al. (2010:1), who concluded that the creation of community awareness about factors associated with CKD could influence people's decision making on seeking medical care for CKD. It would also equip health professionals with information on how best to deliver good-quality care for patients and their families. In support, Mathew and Corso (2009:367) recommend that a community awareness

campaign about CKD can facilitate early diagnosis of CKD and allow preventive measures to be put in place for a positive impact on clinical outcomes, in facilitating a smooth, orderly and less morbid transition and preventing early mortality in children.

## **6.7 Recommendations**

### **6.7.1 Recommendations for the Ministry of Health/Paediatric Renal Unit-KATH**

The current study revealed a delay in referral from the local health facility as a contributory factor in primary care givers' delay in presenting their children with CKD to KATH for appropriate medical care. It is therefore recommended that a policy to enhance early referral of children with renal failure be developed by the Ministry of Health and be distributed for implementation at all local health facilities in Ghana. Early treatment of the underlying conditions can slow down CKD progression and prevent early mortality.

### **6.7.2 Recommendations for Ghana Kidney Association**

The findings of the current study revealed lack of knowledge about CKD at the local health facility level and within the communities as a contributory factor to primary care givers' delay in presenting children with CKD for medical care. It is therefore recommended that Ghana Kidney Association develop and promote the implementation of community awareness campaigns to provide health education programmes for health professional and communities nationwide.

### **6.7.3 Recommendations for future study**

The qualitative findings from the current study provide the basis for understanding the factors contributing to primary care givers' delay in presenting children with CKD for medical care. It is recommended that further research be conducted using a larger sample and quantitative studies in order to identify more factors that contribute to primary care givers' delay in presenting children with CKD for medical care.

#### **6.7.4 Recommendations for education**

The current study findings revealed that health professionals' lack of knowledge about CKD and its management was a contributory factor to delay of primary care givers' in presenting children with CKD for medical care. It is recommended that the findings of this study should be reported in the curriculum for all health professionals. Educating health professionals about CKD will guide them in early detection and recognition of CKD (i.e. in order to detect CKD a urine dipstick test can be done at all health facilities to detect protein, one of the markers of CKD). Incorporating the findings into nursing practice will guide nurses in planning good nurse care in managing CKD.

#### **6.7.5 Recommendations for political policy makers**

The current study findings revealed that the poor road network and transportation system contributed to primary care givers' delay in presenting children with CKD for medical care. I recommend and appeal to the regulatory body of Ghana to develop the road networks and implement a transportation system to facilitate easy transportation for rural communities seeking medical care.

#### **6.8 Conclusion**

Many factors were found to be contributing to primary care givers' delay in presenting children with CKD for medical care in Ghana. These include intrapersonal, interpersonal, community and political factors. This highlights the need for multifactorial interventions to prevent delays in presenting children with CKD for appropriate medical care, including the need for community awareness programmes on early recognition of CKD among children.

The current study attained its purpose by identifying the factors contributing to primary care givers' delay in presenting children with CKD for medical care in Ghana. The findings identified are supported by literature from different countries. The

findings from this study may be used to guide health professionals in the management of CKD in Ghana.

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## **APPENDICES**

### **Appendix A:... Information Sheet**

#### **Introduction**

I am Abigail Amoah, a student from the University of Cape Town at the Department of Health and Rehabilitation Sciences, Division of Nursing and Midwifery. I am doing a study to find out what causes primary care givers to delay in presenting their children who suffer from chronic kidney disease for medical care. I would like to give you information and request you to participate in the study.

#### **Purpose of the study**

The study seeks to find what contributes to primary care givers' delay in bringing their children with CKD for medical care at a particular time. The findings will help in educating primary care givers on the need for prompt medical care for their children and eventually improve CKD care in Ghana.

#### **Participant selection**

You are being invited to participate in this study because I feel that you may be able to assist me with the information I need to identify and describe the factors that contribute to the delay in seeking early medical care for children with CKD.

#### **Voluntary participation**

Your participation in the study is totally voluntary, which means you are not forced to participate. Your participation or refusal to participate will not affect the health care services that are given to your child at the hospital in a negative or positive manner. Should you decide to participate, and later decide to withdraw from participation, you are welcome to change your mind during the study and nothing will be held against you.

## **Procedures**

The interview will take place at Consulting Room 10 KATH; however, you may choose a place that is more convenient to you. I will ask you specific question and record your answers through the audio-recorder. Notes will be taken from participants who refuse to be audio recorded.

The information that you provide will be confidential. Digital information will be kept under password accessible to only the researcher and her immediate supervisor. Only my supervisor will have access to the information documented during the interview. The information gathered will be destroyed after five (5) years. Interviews will last for about an hour.

## **Duration**

Interviews will last for about an hour. I will then go and analyse your answers and that of other participants. I may contact you later for another interview to validate the conclusions that I would have identified from your interview and those of others.

## **Risk**

There is no anticipated direct risk. Personal or confidential information shared would be handled with utmost care. You do not have to answer any question if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

## **Benefits**

There will be no direct benefits; however your participation is likely to help me find out the factors contributing to primary care givers' delay in reporting of CKD children to the hospital and help improve the situation.

## **Reimbursement**

There would be no incentive for you to take part in the study. However, I will give you thirty Ghanaian cedi (GHS 30) for your time spent and travel expenses.

## **Confidentiality**

This study might draw attention in the hospital or your place of preference of the scheduled interview and your participation may call in for people to ask you questions. I will not share your information with anyone except my supervisor and the information collected from you will be kept confidentially. Your real name will be replaced with pseudonyms and I would be the only one to know your exact number. I will keep your information safe in a computer under password accessible only to me and my immediate supervisor and put the raw data in a safe box locked with secret codes. It will only be shared with my supervisor, the hospital and the University. The information gathered will be destroyed after five (5) years

## **Sharing of Results**

I want to assure you that, whatever you share with me would not be shared with anyone except my supervisor and me. The acquired knowledge from this study would firstly be shared with you before it is made known to the public and that applies to all participants. Afterwards, then the results would be published for other people to learn from the study.

## **Right to Refuse or Withdraw**

You are not obliged to take part in this study if you do not want to. You may stop participating in the interview at any point in time without your services at the hospital being affected. I will give you an opportunity at the end of the interview to review your remarks and you can ask to add or remove anything that you do not agree with in my notes or if I did not understand you correctly.

## **Who to contact**

If you have any further questions concerning the study, you may contact:

### **SUPERVISOR**

Associate Professor Sinegugu Duma

Tel: +27 21 650 6428

Email: [Sinegugu.duma@uct.ac.za](mailto:Sinegugu.duma@uct.ac.za)

Participants may contact the Faculty of Health Sciences Human Research Ethics Committee (HREC) if they have any questions or concerns regarding their rights or welfare as research participants.

### **FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE**

Professor Marc Blockman

Chairperson

Tel: +27 21 40664986 / +27 21 4066338

Email: [marc.blockman@uct.ac.za](mailto:marc.blockman@uct.ac.za)

Thank You.

Abigail Amoah

Researcher

Tel: +233 20 8640042

Email: [abiamoah@yahoo.com](mailto:abiamoah@yahoo.com)

**Appendix B:... Informed Consent Document**

I ....., voluntarily give consent to Miss Amoah Abigail, studying for Master of Science in Nursing at the University of Cape Town to enrol me for her research project.

The researcher has assured me to keep our discussion or interviews in total privacy and confidentiality. I know the information given to her is the exact truth. The nature of the study has been explained to me and I have read the outline of the project or it has been read to me by the researcher.

The researcher has answered and clarified the purpose and nature of the study to my satisfaction and I (participant) totally agreed to participate voluntarily.

Name of participant.....

Signature or Thumb print.....

Date.....

Name of witness.....

Signature or Thumb print.....

Date.....

Name of researcher.....

Signature.....

Date.....

## Appendix C:... Interview Protocol/Guide

Interview Protocol Project: Factors contributing to primary care givers delay in presenting children who suffer chronic kidney disease for medical care.

Time of interview:

Date:

Place:

Interviewer:

Name and Surname of Interviewee:

Gender                      Male                       Female

Relationship to the child:

Would you mind if I audio-record our conversation?                      Yes                       No

Questions:

1. Please tell me, when did you first notice that there was something wrong with your child? (*Probe: What were the changes that you noticed?*).
2. Now please tell me about what you did to seek help or treatment for your child's condition. (*Probe: What sort of information were you given by others regarding the condition of your child and its treatment?*).

3. Now tell me, what made you to decide to finally bring the child to hospital for treatment? (*Probe: Based on the response, probe why this was not done earlier?*).
4. From what we have discussed so far, are there other things that you think may have made you delay bringing your child to hospital. (*Probe: Identification of the disease, advice sought, distances, health worker behaviour and misconceptions about the disease*).

## **Appendix D:... Twi Translation**

### **Ɛfa : I**

#### **Nnianimu.**

Me din de Abigail Amoah. Mefiri suapɔn a ɛwɔ Cape Town nkorabata a ɛhwɔ apɔmuden ne abɔdeɛmu- nyansape asiesie so. Meredi dwuma bi ahwe nneɛma a ɛma mmaatan twetwe wɔn nan ase ansa na wɔde wɔn mma a, wɔrehunu amane wɔ koankorɔ sawa mu yareɛ no akɔ ayaresabea akɔgye ayarehwe. Merebɔ mo amanneɛ na masere ato nsa afre mu se mommeka me ho wɔ saa dwumadie yi mu.

#### **Adesua No Botaeɛ**

Adesua no behwehwe deɛ nti mmaatan de wɔn mma a wɔyare koankorɔ sawa mu yareɛ no begye ayarehwe mmere petee bi. Nhwehwemu no beboa ama yeama mmaatan no nteteeɛ na wɔahunu hia a ɛhia se wɔde wɔn mmɔfra a wɔyare sawa mu yareɛ koankorɔ no bekɔ ayaaresabea ntem so, na ne korakera no, ama sawa mu yareɛ koankorɔ ayarehwe atumpɔn wɔ Ghana.

#### **Sedeɛ Wobetumi Aka Ho**

Yeto nsa fre wo se beka saa adesua nhwehwemu yi ho efiri se, megyedi se wo wobetumi aboa me ɛwɔ nimdeɛ ehwehwemu ebema yeahunu deɛ nti a wɔtwentwen wɔn nan ase ansa na wɔakɔgye ayarehwe ama mmɔfra wo wɔ koankorɔ yareɛ no.

#### **Ɛye Atuhoakye Mu**

Ka a worebeka saa adesua / nhwehwemu yi ho ye tuhoakye a, akatuasem biara nni mu. Eno nti wobetumi asi gyinaeɛ se wobeka ho anaase wommeka ho. Na mmom, ayarehwe anaase dwumadie a yede bema wo ba wɔ asopiti no nsesa se woba anaa wamma a. Wobetumi nso asesa w'adwene bere a nhwehwemu no rekɔ so no ara, na biribiara nto wo anaase w'abɔfra.

## **Nhyehyee**

Nsemmisa no bekɔ so wɔ akwankyerɛ dan a ɛtɔ so du (10) wɔ Komfo Anokye Ayaresabea kɛsɛɛ no mu (KATH). Na mmom, wobɛtumi nso akɔ baabi a ɛben wo. Mɛbisa wo nsemfuo bi a nyinaa yɛbekyere agu abɛɛfo afidie so. Nsemmisa ne mu anoyie nyinaa mpue ma ɔdasani biara nte bi. Mehwɛfoɔ no nko ara na ɔbɛtumi anya akwanya atwerɛ biribi ato krataa so, berɛ a nsemmisa no rekɔ soɔ no. Nsem biara nso a yɛbekyere anaa sɛ yɛbɛtwɛrɛ no yɛbɛto agu mfee num akyi pɛpɛɛpɛ. Nsemmisa nso ɛmmoro dɔnhwere baako.

## **Berɛ tenten a wɔde di dwuma no**

Nsemmisa nso ɛmmoro dɔnhwere baako. Mɛkɔ akɔkika ɛkomodie akosu wo wo ne awofoɔ nyinaa ɛka adesua yi wo. Me saa aba biɔn asa no wo abɛ bi sa nsemfuo beem no me di atutu gyinabea no hu sɛ ɛne nea wo mmaamefoɔ noka ye no ye pɛpɛɛpɛ ana sɛ ɛbɔbura. Sɛ ɛho behia mpo a, nsemmisa foforo bekɔ so sɛdɛɛ ɛbeyɛ a ɛbehye nhwehwe mu no mu kena.

## **Asiane a ɛwɔ ho**

Yerehwe anim sɛ asiane biara mma. Ankorekore nsem anaase asie-sɛm a ɛbɛpue no nye nsam da. ɛnye nhyɛ nso sɛ wobeyi asembisa biara a, wogyedi sɛ ɛye wo ara w'abrabo mu nsem ano, anaase asem bi a woka a, ɛmma wo ahomeka.

## **Mfasoɔ a ɛwɔ ho**

Mfasoɔ a ɛye akyɛdɛɛ biara nni mu. Nanso ka a, worebɛka me ho no, bɛboa me ama mahunu nneema a ɛma mmaatan twetwe wɔn nan ase, sɛ wɔbɛka wɔn mma koankoro sawa no yareɛ no akyerɛ Dɔkota wɔ ayaresabea ne mpuntuo a ɛbɛba mu.

## Akatua

Akatua titire biara nni mu, se wobeka dwumadie yi ho a. Na mmom mema wo biribi ketoa bi wo 30 Ghana sika mu a, wo wo mmere ne eka a woboo no wo wo kaa hyentiadee (kaa sika) ho.

## Awerɛhyemu

Mmom nhwehwemu no betumi atwe asopitifo anaase nnipa a wowa faako a wobegye penee se wobeye nsemmisa no mu bebre betumi afre abisa nsem dee. Nanso me ne nnipa biara nkye wo nsemmisa ne wo mmuae no mu biara gye se mehwefo no nko ara. Me hye bo se nsem biara beka kokoam a erempue. Baabiara a wo din pa ara hye biara no ,mede ne nseso na ebɛhye ho. Me nko ara na mehunu wo din ankasa . Mede wo ho nsem no besie me abeefo afidie badwenmma so, na dee metwere no nso mede besie fee a onipa biara ntumi nhunu.

Sedee madi akan aka no, mehwefo nko ara ne asopiti no, ne suapon no na wobɛnya akwanya wo nsemmisa ne wo ho nsem Onipa biara nte bi.

## Akyirisem - kye

Mehye mo bo se, biribiara a mo ne me bekye no, me ne onipa biara nso nkye da gye se mehwefo no ne me nko ara. Suahunu a menya no wo saa nhwehwemu adesua yi mu no, medi nkan ne wo akye ansa na me ne nnipa nkae no nso akye. Saa ara na meye ama obibiara a aka dwumadie yi ho.

Ansa na akyire yi mede akyirisem no ato abonten atintim no wo krataa so ama obiara nso asua biribi afiri nhwehwemu yi ho.

**Wowo tumi se woka ho anaase wogyaee**

Enye nhye se bra beka saa nhwehwemu yi ho se wompe a. Wobetumi atwe wo ho afiri nsemmissa no ho bere biara a wope nanso enha wo dwumadie wo asopiti ho. Akwanya wo ho se wobetumi asesa mmuae a wode mae no wo nsemmissa bere mu. Wobetumi ayi mmuae no bi nso afiri mu. Se mpo mante wo ase na metwere biribi a, wo wo ho kwan se woyi firi mu bere a woreko nsemmissa no akyi ahwehwe mu no.

### **Wɔn a wobɛtumi abisa wɔn nsem**

Se wowo nsemmissa bi a wobetumi abisa no seisei ara anaase akyire yi a na wabisa. Na mmom se worepe nkyeremu foforo bi a, wobetumi abisa wɔn a wɔn akyirikwan wo ase ha yi.

1. Obenfo Abadiakyerɛ Sinegugu Duma

Research Supervisor

Tel: +27216506428

Email: Sinegugu.duma@uct.ac.za

### **FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE**

2. Obenfo Marc Blockman

Chairperson

Tel: +272140664986

Email: marc.blockman@uct.ac.za

Se wogyɛ tom beka saa nhwehwemu anaa adesua yi ho a, ese se wode wo nsa ano agyinae hye krataa ase de ye adansedie kyere se, wote nhwehwemu no ase, na worebeka ho wo atuoakye. kwan so a akatuasem biara nni mu.

### **Hyɛ no nso**

Wɔn a wɔka saa nkwehwɛmu dwumadie ho no betumi ne asoee a ehwe nnipa mu apɔmaden nkabom a wɔtwa no tia se, (HREC) adi nkutaho afa nsemmisa ne adwenkyere biara a efa wɔn fawohodie ne wɔn nkankɔ ho.

Meda wo ase

Abigail Amoah.

Nhwehwɛmuyefo.

Tel: +233 20 8640042

Email: abiamoah@yahoo.com

**Ɛfa 2: Nsem̄misa mp̄enesō krataa**

Me ..... de atuhokye ma kwan se Awuraa Abigail Amoah, a ɔresua abodee mu nyansape a efa n'ese ho wo suapon a ewo Cape Town se omfa me nka ne nhwehwemu dwumadie yi ho.

Nhwehwemuyefo no ahye me bo se, nsem biara a efa me ho a, meka akyerɛ no no, ode behinta kokoam.

Asem biara nso a maka akyerɛ nhwehwemuyefo no nse eye nokore turodo. Nhwehwemu no botae ne mpimpenso nyinaa nso menim. Mekan ekwan ahodo a nhwedwemu no befa so nso nyinaa na mete ase nso.

Nhwehwemuyefo no ayiyi nsem̄misa ne botae nti a ɔreye saa nhwehwemu no, na megye tom se mede me ho besi ho ama nhwehwemu no wo tuhokye kwan so.

Wo din .....

Nsaano Agyinakyede .....

Ɛda .....

Adansine no din.....

Nsaano Agyinahyede .....

Ɛda.....

Nhwehwemuyefo no din .....

Nsaano Agyinahyede .....

Ɛda.....

### Ɛfa 3: Nsem̄misa nhyehyee

Nsem̄misa nkyehyee no befa nneema a eka ho bi ma mmaatan twetwe won nan ase. Se wode mmofra a woyare koankoro sawa mu yaree no beko beko asopiti akogyey ayarehwe.

Nsem̄misa no bere: .....

Ɛda: .....

Beaee: .....

Obisafo: .....

Dee oreyi nsem̄misa no ano: .....

Deeoreyi nsem̄misa no ano no dibere: .....

Ne bosuo/bobere: .....

Woye abofra no deen: .....

Yenkyere ngu afidie so anaa:           Aane .....           Dabi .....

Nsem̄misa no nie:

1. Mepa wo kyew, ka kyere me bere a wohunuu se wobofra no nte apo? (Beemo: eden sunsunoye bee no wo hunu ye?).
2. Afeyi, ka kyere me adee wo ye di pee mmoa wo abofra no tibeamu. (Beemo: edee nsem anaa efutuo ben an nkrofo kakyere wo efa w'abofra no tibeanom?).
3. Afeyi, kakyere me Da woyee w'adwene se wode no beba ayaresabea na aden nti a? (Beemo: gyena eno so bisa adikoro enti wafa abofra no ama tem).

4. Wɔ nkɔmɔ a yedi, biribi pɔtɔii bi wɔ hɔ enti na wo afa abɔfra no ama ayaresabea etem. (Beeɔ: yare no ahyensodea anaa, efutuo wo pɛ ye, ekwantwaa, ɔduroyefoɔ bi suban ene yadieɛ no mu tiremuka).

# Appendix E:... Ethical Approval from Human Research Ethics Committee. Faculty of Health Sciences



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E53-46 Old Main Building  
Groote Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6492  
Email: [sumyah.ariefdien@uct.ac.za](mailto:sumyah.ariefdien@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

01 September 2016

HREC REF: 402/2016

A/Prof S Duma  
Health & Rehab  
F-floor, OMB

Dear A/Prof Duma

**PROJECT TITLE: FACTORS CONTRIBUTING TO PRIMARY CARE GIVERS' DELAY IN PRESENTING CHILDREN WITH CHRONIC KIDNEY DISEASE FOR MEDICAL CARE IN GHANA (Masters-candidate-A Amoah)**

Thank you for your response letter dated 08 August 2016, addressing the issues raised by the Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30 September 2017.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

**Please quote the HREC REF in all your correspondence.**

***We acknowledge that the student, A Amoah will also be involved in this study.***

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

Signed

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

HREC REF 402/2016

# Appendix F:... Ethical Approval from School of Medical Sciences/Komfo Anokye Teaching Hospital Committee on Human Research, Publication and Ethics



KWAME NKURUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY  
COLLEGE OF HEALTH SCIENCES

SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL  
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS



Ref: CHRPE/AP/509/16

12<sup>th</sup> December, 2016.

Miss Abigail Amoah  
Department of Child Health  
Paediatric Renal Unit  
Komfo Anokye Teaching Hospital  
KUMASI

Dear Madam,

## LETTER OF APPROVAL

**Protocol Title:** *“Factors Contributing to Primary Care Givers’ Delay in Presenting Children with Chronic Kidney Disease for Medical Care in Ghana.”*

**Proposed site:** *Komfo Anokye Teaching Hospital, Department of Child Health, Paediatric Renal Unit.*

**Sponsor:** *Principal Investigator.*

Your submission to the Committee on Human Research, Publications and Ethics on the above named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 15<sup>th</sup> September, 2016 from the Komfo Anokye Teaching Hospital (study site) indicating approval for the conduct of the study in the Hospital.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning 12<sup>th</sup> December, 2016 to 11<sup>th</sup> December, 2017 renewable thereafter. The Committee may however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you Madam, for your application.

Yours faithfully,

**Signed**

Osomfuor Prof. Sir J. W. Acheampong MD, FWACP  
Chairman

**Appendix G:... Certificate of Registration with Komfo Anokye Teaching Hospital  
Research and Development Unit**



**KOMFO ANOKYE TEACHING HOSPITAL  
RESEARCH AND DEVELOPMENT UNIT (R & D)  
CERTIFICATE OF REGISTRATION**

REG. NO: RD/CR16/250

This is to certify that

Prof/Dr/Mrs/Mr/Ms. Amoah Abigail  
has registered his/her proposed study titled Factors Contributing to  
Primary Care Givers' Delay in Presenting Children with Chronic Kidney  
Disease for Medical care in Ghana  
.....with the Research and Development Unit.

Date: 15th September, 2016

Name of issuing officer

Ms. Juliet Ampomah Frimpong

Signature

**Signed**

K/16/0020465

Receipt No

\*\*This certificate does not constitute ethical clearance for the conduct of the study but proof of registration of study with KATH. Ethical clearance from the Committee of Human Research Publications and Ethics (CHRPE) is required to conduct the study

## Appendix H:... Approval from Department of Child Health

**KOMFO ANOKYE  
TEACHING HOSPITAL**



P. O. Box 1934  
KUMASI - GHANA  
Tel: +233 - 3220-22301 - 4  
Fax: +233 - 3220 - 24654/24621  
Website: www.kathsp.org

**DIRECTORATE OF CHILD HEALTH**

Our Ref. No:.....

Your Ref. No:.....

**13 SEPTEMBER 2016**

ABIGAIL AMOAH  
PAEDIATRIC RENAL UNIT  
KATH - KUMASI

LETTER OF APPROVAL

RE: "FACTORS CONTRIBUTING TO PRIMARY CARE GIVERS' DELAY IN PRESENTING CHILDREN WITH CHRONIC KIDNEY DISEASE FOR EARLY MEDICAL CARE IN GHANA"

Approval is hereby given provisionally for you to conduct the study entitled "Factors Contributing to Primary Care Givers' Delay in Presenting Children with Chronic Kidney Disease for early Medical Care in Ghana subject to ethical approval.

It is required that any future revisions or amendments are duly communicated to the directorate.

Thank you.

**Signed**

PROF. E.O. D. ADDO-YOBO  
HEAD OF DIRECTORATE

A Centre of Excellence

## Appendix I:... Sample of Signed Informed Consent

### Appendix B:....29. Informed Consent Document

I Ruth Bempah....., voluntarily give consent to Miss Amoah Abigail, studying for Master of Science in Nursing at the University of Cape Town to enrol me for her research project.

The researcher has assured me to keep our discussion or interviews in total privacy and confidentiality. I know the information given to her is the exact truth. The nature of the study has been explained to me and I have read the outline of the project or it has been read to me by the researcher.

The researcher has answered and clarified the purpose and nature of the study to my satisfaction and I (participant) totally agreed to participate voluntarily.

Name of participant..... Ruth Bempah  
Signature or Thumb print..... **Signed**  
Date..... 20 - 12 - 2016

Name of witness..... Alexandra Oduy  
Signature or Thumb print..... **Signed**  
Date..... 20 - 12 - 2016

Name of researcher..... Abigail Amoah  
Signature..... **Signed**  
Date..... 20 - 12 - 2016

**Appendix C:....30. Interview Protocol/Guide**

Interview Protocol Project: Factors contributing to primary care givers delay in presenting children who suffer chronic kidney disease for medical care.

Time of interview: 10:40 am

Date: 20 - 12 - 2014

Place: Consulting Room 10

Interviewer: Abigail Amoah

Name and Surname of Interviewee:

Signed

Gender

Male

Female

Relationship to the child: Mother

Would you mind if I audio - record our conversation?

Yes

No

Questions:

1. Please tell me, when did you first notice that there was something wrong with your child? (Probe: What were the changes that you noticed?).
2. Now please tell me about what you did to seek help or treatment for your child's condition. (Probe: What sort of information were you given by others regarding the condition of your child and its treatment?).
3. Now tell me, what made you to decide to finally bring the child to hospital for treatment? (Probe: Based on the response, probe why this was not done earlier).