UNIVERSITY OF CAPE COAST

EXPERIENCES OF FAMILY CAREGIVERS OF YOUNG PERSONS LIVING WITH TYPE 1 DIABETES AT THE EFFIA NKWANTA REGIONAL HOSPITAL

BY

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DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature: ………………………… Date: ……………………….

Name: Alice Amooh

Supervisor's Declaration

I hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature: …Ampof………………… Date: 05/05/2023

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ABSTRACT

The purpose of the study was to explore the experiences of family caregivers of young persons living with type 1 diabetes (T1D) at the Effia Nkwanta Regional Hospital in the Sekondi/Takoradi Municipality of the Western Region. This study made use of a qualitative research approach with exploratory-descriptive design and recruited fourteen family caregivers of young persons living with T1D. Participants recruited for this study were 18years and above. From the study findings emerged four major themes, namely: perceptions, experiences, challenges and coping strategies. Generally, participants reported having not heard about T1D prior to their child being diagnosed of the condition. As a result, most of them delayed in reporting their child's condition to the hospital and went through varied experiences on hearing the news about their child's diagnosis. However, after the diagnosis, they became very conversant with the basic knowledge required for the management of T1D at home through the health education they received at the clinic. With T1D being identified as a serious chronic disease associated with complications, participants attributed its cause to several factors. Although T1D was reported as a difficult diagnosis, participants learnt how to manage the condition and all of them were able to recount the role they play in diabetes management with the goal of seeing their child's blood glucose within the normal ranges. Most of these participants were familiar with the signs and symptoms of hypoglycaemia. Also, the study participants reported challenges that bothered on the psychological, social and financial aspects of their lives. Finally, in order to cope with the stress associated with T1D and its managements, findings from the study identified the coping strategies family caregivers use such as religious beliefs, social support, family involvement and embracing the new normal.

KEY WORDS

Experiences

Family caregivers

Young persons

Type 1 diabetes

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DEDICATION

This work is dedicated to my husband, Mr. Gordon Dome-Iguu Yibey and my mom, Miss Hannah Adjei.

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LIST OF ABBREVIATIONS

ADA	American Diabetes Association
DOC	Diabetes Outpatient Clinic
EDQ	Exploratory-descriptive Qualitative Research Method
ENRH	Effia Nkwanta Regional Hospital
FMSF	Family Management Style Framework
HbA1c	Glycated Haemoglobin
IDF	International Diabetes Federation
OGTT	Oral Glucose Tolerance Test
T1D	Type 1 Diabetes
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

This section provides an introduction to the research study. It presents the background to the study, the problem statement, the purpose of the study, the specific objectives of the study, the significance of the study and definition of terms.

Background to the Study

Diabetes as described by the American Diabetes Association (ADA), 2014) is a group of metabolic diseases marked by hyperglycaemia resulting from defects in insulin secretion, insulin action, or both. The chronic hyperglycaemia of diabetes is associated with long-term damage, dysfunction, and failure of different organs, especially the eyes, kidneys, nerves, heart, and blood vessels. According to the International Diabetes Federation (IDF), 2020), there are three main types of diabetes namely- type 1 diabetes, type 2 diabetes and gestational diabetes.

Specifically, type 1 diabetes (T1D) is the body's inability to produce insulin (WHO, 2016). It is characterized by an immune-mediated depletion of pancreatic beta cells that results in lifelong dependence on exogenous insulin (Chiang, Kirkman, Laffel, & Peters, 2014). The difference between type 1diabetes and type 2 diabetes is that the pancreas does not produce any insulin in type 1diabetes, and insulin production is decreased or inhibited in type 2 diabetes (WHO, 2016).

Insulin is the hormone required to change sugar, starches, and other foods into energy required by the body for the performance of its daily function (ADA, 2014); therefore, when insulin production is interrupted, diabetes results. The American Diabetes Association (ADA) defines the criteria for the diagnosis of diabetes as fasting plasma glucose higher than or equal to 126mg/dl (7.0mmol/l) or two-hour plasma glucose higher than or equal to 200mg/dl (11.1mmol/l) during oral glucose tolerance test (OGTT) or random plasma glucose higher than or equal to 200mg/dl (11.1mmol/l) in individuals with classic symptoms of hyperglycaemia or hyperglycaemic crisis (ADA, 2014). In order to monitor long-term diabetes control, physicians often use the glycated haemoglobin (HbA1c) test results to determine a patient's average glucose levels over a period of time. The HbA1c test result can provide a glimpse of diabetes management over 2-3 months HbA1c level of greater than or equal to 6.5% indicates poor diabetes control, thus increasing the risk of diabetes related complications (Mayo Clinic , 2021).

Over the last 20 years the incidence of type 1 diabetes in children under 5 years of age has increased. Although the cause of this age-specific diabetes remains unknown, there is clear evidence of a genetic predisposition and strong, but circumstantial, evidence for environmental factors triggering an autoimmune destruction of the beta cells leading to absolute dependence on insulin treatment (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003; Patterson, Guariguata, Dahlquist, Soltesz, Ogle, & Silink, 2014; International Diabetes Federation (IDF), 2019).

Type 1 diabetes is the most common metabolic disorders in children. The incidence of childhood onset diabetes is increasing in many countries. Around 86 000 children develop diabetes each year, and the incidence has been increasing by 3% per year worldwide (Piloya-Were, Sunni, Ogle, & Moran, 2016; Patterson, Karuanga, Salpea, Dahlquist, Soltesz, & Ogle, 2019). Studies indicate that there are almost 500,000 children aged 14 years old and younger with type 1 diabetes worldwide (Patterson & Guariguata et al., 2014). Although the epidemiology of diabetes mellitus in sub-Saharan Africa including Ghana is limited (Sarfo-Kantanka, Asamoah-Boaheng, Arthur, Agyei, Barnes, Tenkorang, & Midodzi, 2020; Mbanya, Motala, Sobngwi, Assah, & Enoru, 2010), contrary to a commonly held belief, diabetes is not rare in this continent; the projected global estimates for the years 2000-2010 reported the prevalence of type 1 diabetes was expected to increase from 85,000 to 219,000 between 1995 and 2001 (Motala, Omar, & Pirie, 2003).

The main goals of diabetes treatment among children with T1D are to achieve the best feasible glycemic control; to reduce the risk of hypoglycaemia, diabetic ketoacidosis; and to prevent long-term complications (Rewers et al., 2014). Thus, as a complex, chronic illness, T1D requires continuous medical treatment with a wide range of health-related behaviours in disease management, such as monitoring blood glucose, insulin therapy, dietary restrictions, and exercise everyday (ADA, 2014; Iversen, Graue, Hausgstvedt, & Raheim, 2018).

There is evidence indicating that childhood illness has a powerful impact on the total family system. This is in line with the Family System Theory which states that the family shares a reciprocal, interactive relationship with the illness. The theory assumes that behaviour takes place in an interpersonal context and as such, not only does the family affect diabetes, but diabetes also affects the family (Helgeson, Becker, Escobar & Siminerio, 2012). For instance, in addition to the usual challenges of fostering physical, cognitive, and socioemotional growth and development, caregivers are directly responsible for the performance of the disease management, including blood glucose monitoring, insulin administration, accounting for carbohydrate intake and diet tracking; and the complex task of taking care of a child with diabetes in everyday life can have profound impact on them (Sullivan-Bolyai et al., 2003; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Boogerd, Schaaijk, Noordman, Marks, & Verhaak, 2015; Helgeson et al., 2012). The treatment is especially demanding with the administration and adjustment of small doses of insulin, picky eating, and difficulty recognizing and communicating hypoglycemic symptoms and continuous need for supervision and caregiving (Grey et al., 2011; Iversen et al, 2018).

For most family caregivers with such children, there is radical disruption of their lives after diabetes diagnosis. Their lives are not so easier than before; they experience many losses including loss of their previously healthy child, their freedom and confidence. They feel the child is invisibly ill and they feel insecure and have concerns connected to the future. Family caregivers also have long-term emotional responses to the diabetes even several years after diagnosis (Marshall, Carter, Rose & Brotherton, 2009; Rintala, Paavilainen, Astedt-Kurki, 2013). Some family caregivers even curtail their own activities and lifestyles including giving up recreational activities that take them out of their homes, some can also neglect their own health and wellbeing to care for the young child with diabetes (Lawton, Ranklin, Elliot, Heller, Rogers, De Zoysa & Amiel, 2014). Therefore, the diagnosis of this chronic illness in a child leads to a major stressful event for family caregivers leading to family upheaval and reorganization (Patterson & Garwick, 1998).

Globally, diabetes is a chronic, debilitating and costly disease associated with severe complications which constitutes one of the major challenges for development in the twenty-first century. It also undermines social and economic development throughout the world and threatens the achievement of internationally agreed development goals (United Nations General Assembly, 2007; 2012). The costs of diabetes include both direct costs from medical care as well as indirect costs incurred through loss of productivity or earnings, both of which are important contributors to the global economic burden (Bommer & Sagalova et al., 2018).

In addition to the above, the ninth edition of the IDF Diabetes Atlas records that, 10% (USD 760 billion) of the global health expenditure is spent on diabetes (IDF, 2019). As stated in a study by Mutyambizi, Pavlova, Chola, Hongoro and Groot (2018), despite the scarcity of data on diabetes in Africa, it is estimated that Africa spends 7% of its healthcare budget on diabetes and this cost of diabetes care places immense pressure on the already overstretched healthcare systems in Africa. With regards to the family, costs associated with dietary restrictions, more frequent visits to a physician, specialists' care, and prescriptions contribute to the financial burden associated with care for a child with diabetes. This results in financial strain on many families, especially in low-income and middle-income countries where health-care coverage or access is poor (Burns, Nicolucci, & Holt et al., 2013; Lancet, 2018).

According to the International Diabetes Federation (IDF), insulin is associated with significant out-of-pocket payment that can consume about two-thirds of disposable income; and blood glucose monitoring alone in many such countries can consume half of a family's average disposable income

(International Diabetes Federation, 2016). It was stated emphatically in a study by Volman (2008) that high direct costs for patients result in families living in increasing poverty. Indirect costs for family members, such as effects on ability to work, can also contribute to the negative economic impact on families affected by diabetes and other chronic diseases (The Lancet Diabetes Endocrinology, 2018).

Problem Statement

Being a family caregiver of a young person with T1D is associated with numerous unique challenges (Zysberg & Lang, 2015; Iversen et al., 2018). Family caregivers may become so burdened with concerns related to the day-to-day illness management, such that they lose sight of their psychosocial interaction, as well as other family-related needs. (Sullivan-Bolyai et al., 2003).

While the role of family caregivers in moderating and normalizing the disruptive effects of the illness is well recognized clinically (Rintala et al., 2013; Lawton et al., 2014; Baig, Benitez, Quin, & Burnet, 2015), very little is known about these family caregivers' day-to-day experiences and their support needs (Lawton et al., 2014). Also, despite an increasing number of studies on the experiences of children and adolescents with diabetes (Wang, Brown & Horner, 2010; Scholes, Mandleco, Roper, Dearing, Dyches & Freeborn, 2013; King, King, Nayar & Wilkes, 2017), there have been few about the experience of being a family caregiver of a young person with type 1 diabetes (Stodberg, Sunvisson, & Ahltrom, 2007, Zysberg & Lang, 2015). For these reasons, it is critical to understand the day-to-day experiences of these caregivers in order to provide appropriate clinical guidance and support.

More so, the body of research and educational programmes on family caregivers of young people with T1D (Sullivan-Bolyai et al., 2003; Grey et al, 2011; Iversen et al., 2018) focus on the developed countries. Although lots of studies have been conducted on family caregivers in Ghana, majority of these studies are centered on family caregivers with children living with cancer (Bekui, Ohene, Badzi, Ampomah, & Aziato, 2023; Mensah, Nunoo, Mensah, Okyere, Dzomeku, Apiribu, Asoogo, & Clegg-Lamptey, 2023; Bekui, Aziato, Ohene, & Richter, 2020).

In support of this fact, Kratzer (2012) rightly asserted that experiences of families living with young persons with T1D have been documented in many developed countries, however, there is a void in the literature for such families living in Ghana. Thus, within diabetes care in Ghana, there appears to be a gap between what is known about type 1 diabetes as a physical disease and the experiences of Ghanaian family caregivers who provide practical support in the day-to-day management of their young children with diabetes. This study is therefore designed as an attempt to fill in gaps in the literature that has not provided sufficient data on the experiences of Ghanaian family caregivers with young children living with T1D.

Purpose of the Study

The purpose of this research was to explore the experiences of family caregivers of young persons living with T1D at the Effia Nkwanta Regional Hospital.

Research Objectives

The general objective of the study was to explore the experiences of family caregivers of young persons living with T1D at the Effia Nkwanta Regional hospital in the Sekondi / Takoradi Municipality. The specific objectives are as follows:

1. To investigate the perception of family caregivers of young persons living with T1D about the disease.
2. To explore the experience of caring for a young person living with T1D.
3. To describe the challenges family caregivers face while participating in the care of a young person living with T1D.
4. To identify the strategies family caregivers use to cope with the demands related with the care of a young person with T1D.

Research Questions

1. What perception do family caregivers of young persons living with T1D have about diabetes as a disease condition?
2. What is the experience of caring for a young person with T1D?
3. What challenges do family caregivers face while participating in the care a young person with diabetes?
4. How do family caregivers cope with the demands related with the care of a child with T1D?

Significance of the Study

Nurses need to provide support for family caregivers as well as care for the patients and this requires a profound understanding of family caregivers from their own perspective. Therefore, the knowledge acquired about the everyday life of family caregivers of young persons with type 1 diabetes from this study will provide a better insight into the nature of caregiving among families with a child suffering from T1D. This information will help health care providers offer more precise management guidance for families who are directly involved in the care of children with this condition.

Also, the findings in turn can be used by the management of ENRH in the development of educational programs and support approaches for these family members. Furthermore, findings from this study will add to the body of knowledge since there is a void in the literature for experiences of families caring for young children living with T1D in Ghana.

Delimitation or Scope of Study

The participants in this study consisted of family caregivers who have established relationship with the young person living with T1D, who are regular attendants at the diabetic clinic in ENRH, Takoradi in the Western Region of Ghana. Participants were selected purposefully with different demographic characteristics (in terms of age, education, duration of caregiving and duration of diabetes among children).

Limitations of the Study

A limitation of this study is that the interviewees might have chosen only to disclose what they thought was socially acceptable which might have affected the outcome of the study. To reduce the effect of obtaining socially acceptable answers, the researcher built trusting relationships with participants which enabled them to freely share their experiences and collected data until saturation was reached as suggested by Streubert and Carpenter (2011)

Operational Definition of Terms

1. Experience: A representation of family caregivers' practical contact with and observation of facts or events about T1D and the diabetes-

related management choices these family caregivers of young children living with diabetes make daily.

2. Family caregiver: Mothers and fathers or other close relatives who directly take up the complex management of the disease including blood glucose monitoring, insulin administration, accounting for carbohydrate intake and diet tracking.
3. Young person: For the purpose of this study, a young person is any child between the ages of 10 to 14 years who has T1D
4. Type 1 diabetes (T1D): Once known as juvenile or insulin-dependent diabetes is a chronic multisystem condition in which the pancreas produces little or no insulin.

Organisation of the Study

The study is structured into five main chapters. Chapter one discusses the background to the study, statement of the problem, the purpose, objectives, research questions, significance, delimitations as well as the limitations of the study, operational definition of terms and the organisation of the study. Chapter two consists of the empirical review of related studies on the research topic, discussion of the theoretical and conceptual framework of the study and chapter summary. Chapter three discusses the methodology of the study which includes the study design, setting and population, sampling procedure, data collection procedure and instrument, data processing and analysis, ethical consideration and chapter summary. The fourth chapter gives a detailed discussion of the results based on the research objectives and questions. The fifth chapter gives a summary of the study with conclusion, relevant recommendations and direction for future studies.

Chapter Summary

The chapter one is basically the introductory phase of the entire study. Consisted of the background which gave a general overview of T1D, the problem statement dealt with the issues associated with managing a child with T1D as a family caregiver whereas the purpose of the study identified what the study sought to achieve in the form of a broad statement. Specific objectives which is a breakdown of the general objective spelt out the specific aspects of the topic that needed to be researched into within the scope of the study. Furthermore, the research questions formulated from the specific objectives identified the questions that required answering in order to achieve the intended purpose of the study.

Significance of the study on the other hand brought to bare the importance of the study and the its impact in my field of work as professional nurse, its contribution to new knowledge and how others will benefit from it. The delimitations and limitations described the boundaries set for the study; and those factors of the methodology that will influence the interpretation or application of the study findings respectively. The last but not the least, the aspect of operational definition of terms allowed the researcher to describe in a specific way what it means when a certain word or term is used.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Literature review is a critical method used to focus the research problem and statement of purpose. It involves finding relevant research reports, critically appraising the studies, and synthesizing the study results. Thus, noting the similarities and differences in research results, evaluating the strengths and limitations of previous studies and identifying gaps in knowledge to the relevant research problem (Grove, Gray, & Burns, 2015). This chapter reviews journals of health sciences from EBSCO, ERIC (Educational Resources Information Center), Google Scholar, PubMed, PsycINFO and relevant books both in the library and online, reports from workshops, seminars and other previous studies on the key concepts of this current studies. The theoretical and conceptual framework of this study has also been discussed in this chapter.

Overview of Type 1 Diabetes (T1D)

Type 1 diabetes is one of the most common chronic metabolic disorders in children and adolescents; its incidence is on the increase in many countries. Although the cause of this age-specific diabetes remains unknown, there is clear evidence of a genetic predisposition and strong, but circumstantial, evidence for environmental factors triggering an autoimmune destruction of the pancreatic beta cells leading to absolute lifelong dependence on exogenous insulin treatment (Sullivan-Bolyai et al., 2003; Patterson et al., 2014; Rifshana, Breheny, Taylor & Ross, 2017). The hormone insulin is a very important hormone required to maintain metabolic homeostasis, regulate carbohydrate, lipid and protein metabolism; and so, insulin deficiency in T1D results in myriad of metabolic disturbances (Bervoets, Massa, Guedens, Louis, Noben, & Adraensens, 2017).

Classic symptoms of type 1 diabetes resulting from excess glucose in the blood (hyperglycaemia) in the absence of insulin (Doyle & Grey, 2010, Rifshana et al., 2017) include polydipsia, polyuria, polyphagia, weight loss, tiredness and blurred vision. Perineal candidiasis may be present in young girls (Usher-Smith, Thompson, Zhu, Sharp, & Walter, 2015; Chiang, Maahs, Garvey, Hood, Laffel, Weinzimer, Wolfsdorf, & Schatz, 2018). In patients with classic symptoms, measurement of plasma glucose is sufficient for the diagnosis of diabetes. That is, random plasma glucose greater than or equal to 200mg/dL (11.1mmol/L). However, in patients without symptoms who are screened on account of a high risk for diabetes, diagnosis may be done on the basis of a test with fasting plasma glucose greater than or equal to 126mg/dL (7mmol/L), or two-hour plasma glucose higher than or equal to 200mg/dL (11.1mmol/L) during oral glucose tolerance test (OGTT) or HbA1c level greater than or equal to 6.5% (Chiang et al., 2018).

Diabetes is a complicated illness with a wide range of pathogenesis, clinical manifestations, and clinical outcomes. T1D requires continuous medical treatment with a wide range of health-related behaviours in disease management, such as monitoring blood glucose, insulin therapy, dietary restrictions, and exercise on daily basis (Tamborlane, Boland & Grey, 2003; ADA, 2014; Zysberg & Lang, 2015). Severe hypoglycaemia and diabetic ketoacidosis (DKA) are short-term complications of T1D whereas long -term complications include macrovascular and microvascular problems such as nephropathy, retinopathy as well as coronary and peripheral vascular disease, kidney disease and amputations. The maintenance of normal blood glucose levels with intensive therapy has proven to be effective in delaying the onset and the progression of such complications (Doyle & Grey, 2010, Rifshana et al., 2017).

Empirical Studies

The empirical studies reviewed for this study were guided by the objectives of the study namely: perception, experiences, challenges and coping strategies of family caregivers of young children with T1D.

Family Caregivers Perception of T1D in Young Persons

Accurate information is a very important tool required for the maintenance of the glycaemic control and treatment adherence of young children living with T1D. Therefore, it can be rightly said that poor glycaemic control, poor adherence and insufficient treatment could be attributed to lack of or inaccurate information about T1D on the part of the family caregiver (Gomes, Santos, Pizarro, Barros, de Melo, & Negrato, 2018). For this reason, different aspects of parental or family caregivers' perception of T1D in young persons have been extensively studied in literature which are also relevant to this study (Davis, Telan, Jain, Ramos, Ward, Jindal, Aschkenasy, Glover,& Shah, 2019; Riso, Bassi, Mancinelli, Zaffani,Salcuni, & Maffeis, 2020; Katz, Kaushal, Guo, Cheema, Gerrard, & Laffel, 2021; Rahman, Zabeen, Baki & Khanum, 2021; Junco, & Fernandez-Hawrylak, 2022). Aspects of family caregivers' perception relevant to this study reviewed focused on causes, clinical manifestation, processes leading to diagnosis, and the meaning ascribed to T1D in young persons.

Following the diagnosis of T1D in children, many family caregivers seek information about the causes of this "strange disease". This quest exposes most family caregivers to T1D in young children for the first time. Baxter (2004) writes that what people believe is the cause of their illness impact on their response to the illness. Korsah, Dyson and Anthony (2021) in their exploratory descriptive study of the impact of cultural practices and beliefs on the experiences of newly diagnosed diabetes patients, and the implications for their health care providers within the settings of the Ghanaian health care identified the intake of too much sugary drinks as a cause of diabetes.

Also, findings from a study conducted by Allan and Rowlands (2020) in the United Kingdom to investigate the beliefs of parents about the causes of their child's T1D and to understand if this affects the way diagnosis is processed and if this impacts their parenting of their other children suggested that some family caregivers (parents) suspected that their child's diabetes was caused by genetic factors. The parents further added that these genetic factors were triggered by factors such as stress, infection, vaccination or virus. This position held by parents, is supported by Ferreira, Ferreira and Geralda (2014) who also identified the onset of diabetes to be caused by stressful events and genetic factors.

In addition to the above, in their attempt to explore the effect of cultural practices and beliefs on the experiences of Ghanaian patients who have been newly diagnosed with diabetes and the implications for health care professionals who provide diabetes care in Ghana, Korsah, Dyson, and Anthony (2021) found out the intake of food contaminated by agrochemicals among the causes of diabetes identified by their study participants which included family caregivers. They also alluded to witchcraft or evil spirits and the intake of too much sugar as other causes of diabetes. The spiritual cause of diabetes was also mentioned in the findings of Korsah (2015) in his qualitative study to explore how patients newly diagnosed with type 2 diabetes in Ghana cope with the condition. Findings from both studies indicated that the overall treatment and management of diabetes should be linked with mystic and magico-religious processes (Korsah, 2015; Korsah, Dyson & Anthony, 2021). Based on the above studies referenced, family caregivers attribute the causes of T1D to so many factors.

Concerning family caregivers' perception of the signs and symptoms of T1D in young persons, it has been shown that clinical manifestations, are clearly seen during the development of T1D in children on account of hyperglycaemia. These clinical manifestations include polydipsia polyuria, polyphagia, dry mouth, fatigue and weight loss (Turkish Endocrinology and Metabolism Association, 2019). However, to determine the awareness and knowledge of T1D in children among parents in Turkey, Cinar and Binay (2021) revealed that parents had little information about T1D and thus recommended educating families about the signs and symptoms of T1D.

Conversely, a cross-sectional study conducted in Bangladesh by Rahman, Zabeen, Baki and Khanum (2021) which involved 101 parents of children and adolescents with diabetes was aimed at exploring the awareness and diabetes care practices among parents of type 1 diabetic children and adolescents. Findings from the study indicated that about 84. 2% of these parents were aware of the signs and symptoms of diabetes. These participants had significant understanding of diabetes related complications and as well as good control of glycaemic status.

The ways leading to family caregivers becoming aware that their children have T1D may be described as prompt or delayed. Rankin and Harden et al (2014) in their study aimed at exploring the perspectives of parents regarding the circumstances and events which led to their child being diagnosed with T1D in Scotland reported that parents who considered diagnosis to be prompt described how they or others identified their children had developed symptoms of T1D which prompted them to seek for immediate medical attention. On the other hand, parents who perceived their children's diagnosis to be delayed did not recognise the signs of T1D and attributed their child's deteriorating health to other conditions, or to their developmental stage. However, as symptoms worsened, these parents sought for medical attention, and were consequently shocked at the contrasting urgency portrayed by the healthcare professionals. Hence the unexpectedness and speed of the diagnoses left them unprepared to deal with the situation despite their suspicion that their child had a health problem (Lowes, Gregory & Lyne, 2005, Rankin et al., 2014).

Kear, Fisher, Westwood, Sachdev and Denvir (2016) in their retrospective series analysis of delayed presentation to secondary care in an attempt to ascertain reasons for this delay in the University of Nottingham Hospital also identified failure to recognise signs and symptoms of T1D as one of the reasons for delayed presentation at the hospital.

Also, a descriptive phenomenological study by Khandan, Abazari, Tirgari, and Cheraghi (2018) on the lived experiences of mothers with diabetic children from the transfer of caring role, semi-structured interviews of 11 Iranian mothers of children aged 14 years or below with T1D was conducted. Evidence from the study showed that mothers' failure to follow-up on their children's health condition with its resultant delay in their diagnosis were because some mothers were not familiar with the symptoms of T1D and they thought their children had one of the most common childhood diseases. Others thought the symptoms were not serious because they were non-classic in nature. On the other hand, some mothers stated they identified the changes in their children and made attempt to find out the underlying cause.

On the aspect of meaning ascribed to T1D, Stodberg et al (2007) and Ferreira et al (2014) identified that parents perceived T1D as a very severe disease and were very much aware of the risk of the person with T1D developing complications. Also, regarding future expectations, participants associated the onset of T1D with a shorter lifespan. Furthermore, a study conducted by Katz, Kaushal, Guo, Cheema, Gerraard and Laffel (2021) to explore the adolescents and parents' perspectives regarding their knowledge of long-term complications, where they receive this information and what they would like to learn from clinicians indicated that parents perceived T1D as condition that is associated with long-term complications.

According to Ferreira et al (2014) the severity of T1D is described as how the parents judge the seriousness of the illness of the child and how they cope with the effects of the disease. It is the perception of this severity that helps the parents in their understanding of the situation of susceptibility and vulnerability and also help them to develop the means for coping with the situation.

Bekker, Deacon and Segal (2019) in their parent-centered qualitative study conducted in South Africa made use of nine parents of children with well-controlled diabetes who participated in semi-structured interviews to explore how they make meaning of living with a child with diabetes. Findings from this study suggested that the participants in this study perceived diabetes as chronic disease that can be managed. T1D in a child also meant that parent had to make lots of adjustments in order to create a new normal. Although the study participants were aware that their children had to do some things differently from other children without T1D in order to manage their diabetes well, they emphasised the need to raise their children with T1D as normal children and not to be treated any differently.

Finally, the limitations imposed by T1D on children from the perspectives of parents have also been enunciated in a study of 153 parents of young children with T1D in North America. The study applied a qualitative descriptive design using online crowdsourcing and focus group methods to describe the perspectives of parents about their challenges as parents of children with T1D. The study findings indicated that frequent medical appointments, the need for around the clock adult supervision, and TID tasks restricted flexibility in eating and playing. It was also reported that T1D literally prevented their children from living care free lives (Pierce et al., 2017).

Family Caregivers Experience in Caring for Young Persons with T1D.

Generally, there is an enormous pile of literature that bothers on parents' experiences of caring for children living with T1D (Helgeson & Becker et al., 2011; Smaldon & Ritholz, 2011; Boogerd & Nienke et al., 2015; Rifshana, Breheny, Taylor & Ross, 2017; Khandan & Tirgari et al., 2018; Kimbell & Lawton et al., 2021). However, for the purpose of the objectives of this study, this section is a reflection of an extensive report and review of literature on the aspect of family caregivers experience at the time of the child's diagnosis, experience with daily living, learning the care, role, goals and hypoglycaemia recognition.

Studies have shown that family caregivers go through various feelings immediately after the diagnosis of T1D in their child. A study conducted by Smaldon and Ritholz (2011) to explore perceptions of psychosocial adaption in parenting young children with type 1 diabetes (T1DM) from diagnosis through childhood, revealed that fear was one of the feelings that pervaded the experiences of participants immediately following their child's diagnosis. Findings of other studies have revealed that participants expressed the feeling of surprise at the contrasting urgency portrayed by the healthcare professionals upon the diagnosis of T1D in their child because they in a way attributed the signs and symptoms portrayed by their child to other conditions. Hence the unexpectedness and speed of the diagnoses left them unprepared to deal with the situation despite their suspicion that their child had a health problem (Lowes, Gregory & Lyne, 2005, Rankin et al., 2014).

The findings of other qualitative studies revealed that the study participants did not believe the TID diagnosis in their children and the tests results because they thought diabetes was a disease of adults (Smaldon & Ritholz, 2011; Kratzer, 2013; Khandan, Tirgari, Abazari, & Cheraghi, 2018). The finding of Smaldon and Ritholz (2011) further indicated that participants in addition to their fear and doubt also felt they had not been taken seriously and were also blamed for their lack of parental experiences.

Caring for young person with T1D is regard as a tiring experience by many family caregivers. A qualitative study by Symons (2013) examined the experiences of parents caring for a child with type 1 diabetes in New Zealand. This study involved six semi-structured interviews of nine parents with a child who had T1D, aged 4-14years. Analysis of the study findings showed that the participants described T1D as a condition that caused significant disruption of family life due to the intrusiveness and lack of spontaneity that results from the management of the condition. They also expressed a persistent burden that comes with caregiving demands. Additionally, findings from a descriptive naturalistic study of 28 mothers caring for young children with T1D in the UK described the experience of daily living with a child with diabetes as time-consuming because of that the constant monitoring necessary to control the disease (Sullivan-Bolyai et al., 2003)

Furthermore, the result of a qualitative synthesis from a systematic mixed-studies review of 34 articles to describe the psychological experience of parents of children with T1D revealed that apart from parents of children with T1D perceiving it as a difficult diagnosis that leads to family disruption, they also asserted that the complex and unpredictable nature diabetes of makes mastery over its management difficult (Whittemore, Jaser, Chao, Jang & Grey, 2012).

A similar finding was revealed by Kimbell, Lawton, Boughton, Hovorka and Rankin (2021) from their thematic synthesis of 14 papers that reported the views and experiences of 274 parents in 7 countries: United States of America, United Kingdom, Canada, Iran, Sweden, Norway and Palestine. Findings from this study described caring for a young child with T1D as an involving and a never-ending task that can have a negative impact on the relationships, health, everyday activities and choices of parents. In addition to these findings, the research conducted by Iversen et al (2018) to explore the lived experience of being mothers and fathers of a child with T1D aged 1 to 7years also highlighted how impossible it is for parents to feel completely confident about the responsibility of controlling their child's blood sugar.

Contrary to these finding, Sullivan-Bolyai and Lee (2011) in their qualitative descriptive interviews with 6 parent mentors who provided social support to parents of children who have been newly diagnosed with T1D found that parents quickly become experts in T1D management at the diagnosis of their children while at the same time teaching others about the proper care of T1D. Findings from other studies have also shown that family caregivers gained mastery over diabetes care procedures from self-study materials and informational sessions to technical training to develop mastery over diabetes care procedures (Zysberg, Lang & Zisberg, 2013; Zysberg & Lang, 2015).

On the issue of how family caregivers learned diabetes care, in a descriptive exploratory study done in Scotland about the information and support needs of parents when their child is diagnosed with T1D, Rankin et al (2016) reported that parents were given information about how to handle their child's T1D at home, along with other relevant information while in the hospital. Additionally, the diabetes team's contact information and after-hours phone numbers were given to them in case they needed assistance with managing their child's diabetes at home.

Similar narratives from other studies have shown that family caregivers of young children with T1D gain knowledge about the condition of their children from the self-study materials informational sessions and technical training given to them by their healthcare team and this helped them gain confidence over diabetes care procedures (Whittemore et al., 2012; Zysberg, Lang & Zisberg, 2013; Zysberg & Lang, 2015).

Furthermore, findings from Watt’s (2017) exploratory studies in Ontario (Canada) on how parents with children living with diabetes understand worry revealed that parents learned about diabetes management from the diabetes education and treatment conducted by diabetes nurse educators at paediatric clinics.

A qualitative study in the Netherlands by Boogerd, Schaaijk, Noordam, Marks and Verhaak (2015) used group interviews to explore the experience, needs and preferences of parents of children with diabetes with particular emphasis on the use of internet care. Relevant statements from the interviews were classified into seven (7) interconnected themes as: (i)impact of diabetes on daily life (ii) social and professional support (iii) local peer support (iv) development-oriented and demand driven care (v) involvement and alignment of the healthcare team (vi)applicable information on disease and treatment (vii) accessibility of the healthcare team. In the findings, parents explicated a need for additional information which they had by searching on the internet but they were overwhelmed by the amount of information they found about complications and other diabetes related problems.

Similarly, a quantitative survey of 321 parents of youths with diabetes, 248 of the parents answered all the open-ended questions based on the what, when and how to teach parents and youths the long-term complications of T1D. Findings from the study revealed that other than the diabetic team, parents seek and obtain information on long-term complications from a variety of sources. Diabetes teams are required to present and interpret this information to families responsibly and sensitively because the information they collect may be of varying quality. As a result, parents should be helped in finding current and accurate educational resources (Buckloh, Wysocki, Antal, Lochrie, & Bejarano, 2016). Also based on the evidence of a study, it has been suggested that parents of children with long-term conditions including diabetes can benefit from the information on the internet in their care (El-Gayar, Timsina, Nawar, Eid, 2013).

Even though all the three studies highlighted some importance of the internet in helping parents to access information T1D care in children with T1D, its emphasis on the internet as a means of satisfying the varying needs and preferences of parents is only applicable to the healthcare settings in developed countries but may remain a myth in developing countries like Ghana where eHealth has limited role (Afarikumah, 2014). Furthermore, emphasis on the internet means giving priority to family caregivers who are perhaps of better educational background and higher socioeconomic status which may not be true of the general population of the family caregivers of children with T1D in Ghana

Family caregivers play an invaluable role in illness management among young children with type 1 diabetes. This is due to the fact that young children are not able to make lifestyle choices or completely adhere to the plan of diabetes management with the input of their family caregivers and this tends to have a toll on family life (Chiang et al., 2014). Parents together with the healthcare team play also an inalienable role by providing the child's school with the necessary knowledge and guidelines that will enable them provide the child with needed care as he or she transitions from the home to the school setting (Siminerio & Albanese-O'neill et al., 2014).

To review the management of diabetes in children during illness, Soni et al (2016) carried out a questionnaire survey of 127 units in England and Wales. Findings from this survey showed that in order to ensure that the child's blood glucose level is within a healthy range, there is the need for family caregivers to do close monitoring of the child's diet, activity, insulin injections and blood glucose levels. Most children require more than one injection of insulin with monitoring of blood glucose levels several times each day. Family caregivers are responsible for the performance of insulin administration and continual monitoring of their children for symptoms of hypoglycaemia and hyperglycaemia; to provide the appropriate response to resolve the symptom in order to bring the child's blood glucose back to the normal range. Increased monitoring and additional management are required during periods of illness (Soni et al., 2016).

Additionally, Helgeson, Becker, Escobar and Siminerio (2012) in their study conducted to examine the relationship of parent stress to mental health and child mental and physical health indicated that parents were directly responsible for the performance of the disease management, including blood glucose monitoring, insulin administration, accounting for carbohydrate intake and diet tracking. Similar findings were identified by Sullivan-Bolyai et al., 2003; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Boogerd et al., 2015.

To assess the feasibility and effectiveness of a telephone-based support intervention for parents of young children with type 1 diabetes, with the aim to enhance parental quality of life by reducing stress on the parents, boosting social support, and improving daily management of their child's diabetes, 24 parents of young children with T1D participated in a pilot study of the program and completed psychosocial questionnaires and program satisfaction survey. It was noted in the findings of the study that in addition to the usual role of fostering physical, cognitive, and socioemotional growth and development parents of younger children also bear complete responsibility for diabetes care, where they attend to constant and unrelenting demands of daily management (Monaghan, Hilliard, Cogen, & Streisand, 2011).

Although adolescents are generally encouraged to become independent in their self-management, and can become less reliant on parents with day-to-day management of diabetes (Spencer, Cooper, & Milton, 2013), however, report from a study carried out among a sample of 76 parents of Australian adolescents with T1D to assess family functioning and adolescent behaviour/ adjustment and examine the relationships between these parents-reported variables and adolescent metabolic control, self-reported health and diabetes self-care showed that parents continue to play a vital role through monitoring, reminders and provision of support to adolescents in self-managing their condition because they have the tendency to neglect self-care routines due to pressures and changes related to normal adolescent development (Moore, Hackworth, Hamilton, Northam, & Cameron, 2013). Parental involvement continues to remain crucial during this period because it has been found to contribute to better metabolic control, better treatment adherence, quality of life and few diabetes-related hospitalisations (Mellin, Neumark-Sztainer, & Patterson, 2004; Jaser, 2011).

With regards to family caregivers' goal for actively participating in the management of their children's condition, a study was conducted by Robinson, Iannotti, Schneider, Nansel, Haynie, and Sobel, (2011). The objective of this study was to develop a measure of parenting goals that is diabetes-specific for parents of children with T1D and also to assess if parenting goals could predict a change in the involvement in the disease management. In this study, a random sample of 87 primary caretakers of children aged 10 to 16 years with T1D were made to complete questionnaires that bothered on parenting goals. Findings from the study indicated that generally, disease-specific goals are more important to parents of children with T1D than those concerning general parenting. The finding was also suggestive that ensuring that their child's blood glucose levels are within the targets recommended by their physician was of prime importance to parents.

Again, in an attempt to explore the lived experience of being mothers and fathers of a child with T1D, Iversen et al (2018) conducted an interpretive phenomenological study in Norway. Data collection was done with aid of in-depth interviews. The findings from the study also support the fact that the number one goal of parents for being actively involved in their child's diabetes management is for the child to register an acceptable glycated haemoglobin value during clinic appointments.

With regards to hypoglycaemia recognition, Rintala, Paavilainen & Astedt-Kurki, (2013) in their qualitative study using the grounded theory method to explore the everyday life of families with adults living with T1D noted that the faley caregivers' involvement in a family member's diabetes care is determined principally by their awareness of hyperglycaemia and hypoglycaemia. Not this but also, findings also indicated that based on their earlier experiences of severe episodes of hypoglycaemia, family caregivers learn to identify even the most subtle signs of hypoglycaemia (Rintala, Paavilainen & Astedt-Kurki, 2013).

Another similar finding was identified from the narratives of a research aimed at gaining in-depth understanding of what hypoglycaemia means to significant others through a narrative inquiry methodology utilized in-depth interviews among 7 significant of T1D patients. Participants asserted that their encounters with severe episodes of hypoglycaemia helped them equip themselves with information about it as well as the most effective line of action to take in emergency situations (King, Overland, Fisher & White, 2015). On the other hand, the outcome of a recent qualitative synthesis conducted by Kimbell et al (2021) on the experiences of parents caring for a child with T1D to find out the challenges they encounter, their views about support received, ways in which support could be improved and directions for future research revealed that the awareness of the unpredictable nature of T1D and the potential deadly effects of hypoglycaemia were the factors that made parents of children with T1D arm themselves with the knowledge about hypoglycaemia

Challenges Family Caregivers Face in Caring for Young Persons with T1D

Managing type 1 diabetes in young persons involves wide spread challenges. Their limited motor and communication skills, cognitive abilities and emotional maturity makes them depend solely on their family caregivers for daily T1D care (Sullivan et al., 2003; Siminerio & Albanese-O’neill et al., 2014). Yet, it has been shown that 73% of young children exceed the American Diabetes Association Haemoglobin AIC target of <7.5% for young children with diabetes (Wood, Miller, Maahs, Beck, DiMeglio, Libman, & Woerner, 2013; Chiang et al., 2014). This is evidence that family caregivers face lots of challenges while managing T1D in these children.

Some of the extensively studied aspect of the challenges family caregivers encounter while participating in diabetes care according to literature include: psychological, social and financial challenges (Lawton et al., 2014; Boogerd et al., 2015; Watt, 2017; Iversen et al., 2018; Lancet, 2018; Khandan et al., 2018; Kimbell et al., 2021). This section is therefore a presentation of a comprehensive report and discussion of related literature on the above-mentioned aspects of the various challenges family caregivers encounter.

Regarding the psychological challenges family caregivers encounter, there is an enormous pile of descriptive data that clearly document the impact of managing a young person with T1D on the psychological well-being of parents. In a focus group interview of 32 parents of children (2-12 years) with T1D, Boogerd et al (2015), reported that parents found the confrontation with their child’s diagnosis and the introduction to the complex skills involved in the management of diabetes as very challenging. Majority were uncertain and anxious by the switch from intensive coaching by healthcare professionals in the first week, to independently performing self-management tasks at home

A systematic review of the psychological experience of parents with T1D children conducted by Whittemore et al (2012) revealed that 1 to 4 years following diagnosis, 19% of parents reported experiencing substantia distress. Similar to this, a previous descriptive study of 73 parents of children with T1D (ages 2-6) discovered that 21% of parents experienced considerable anxiety symptoms (Hlliard, Monaghan, & Streisand, 2011).

Furthermore, Streissand and Monaghan (2014) in their a review of research findings relating to young persons with T1D, potential clinical implications, and discussion of areas for future future research found that the daily care of young children with T1D has significant psychosocial impact on parents which also put them at risk of anxiety, depression, sleep disorder, stress and fear of hypoglycaemia.

Also, from the narratives of 153 parents of chidren living T1D involved in a qualitative descriptive study using online crowdsourcing and focus group method methods, it was found that most parents experienced anger, guilt, grief as well as depression and posttraumatic stress (Pierce et al., 2017)

Several studies have also reported that stress related to fear of hypoglycaemia especially during nap time and night time is a common concern among family caregivers of young persons with T1D borne from several considerations such as the child being too young to recognise and report symptoms; and family caregivers' awareness of its potential serious effect. In order to prevent hypoglycaemia, family caregivers describe the need to be constantly watchful in monitoring their child's diet, activity and blood glucose readings (Sullivan et al., 2003; Iversen et al., 2018; Kimbell et al., 2021).

In addition to the above, a study was conducted by Watt (2017) to explore the caregiving experience of parents within the context of diabetes management. The study adopted Arlie Hochschild’s concept of “emotion work” and Dorothy Smith’s concept of work to examine how parents engage in the emotion of work in doing work. Findings from the transcribed data of interviews with 7 parents of children living with diabetes identified the fear of hypoglycaemia as a pervading psychological challenge.

Findings from an exploratory qualitative study by Lawton et al (2014) suggest that most family members curtail their own activities and lifestyles including giving up recreational activities that take them out of their homes for the fear of hypoglycaemia. In addition to this finding, an outcome of a systematic revie of 639 articles carried out in accordance with the Preferred Reporting Items for Systematic Review indicated the fear of hypoglycaemia also restricted the lifestyle of family caregivers in the areas of employment and health needs (Hartill, Gillis, Imran, Recchia, Meal, & Adams, 2018).

Not only the afore mentioned psychological challenges but also, findings identified in a systematic review and synthesis of qualitative evidence conducted by Kimbell et al (2021) showed that parents expressed worry about how diabetes would affect their children’s lives in future despite the fact these children were young. A similar finding was identified by Pierce et al (2017) in a qualitative descriptive study which was aimed at giving a comprehensive description of the challenges of parents of children with T1D face while managing their child’s condition.

Furthermore, studies conducted in Palestine to explore the experiences of daily life in children with T1D and their parents identified parents who were worried about diabetes marring their girls' chances of being married in future based on the fact that these girls may be seen as unsuitable marriage partners; and also put their children at risk of inheriting the disease (Ellisa et al., 2017). A similar finding was reported by Khandan et al., (2018) study in Iran purposed to explore the experiences of mothers with diabetic children after the transfer role.

Across all age groups,T1D care places significant social challenge on family caregivers. In addition to the usual challenges of fostering physical, cognitive, and socioemotional growth and development, parents of younger children also bear complete responsibility for diabetes care, where they attend to constant and unrelenting demands of daily management (Monaghan et al., 2011). Studies have shown that diabetes management is made more complex by issues such as the need to administer and adjust small doses of insulin, and practical aspects of care such as meal planning, blood glucose monitoring, accounting for carbohydrate intake and diet tracking; and the complex task of taking care of a child with diabetes in everyday life can have profound impact on parents. (Sullivan-Bolyai et al., 2003; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Helgeson et al., 2012; Boogerd et al., 2015). The constant care suggests inability for family caregivers to take breaks.

Smaldone and Ritholz (2011) completed semi-structured interviews with 14 parents of young children with T1D and identified that parents of young children with T1D often experienced social isolation resulting from deterioration in family relationships and friendships because it was difficult for family and friends to comprehend and participate in diabetes management. Although when parental responsibility for diabetic decision-making is shared, parental adaptation becomes more effective; nevertheless, relatives and friends in this study had little comprehension of T1D. They also reported that even family members were hesitant to babysit because of the fear of not knowing how to manage insulin and the child's responses to it. Conversely, findings from the interpretive phenomenological study carried out by Iversen et al (2018) demonstrated that other family members and friends were allowed to take up responsibility for the child once parents became conversant with their child's diabetes although this step was challenging initially.

Also, a recent exploratory study on parent perceptions of the burdens of caring for very young children with T1D utilized semi-structured qualitative interviews of 85% mothers of 79 children with T1D, from four diverse pediatric diabetes clinical centers in the USA. From the findings, it was discovered that many parents may not be comfortable leaving their children in the care of others due to the complexities of management and the concern that many young children with T1D may not be able to vocalize their medical needs or symptoms of hypoglycaemia or hyperglycaemia (Commissariat et al., 2020). Consequently, many parents had challenges in terms of engaging the services of babysitters, day-care centres and preschools.

In addition to the above, findings from several studies report that the concerns of several parents pertaining to some of these centres meant to provide respite for them involve both receptivity and the abilities of staff to care for a child with diabetes appropriately. Also, most day-care centres decline accepting these children with diabetes into their facility on the basis that the demands related to the illness would take time from the other children in the centre. (Sullivan et al., 2003; Smaldone & Ritholz, 2011; Pierce et al., 2017; Kimbell et al., 2021).

Furthermore, findings from a study of 134 parents of young persons with T1D by Herbert, Clary, Owen, Monaghan, Alvarez and Streisand (2015) showed that T1D affected the decision of 44% of parents to enrol their children in a day-care or school and 12% removed their children from a day-care or school because of difficulty in managing T1D in those settings. Pierce et al (2017) further added that many parents had difficulty choosing between home-schooling and sending their child to a formal school because of the anxiety they experienced with kindergarten entry. Those parents who chose to send their children to a formal school ensure that the right accommodations for their young children with diabetes were available including access to a school nurse.

Finally, where as many parents share responsibilities for T1D management equally, in many other families, one parent takes an exclusive responsibility for T1D care. In most families, division of responsibility whether explicitly or not tends to fall somewhere along this spectrum. (Smaldone & Ritholz, 2011; Pierce et al., 2017). Similar to this finding, a review of research findings about young children with T1D, potential clinical implications, and discussion of areas for future research found that mothers shoulder the majority of the responsibility for T1D care, performing 79% of insulin injections and 70% of blood sugar monitoring (Streissand & Monaghan, 2014)

Not only the above challenges but also, because of the all-encompassing nature of T1D management, the financial impact on family caregivers is substantial and can result in financial constraint particularly on those family caregivers with low incomes, as well as those in low and middle-income countries.

It was reported during the world's diabetes day by The Lancet Diabetes Endocrinology (2018) that many families especially those in the low and middle-income countries where healthcare access is limited, the cost of accessing diabetes care can be very burdensome. Additionally, indirect costs for family caregivers, such as reducing working hours or quitting jobs in order to care for a child with T1D can also contribute to the negative economic impact on families affected by diabetes and other chronic diseases.

Also, according to the International Diabetes Federation (IDF), insulin is associated with significant out-of-pocket payment that can consume about two-thirds of disposable income; and blood glucose monitoring alone in many low and middle-income countries can consume half of a family's average disposable income (International Diabetes Federation, 2016).

In order to estimate the direct costs of supplies require for providing the minimum of care for a child with T1D 15 countries where such supplies are not routinely provided by the public health system, Ogle, Kim, Middlehurst, Silink, and Jenkins (2016) reported that the costs involved diabetes can be astronomical for families. The expense of diabetes consumables for most poor households would consume all of their income, leaving nothing for food, shelter, and clothing. Others must borrow money or sell their assets. Under the theory of opportunity cost, many people are forced to face unsettling decisions, such as whether to pay for the child's diabetes treatment or to fund their other children's schooling. To reduce expenditures and lengthen the period before insulin can be obtained, doses are frequently skipped or reduced.

Findings from a cross-sectional conducted among 180 diabetic patients in Tamil Nadu (India) to estimate the out-of-pocket expenditure on diabetes among diabetic patients revealed that the financial effects of diabetes treatment include direct medical expenses such as consultations, tests, medications, hospital stays, and the management of complications as well as indirect expenses like travel, lifestyle changes, and missed wages from absenteeism from work (Pushparani, & Paulin, 2019). This places a significant financial strain on families, forcing them to cut back on other family expenses to cover the treatment costs (Pierce et al, 2017; Khandan et al., 2018). Volman (2008) stated that high direct costs associated with diabetes care result in families living in increasing poverty.

Resonating with this finding is a study conducted by Kimbell et al (2021) who found out that even middle-class parents who were in possession of medical insurance also reported financial constraint related to diabetes care owning to the fact some treatment supplies required that they paid directly from their own pockets.

Apart from the afore mentioned psychological, social and financial challenges associated with T1D care, it has also been identified that managing adolescents with diabetes can present a daunting challenge for most family caregivers. This is because findings from the longitudinal study conducted by Luyckx, Seiffge-Krente, Missotten, Rassart, and Goethals (2013) to investigate how parent-adolescent conflicts relate to treatment adherence and glycaemic control revealed that adolescence is a stage of life that is increasingly marked by striving for more freedom. Generally, shifting of responsibility for diabetes management from parents to a child increases gradually as the child ages.

Additionally, a study that examined the associations of parent-adolescent relationship quality with adolescent type 1 diabetes management and depressive symptoms in 118 Latino and Caucasian adolescents and their mothers showed that as the adolescent grows older, parental support for diabetes treatment also diminishes during this transition even though treatment adherence is higher and less diabetes-related hospitalizations occur when parents are more involved in diabetes care during adolescence. However, parent-adolescent conflicts may arise when parents are viewed as lacking understanding and their strategies regarding diabetes care also viewed as intrusive and judgmental from the perspective of the adolescent (Main, Weibe, Croom, Sardone, Godbey, Tucker, & White, 2014). Also, the American Diabetes Association (2013) posited that family caregivers may also experience challenges with the child’s refusal to cooperate with the diabetes care plan as the child develops and desires greater autonomy.

Coping Strategies of Family Caregivers in T1D management.

Family caregivers’ coping with the demands associated with diabetes plays a significant role in a child’s and family's adjustment to the disease (Grey, Jaser, Whittemore, Jeon, & Lindemann, 2011). Family caregivers use different sources of supports in adapting to the demands related to their caregiving role. some of these widely used researched coping strategies across literature include engaging in support groups and religious activities; support from the involvement of other family members and spouses as well as normalization

(Sullivan-Bolyai et al., 2003; Smaldone & Ritholz, 2011; Sullivan-Bolyai & Lee, 2011; Grossoehme, Cotton, Ragsdale, Quittner, McPhail and seid, 2013; Purcell, Whisenhunt, Cheng, Dimitriou, Young, & Grossoehme, 2011; Grover et al., 2016).

On the aspect of support groups, there is evidence that participating in support groups provides a means by which majority of family caregivers cope and adjust to the challenges associated with T1D in their child (Sullivan-Bolyai et al., 2003; Smaldone & Ritholz, 2011; Grover et al., 2016). In an exploratory study involving 14 parents of 11 children with T1D from diagnosis through childhood on the perceptions of psychosocial adaptations in parenting young children with T1D. Findings from data analysis using content analysis showed that the majority of the mothers talked about how joining a gave them the chance to feel understood for the first time. They were able to talk freely and gained knowledge from those who had comparable experiences. Several of them spoke about how the support group helped them feel less isolated (Smaldon & Ritholz, 2011).

Similarly, a study was conducted at the Department of Endocrinology's outpatient clinic in a tertiary care hospital in India. The purpose of the study was to learn about the coping mechanisms employed by parents of children and teenagers with T1D. Findings from the study which involved 41 participants indicated that caregivers used adaptative coping strategies including social support while they dealt with the challenges involved in managing their children and adolescents with T1D (Grover et al., 2016).

One study conducted a qualitative descriptive interview with 6 parent mentors who provided social support to 34 mothers and 19 fathers of children less than 13 years old who have been newly diagnosed with T1D over a period of 12months (Sullivan-Bolyai & Lee, 2011). The purpose of the study was to describe the experience of parent mentors who provide social support to parents of children with T1D. The parent mentors described how social support provided a means for parents of children with T1D to interact with each which helped to normalise and validate their experiences. These parent mentors were regarded as an effective support group by helping parents of children newly diagnosed with T1D to identify available resources in the community and through their provision of emotional support (Sullivan-Bolyai & Lee, 2011; Smaldone & Ritholz, 2011).

Additionally, it has been shown that other family caregivers seek strength through religion and spirituality as a kind of support to alleviate suffering and to accept the disease (de Oliveira, Nascif-Junior & Rocha, 2010). Findings from a study carried out by Grossoehme, Cotton, Ragsdale, Quittner, McPhail and Seid (2013) which explored whether parents with different levels of adherence would describe use of faith differently revealed that parents of children with chronic illness explained how their faith enabled them to provide their children with the difficult but essential care, guided medical decisions, and affected how much home care they actually gave. In this study, interviews were completed and analysed using grounded theory methodology.

Congruent to this finding, narratives from an exploratory study of parental use of faith when the diagnosis is not life-shortening, utilizing grounded theory methodology and semi-structured telephone interviews with 12 parents showed that parents found comfort in the belief that God had a plan for their family and that their child's illness was part of that plan. The majority of parents also mentioned how their religious beliefs and practices supported them during the trying diagnosing process and provided them a sense of strength. In addition to spending time in private prayer, many parents found solace in knowing that others were also praying for their child. Therefore, religion and spirituality offer a framework for practices that increase resilience, social and emotional support, and meaning making (Purcell, Whisenhunt, Cheng, Dimitriou, Young, & Grossoehme, 2015).

Furthermore, family support is also another strategy family caregivers employ in coping with the stress of managing a child with T1D. Smaldon and Ritholz (2011) asserted that working together as a team among parents brings about shared responsibility in daily decision-making and in the performance of daily activities in diabetes management. This facilitate family adjustment and also helps to relieve the stress of being solely responsible for the well-being of the child. Conversely, some participants described how the lack of support and understanding by their family members made them feel alone in managing their child’s diabetes.

Again, finding from another study which resonates with that of this study is the finding of Kimbell et al (2021). In their synthesis of the qualitative evidence on parent’s experiences of caring for a child with T1D to identify the challenges they encounter; their views about support received; ways in which support could be improved; and directions for future research, the parents recounted drawing on the support of their spouses or other family members for the management of their child’s diabetes. They however asserted irrespective of how useful this support was, it was still not enough due to the family member’s limited knowledge and understanding about diabetes. Other parents also indicated that the support provided by their family and friends was not enough because more often than not they had difficulty adjusting to the condition and its management (Boogerd et al., 2015).

Normalizing is also a coping strategy for family caregivers which describes their ability to integrate diabetes into the background of their lives through the establishment of routines to make diabetes a part of them Babler & Strickland, 2015). A study conducted to explore family members' experiences of everyday life in families with adult people living with T1D used grounded theory method to gather and analyse data from the interviews of 19 family members showed that in order to cope and adjust to the diabetes management with its associated challenges, family members become accustomed to living with diabetes over time. The tremendous amount of tacit knowledge they possess about diabetes gave them the enablement to go about their daily activities without having diabetes on their minds constantly (Rintala, Paavilainen, & Astedt-Kurki, 2013).

A finding that resonates with this finding was revealed by Edmonds-Myles, Tamborlane and Grey (2010). They used a qualitative descriptive method to explore the psychosocial impact of T1D on low-income families from three racial backgrounds (African American, Hispanic and white). In all, 21 patient-parent dyads were interviewed to explore each family's attitudes and beliefs with regards to diabetes. One of the findings from the study showed that the families made mentioned of normalization as one of the methods they used in coping with the diabetes related challenges.

Theoretical Framework

The exploration of the experiences of family caregivers of young persons with T1D required an understanding of the theoretical framework that will guide the study. The Family Management Style Framework (FMSF) (Knafl, Deatrick & Gallo, 2008; Knafl, Deatrick, & Havill, 2012) was the main framework that guided this study and also provided a framework for the analyses of its findings. How this framework informed this study has been discussed in detail in the subsequent paragraphs. The FMSF has evolved from 20 years of research and theory development and defines family management as families’ response to childhood chronic conditions, that is how families actively organise, integrate and accomplish work related to the condition (Knafl et al., 2008; Beacham & Deatrick, 2013).

Knowledge of this framework provides insight into family strengths with regard to condition management as well as areas of difficulty. The intent is to provide a helpful resource for more understanding of family life in the light of a child's chronic illness. Its purpose is to guide researchers and clinicians in evaluating a family's response to a child's chronic condition, particularly in terms of how condition management is integrated into daily family life. The FMSF does not define or specify how the family manages the condition; rather, it focuses the researcher's or clinician's observations without trying to predict what they will see (Knafl et al., 2008).

In the light of this current study, the FMSF helped the researcher to understand family caregivers’ life in terms of caring for a child with T1D, and how these caregivers integrated the management of T1D into their everyday lives. The FMSF consists of three major components and their underlying dimensions (Knafl & Deatrick, 2003; Knafl et al., 2008; Knafl et al., 2012) as follows:

Defining the Situation: the first component examines the subjective meaning family members attribute to important aspects of having a chronically ill child; it has the sub-themes of child identity, illness view, management mindset and parental mutuality. The definitions of these underlying dimensions or sub-themes are:

- Child Identity: Parents' views of the child and the extent to which those views focus on illness or normalcy and capabilities or vulnerabilities.
- Illness View: Parents' beliefs about the cause, seriousness, predictability, and course of the illness.
- Management Mindset: Parents' views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively.
- Parental Mutuality: Caregivers' beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their approach to illness management.

Management Behaviours: it is the second major component of the FMSF which has been defined as the actions parents perform to manage the illness and to adapt family life to illness-related demands. This component encompasses the parenting philosophy and management approach which are defined as follows:

- Parenting Philosophy: Parents' goals, priorities, and values that guide the overall approach and specific strategies for illness management.

- Management Approach: Parents' assessment of the extent to which they have developed a routine, and related strategies, for managing the illness and incorporating it into family life.

Perceived Consequences: the third component refers to how the parents describe the impact of the illness on family life. The dimensions in this component are family focus and future expectations; these are defined as:

- Family Focus: Parents' assessment of the balance between illness management and other aspects of family life.
- Future Expectation: Parents' assessment of the implications of the illness for their child's and family's future.

Variation in these components and their underlying dimensions result in patterns of family's response known as family management styles. The management styles reflect the ease or difficulty the family members experience as they incorporate condition management into family life and the extent to which the family members have common or differing perspectives on the three dimensions. Previous work with families caring for children with chronic illness revealed five management styles: thriving, accommodating, enduring, struggling, and floundering. Knowing a family's management style provides insight into the family's weaknesses and strengths (Knafl, & Deatrick, 2003; Knafl et al., 2008)

As a whole, the FMSF also recognizes the influences contextual factors (social network, access to resources, and interchanges with healthcare and school systems) have on family management and identifies two outcomes – the functioning of the family as a unit, and the functioning of the individual child (Knafl et al., 2012). Below is the FMSF

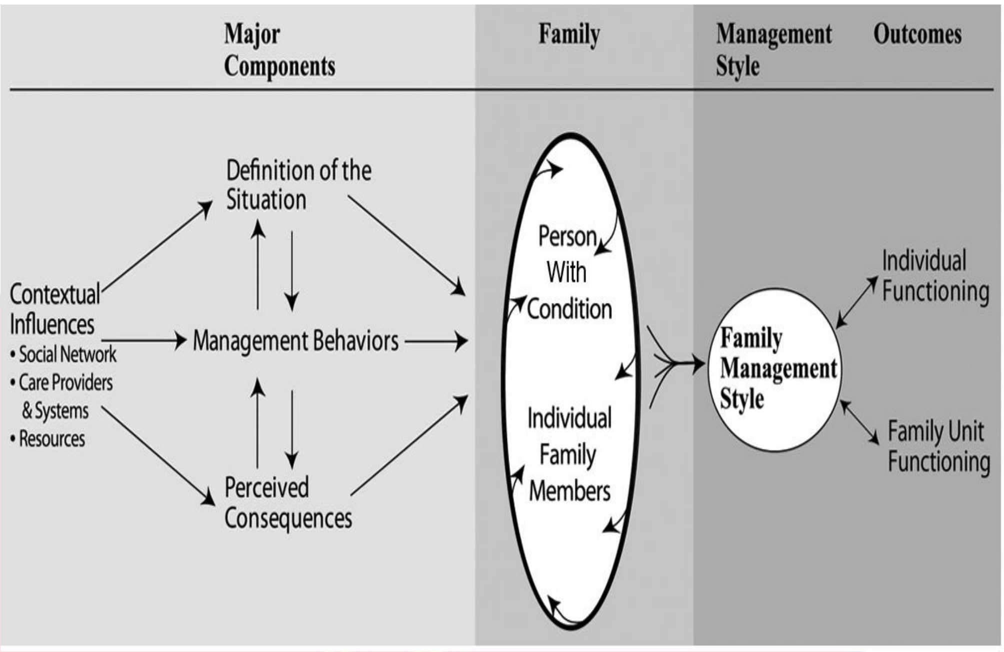

Figure 1: Revised Family Management Framework (Knafl et al., 2012)

Conceptual Framework

The conceptual framework consists of the three components of the FMSF-definition of the situation, management behaviours, and perceived consequences; and some of their dimensions. The framework informed the objectives under investigation in this study: perceptions family caregivers have concerning T1D; the experiences of family caregivers of young persons with TID; the challenges caregivers encounter in the management of TID in young persons; and their coping strategies. Thus, child identity and illness view which are dimensions under the major component definition of the situation in the framework answered the first objective. This objective sought to explore the perceptions and subjective meanings family members ascribe to diabetes as a condition, how family caregivers viewed their child with T1D as being normal and capable as their peer without T1D or as being vulnerable, and their beliefs about the cause and seriousness of the condition.

Management mindset also a dimension of definition of the situation, and parenting philosophy, a dimension under the major component, management behaviour answered the second objectives. This objective investigated the experiences of family caregivers in the management of their children with T1D including their psychological and psychosocial experiences; the ease or difficulty with which they managed their children's illness; the involvement of other family members; and the role these family caregivers play in the management of these children.

Perceived consequences answered the third objective which sought to determine the challenges family caregivers encounter while managing the child with T1D and the impact on family life. Finally, management approach, a dimension under the major component management behaviour answered the fourth and final objective which described the routines and related strategies family caregivers use to incorporate the illness management and its related-demands into the family life.

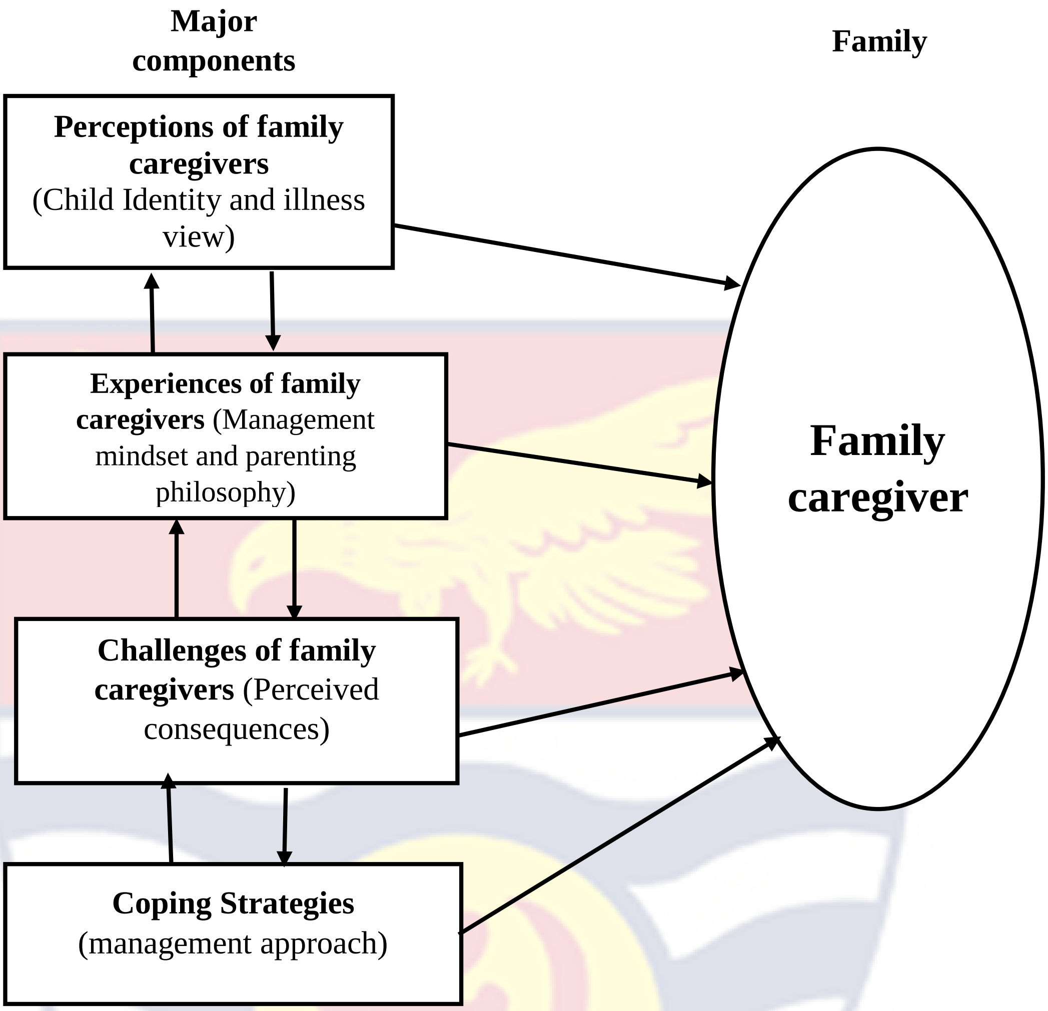

Figure 2: Adapted family management style framework

Chapter Summary

This chapter dealt with early studies conducted in the area of experiences of family caregivers of young persons with T1D. The review was divided into three parts. The first part was an overview of T1D and which encompassed areas such as the epidemiology, causes, management and complications, and a review of empirical findings of other studies on the experiences of family caregivers of young persons with type 1 diabetes. These experiences were explored across the perceptions, the daily experiences of caring for a young person with T1D, challenges associated with TID care, and the coping strategies family caregivers use to deal with these challenges.

Some of the widely studied aspects of the perceptions of family caregivers of young persons with T1D about the condition include causes, clinical manifestation, pathways leading to diagnosis, diagnosis experience and the meaning ascribed to T1D in children. Furthermore, on the aspect of the experiences of family caregivers with the care of a young person with T1D, some of the extensively reported areas in literature include experience with daily living, learning the care, role, goals and hypoglycaemia recognition.

Additionally, an enormous pile of studies that bordered on the challenges family caregivers encounter while participating in diabetes care in young persons were identified in areas such as psychological, social and financial challenges. Also, family caregivers use different sources of supports in adapting to the demands related to their caregiving role. Some of these widely used researched coping strategies across literature include engaging in support groups and religious activities; support from the involvement of other family members and spouses as well as normalization.

The second part reviewed the guiding theory of the study. The theoretical perspective that underpins the study is the family management style framework (Knafl et al., 2012). The final part touched on the conceptual framework and how it influenced the study objectives.

CHAPTER THREE

RESEARCH METHOD

Introduction

To ensure proper collection and analysis of data in this study, this section was designed to cover the research design, study area, population, sampling procedure and the justification for its use, data collection instrument, data collection procedure, study, sample size, data processing and analysis, and ethical consideration.

Study Design

Research design is the conceptual blueprint for the conduct of a study. Its purpose is to provide an appropriate framework for a study and thus maximizes control over factors that could interfere with the study’s desired outcome (Grove et al., 2015; Akhtar, & Islmia, 2016). The three main research approaches are quantitative research, qualitative research and mixed methods designs (Williams, 2007; Creswell, 2014). Quantitative research involves the formal, objective, systematic process of collecting numerical data that are used to obtain information about the world. It is conducted to test theory by describing variables, examining relationships among variables and determining cause and effect interactions between variable (Grove et al., 2015).

Qualitative research on the other hand is the systematic inquiry into social phenomena in natural settings (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015). It uses an interpretive and naturalistic approach to explore and understand the meaning individuals or groups ascribe to a social or human problem (Denzin and Lincoln, 2005; Creswell, 2014). Qualitative researchers place more emphasis on the quality and texture of experience rather than identifying cause-effect relationships, (Willig, 2001). In qualitative methodology, detail openness and depth are the focus of inquiry (Taylor, Bogdan, & DeVault, 2016), with primary emphasis placed on depth of understanding over breadth in qualitative research; this means researchers are more interested in gathering plausible in-depth and intimate information about a smaller group of people than drawing from a large, representative sample of the population of interest (Patton, 2002; Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015). In addition, qualitative inquiry values the crucial role played by context and people holistically, and how these can impact on the ways we describe and understand phenomena. Qualitative research is concerned with learning about how people make sense of their experiences rather than focusing on outsiders' views of what people do (Taylor et al., 2016).

Finally, mixed methods involve the collection and integration of both quantitative and qualitative data in a study. Thus, researchers collect both numerical data, which is customary for quantitative research, and narrative data, which is the norm for qualitative research in order to address the research question(s) of a particular research study. Mixed methods approach is intended make use of the strengths and minimize the weaknesses of the quantitative and qualitative research approaches (Williams, 2007; Creswell, 2014).

There are several methods for conducting qualitative research; however, Grove et al. (2015) recommended the following five: phenomenological, ethnographic, grounded theory, exploratory-descriptive and historical research. This study adopted qualitative research approach with exploratory-descriptive design which was deemed appropriate to assist the researcher in meeting the study objectives. Exploratory-descriptive qualitative (EDQ) research is conducted to address an issue or problem in need of a solution and/ or understanding (Grove et al., 2015). It has been identified as suitable to study areas within health care practice that have previously received little or no attention with the aim to explore and describe the experiences of participants with regards to phenomenon of interest (Hunter, McCallum, & Howes, 2019). Alternatively, Prink and Wood (1998) posit that EDQ research is also conducted when prior research on the phenomenon of interest may have been conducted but only in populations other than the one currently under study. These reasons make the EDQ research design suitable for this study in that as mentioned in the problem statement, there is paucity in literature with regards to the experiences of family caregivers of young children with T1D in Ghana.

Again, the philosophical basis of this study is interpretivism because the analytical process involved interpreting the meanings, opinions and experiences of participants (Jaye, 2002).

Study Area

The Effia Nkwanta Regional hospital is situated about 200 metres off the coast of Sekondi and is the only secondary level facility in the Western and Western North regions of Ghana. Established in 1938 as a military hospital by the colonial government of the Gold Coast for the British West African Royal Frontier Force which was located in Takoradi during the Second World War. After the war however in 1945, the hospital was handed over to the Ministry of Health of the Gold Coast government in 1948. This resulted in the relocation of an old hospital at Sekondi to the present location and eventually developed to its current state. The service and the maternity blocks were built and commissioned in 1995.

The hospital covers a land area of 202 hectares. Apart from receiving referrals from the whole western corridor of country, some core functions of the hospital are: Provision of public health care, clinical care, technical support to districts, training centre for other health workers. The hospital also offers practical training for nursing and midwifery students and interns, medical students and medical housemen, health service administrators, and clinical psychology interns among others. It has 125 inpatient beds and provides lots of outpatient services including the diabetes outpatient clinic.

This study was conducted specifically at the Diabetic Outpatient Clinic (DOC) which is one of the several specialist units of the Effia Nwanta Regional Hospital. The young diabetic clinic which forms part of the DOC provides the only young diabetic specialty outpatient services, and therefore caters for children across the Sekondi/Takoradi metropolis and the entire Western Region. On the average, a total of 60 to 70 adult patients attend the clinic each day. The young diabetic clinic which is organised on the second Saturday of each month sees about 10 to15 children at the clinic. Amongst their services, they offer specialised clinical and educational programmes to meet the needs of children and adolescents with T1D, including subcutaneous insulin injection therapy.

Study Population

The study population refers to a particular group of individuals with common observable characteristics in which the researcher is interested (Polit,

& Beck, 2004; Grove et al., 2015). The population for this study were family caregivers of young persons aged 10 to 14 years who have been diagnosed with T1D and have been actively involved in the care of the patient for at least one year were eligible for participation. Limiting the age of the children to this range is because literature review revealed that 10 to14 years is the age range with the highest incidence of T1D (Maahs, West, Lawrence, & Mayer-Davis, 2010; Rifshana et al., 2017).

Participants were 18 years and above with an established caregiving relationship with the child and not simply an accompanying adult; were willing to participate, and the able to communicate experiences and opinions in an articulate, expressive, and reflective manner either in Twi, Fanti or English. The passage of at least one year from the diagnosis of diabetes in the children, and the maximum age of the children not more than 14 years with minimum age being 10 years were also included. Limiting the range to this age group restricted the group to children with more similar developmental needs and more consistency in the level of care.

Exclusion criteria for participation were lack of willingness to participate in the study; being simply an accompanying adult; under 18 years; those whose children were younger than 10years or older than 14years as well a family caregiver whose child had been newly diagnosed (less than a year) of T1D.

Sampling Procedure

A sample is a subset or portion of the population selected for a particular study, and sampling is the process of selecting a portion of the population to represent the entire population (Polit, & Beck, 2004). In this study, purposive sampling, maximum variation was used to recruit family caregivers of young persons with T1D because apart from it being used most commonly in qualitative inquiry, it is said to be the most suitable technique for descriptive qualitative research (Sandelowski, 2000; Polit, & Beck, 2004).

Purposive sampling, also referred to as a judgmental or expert sampling, is a type of nonprobability sampling technique (Lavrakas, 2008) that selects individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge (Streubert, & Carpenter, 2011).

The rationale and power of purposive sampling lies in selecting information-rich cases related to the phenomenon of interest. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposive sampling (Patton, 1990; Creswell, 2014; Palinkas et al., 2015). Therefore, the purposive aspect ensured that inclusion criteria secured a rich content from caregivers who have had reasonable length of experience. The maximum variation was achieved using demographic characteristics of age of caregiver, differing durations of caring, caregiver's employment status, gender and relationship to patient.

Therefore, with the help of the nurse in-charge and the attendance register at the DOC, family caregivers who had been regular at the clinic for at least a year, involved with the management of their children's condition and were willing to participate in the study were approached and informed about the study.

Sample Size

There has been an extensive discussion in literature concerning sample size determination in qualitative studies (Corbin & Strauss, 2008; Streubert & Carpenter, 2011; Cresswell, 2013). Studies have shown that sample size determination in qualitative research should be based on information needs. Thus, a guiding principle in sampling is data saturation- that is sampling to the point at which no new concept or information is obtained and redundancy is achieved (Polit & Beck, 2004; Corbin &Strauss, 2008).

According to Stebins (2001), a sample size of 30 participants is necessary to allow important categories and sub-categories to emerge. Notwithstanding, he also recognises that smaller sample size may be appropriate. Guest, Bunce & Johnson (2006) on the other hand suggest that saturation can occur after interviewing 12 participants. Furthermore, after consideration of studies that made use of exploratory-descriptive approach, Hunter et al (2019) recommend an average sample size of 15. Therefore, the proposed sample size for this study was between 12 and 15 participants. However, saturation was reached after interviewing 14 participants.

Data Collection Instrument

There are a variety of instruments or ways for collecting qualitative data: interviews, observations, narrative, and focus groups (Streubert, & Carpenter, 2011). In this current study however, semi-structured interview guide developed by the researcher with assistance from the research supervisor was used to elicit the experiences of family caregivers of young children living with T1D. Semi-structured interview guide is a flexible tool for data collection in which a number of carefully constructed questions are asked, while allowing enough flexibility to enable new questions to emerge based on the answers the interviewees give (Isaac, Duma, & Mayers, 2013).

More so, just as indicated by Willig (2001) and Taylor et al (2016), this method presented an opportunity to gain an understanding regarding participants' lives, experiences or situations as expressed in their own words due to its the flexibility and dynamism. The semi-structured interview guide for this study was in two main parts namely: the demographic and interview sections respectively. The interviews conducted were framed to address the study objectives. Follow up questions were asked for clarifications.

Pre-testing of Data Collection Instrument

Pre-testing is a method of ensuring that questions work as expected and those who are likely to respond to them understand them (Hilton, 2015). It involves simulation of the formal process on a small scale in order to recognise functional issues with data collection instruments, sessions and methodology. Pre-testing provides an opportunity to make revisions to study materials and data collection procedures and can also provide advance warning about how or why a research project can fail by indicating where research procedures are not adhered to or not feasible. (Hurst, Arulogun, Owolabi, Akinyemi, Uvere, Warth, Ovbiagele, 2015).

Again, Hurst et al (2015) suggest that in pre-testing, the data collection instrument must be administered to individuals that have similar characteristics to the study population, and in a way that replicates how the data collection session will be introduced and the type of study materials that will be administered. Based on this, the instrument was pre-tested among two people from the population intended for this study. However, these two were not included in the study. At the end of the pre-testing, the researcher identified a need to revise the data collection instrument because some of the questions posed were similar and as a result elicited the same response from the participants.

Data Collection Procedure

Before interviewing the participants, a copy of ethical clearance from the Institutional Review Board of UCC together with a letter requesting for permission to conduct the study in the facility were taken to the Medical Director of Effia Nkwanta Regional Hospital on the 2nd of December, 2021. Permission was granted to conduct the study in the facility on 16th of December, 2021. The researcher visited the Diabetes Outpatient Clinic (DOC) where young children with diabetes visit the first Saturday of every month with their caregivers for routine checkups and other services. After a brief introduction by the unit in-charge, a general information about the purpose of the study was given by the researcher as well as assurance of confidentiality.

With the help of the nurse in-charge and the attendance register at the DOC, family caregivers who had been regular at the clinic for at least a year, experienced about the management of their children's condition and were willing to participate in the study were informed about the interview. Some agreed immediately to be interviewed whereas others gave their contact numbers and after being contacted via mobile phone, they also agreed to be interviewed.

Each participant was provided with a written informed consent which was fully explained by the researcher, read, and signed or thumb printed by the participants before the interview. They were interviewed individually with the aid of a semi-structured interview guide. Each interview started with collection of demographic data such as; age, gender, employment status and marital status.

All the interviews lasting between thirty to thirty-five minutes were conducted in either Fanti, Twi or English language depending on which of the three languages participant could speak fluently. Participants were given numbers in place of their names; privacy was ensured and they were also encouraged to freely share their thoughts. Hunter et al (2019) highlights that consideration of time and venue that is convenient to participants helps reduce the researcher-participant imbalance. For this reason, the venue and time for the interview were agreed upon by both the researcher and the participants. Five of the interviews were conducted in a free consulting room at the DOC whereas nine were conducted at the residence of the participants.

Each interview was conducted by the researcher and tape-recorded. Non-verbal cues as well as all that the researcher did, saw and felt were written immediately after the interview in the researcher's journal. Data collection which was done alongside with the analysis started from 16th of December, 2021 and ended on 14th January, 2022.

Data Analysis

Data processing and analysis commenced alongside data collection. Thematic analysis based on the work of Braun and Clarke (2006) was chosen as the approach for data analysis. It is a method for identifying, analysing and reporting patterns or themes within data (Braun & Clarke, 2006). Thematic analysis was appropriate as a data analysis method for this qualitative study on account of several reasons.

Firstly, as an EDQ research, the study was intended to explore and describe the experiences of participants in relation to a phenomenon under study. Thematic analysis, according to Green and Thorogood (2014), is well-suited for this purpose. Secondly, since the exploratory component of EDQ has to do with discovering generalizations, thematic analysis identified the key statements that resonated across all the accounts of participants as Hunter et al (2019) proposed.

According to Braun and Clarke (2006), thematic analysis consists of detailed six phased step-by-step guide which is as follows: familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing report.

Data analysis consistent with Braun and Clarke's thematic analysis were done as follows:

To begin with, the researcher listened to the tape-recorded interviews over and over and transcribed them verbatim. The transcription of each interview lasted between three to four hours. The interviews conducted in Twi or Fanti were first translated into English before being transcribed where as those conducted in English were transcribed verbatim. The researcher then read the transcript over and over again to get familiar with them. Each section of the data that captured something significant to the research question was coded. All the coded transcripts were confirmed by my supervisor while each transcribed data or transcript was coded separately and data relevant to each code were gathered.

Furthermore, the codes from the various transcripts that had the same idea were labelled as sub-themes. This was done for each research question. The sub-themes that connoted the same idea were then brought together as themes. Repetitive codes within a sub-theme were discarded. In all, there were four themes with sixteen sub-themes. The researcher then reviewed and refined the emergent themes. That is the researcher read all the coded data extracts again to ensure that they formed a coherent pattern. Further analysis was done to identify the essence of what each theme was about and to determine the aspect the data was captured by each theme.

Finally, in order to produce a scholarly report of the analysis, it was related back to the research question and literature. More so, in order to ensure credibility of the study findings, member checks were conducted via phone calls to allow participants confirm key issues at the end of each transcribed data. This process showed that the data were the actual reflections of the experiences of the study participants.

Methodological Rigour

Rigour is striving for excellence in research and its goal in qualitative research is to accurately represent the experiences of participants (Streubert & Carpenter, 2011). Lincoln and Guba (1985) have identified four criteria for establishing the rigor or trustworthiness of qualitative data as credibility, transferability, dependability and confirmability.

Credibility refers to confidence in the accuracy of data and their interpretations (Polit & Beck, 2004). It establishes if the research findings are a valid interpretation of the participants' initial perspectives and represent plausible information derived from their original data (Korstjens & Moser, 2018). In this study credibility was achieved by ensuring that only participants who fell within the criteria for eligibility and could give an in-depth information on the phenomenon of interest were recruited. Also, the researcher conducted member checking by returning the research findings to the study participants in order to find out if they represent the participants' views and also to find out if it is a correct interpretation of the participants' original meaning.

Secondly, transferability is the extent to which findings of qualitative data could be applied to other settings or groups (Polit & Beck, 2004). In order to ensure transferability of the study findings, the researcher presented a detailed description of the research setting, methodology, design and background of the participants.

Thirdly, dependability, referred to as the stability of findings over time by Korstjens and Moser, (2018) which also a criterion for establishing trustworthiness in qualitative data, was achieved by the researcher working with her supervisor from the start to the end of the study. Also, all interviews were conducted using the same interview guide, and transcripts were subjected to the same method of arriving at themes and sub-themes. There was also transparent description of the steps taken from the start of the project to the development and reporting of findings. All documents concerning the research path were kept for audit trail.

Finally, confirmability is the ability of the researcher to present study findings that is a true representation of the of the participants' experiences, narratives and words (Shenton, 2004). Confirmability is concerned with proving that data and interpretations of findings are derived from the data and not a product of the researcher's imagination (Korstjens, & Moser, 2018). To achieve confirmability, the researcher did an in-depth exploration and description of the experiences of family caregivers. Again, interviews conducted were transcribed immediately to prevent mixing of information

Ethical Issues

Ethical approval was sought from the Institutional Review Board of the University of Cape Coast who reviewed any considerations in relation to participation by family caregivers. A letter requesting for permission to conduct the study was attached to the ethical approval form and taken to the Medical Director of Effia Nkwanta Regional Hospital in order to seek approval for the study. Some of the ethical issues that were considered in this study were informed consent, sound participant-researcher relationship and confidentiality.

Informed consent is a basic requirement for all research involving identifiable subjects. In order to obtain participants informed consent, the researcher provided each participant with relevant and adequate information regarding the purpose and scope of the study, the types of questions that were going to be asked, how the results were going to be used, and how their anonymity were going be protected. They had the power of free choice which enabled them to consent voluntarily to participate in the research or decline participation (Polit, & Beck, 2004).

Also, to ensure sound participant-researcher relationship in this study, the researcher: made every effort to maintain her role as an investigator other than a counsellor or therapist; tried to guide the interview and maintained focus on the topic under investigation; refrained from asking questions that might result in participants offering more information than they had originally consented to; and following the closure of the interview, the researcher did a recap for the participants' issues of concern that emerged during the interview and also provided follow-up (Streubert & Carpenter,2011).

Finally, confidentiality is the researcher's safe management of information or data shared by a participant of a study to ensure that the data are kept private from others (Grove, Gray, & Burns, 2015). Confidentiality was ensured by recording participant numbers instead of participants' names and also used anonymous quotes while reporting the results of the study. No identifying information were included in the transcripts of the interviews or in any of the reports that arose from the study.

Data Management

Before data collection, the date, time and venue of the interviews were recorded in a field diary. With participants' permission, data were transcribed verbatim and stored in a Microsoft Word document after each interview. After transcription, hard copies of each document, audiotapes, field notes and diaries were locked in a safe cabinet. The background information was labelled with the same numbers used in place of participants' names during the interview and stored safely in the same cabinet. Information will be discarded after five years.

To address the ethical issues associated with the use of electronic gadgets for data collection, participants were made aware that the conversation was going to be taped for data-recording accuracy purposes, but all their comments were going to be kept confidential. In order to guarantee confidentiality, participants were not identified specifically with anything they said during the interview.

Chapter Summary

This chapter is a description of the design of the study, the setting of the study, participant selection, data collection tool, data collection process and data analysis done with Braun and Clarke approach for thematic analysis.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

This chapter provides the presentation of the study results as well as their interpretations and discussions. The purpose of the study was to explore the experiences of family caregivers of young persons living with T1D at the Effia Nkwanta Regional Hospital. Specifically, the study sought to investigate the perception of family caregivers of young persons with T1D about the disease; explore subjective experiences of caring for a young person with T1D; determine the challenges of family caregivers of young persons with T1D; and to identify the strategies family caregivers use in coping with the demands associated with the care of a young person with T1D.

In order to answer the research questions, 14 face-to-face interviews were conducted with the aid of a semi-structured interview guide. Data analysis based on Braun and Clarke (2006) thematic analysis was done. In all, there four (4) themes and sixteen (16) sub-themes emerged.

Results

Demographic Data

The sample was made up of fourteen (14) family caregivers: five (5) mothers, two (2) fathers, one (1) elder sister, two (2) aunts, three (3) grandmothers and one (1) uncle of a child with T1D (aged 10 to 14 years). All the participants have been actively involved in the care of a child with T1D and have been regular at the Diabetic Outpatient Clinic at the Effia Nkwanta Regional Hospital for at least one year. Ages of the participants ranged from 25-70years. six (6) out the fourteen (14) were married, three (3) were divorced, two (2) had lost their spouses and two (2) were single. The educational level also ranged from junior high school (JHS) to tertiary education levels. One (1) had education up to the JHS level, five (5) had up to the secondary level, one (1) had up to the sixth form level and seven (7) had up to the tertiary level.

Also, two (2) out of the fourteen participants were on retirement, one (1) fashion designer, one (1) seamstress, one (1) farmer, five (5) traders and four (4) formally employed. The duration of participating in the care of the child living with T1D varied from one and half years to eight years. One (1) participant had participated in the care for one and half years ($1^1/_2$), three (3) had participated in the care for two years, four (4) had participated for three years, one (1) had participated for four years, two (2) had participated for five years, two (2) had participated in the care for six years and one (1) had participated in the care for eight years. Finally, majority (11) of the participants were Christians and three (3) Muslims.

All the fourteen participants in the study were given code numbers. Five (5) of the interviews were conducted in a free consulting room at the DOC whereas nine (9) were conducted at the residence of the participants. Table 1 is a summary of the participants' characteristics.

Table 1: Demographic Data

Number	Code numbers	Age (yrs)	Marital status	Relationship to child	Educational level	Religion	Occupation	Age of Child (yrs)	Number of years
1	P1	37	Single	Mother	SHS	Christian	Trader	13	6
2	P2	25	Married	Aunt	Tertiary	Christian	Fashion designer	14	2
3	P3	49	Married	Father	Tertiary	Muslim	Police	14	8
4	P4	29	Single	Elder sister	SHS	Christian	Seamstress	10	$1^{1}/_{2}$
5	P5	37	Married	Mother	Tertiary	Christian	Teacher	10	5
6	P6	34	Divorced	Mother	SHS	Muslim	Trader	11	2
7	P7	50	Widowed	Grandmother	Tertiary	Muslim	Retired	$11^{1}/_{2}$	6
8	P8	52	Divorced	Grandmother	JHS	Christian	Trader	13	3
9	P9	45	Married	Aunt	SHS	Christian	Trader	10	4
10	P10	45	Widowed	Father	6th form	Christian	Farmer	12	2
11	P11	30	Single	Mother	SHS	Christian	Trader	12	3
12	P12	35	Married	Mother	Tertiary	Christian	Accountant	14	3
13	P13	37	Married	Uncle	Tertiary	Christian	Mechanical engineer	12	3
14	P14	70	Divorced	Grandmother	Tertiary	Christian	Retired	10	5

Source: Field survey (2022)

Table 2: thematic framework of the findings

Themes	Sub-themes
Perception	Pathways leading to diagnosis Beliefs about causes of T1D Ascribed meaning to child's condition
Experiences	Diagnosis experience Difficult diagnosis Learning the care Caring role Care goal Recognition of hypoglycaemia
Challenges	Emotional Social Financial
Coping strategies	Religious beliefs Social support Family involvement Embracing the new normal

Source: Fieldwork, (2021)

Family Caregivers' Perception of TID

In answering the research question regarding family caregiver's perception of TID, three (3) sub-themes emerged: pathways leading to diagnosis, causes of T1D and ascribed meaning to child's condition. The following are some of the responses from the study participants regarding the sub-themes.

Pathways leading to diagnosis

Most of the participants in this study indicated that although their children showed signs of deteriorating health such as persistent thirst, general body weakness, frequent urination, and prolonged unexplained ill-health, they did not associate them with T1D and so sought for medical attention only when the symptoms became worse. It was therefore at the hospital that they were informed that their children had T1D.

The summary of their responses are as follows:

"He fell sick for a long time and after all my home remedies failed, I took him to a priest thinking it was spiritual but that also yielded no result. Later, I took him to the hospital upon the advice of a friend; it was there he was diagnosed of T1D after several investigations". (P6).

"My boy had persistent thirst and fever for some weeks so we reported at the Out Patient Department of a near-by hospital. Laboratory investigations were carried out, and the doctor after seeing the results with a stern face said my boy had DKA as a result of unmanaged T1D" (P3)

She would drink water and within a short time go and urinate, this continued for a long time so she was taken to the hospital and the laboratory investigations carried out indicated that she had "the sugar disease" (9).

Beliefs about the causes of T1D

Participants shared their beliefs about the causes of T1DM. Here, majority of them attributed the cause of their children's condition to too much intake of sugary foods, evil spirits or witchcraft and genetics. Below are some responses from the participants

"*I don't really know anything that can cause this disease. But I believe it occurs when you eat lots of sugar and it becomes much in blood*" (P10).

"*I have read about the cause from books but as for me I believe a witch in my family bought this disease for my child; and very soon (raises his voice) God will punish him*" (P3).

"*It runs through families. A child can develop it if either his mother or father has it*" (P7).

Meanings participants ascribed to their children's condition

Majority of the participants in this study saw T1DM as a serious chronic disease that is associated with dietary restrictions, play restrictions and complications. Some responses from the participants are:

"*………yes!! (exclaimed). Personally, I know it is a very serious disease. This is because I have seen adults with such disease who have swollen feet and others have wounds that are not healing*" (P14)

"*This condition has really limited my child because there are lots of foods he cannot eat compared to his other age mates who do not have the condition*" (P11)

"*He cannot play like the other kids because I have learnt that the wounds of people living with diabetes donot heal easily. I also know that he may collapse if he engages in very vigorous activities right after his injection*" (P7)

Family Caregivers' Experiences of Caring for a Young Person with T1D

In answering the research question regarding the participants' day-to-day experiences as they care for children living with T1D, sub-themes that emerged were: diagnosis experience, difficult diagnosis, learning the care, role, goal, and hypoglycaemia recognition. The paragraphs below are the summary of the participants' responses to the sub-themes.

Diagnosis experience

Family caregivers described their experiences immediately after their children's diagnosis. Fear, surprise and doubt pervaded their experiences. Most of them presented complaints of symptoms which they had attributed to other conditions at the hospital but left with their children who had been diagnosed of T1DM.

Their responses were as follows:

"*Oh, I was very surprised and became devastated by the news even though I had heard of such issues. All along I thought what my child was going through wasn't serious; I thought it was one of those usual sicknesses that happen to kids. Notwithstanding I went ahead to ask why a little child at that age could have such disease"* (P13).

"*Hmmm (sighs), I remember it was a very difficult moment for me, accepting the diagnosis wasn't easy. I doubted the results and the diagnosis, because I know it happens to only old people but I later had to because there was nothing I could do about it. More so, no one can determine what disease should come to them"* (P5).

"Everything came to a standstill for a moment and when reality dawned on me, hmmm (wiped a tear) I became sore afraid because I did not know the outcome of this strange disease. I still remember that cold Monday morning" (P3)

Despite the fear, doubt and surprise experienced by participants upon hearing the news of their child's diagnosis, most of them expressed satisfaction with the attitude of their healthcare providers at the initial diagnosis of their child. For instance:

"……. *But my nurse did so well; she was full of hope and spoke kind words to us. I then realized my perception of nurses being rude was not true*" (P4)

"*The nurses and doctors were very helpful when he was first diagnosed; they took their time to explain things to me*" (P7)

"*Based on the explanations given us by the nurse, I understood that it could happen to anyone and so I encouraged myself and decided to have a positive outlook on the future*" (P13)

Difficult diagnosis

Regarding this sub-theme, all the participants reported that T1D was a difficult diagnosis which interferes with family routines, more so, the different dimensions of involved in its management makes it difficult to gain mastery over it.

"*This condition is very difficult to manage, no one seem to know it all about how to manage it*" (P5)

"*It comes with lots of changes in the things we do daily, and this makes it so hard especially with the diet*" (P2)

"*It has become part of my life but the constant monitoring makes it difficult; my thoughts are always occupied with what she might be eating, whether her sugar is being checked in my absence*" (P1)

Learning the care

Majority of the participants learnt how to care for their children through the health education they were given while their children were on admission mostly by their health care team; all of them mentioned the young diabetic clinic as the place they mostly seek help from whenever they need any advice or clarification or encounter any challenge in the course of caring for their children. A few also spoke of getting additional information about T1D care from the internet apart from what they receive at the hospital.

"While on admission, the nurses would put in a few tips here and there; we also visit clinic and learn; and I also read about it from the internet. However,

on the internet there are information you find about the condition that is very scary" (P3)

"……. *he was actually very sick at the time of diagnosis so we were made to sleep at hospital. It was during our stay that they taught us about how to care for. The clinic has also been very helpful*"

"In fact, learnt all I know about how to care for my child with regards to the condition first from the young diabetic clinic. We were also made to visit a nurse at the place where people are taught what to eat" (P4)

"I learnt how to care for him from the continuous health talks given us at the clinic. I also have the phone numbers of the nurses at the clinic and so in case I need any information that cannot wait until our review date, I call" (P8)

Caring role

Almost all the participants were able to recount the role they play in the management of their children's condition. These included blood glucose monitoring, insulin injection, going for routine check-ups with the children, ensuring the children stick to the prescribed diet plan among others.

"I do give him his insulin injections but he is learning how to inject himself small; I also monitor his diet because you know there are stuff he is not supposed to eat. For the checking of his sugar, he does it himself because he says I prick him so hard (laughs) but I still have to oversee that" (P8)

"I check his sugar; give him his insulin injections; ensures he eats only what he has been asked to eat; I also make sure he doesn't walk barefooted" (P10)

"………I take her to the clinic for check-ups and also for medication refill any time she is due for check-up" (P13)

Care goal

With regards to their goal for actively participating in the management of their children's condition, most of the participants stated emphatically that they wanted their children's blood glucose to remain within normal ranges so that they will be healthy and live long even though they were aware the condition could not be cured.

"……. hmmm (paused briefly), that her sugar remains normal so she will grow up as healthy child and live all her dreams because there are several people out there with even worse health conditions" (P5)

"I'm doing all these because I want him to grow up being healthy and I also don't want to lose him. I really want him to live long" (P7)

Recognition of hypoglycaemia

Most of the participants knew what hypoglycaemia was and its presenting signs and symptoms because their children have experienced at least and episode before. There were others who have only heard about through the health education at the hospital.

"*I have heard about it; it happens when the sugar goes down beyond normal. In fact on the first day we rushed her to the hospital, we were told she had hypo. Some of the signs and symptoms are dizziness and excessive sweating*" (P12)

"*……an experience I will never forget; there was a day I stepped out and he injected himself but failed to eat afterwards. I found him extremely weak and shaking so I quickly put some sugar in his mouth just as I was taught at the clinic. I know he would have died if I hadn't returned home early*" (P6)

"*I was told about it at the hospital but my son has never experienced some before. I was told that any time I observe he has become weak, confused or sweating so much then it means his sugar has gone down*" (P11)

Challenges Family Caregivers Face in Caring for a Young Person with T1D

In answering this research question, the challenges described by participants while they care for their young children living with diabetes were categorized under three sub-themes as: psychological, social and financial challenges. The summary from the responses of the participants regarding the sub-themes are as follows:

Emotional challenges

Here, fear of hypoglycaemia was an all-pervasive concern of the family caregivers whereas the narratives of many also revealed a never-ending feeling of anxiety and worry about their children's condition.

"*mmmmm……* (wipes a tear) *the hypoglycaemia she experienced the last time has made me so scared because I know it can kill her. I have stopped going on long business trips*" (P9)

"*I am very much afraid of the blood sugar going very down because I know she can die from it*" (P4)

"*hmmmm, it is not easyooo; I'm worried that he is not like the other kids. This fact makes me anxious about his tomorrow and his ability to live independently as an adult. I wonder what will become of him if he eventually leaves home*" (P7)

"*Thoughts of whether she will be able to manage herself well without us and whether she will be able to find a potential lover who will accept her just the way she is keeps me worried all the time*" (P8)

Social challenges

Majority of the participants including those who have family support in the management of their children's condition described their experience of social isolation and lack of leisure. A few however spoke of letting other members of the family care for their children in order to take some time off.

"*Now her condition has ceased me from going out with friends; and I am no longer comfortable in leaving her in the care of others for funerals and weddings. I tried it once but had to rush home quickly because I was informed her sugar was going down*" (P2)

"*……you are either keeping an eye on him so he doesn't get hurt or checking his sugar or being busy with other things concerning him. The care is so continuous such that you hardly have any leisure time*" (P6)

"*There are others at home who understand the condition and conveniently takes care of him in my absence so I travel, go to work and attend social gatherings without any fear*" (P13)

Financial challenges

Almost all the participants described the various ways by which the demands related to the management of the condition has brought financial burden to them.

"*The strips are very expensive but we must always have some available so I can check his sugar. I always have to make sure what he is supposed to eat is available. He sometimes become ill when there is no money and when that* *happens, I have to go and borrow money. Hmmmm, money issues have been quite difficult since he had this disease*" (P11)

"*Now the disease has come to stay and so I have to set some money aside for his medication and the thing used to check his sugar. All these are expensive and has brought another cost*" (P10)

"*The management is draining financially. Now prices of everything including glucostrips are rocketing yet the national health insurance does nothing to help*" (P3)

Coping strategies

The study participants identified their various means of coping with the demands related with their child's illness as: engaging in religious activities, support groups, support from other family members as well as spouses. A few spoke of embracing the new normal (that is coming into acceptance with their child's illness) as their means of coping. The summary of participants responses are as follows:

Religious beliefs

Most of the participants described their belief in religious activities and their participation in them as a means of coping with T1D related demands.

"*Frankly speaking, God has been my comforter since day; he is the one who gives me strength and I know he won't bring anything our way that is beyond us. He will definitely see us through, because he is in control of this disease; I believe this with all my heart*" (P9)

"I *pray little by little, and by this, I am encouraged to go on. After all, everything happens for a purpose and God is the one who cares for people*" (P11)

"*As a Christian I know this is a test meant to strengthen my faith, so any day I become so stressed, I resort to the reading of my bible and prayers and I become ok*" (P2)

Support group

A number of family caregivers also asserted that their involvement in support groups served as a coping strategy for them.

"*By going to the young diabetic clinic, I see younger children than mine with the same condition and this gives me hope knowing that I'm not the only one going through this*" (P7)

"*At the clinic where we go for reviews, I have gotten to see other parents with their children some of whom I have made friends with. We share our challenges and also encourage ourselves*" (P12)

"*There are a lot of things that gives me inspiration at the clinic especially a little girl who was said to have been diagnosed when three years and became seriously ill but now looks healthy and has gone far in education*" (P4)

Family involvement

Some of the study participants had family members who were very much supportive in the management and this helped them cope with the many demands of the condition of these children. There were however a few who had no family support.

"*My wife is late but my two sisters have been very supportive. in fact, they take turns in caring for him any time I have to travel. They even go with him to the clinic for check-ups anytime they are free to do so*" (P10)

"*My husband and my mum have been very much involved all these while and so I have no fears any time I have to be away*" (P12)

"*I expected that we will take turns in caring for her but because I'm not a government worker, everything has been left on me*" (P4)

"*I wish his father would provide financial assistance and any of my family members will come around to provide support, but no one helps, I care for him all by myself*" (P11)

Embracing the new normal

In order to cope and adjust to the diabetes management with its associated challenges, some of the family caregivers described how after a period of managing the condition at home, they became used to it and accepted it as a normal part of their everyday lives.

"*Ooh, (shrugs) I see it as becoming a part and parcel of us and we have become used to it. I believe that by following the instructions given us by the doctor, if we give him his injections and take good care of him, he will be fine. This is how I cope*" (P8)

"*……strange though as it is, it has come to stay so I also see it as normal part of our everyday lives. It could have happened to anyone and so we are cool with it*" (P1)

Participants' Recommendations

During the interview process, the study participants made certain recommendations some of which were aimed at solving their own unique challenges regarding diabetes care, others aimed at early identification and management of T1D in children, and accessibility of diabetes clinics. Below is a summary of the participants' recommendations.

"*I suggest that hospital must make available insulin and strips at a lesser price or give some out for free; it will be very helpful if it is done*" (P7)

"*I think the young diabetic clinic should be maintained and more should be opened if possible*" (P8)

"*I wish Dm screening in schools will be done in schools as a routine for early detection and management*" (P12)

"*Health education about TID must be done in our communities because there may be children having it but whose parents are not aware*" (P9)

"*Just as nurses go round remote villages to organize child welfare clinics, I suggest centres should be opened by the government in such areas to care for young children living with diabetes. This is because not all people can travel with their children to big hospitals for healthcare*" (P14)

Discussion

This part of the chapter deals with the discussion of the results of this study by comparing them with existing research, the conceptual framework of this study and the literature that has been reviewed. The discussion is organized according to the set objectives – perception, experiences, challenges and coping strategies of family caregivers of young children living with T1D and other issues that emerged during the analysis of the data.

Pathways leading to diagnosis, which refers to all the circumstances and events which led to the children being diagnosed of T1D, was one of the sub-themes that emerged under the perception that family caregivers have concerning T1D in their young children.

The pathways may be prompt or delayed (Rankin et al., 2014). For parents who consider the diagnosis of their children to be prompt, they or others identify their children have developed symptoms of T1D which make them seek early medical attention. On the other hand, for children whose diagnoses are delayed, their parents do not recognize the signs of T1D and attribute the children's deteriorating health to other conditions. These parents only seek medical attention as the symptoms worsen (Lowes, Gregory, & Lyne, 2005; Rankin et al, 2014). This was reflected in the findings of this current study where almost all the family caregivers reported that although their children showed signs of deteriorating health such as persistent thirst, general body weakness, frequent urination, and prolonged unexplained ill-health, but they did not associate them with TID and so sought for medical attention only when the symptoms became worse. It was therefore at the hospital they were informed that their children had T1D.

Also, this finding is also similar to the findings of other studies which revealed that delay in the diagnosis of T1D was attributed to participants' lack of familiarity with symptoms of T1D and so thought their children had one of the most common childhood diseases (Kear, Fisher, Westwood, Sachdev & Denvir, 2016; Khandan, Tirhari, Abazari, & Cheraghi, 2018). Again, another reason for the delay presentation to the hospital similar to the finding in this study is that some mothers thought the symptoms exhibited by their children were not serious because they were non-classic in nature (Khandan, Tirgari, Abazari, & Cheraghi, 2018). This implies that general knowledge about T1D may be widespread but not many people can identify the symptoms in children and this calls for intensive public health education on the clinical manifestations of T1D.

Following the diagnosis of T1D in children, participants looked for the cause of this disease. Regarding their beliefs about the causes of T1D, a number of them identified intake of too much sugary food as the cause of the changes that had emerged in their children's health. This finding is congruent with the findings of a study conducted by Korsah, Dyson and Anthony (2021) who posited that a number of their study participants alluded to the fact that diabetes is caused by the intake of too much sugary drinks.

Also, some of the caregivers indicated that diabetes runs through the bloodline and that an individual is likely to suffer it if someone in the family has it. This current finding agrees with the finding of other studies which suggested that parents made claims of underlying genetic factors caused their child's diabetes (Ferreira, Ferreira & Geralda, 2014; Allan & Rowlands, 2020).

Others attributed the cause of their children's ill-health to evil spirits or witchcraft. Similar expressions were enunciated by participants in other studies who were very emphatic about diabetes being caused by evil spirit and that its treatment and overall management should be aligned with mystic and magico-religious processes (Korsah, 2015; Korsah, Dyson & Anthony, 2021). This show that family caregivers attribute the causes of T1D to many unique factors which must all be taking into consideration when interacting with them.

On the aspect of the subjective meaning family caregivers ascribed to T1D in their children, results from this study showed that some of them perceived T1D as a serious disease that is associated with the development of complications. These results are similar to the results of other studies (Stodberg et al., 2007; and Ferreira et al., 2014) which showed that parents judged T1D as a very serious disease that put people at risk of developing complications. Similarly to the findings of Bekker, Deacon and Segal (2019), findings of the narratives from some family caregivers in this study showed that they viewed T1D as a chronic disease that can be managed. Here, it means that family caregivers have to make a lot of adjustments in order to create a new normal and as such, the healthcare providers must endeavour to help these family caregivers to incorporate diabetes care into their everyday lives well.

Also, most of the study participants identified that T1D in their children meant that the children could not engage in certain games and eat everything like other children who do not have diabetes. A similar finding from a study conducted by Pierce et al. (2017) reported that T1D task restricted spontaneity in eating and playing. With this, parents felt T1D literally prevented their children from living carefree lives.

With regards to the experience of family caregivers, diagnosis experience was identified as a sub-theme. Here, the study participants gave descriptions of their experiences immediately after their children's diagnosis of T1D. these were experiences of fear, surprise and doubt facing the fact that their children had T1D. Findings from the study showed that most of participants were fearful of the unknown outcome of their child's diagnosis. This finding is consistent with the finding of a study conducted by Smaldon and Ritholz (2011) which revealed most participants were afraid immediately after hearing the diagnosis of their child.

Also, some of the study participants were surprised at the urgency with which the healthcare professionals attended to their children because they thought the symptoms were as a result of some common childhood conditions and that it was not serious. Similar to this finding are the findings of other studies which revealed that participants expressed the feeling of surprise at the contrasting urgency portrayed by the healthcare professionals upon the diagnosis of T1D in their child because they in a way attributed the signs and symptoms portrayed by their child to other conditions. Hence the unexpectedness and speed of the diagnoses left them unprepared to deal with the situation despite their suspicion that their child had a health problem (Lowes, Gregory & Lyne, 2005, Rankin et al., 2014).

Finally, under the diagnosis experience, a number of the caregivers were doubtful of the results of the tests conducted as well as the diagnosis of T1D in their children because they believed diabetes was a disease that occurred among adults. The findings of other qualitative studies are consistent with the finding of this study. In their findings it was revealed that the study participants mistrusted the diagnosis of T1D in their children and the tests results because they thought diabetes was a disease of adults (Smaldon & Ritholz, 2011; Kratzer, 2013; Khandan, Tirgari, Abazari, & Cheraghi, 2018). This means that, raising awareness in the society will enable these family caregivers to be familiar with symptoms of T1D and follow-up their child's health quickly.

Despite the fear, surprise and doubt experienced by participants upon hearing the news of their child’s diagnosis, most of them expressed satisfaction with the attitude of their healthcare providers at the initial diagnosis of their child. This is however in contrast with the finding of Smaldon and Ritholz (2011) which indicated that participants in addition to their fear and doubt also felt they had not been taken seriously and were also blamed for their lack of parental experiences.

Also, T1D was reported to be a difficult diagnosis as a sub-theme. Here, findings from the narratives of all the study participants revealed that T1D is a difficult diagnosis because it interferes with family routines. More so, the different dimensions involved in its management makes it difficult to gain command over it. Similar to this result is the results from a systematic mixed studies-review of 34 articles conducted by Whittemore et al (2012) which revealed that parents of children living with T1D viewed the condition as difficult diagnosis because understanding the large amount of complex information provided was challenging.

Furthermore, Kimbell et al (2021) added that parents of children with T1D perceived its management to be very difficult due to its complex and unpredictable nature and thereby making mastery difficult. In addition to this, findings from the research of Iversen et al (2018) also highlighted how impossible it is for parents to feel completely confident about the responsibility of controlling their child's blood sugar.

Contrary to this finding, Sullivan-Bolyai and Lee (2011) in their qualitative descriptive interviews found out that parents of children who have been newly diagnosed with T1D quickly become experts in T1D management at the diagnosis of their children while at the same time teaching others about the proper care. Findings from other studies have also shown that family caregivers gained mastery over diabetes care procedures from self-study materials and informational sessions to technical training to develop mastery over diabetes care procedures (Zysberg, Lang & Zisberg, 2013; Zysberg & Lang, 2015).

Another sub-theme that emerged under the experiences of family caregivers is learning the care. With this, findings showed that all of the participants reported they learnt to care for their children through the health education, instructions and technical training they were given at the hospital by their health care team; and were also given phone numbers of the diabetes team if they needed any information about how to manage their children at home. Similar to this finding is that reported by Rankin et al (2016) which showed that parents were given explanation about how to handle their child's T1D at home, along with other relevant information while on admission. Additionally, the diabetes team's contact information and after-hours phone numbers were given to parents in case they needed assistance with managing their child's diabetes at home**.** Findings from the current studies and empirical data shows the existence of a cordial relationship between healthcare professionals and the family caregivers which is pivotal in proper T1D management

Similar narratives from other studies have shown that family caregivers of young children with T1D were able to learn about the condition of their children and gain confidence over the daily diabetes care procedures required for the health of their child because of their ability to access their healthcare providers easily and constantly coupled with the self-study materials, informational sessions and technical training given to them by their healthcare providers (Whittemore et al., 2012; Zysberg, Lang & Zisberg, 2013; Zysberg & Lang, 2015). Furthermore, findings from Watt’s (2017) exploratory studies on how parents with children living with diabetes understand worry revealed that parents gained knowledge of diabetes management from the diabetes education and treatment conducted by diabetes nurse educators at paediatric clinics.

A few participants spoke of getting additional information about T1D care from the internet apart from what they receive from their healthcare providers. However, they also asserted that certain information they get about the complications of diabetes makes them afraid and anxious. There are similarities between the above finding and that of Boogerd et al (2015). In their findings, parents explicated a need for additional information which they had by searching on the internet but they were overwhelmed by the amount of information they found about complications and other diabetes related problems. Also based on the evidence of a study, it has been suggested that children with long-term conditions including diabetes can benefit from the information on the internet in their care (El-Gayar, Timsina, Nawar, & Eid, 2013). Notwithstanding, due to the enormous pile of information about diabetes available on the internet, diabetes healthcare providers must endeavour to guide these family caregivers to the right sources of diabetes information.

Furthermore, with the caring role of family caregivers, almost all the participants were able to recount the many roles they play in the management of their children’s condition because of their awareness that these young children will not be able to adhere strictly to the management without their (family caregivers) support. These roles they mentioned included blood glucose monitoring, insulin injection, going for routine check-ups with the children, ensuring the children stick to the prescribed diet plan among others.

Similar findings from other studies have shown that family caregivers have the responsibility to ensure their children's blood glucose are within a healthy range through close monitoring of their children's diet, activity, insulin and glucose levels. Also, family caregivers are responsible for the continuous monitoring of their children for symptoms of hypoglycaemia and hyperglycaemia; to provide the appropriate response to resolve the symptom in order to bring the child's blood glucose back to the normal range (Sullivan et al, 2003; Soni et al., 2016).

In line with the finding from this study, narratives from Monaghan et al (2011) indicated that apart from the usual role of fostering physical, cognitive, and socioemotional growth and development, family caregivers of younger children also bear complete responsibility for diabetes care, where they attend to constant and unrelenting demands of daily management. Findings from other studies have noted that family caregivers are directly responsible for the performance of the disease management, including accounting for carbohydrate intake and diet tracking (Sullivan-Bolyai et al., 2003; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Helgeson et al., 2012; Boogerd et al., 2015).

Other findings which lays much emphasis on parental roles that are consistent with the findings of this current study suggest that although adolescents are generally encouraged to become independent in their self-management, and can become less reliant on parents with day-to-day management (Spencer, Cooper, & Milton, 2013), however, because they have the tendency to neglect self-care routines due to pressures and changes related to normal adolescent development, parents continue to play a vital role through monitoring, reminders and provision of support to adolescents in self-managing their condition (Moore, Hackworth, Hamilton, Northam, & Cameron, 2013). Therefore, family caregiver's involvement in the diabetes management of young persons is very important. This because it has been found to contribute to better metabolic control, better treatment adherence, quality of life and few diabetes-related hospitalisations (Mellin, Neumark-Sztainer, & Patterson, 2004; Jaser, 2011).

With regards to their goal for actively participating in the management of their children's condition, most of the participants stated emphatically that they wanted their children's blood glucose levels to be normal so that they will become healthy and live long even though they were aware the condition could not be cured. Similar to the finding of this study, evidence from a study conducted by Robinson, Iannoti, Nansel, Haynie and Sobal (2011) is suggestive that ensuring that their child's blood glucose levels are within the targets recommended by their physician was of prime importance to parents.

Again, findings from Iversen et al (2018) also support the fact the number one goal of parents for actively being involved in their child's diabetes management is for the child to register an acceptable glycated haemoglobin value during clinic appointments. This means that family caregivers were aware of the complications associated with persistently high blood glucose levels and so by having blood glucose levels within target range means that it is the ultimate goal of parents to have their children being free from complications and other diabetes-related problems.

Under the sub-theme hypoglycaemia recognition, most of the participants knew what hypoglycaemia was and its presenting signs and symptoms because their children have experienced at least an episode before. There were others who had only heard about it through the health education at the hospital. Findings from an earlier study that support this current finding have shown that, based on their earlier experiences of severe episodes of hypoglycaemia, family caregivers learn to identify even the most subtle signs of hypoglycaemia (Rintala, Paavilainen & Astedt-Kurki, 2013).

Another similar finding was identified by King, Overland, Fisher and White (2015). In their study, participants asserted that their encounters with severe episodes of hypoglycaemia helped them equip themselves with information about it as well as the most effective line of action to take in emergency situations. However, for some participants in another study, their awareness of the unpredictable nature of T1D and the potential deadly effects of hypoglycaemia were the factors that made them arm themselves with the knowledge about hypoglycaemia (Kimbell et al., 2021). This finding also agrees the finding of this study.

With regards to the sub-theme psychological challenges under the main theme challenges, fear of hypoglycaemia was a major concern of all the study participants. This fear stemmed from the fact that they were aware of the grave effects hypoglycaemia could have on the health of their children. Fear of hypoglycaemia as identified in this study is a widespread concern across several studies (Watt, 2017; Iversen et al., 2018; Kimbell et al., 2021). Similar to the findings mentioned, parental fear of hypoglycaemia emanates from several factors including some children’s poor knowledge of hypoglycaemia (Rankin et al., 2015; Lawton et al. 2015).

Again, narratives from parents in the study conducted by Lawton et al (2015) further suggested another reason for fear of hypoglycaemia was parental knowledge of the potential grave consequences of hypoglycaemic episodes. This fear is heightened at night when parents become concern that they may not be able to detect severe episodes of hypoglycaemia and so in order to curb this, they would check their children's blood glucose several times in the night leading to sleep deprivation.

In addition to the afore mentioned psychological challenge, findings from this study also revealed a never-ending experience of worry and anxiety among family caregivers. Many were worried and expressed anxiety about the children's future and their ability to live on their own as adults. Another source of worry among family caregivers from the findings of this study was the children's ability to find potential suitors and eventually get married when they grow up. Similar to this finding was the finding identified in a systematic review and synthesis of qualitative evidence conducted by Kimbell et al (2021) where parents expressed worry about how diabetes would affect their children's lives in future despite the fact these children were young.

Furthermore, studies conducted in Palestine (Ellisa et al., 2017) and Iran (Khandan et al., 2018) identified parents who were worried and anxious about diabetes marring their girls' chances of being married in future based on the fact that these girls may be seen as unsuitable marriage partners; and also put their children at risk of inheriting the disease.

Another challenge explicated by the participants in this study was social challenge. Majority of the participants narrated how their caring role impacted their social lives negatively. This challenge was predominant among female participants because they are the primary caregivers in most families. Here, their quest to keep a close eye on their child with T1D eventually denied them opportunity to participate in social activities; for others, the constant and never-ending demands of the management deprived them of leisure. Although, some of these participants had family support, they were however not willing to relinquish some of their responsibilities to them and take breaks. This was because they felt these family members did not understand diabetes care. A few however spoke of letting other members of the family care for their children in order to take some time off. Similarly, findings from Whittemore et al (2012) indicated that with mothers being most families' primary caregivers, many of them have to change job schedules and curtail other social activities in order to provide full-time childcare.

Results from Boogerd et al (2015) which is in agreement with this study revealed parents found the confrontation with their child's diagnosis and the introduction to the complex skills involved in the management of diabetes overwhelming and the demands associated with caregiving restricted their work and social activities.

Similar results from other studies have proven that in order to prevent hypoglycaemia, family caregivers described the need to be constantly watchful in monitoring their child's diet, activity and blood glucose readings (Sullivan et al., 2003; Iversen et al., 2018; Kimbell et al., 2021). Because of this fear of hypoglycaemia, findings from an exploratory qualitative study by Lawton et al (2014) suggest that most family members curtail their own activities and lifestyles including giving up recreational activities that take them out of their homes.

Furthermore, Smaldone and Ritholz (2011) identified that parents of young children with T1D often experienced social isolation resulting from deterioration in family relationships and friendships due to having trouble connecting with them and letting go of the duty of caring for them. Although when parental responsibility for diabetic decision-making is shared, parental adaptation becomes more effective; nevertheless, relatives and friends in this study had little comprehension of T1D. They reported even family members were hesitant to babysit because of the fear of not knowing how to manage insulin and the child's responses to it.

On the contrary, finding from Iversen et al (2018) demonstrated that once parents became familiar with their child's diabetes, they allowed other family members or friends to take up the responsibility for the child. Although this move was challenging initially, they realised it went well and so became encouraged.

Financially, almost all the participants especially those with low incomes described the various ways by which the demands related to the management of the condition had brought financial burden to them. These demands included, cost for glucostrips, unplanned hospital visitations, trips for clinic appointments, special diet. Even those who were on the national health insurance and those who were in the class of the middle income described their financial constraint with diabetes care.

Several findings from existing literature that are consistent with the financial constraints associated with diabetes management have demonstrated that for many families, particularly those with low incomes, as well as those in low and middle-income countries, the costs of specialists' care, lifelong insulin therapy, frequent visit for clinic appointments, constant blood sugar monitoring, special diabetes diets and other requirements for managing T1D in children are extremely difficult. This puts a heavy financial burden on them, requiring them to make sacrifices with other household expenses to pay for the treatment (Pierce et al, 2017; Khandan et al., 2018, Kimbell et al., 2021).

According to the International Diabetes Federation (2016), insulin is associated with significant out-of-pocket payment that can consume about two-thirds of disposable income; and blood glucose monitoring alone in many of such countries can consume half of a family’s average disposable income. Volman (2008) stated that high direct costs associated with diabetes care result in families living in increasing poverty. Indirect costs for family caregivers, such as reducing working hours or quitting jobs in order to care for a child with T1D can also contribute to the negative economic impact on families affected by diabetes and other chronic diseases (The Lancet Diabetes Endocrinology, 2018).

Furthermore, resonating with this finding is a study conducted by Kimbell et al (2021) who found out that middle-class parents who were in possession of medical insurance also reported financial constraint related to diabetes care owning to the fact that some treatment supplies required that they paid directly from their own pockets.

Under the theme coping strategies most of the participants identified their strategies for coping with the many demands related with diabetes management as engaging in religious activities and support groups; support from the involvement of other family members and spouses were also widely spoken of. A few spoke of embracing the new normal as their means of coping.

Evidence from this study has shown that the regular attendance of the young diabetic clinic by family caregivers and their children serves as a form of support group for the majority of these caregivers. Here, they asserted they got to meet other caregivers whom formed relationships with, exchanged ideas, challenges and encouraged themselves. Those with rich sources of experiences by virtue of their long years of participating in the diabetes care served as mentors to family caregivers who were novice in the care. This invariably provided a means by which family caregivers cope with the demands related to T1D management.

Similar findings across studies have revealed that participating in support groups provides a means by which majority of family caregivers cope and adjust to the challenges associated with T1D in their child (Sullivan-Bolyai et al., 2003; Smaldone & Ritholz, 2011; Grover et al., 2016). These support groups give family caregivers the chance to interact with other family caregivers of children with diabetes, which helps to normalize and validate their own experiences (Sullivan-Bolyai & Lee, 2011); and the knowledge that others have been through their experiences gives them a sense of relief (Boogerd et al., 2015).

Also, Smaldone and Ritholz (2011) in their study indicated that majority of mothers noted how the support group helped them feel less lonely as they cared for their child with diabetes. Similarly, support group for parents of children newly diagnosed with T1D has been proven to be very effective through the provision of emotional support and the identification of resources available in the community (Sullivan-Bolyai & Lee, 2011; Smaldone & Ritholz, 2011).

Also, participants commented on using beliefs in religious activities to cope with the stress that comes with their child’s illness. The belief that their child’s illness happened for reasons only known to God was commonly expressed and this was not meant to punish them but to test their faith. This belief gave them meaning and comfort as well as strength to carry on with the daily demands that T1D presented.

Similar to this finding, in Grossoehme, Cotton, Ragsdale, Quittner, McPhail and Seid (2013) study, parents of children with chronic illness explained how their faith enabled them to provide their children with the difficult but essential care, guided medical decisions, and affected how much home care they actually gave.

In agreement with the findings also, narratives from another study showed that parents found comfort in the belief that God had a plan for their family and that their child's illness was part of that plan. The majority of parents also mentioned how their religious beliefs and practices supported them during the trying diagnosing process and provided them a sense of strength. In addition to spending time in private prayer, many parents found solace in knowing that others were also praying for their child. Therefore, religion and spirituality offer a framework for practices that increase resilience, social and emotional support, and meaning making (Purcell, Whisenhunt, Cheng, Dimitriou, Young, & Grossoehme, 2015).

In addition, majority of the study participants had family members who were very much supportive in the management; they make decisions together and took turns in caring for the child with T1D. This helped them cope with the enduring and relentless nature of the condition of these children. There were however a few who had no support family support and were solely responsible for the care of the child. Resonating with this finding, Smaldon and Ritholz (2011) asserted that working together as a team among parents brings about shared responsibility in daily decision-making and in the performance of daily activities in diabetes management. family support facilitates family adjustment and also helps to relieve the stress of being solely responsible for the well-being of the child. Conversely, some participants described how the lack of support and understanding by their family members made them feel alone in managing their child's diabetes.

Again, finding from another study which is congruent with that of this study is the finding of Kimbell et al (2021). In their study, parents recounted drawing on the support of their spouses or other family members for the management of their child's diabetes. They however asserted that irrespective of how useful this support was, it was still not enough due to the family member's limited knowledge and understanding about diabetes. Other parents also indicated that the support provided by their family and friends was not enough because more often than not they had difficulty adjusting to the condition and its management (Boogerd et al., 2015).

Finally, embracing the new normal or normalizing as a coping strategy for family caregivers is their ability to integrate diabetes into the background of their lives through the establishment of routines to make diabetes a part of them Babler & Strickland, 2015). In order to cope and adjust to the diabetes management with its associated challenges, some of the family caregivers described how after a period of managing the condition at home, they became used to it and accepted it as a normal part of their everyday lives. Rintala et al (2013) demonstrated a similar finding. In their studies, they identified that over time, family members become accustomed to living with diabetes. The tremendous amount of tacit knowledge they possess about diabetes gives them the enablement to go about their daily activities without having diabetes on their minds constantly. Resonating with this finding, the narratives from the study carried out by Edmonds-Myles, Tamborlane and Grey (2010) also indicated that family caregivers used normalizing as a means of coping with the challenges associated with diabetes care in children. Similarly, findings from Whittemore et al (2012) indicated that in order to cope with the demands of diabetes care, parents from their study worked hard to develop routines and to establish daily diabetes management tasks as part of their everyday life.

Chapter Summary

The major findings of identified in this study were categorized under four (4) themed with sixteen (16) sub-themes. With regards to the knowledge of family caregivers, participants shared how they got to know their children had diabetes, their beliefs about the causes of T1D and the meaning they ascribe to T1D as a disease.

Under the theme experiences, family caregivers described experiences immediately following the diagnosis of their child, how difficult T1D as disease is, how they learnt T1D management, their role in the management, their goals for participating in the management as well as their experience with hypoglycaemia recognition. On the aspect of the challenges, they recounted the enduring and unrelentless toll T1D management and diabetes-related problems had on them emotionally, socially and financially.

On the final sub-theme which borders on coping strategies, it was identified that family caregivers adopted different means of coping such as religious beliefs, social support, family involvement and embracing the new normal that helped them adjust and cope with stress associated with diabetes management.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter is a discussion of the summary of the study; implications of the study for nursing practice, research and education; as well as the conclusion and recommendations of the study.

Summary of the Study

This study explored and described the experiences of family caregivers of young persons with T1D in the Effia Nkwanta Regional Hospital, Takoradi. The study utilized exploratory-descriptive design. before being carried out, approval was received from the Institutional Review Board of the University of Cape Coast and permission was sought for from the ENRH. Pre-testing of the research instrument was carried out among two people of the population intended for the study. In all, the fourteen participants who were recruited from the DOC of the ENRH were all family caregivers of young persons aged 10 to 14 years who had been diagnosed with T1D and these participants had been actively involved in the management of the children for at least a year.

Data were obtained through semi-structured interviews until saturation was achieved. All the participants who agreed to be part of the study signed a consent form; and interviewing and transcription of the audiotaped information occurred concurrently from January to March 2022. Thematic analysis by Braun and Clarke (2006) was used for the data analysis which revealed four major themes- knowledge of family caregivers, experiences, challenges and coping strategies.

Regarding the perception of family caregivers, it was revealed that most of them had not heard about T1D but they became conversant with the basic knowledge for the management of their child's condition after the diagnosis when they had the opportunity to care for their child. Most of them also delayed in reporting the child's condition to the hospital due to their unfamiliarity with the signs and symptoms of T1D and attributed the signs and symptoms to other conditions. However, their narratives showed they were very satisfied with the attitude portrayed by their healthcare providers during that period of initial diagnosis. Participants also identified cause of T1D as intake of too much sugary food, genetics and witchcraft or evil spirits. Findings from the study also revealed that most family caregivers viewed T1D as a serious chronic disease that is associated with complications but can be managed; and a disease that limited the children in terms of their diet and play.

On the aspect of the experiences, on hearing the news of their child's diagnosis, most of these participants reported their experiences, of fear, surprise and doubt. T1D was also reported as a difficult diagnosis that interfered with family routines. However, findings showed family caregivers learnt how to manage the condition through the health education, instructions and technical training they received at the hospital; and a few had additional information from the internet. All the participants were able to recount the role they play in diabetes management including blood glucose monitoring, giving insulin injections and taking he child for routine checkups among others. The findings also showed that desire to see the child's blood glucose level within the normal ranges so that the child can live long and healthy lives was the main goal for participating in diabetes care. In their everyday experience, most family caregivers also learnt to recognize hypoglycaemia because their child had experienced at least an episode before where as others heard of it through health education.

Also from the narratives, it was identified that family caregivers had psychological, social and financial challenges associated with diabetes care. Findings revealed that the fear of hypoglycaemia, worry and anxiety were the major psychological challenges experienced by these caregivers. On the aspect of the social challenges, participants reported lack of leisure and social isolation in their attempt to keep close eye on their child and also due to their inability to relinquish their responsibilities to others; a few however allowed others to care for their child in order to take breaks. Financially, all the participants described the various ways by which the diabetes related demands bring financial constraints on them including the cost associated with purchase of glucostrips, unplanned hospitalization, as well as routine checkups among others.

Finally, in order to cope with the stress associated with T1D and its managements, findings from the study identified the coping strategies family caregivers use such as religious beliefs, social support, family involvement and embracing the new normal

Conclusion

The findings from this study add up to filling the gap in the knowledge about the experiences of family caregivers of young persons with T1D in Ghana. Family caregivers with a young child diagnosed with this chronic condition became overwhelmed and saddled with varied emotional reactions but learnt how to manage the condition irrespective of its demanding nature. Findings from the study also underscore the fact that being family caregiver of a child with T1D is extremely difficult and is associated with psychological, social and financial challenges. Support from the healthcare team at the outpatient clinic is primarily concerned about helping family caregivers to obtain knowledge about the condition and practical task associated with it as well as some form of social support, which are all very essential. Notwithstanding, this study identifies family caregivers need to tell their story from their own perspective and their need for support in handling their different psychological challenges as well.

Recommendations

With reference to the findings of this current study, some recommendations have been made in the areas of nursing practice, education, administration and the ministry of health.

Nursing Practice

To deepen and apply family – centered care by nurses in the care of children with T1D, I recommend that the nurses in ENRH acknowledge and recognize the important role played by these family caregivers as well as their daily experiences in caring for a young child with T1D. This will form a powerful means of providing these family caregivers with the support they need while they care for their child with T1D.

Moreso from the study findings, while family caregivers receive some form of educational support at the clinic, the opportunity to share their challenges and experiences was limited. Therefore, I recommend that the nurses must provide adequate platform and encourage family caregivers to share their challenges and experiences and then help them identify a solution if possible or means of coping.

Nursing Education

There is the need for the in-service coordinators at ENRH to organise more extensive in-service training on T1D and its management that will take into consideration the peculiar experiences of family caregivers.

Nursing Administration

As an add-on to the usual diabetes care, a portal which is moderated and organized by the healthcare team at ENRH and the Western Regional health directorate could be created to serve as an online library that will provide reliable information in the form of videos and documents for those family caregivers who have interest in searching for information on the internet. Also, the healthcare team must show family caregivers some certified websites where they can get reliable information about T1D and its management.

Ministry of Health

Giving the prevalence of diabetes and the fact that lots of the study participants had not heard of T1D prior the diagnosis of their child, more diabetes outpatient clinics should be opened especially in rural and economically disadvantaged areas to ensure accessibility to diabetes care. Also, the Ministry of Health should endeavour to have all the medical cost of young children living with T1D covered by National Health Insurance Scheme.

Furthermore, the study findings suggests the need to intensify public education about both type I and type II diabetes, having in mind the many perceptions about diabetes which are inappropriate including the beliefs about causes and meanings associated with it. Such education may bring about changes in health and illness behaviours among family caregivers of young children living with T1D in Ghana. Lastly, diabetes screening should be made a routine at child welfare clinics to facilitate early detection.

Suggestion for further Research

In order to gain an in depth understanding of the experiences, challenges, and coping strategies of family caregivers of young children with T1D, a longitudinal study using a larger sample size ought to be conducted. This will provide an enormous pile of data and knowledge that what has been uncovered in this current study.

More so, in order to make bare the Ghanaian perspective on the experiences of being a family caregiver of a young child with T1D, similar study should be conducted in the other regions of Ghana to determine if similar results will be produced.

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APPENDICES

APPENDIX A

INFORMED CONSENT FORM

Title: Experiences of family caregivers of young children with type 1 diabetes at the Effia Nkwanta Regional Hospital

Principal Investigator: Alice Amooh

Postal Address: P. O. Box MC 2376, Takoradi

General Information about the Research

I am a Master of Nursing student at the University of Cape Coast conducting a study on the afore mentioned topic in partial fulfilment for the award of Master Nursing degree. The purpose of the study is to explore the experiences of family caregivers of young children with type 1 diabetes at the Effia Nkwanta Regional Hospital, Takoradi.

Procedures

To find answers to some of these questions, we invite you to take part in this research project. If you accept, you will be required to participate in an interview with myself, Alice Amooh and tape recorded. You are being invited to take part in this interview because we feel your experience as a family caregiver can contribute much to the purpose of this study.

As part of the interview process, you will be required to freely share your thoughts. As a starting point, you will be asked to "talk about how you got to know about your child had type 1 diabetes", how the moment was and the meanings you ascribe to type 1 diabetes as a condition. Subsequent questions will focus on gaining a detailed description of "a typical day", what you do to manage your children's illness in order to elicit a full picture of your day-to-day life. Probes will focus on issues such as how you learned your child's care, what you do to manage the child's condition how you learned to recognize hypoglycemia, what kinds of physical signs and behaviors you looked for. Other questions will also bother on your day-to-day concerns and challenges you experience as well as the strategies you employ in coping with these challenges.

If you do not wish to answer any of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will be conducted at a place and time of day agreed on by both of you. The information that will be recorded is considered confidential, and no one else except myself, and my supervisor will have access to the information documented during your interview. The expected duration of the interview is thirty to thirty-five minutes.

Possible Risks and Discomforts

It is not expected that your participation in this study will put you at risk of any discomfort or physical harm.

Possible Benefits

Although there will not be any immediate material benefit to you, the findings from the study will help health care providers offer more precise management guidance for families who are directly involved in the care of children with this condition. Also, the findings can be used by the Ghana health service and the ENRH management to develop in-service training programs for nurses caring who care young children with T1D; and also add to the body of knowledge.

Confidentiality

The researcher will ensure your personal information is protected to the best of her ability. You will be identified with a coded name; every information you provide will be kept confidential with only the principal researcher being privy to it. No individual references of any participant will be made in any report from the study since all data will be aggregated.

Compensation

There are no reward packages either in cash or in kind for participating in this study.

Voluntary Participation and Right to Leave the Research

Participation in this study is completely voluntary and so you can withdraw from it at any point in time without any penalty. In the event of withdrawal, your permission will be sort for regarding the use of any data you may have already provided.

Notification of Significant New Findings

You will be informed of any development during the course of the study that may relate to your willingness to continue participation in the study.

Contacts for Additional Information

You may contact the principal investigator or her supervisor for any clarifications or enquiries about the study:

Alice Amooh (Principal Investigator)
Phone Number: 0541220901
Email: Promisedalice@gmail.com
OR
Dr. (Mrs.) Evelyn Asamoah Ampofo (Supervisor)
School of Nursing and Midwifery
Department of Maternal Health, UCC.
Phone Number: 0208131658

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 p.m. through the phone lines 0558093143/0508878309 or email address: irb@ucc.edu.gh.

VOLUNTEER'S AGREEMENT

The above document describing the benefits, risks and procedures for the research title ***(experiences of family caregivers of young children with type 1 diabetes)*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Volunteer's Name: ……………………………………..
Volunteer's Mark/Thumbprint…………
Date: ………………………………………………

If volunteer cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Witness's Name: …………………………………

Witness's Mark/Thumbprint: …………………

Date: ………………………………………………

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Researcher's Name: ……………………………………...

Researcher's Signature: ………….

Date: ……………………………

APPENDIX B

INTERVIEW GUIDE

Interview Guide

The following list of semi-structured questions will guide the researcher to explore and provide an in-depth description of the experiences of family caregivers of young children with type 1diabetes at the Effia Nkwanta Regional Hospital. Please be assured that all your responses will be strictly confidential and used for academic purposes only; your anonymity is also guaranteed and your participation is strictly voluntary. This interview will take about 30-35 minutes of your time, thanks for consenting to participate in this study.

Time of commencement of interview: ………….

Time the interview ended: …………

Date: ……………….

SECTION A – Biodata of Participant

Code number: ……………

Age: …….

Relation to child: ………

Marital status:

Level of Education:

Occupation: ………

Religion: ………

Number of years of caring for child: ………….

SECTION B: Family Caregivers' knowledge of T1D

1. How did you know your child had T1D?

   Probe:

   - When was that?
   - Can you describe to me how that moment was like to you?

2. What meaning do you ascribe to your child's condition?

   Probe:

   - Please, what are your beliefs about the cause, seriousness, and course of your child's illness?

- Do you think your child's condition limits him/her in any way? If you think so, in what ways?

SECTION C: Experiences of Caring for a Child with T1D

3. What are your everyday experiences of caring for a child with T1D?

   Probe:

   - how did you learn your child's care?
   - Please describe to me what you do to manage your child's condition?
   - Tell me about the involvement your other family members, friends (and co-workers if any) in the management of your child's condition?
   - How did you learn to recognise hypoglycaemia?
   - What signs and behaviours do you look out for in hypoglycaemia?
   - Tell me the goals and priorities that guide your treatment approach?

SECTION D: Challenges Associated with the Care of a Child with T1D

4. What challenges are you facing in managing your child's diabetes? (Financially, socially, psychologically)

SECTION E: Coping Strategies

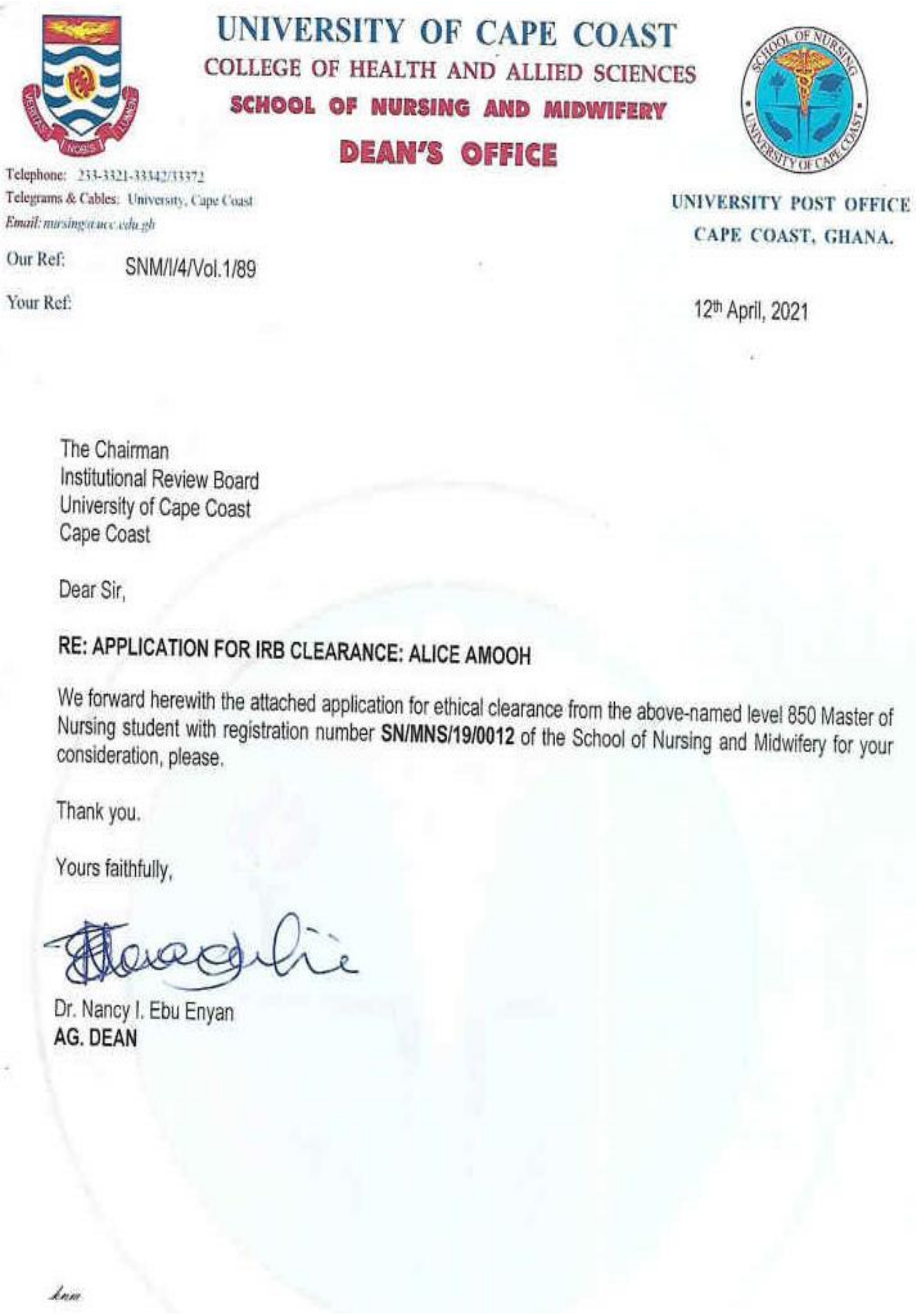
5. What do you do that helps you cope with the demands related with your child's illness?

Is there anything you would want me to know concerning your experience of caring for a child with T1D?

Any suggestion for the healthcare professionals who care for your child?

APPENDIX C

COVER LETTER FOR ETHICAL CLEARANCE FROM THE SCHOOL OF NURSING



UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEAN'S OFFICE

Telephone: 233-3321-33342/33372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref: SNM/I/4/Vol.1/89

Your Ref:

12th April, 2021

The Chairman
Institutional Review Board
University of Cape Coast
Cape Coast

Dear Sir,

RE: APPLICATION FOR IRB CLEARANCE: ALICE AMOOH

We forward herewith the attached application for ethical clearance from the above-named level 850 Master of Nursing student with registration number **SN/MNS/19/0012** of the School of Nursing and Midwifery for your consideration, please.

Thank you.

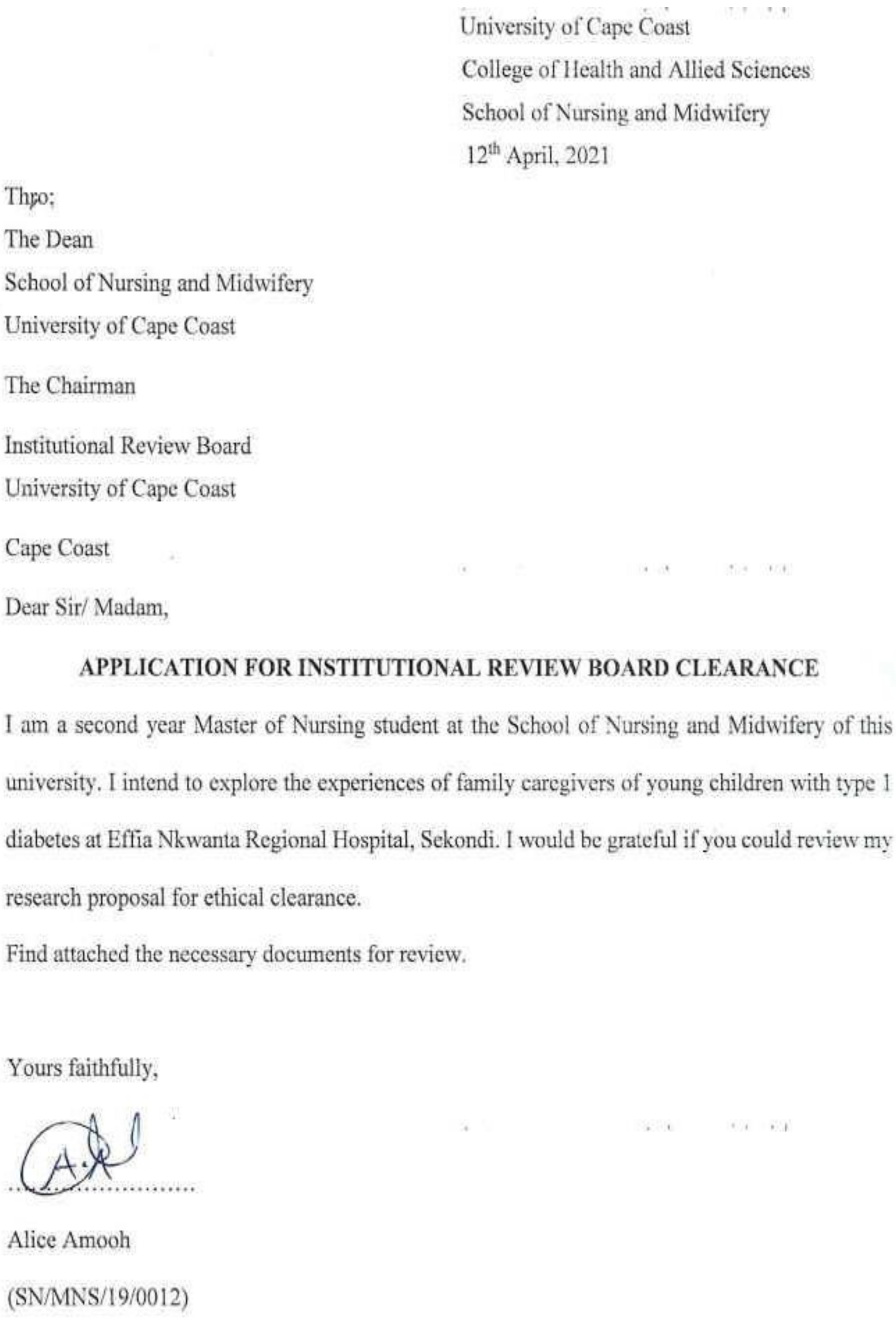
Yours faithfully,

Dr. Nancy I. Ebu Enyan
AG. DEAN

knm

APPENDIX D

APPLICATION FOR ETHICAL CLEARANCE



University of Cape Coast
College of Health and Allied Sciences
School of Nursing and Midwifery
12th April, 2021

Thro;
The Dean
School of Nursing and Midwifery
University of Cape Coast

The Chairman

Institutional Review Board
University of Cape Coast

Cape Coast

Dear Sir/ Madam,

APPLICATION FOR INSTITUTIONAL REVIEW BOARD CLEARANCE

I am a second year Master of Nursing student at the School of Nursing and Midwifery of this university. I intend to explore the experiences of family caregivers of young children with type 1 diabetes at Effia Nkwanta Regional Hospital, Sekondi. I would be grateful if you could review my research proposal for ethical clearance.

Find attached the necessary documents for review.

Yours faithfully,

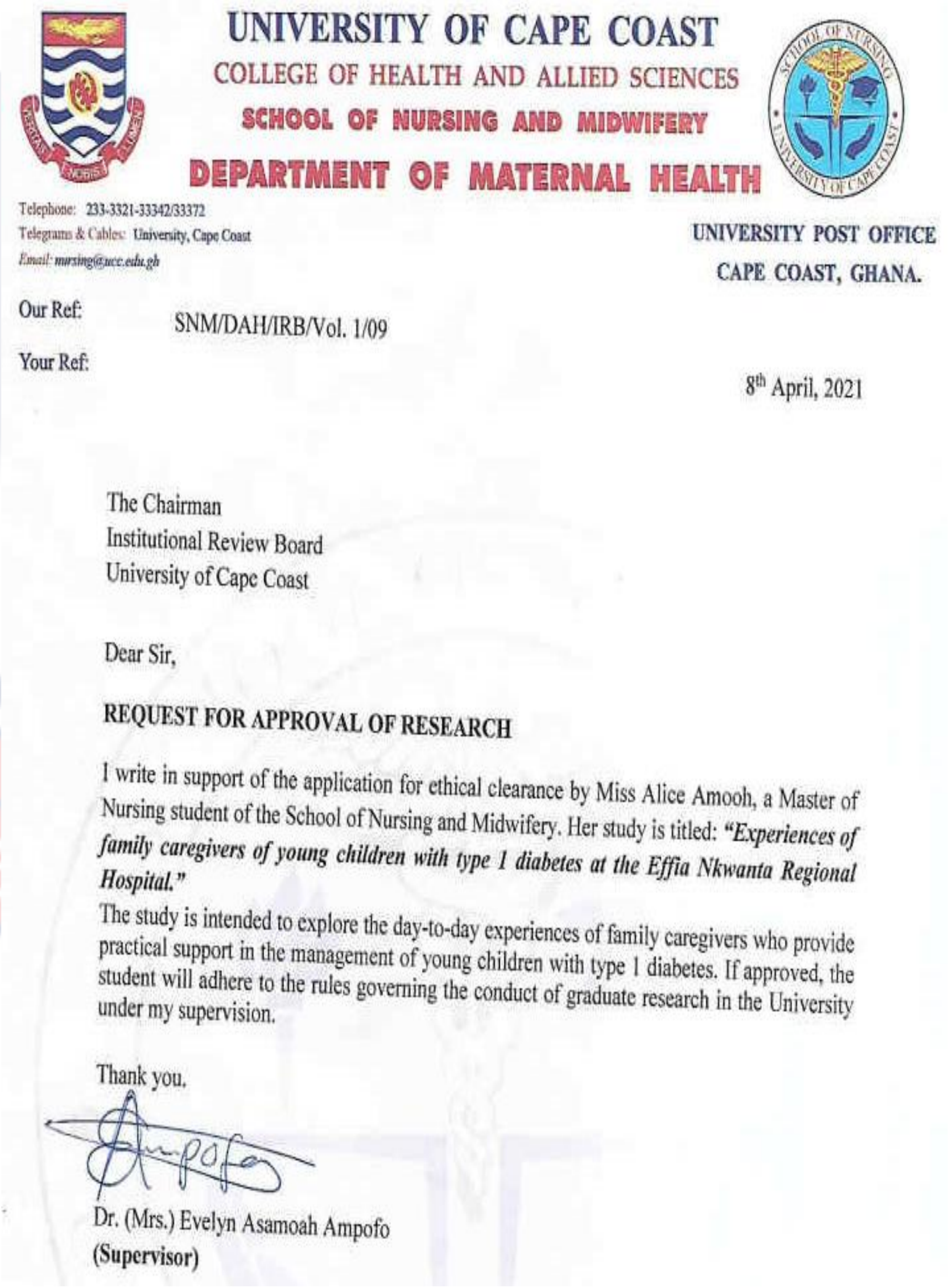
……………………

Alice Amooh

(SN/MNS/19/0012)

APPENDIX E

SUPERVISOR'S REQUEST FOR ETHICAL APPROVAL OF RESEARCH



UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEPARTMENT OF MATERNAL HEALTH

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UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref: SNM/DAH/IRB/Vol. 1/09

Your Ref:

8th April, 2021

The Chairman
Institutional Review Board
University of Cape Coast

Dear Sir,

REQUEST FOR APPROVAL OF RESEARCH

I write in support of the application for ethical clearance by Miss Alice Amooh, a Master of Nursing student of the School of Nursing and Midwifery. Her study is titled: ***"Experiences of family caregivers of young children with type 1 diabetes at the Effia Nkwanta Regional Hospital."***

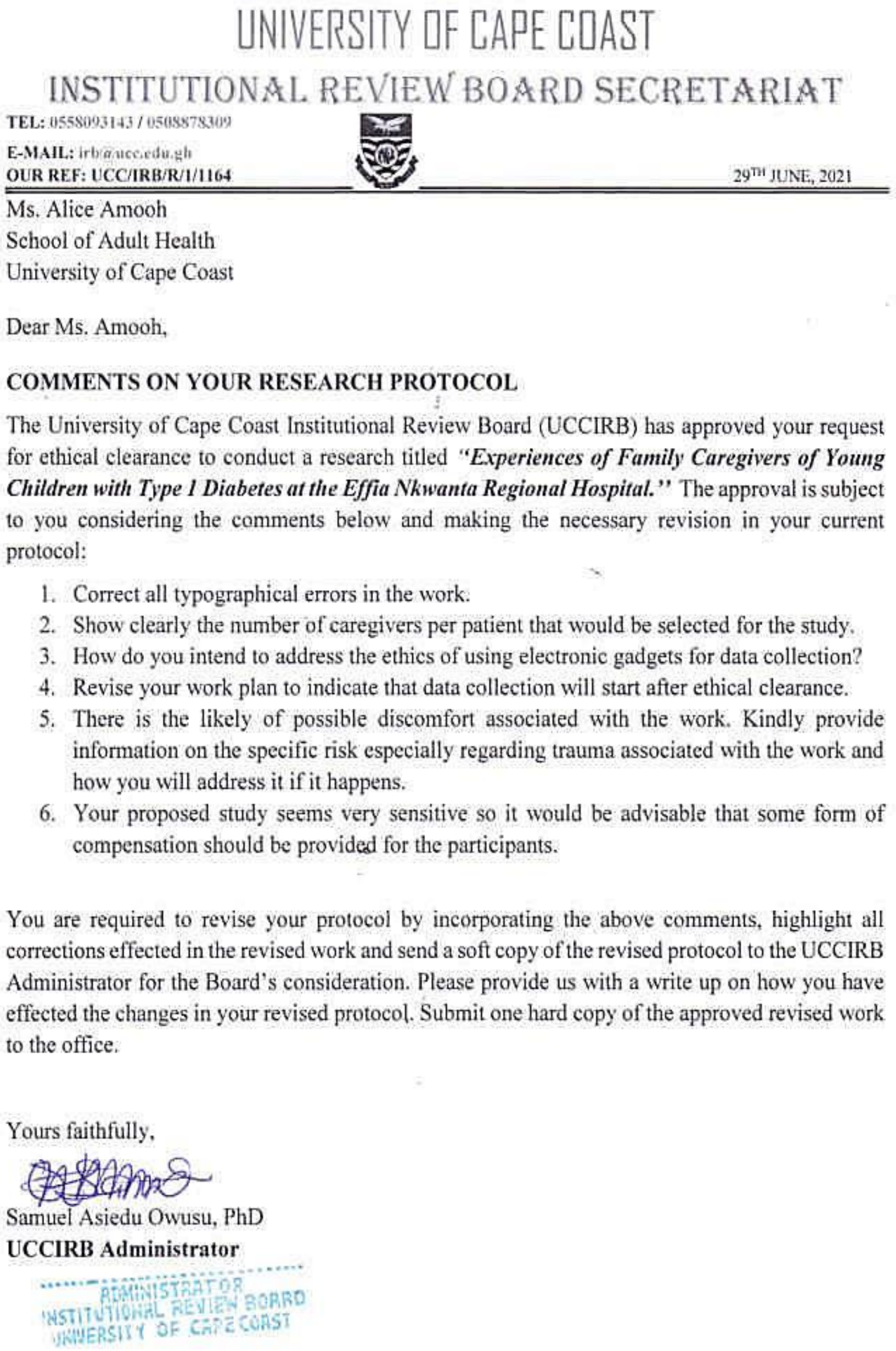
The study is intended to explore the day-to-day experiences of family caregivers who provide practical support in the management of young children with type 1 diabetes. If approved, the student will adhere to the rules governing the conduct of graduate research in the University under my supervision.

Thank you.

Dr. (Mrs.) Evelyn Asamoah Ampofo
(Supervisor)

APPENDIX F

ETHICAL CLEARANCE - UCC



UNIVERSITY OF CAPE COAST
INSTITUTIONAL REVIEW BOARD SECRETARIAT
TEL: 0558093143 / 0508878309
E-MAIL: irb@ucc.edu.gh
OUR REF: UCC/IRB/R/1/1164

29TH JUNE, 2021

Ms. Alice Amooh
School of Adult Health
University of Cape Coast

Dear Ms. Amooh,

COMMENTS ON YOUR RESEARCH PROTOCOL

The University of Cape Coast Institutional Review Board (UCCIRB) has approved your request for ethical clearance to conduct a research titled ***"Experiences of Family Caregivers of Young Children with Type 1 Diabetes at the Effia Nkwanta Regional Hospital."*** The approval is subject to you considering the comments below and making the necessary revision in your current protocol:

1. Correct all typographical errors in the work.
2. Show clearly the number of caregivers per patient that would be selected for the study.
3. How do you intend to address the ethics of using electronic gadgets for data collection?
4. Revise your work plan to indicate that data collection will start after ethical clearance.
5. There is the likely of possible discomfort associated with the work. Kindly provide information on the specific risk especially regarding trauma associated with the work and how you will address it if it happens.
6. Your proposed study seems very sensitive so it would be advisable that some form of compensation should be provided for the participants.

You are required to revise your protocol by incorporating the above comments, highlight all corrections effected in the revised work and send a soft copy of the revised protocol to the UCCIRB Administrator for the Board's consideration. Please provide us with a write up on how you have effected the changes in your revised protocol. Submit one hard copy of the approved revised work to the office.

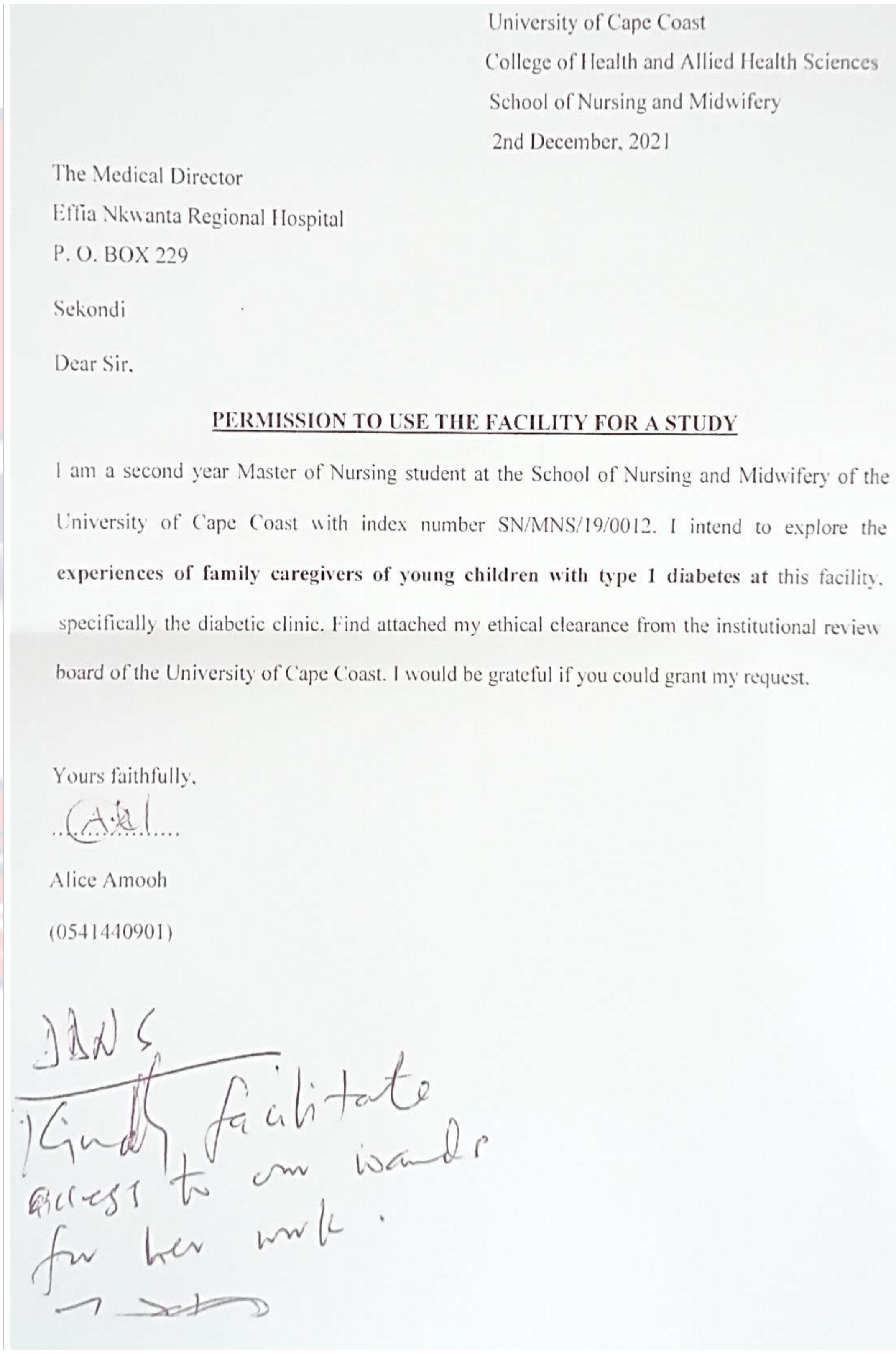
Yours faithfully,

Samuel Asiedu Owusu, PhD
UCCIRB Administrator

ADMINISTRATOR
INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF CAPE COAST

APPENDIX G

PERMISSION TO USE FACILITY FOR RESEARCH- ENRH



University of Cape Coast
College of Health and Allied Health Sciences
School of Nursing and Midwifery
2nd December, 2021

The Medical Director
Effia Nkwanta Regional Hospital
P. O. BOX 229

Sekondi

Dear Sir,

PERMISSION TO USE THE FACILITY FOR A STUDY

I am a second year Master of Nursing student at the School of Nursing and Midwifery of the University of Cape Coast with index number SN/MNS/19/0012. I intend to explore the **experiences of family caregivers of young children with type 1 diabetes at** this facility, specifically the diabetic clinic. Find attached my ethical clearance from the institutional review board of the University of Cape Coast. I would be grateful if you could grant my request.

Yours faithfully,

Alice Amooh

(0541440901)

DDNS

Kindly facilitate access to our wards for her work.