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**EXPLORING PREPARATION NEEDS OF INFORMAL CAREGIVERS OF
TYPE 2 DIABETIC PATIENTS: A STUDY AT THE 37 MILITARY HOSPITAL**

BY

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DECLARATION

I, Gloria Efa Kissi hereby declare that this thesis, with the exception of references to literature which have been duly cited, is my own work produced from research undertaken for the award of the degree of Master of Philosophy in Nursing at the School of Nursing and Midwifery, University of Ghana, Legon. No part of this thesis has been presented for another degree in this University or elsewhere.

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DEDICATION

This study is dedicated to my mother, Mrs. Comfort Nyarkoa Kissi and my late father, Mr. Samuel Kwabena Kissi. A special thank you goes to my husband, Mr. Anthony Amofa for his unflinching support and encouragement throughout this study.



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May God bless each and every one of you

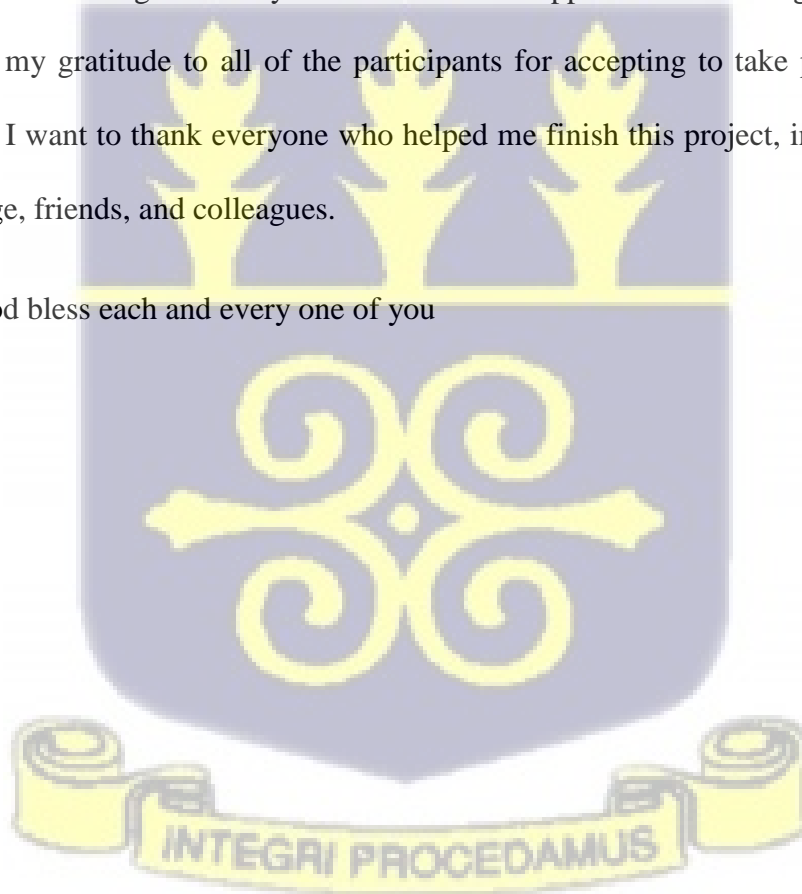


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LIST OF ABBREVIATIONS

ICG:	Informal Caregiver
HCW:	Healthcare Workers
T2 DM:	Type 2 Diabetes Mellitus
37 IRB:	37 Military Hospital Institutional Review Board



ABSTRACT

To successfully manage Type 2 diabetes mellitus (T2 DM), informal caregivers (ICGs) play a critical role. Understanding and addressing the preparation needs of ICGs of persons with T2 DM will lead to improvement in the quality of care and health outcomes of persons with T2DM. The study explored the preparation needs of ICGs of persons with T2 DM at the 37 Military Hospital. The Caregiver-Centered Care Competency model by Parmar and colleagues was adopted for the research. The study employed a qualitative exploratory descriptive design and 20 participants were purposively sampled for the study. One-to-one in-depth interviews were conducted using a semi-structured interview guide and audiotaped. Data were analysed using the thematic content analysis approach. Six themes and 14 sub-themes emerged namely: Communication between HCWs and ICGS (Clarity of communication, Sharing of information, Follow-up phone calls); Partnership with HCWs (Collaboration with HCWs, Accessibility to HCWs, Attitude of HCWs), Recognition of the role of the ICG (Awareness of the role of ICGs, Acknowledgment of ICGs), Building resilience in ICGs (Education from HCWs, Concern about welfare), Navigating the healthcare system (Direction from HCWs, Referral from HCWs) and Culture and context of care (Duty to care, Support system). Communication and partnership between ICGs and HCWs were important resources in the performance of the caregiving role by ICGs of persons with T2 DM. However, HCWs lacked empathy whilst dealing with ICGs. Hospital management should encourage HCWs to continue to develop proper partnerships and communication with ICGs to ensure they understand the treatment process and involve them in decision-making concerning persons with T2DM.

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

Diabetes mellitus (DM) is a chronic metabolic condition defined by an abnormally high blood glucose level due to a deficiency in insulin secretion (Ayubah & Peltonen, 2018). The four primary classifications of diabetes mellitus include diabetes type 1 and II in addition to gestational diabetes mellitus and other types of diabetes that are related to other causes. The most prevalent kind of diabetes is Type 2 DM (T2DM), which is also referred to as non-insulin dependent form of diabetes mellitus or diabetes mellitus with onset in adulthood, and this accounts for the vast majority of cases globally. The Center for Disease Control (CDC) and prevention as well as the World Health Organization (WHO) reports show that type 2 diabetes accounts for more than 90% of all diabetes cases in the world (Ayubah & Peltonen, 2018). Diabetes mellitus (DM) has increased to become one of the world's most common non-communicable diseases, with 425 million people affected in 2017 and 629 million estimated to be affected by 2045 (Messenger et al., 2019).

Accepting T2DM is like accepting it as a part of life. Its treatment becomes an everyday process, which can cause distress and fatigue. Type 2 diabetes can be influenced by psychosocial hardship and socioeconomic strain, which can make self-management difficult. Many diabetics and their families are distressed by T2DM alone. Unmet treatment goals or the start of diabetic complications might create distress. Blood glucose imbalances have an impact on mood and coping (Kamrul-Hasan et al., 2022;

Liu et al., 2020; Nanayakkara et al., 2018). Diabetes mellitus care is tough for carers; covering emotionally, practically, monetarily, behaviorally, and socially stressful events, and all of these areas of care necessitate a period of adjustment (Dhada & Blackbeard, 2019a).

Research shows that informal caregivers (ICGs) can provide support in enhancing the quality of life of those persons with DM that they care for. The ICGs identified the need to be persistent, resilient, resourceful, responsive, and adaptable during the adjustment process. Despite the difficulty of the DM-specific care activities, caregivers are able to enhance their care tasks over time by accumulating knowledge, skills, and practice. They gain confidence, feel at ease, and are even able to fix their problems as their skills improved (Dhada & Blackbeard, 2019b).

To successfully manage T2DM, ICGs play a critical role. For patients to keep their diabetes under control, they typically require the support of a devoted caregiver to execute a variety of regular duties. The relevance of ICGs including family, friends, and coworkers in enhancing well-being and self-management was underlined in a study of more than 5000 persons with diabetes. Frequently, family members are expected to share patient management responsibilities. The ICGs can assist patients in a variety of ways, including driving them to appointments and providing social and emotional support to help them cope with their sickness. Family members often have a substantial impact on a diabetes patient's psychological well-being, the decision to follow medical treatment recommendations, and ability to initiate and maintain dietary and exercise modifications through ICG communication and attitudes (Grabowski et al., 2017; Sousa-Munoz & Sá, 2020).

In conceptualizing the ICG, numerous studies stipulate that he or she is a non-professional person, who gives permanent or temporary, assisted or total help in activities of daily living to someone who is dependent on him/her in his immediate circle or outside of it (Ahmad Zubaidi et al., 2020; Akohoue et al., 2015). Family caregivers are another name for ICGs; they are individuals who render either paid or unpaid assistance in the performance of the regular activities of a person with a chronic disease or inability in an ongoing manner. In most cases, the caregiver provides care in the house for an elderly parent, spouse, other relatives, unrelated persons, or an ill or disabled person. Care includes transportation, food shopping, housework, meal preparation, assisting with dressing, getting out of bed, eating, incontinence, psychological support, hygiene, informational or educational support, financial support, health support such as hospital appointments, assistance in domestic activities amongst others (Roth et al., 2015; Sousa-Munoz & Sá, 2020).

Patients and their ICGs assume the responsibility of treatment when patient transitions from the hospital to the home environment, hence caregiver needs assessment is integral in the health care continuum. As the reliance on ICGs expands, nurses should be worried about several factors that affect patient safety and treatment quality including the preparation needs of their ICGs. Informal caregivers are unintentional patients who suffer serious physical and mental health consequences due to their physically and emotionally demanding obligations as caregivers, as well as a lack of attention to their health and treatment. Some identified effects of caregiving that take a toll on the ICG identified in various studies include depression, anxiety, workplace disruption or a shift in employment status, stress, fatigue, inability to meet own social needs (personal strain)

amongst others and this affects the care they render to the diabetic patient (Ahmad Zubaidi et al., 2020; Langenberg et al., 2020; Towle et al., 2020).

Assessing and providing the needs of the ICGs help develop an individualized support system for a patient, sustains the ICGs' ability to care, postpone the placement of patients in nursing homes and produce better care outcomes for the patient receiving the care (Saito Id et al., 2019). Assessing unmet needs by looking at the patient and their caregivers as one will be highly favorable (Wang et al., 2018). Before a patient's discharge, it is critical to recognize the ICG's requirements and competencies and to train them in caring for the patient to reduce their burden and also, the number of hospital readmissions (Dixe et al., 2019). However, much attention is centered on the patient and not the ICG. Thus, 82.3% of discharge education centers on the disease condition and 80.4% of the time on medication management (Dixe et al., 2019).

In some parts of the globe, ICGs have been on the increase for various groups of patients including T2DM. According to the National Alliance for Caregiving in the United States, from 2015 to 2020, there has been a rise in the number of caregivers (9.5 million) and more than one in five people are caregivers. The caregivers were noted to be in worst health now than they were five (5) years ago (Whiting, 2021). In Ghana, the ratio of being a male or female caregiver is approximately equal. Two adults in every household require some form of care but there seems to be a “ mismatch between the number of people needing care and the number of people providing care” (Sanuade & Boatemaa, 2015).

If ICGs of persons with T2DM are anticipated to make a meaningful contribution to their patients' quality of life, their role must be strengthened. To do so, informal care systems must be adopted and developed following the needs of these caregivers. Informal caregivers lacked in four major areas of the healthcare continuum, according to a systematic review: informational needs, support needs, organizational needs, and society recognition needs (Plöthner et al., 2019). Other studies done showed they lacked in the areas of health and treatment, psychological/emotional assistance, knowledge, physical support, recognition, respect, appreciation, social life-work, and finance (Anker-Hansen et al., 2018; Plöthner et al., 2019; Wang et al., 2018).

Caregivers receive minimal help from health care practitioners in managing their jobs and the emotional demands of caregiving. In the hospital, interacting with nurses and other professionals shows that the two most difficult obstacles for ICGs are managing the condition of the person who is being looked after and communicating with the medical team. Gaps in communication between the hospital and family obstruct effective discharge planning (Nguyen et al., 2021). These gaps can be addressed by involving ICGs in the care of their patient, preparing them adequately for their caregiving role, and assessing and addressing their needs timeously.

The preparation needs of ICGs of persons with T2 DM refer to the needs of caregivers as far as their caregiving role is concerned. This typically involves communication, partnership, recognition, support, and direction that ICGs expect from health professionals (Parmar et al., 2020a). Understanding the preparation needs of ICGs of persons with T2 DM is essential for guiding the development of interventions meant to close the gap between ICGs and resource-constrained healthcare systems (Meyrowitsch

et al., 2023). Many times, caregivers express feeling unprepared for the caring position and feel compelled to take on this role due to inadequacies in service provision (Lieshout et al., 2020). This results in a variety of negative outcomes for the health and quality of life of their care recipients, including hospital readmissions and early death (Kyei-Arthur & Codjoe, 2021).

The Caregiver-Centered Care Competency Framework by (Parmar et al., 2020a) guide the review of pertinent literature for the study. Six constructs make up this framework, which highlights the knowledge, abilities, attitudes, and values that drive caregiver-centered care practice. While the constructions are depicted separately, they are linked. The six constructs are Recognizing the Caregiver Role, Communicating with Family Caregivers, Partnering with Family Caregivers, Fostering Resilience in Family Caregivers, Navigating the Health and Social Systems and Accessing Resources, and Enhancing the Culture and Context of Care (Parmar et al., 2020a).

1.2 Problem statement

According to an assessment of the literature, there is a deficiency in the preparation of ICGs for their role in the caring for patients living with T2DM (Dixe et al., 2019; Lilleheie et al., 2020a). This deficiency makes ICGs feel inadequately prepared for their role which contributes to their stress, affects the care they render, and the subsequent poor patient outcomes. Efforts to address this problem by stakeholders in the health industry have been met with challenges and the inadequacy of skills to render competent care remains a reality that is being compounded by the neglect of the ICG (Lilleheie et al., 2020a). This neglect leads to an increase in ICG burden, medication errors,

complications of disease conditions, and consequently, a rise in the number of hospital readmissions and premature deaths (Dixe et al., 2019).

Thus, the medical system does not consider the needs and competencies of ICGs of patients with T2DM (Dixe et al., 2019; Lilleheie et al., 2020b). Caregivers lack education/information on what is required of them as well as social, emotional and psychological support in carrying out their role (Pesantes et al., 2017). The lack of information results in avoidable complications and premature deaths (Dixe et al., 2019).

The ICG situation in Ghana is no different. Although ICGs render vital care to patients, they may suffer severe consequences (such as depression, anxiety, stress, fatigue, and inability to meet their own social needs) as a result of their lack of preparation before taking on caring obligations and the neglect of their health. The unpreparedness of ICGs for their caregiving responsibilities leads to incompetence, miscommunication, medication errors and complications of their care recipients' illness among other things, which undermine their health and quality of life and can lead to hospital readmission and premature deaths (Kyei-Arthur & Codjoe, 2021). Understanding and addressing the preparation needs of ICGs who care for persons with T2DM will lead to improvement in the quality of their lives as well as that of the recipients of care.

1.3 Purpose of the study

This research was built on the knowledge that the needs and competency concerns of ICGs of persons with T2DM are often neglected. Hence the purpose of this study was to explore the needs of these ICGs that are required to prepare them adequately to achieve competency and build resilience in their caregiving role for persons living with T2DM.

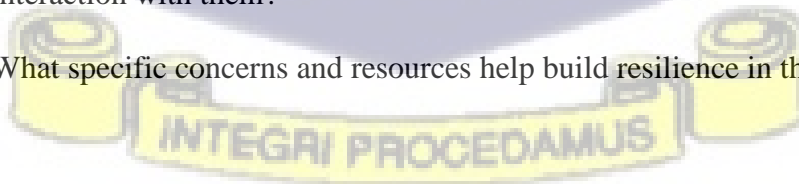
1.4 Objectives of the study

The study's precise objectives were to:

1. Explore how ICGs of T2 DM communicate with healthcare workers and partner with them to provide care.
2. Ascertain ICGs account of how recognition of their roles helps foster their resilience as caregivers in preparation for their caregiving role.
3. Describe how ICGs experiences of navigating the healthcare system as well as the culture and context in which they provide care to persons with T2 DM help shape them for their caregiving role.

1.5 Research questions

1. What are the common concerns regarding caring for persons with T2 DM?
2. How do health care professionals communicate and involve ICGs in providing care for persons with T2DM?
3. What are some of the resources and support systems available to the ICG in caring for a person with T2 DM?
4. What concerns would ICGs want healthcare professionals to address in their interaction with them?
5. What specific concerns and resources help build resilience in the ICG?



1.6 Operational Definitions

Assessment: The methodical gathering of all data and information pertinent to patient care, concerns, and needs.

Informal caregiver: A non-professional person, who provides long-term or short-term, assisted or total help in activities of daily living to a person with T2DM who is dependent on him/her in his immediate circle or outside of it.

Preparation needs: The communication, partnership, recognition, support, and direction that ICGs expect from health professionals.

Preparedness: The ICG's perception of how well prepared he or she is for the work and stress of being a caregiver for a person with T2DM.

1.7 Structure and Organization of study

The study was divided into six chapters; chapter one through six. The first chapter covered the study's introduction and included areas such as the background, problem statement, research questions and objectives, study significance, scope, and organizational structure. The literature review and theoretical framework was covered in Chapter two. The third chapter delved into the methodology, including an overview of the study design, research methodologies, population, sample and sample design, research instruments, data collecting design and procedure, ethical considerations, methodological rigor, data management, and analysis approaches. The results of the examined data were discussed in Chapter four, and the results were discussed in relation

to the literature study in Chapter five. The investigation is concluded in Chapter six with a summary of the main findings, conclusions, and recommendations.



CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This section presented the review of literature on the needs of ICGs of persons with T2DM. Databases on the internet, such as PubMed, Sage, Science Direct, and Google Scholar were searched for information relevant to the research. The search contained the following key terms: “preparation needs”, “needs of informal caregivers of diabetics”, “diabetic caregiver needs”, and “adequacy in caring for diabetic patients” amongst others. The review comprises a description of the conceptual framework, and a review of previous studies on; (1) recognizing the caregiver role, (2) communicating with family members, (3) partnering with family caregivers, (4) building resilience in family caregivers, (5) navigating the health and social systems and accessing resources and (6) enhancing culture and context of care.

2.1 The Conceptual Framework

Quite a number of conceptual models explain ICG needs and their challenges. These include the Caregiver Stress Model (Pearlin et al., 1981; Pearlin et al., 1990), the Caregiver Empowerment Model (Jones et al., 2011), and the Caregiver-Centered Care Competency Framework by Parmar et al. (2020a).

The Caregiver Stress Model was created to evaluate the informal caregiving procedures that have an impact on caregiver health. The symptoms of stress are welfare, physical and cognitive health disorders, and the ability of caregivers to maintain their social roles. The Caregiving Career/Stress Process model proposed that life events can cause

unfavorable changes in people's roles that the persistence of these changes wears away desired aspects of self-concept, and that stress was generated as a result of this set of interconnections. Coping and social support, on the other hand, might intervene at various stages along this process, moderating the outcomes (Pearlin et al., 1981; Pearlin et al., 1990). The model laid small emphasis on the preparation of the caregiver as opposed to the effects of caregiving thereby limiting its use as a guide in this study.

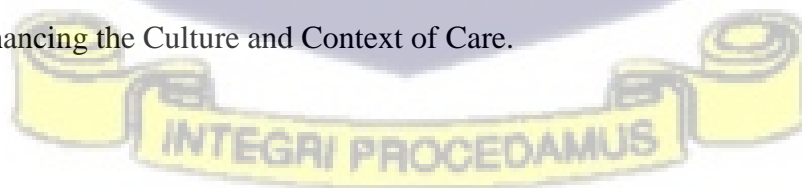
Caregiving obligations, according to the Caregiver Empowerment Model (CEM), are perceived as challenges rather than stressors in the presence of filial values and specific background circumstances. Growing and well-being were linked to viewing caregiving duties as a challenge, finding significance, and employing specific coping mechanisms. The CEM helps us better understand the complexities of caregiving and can be used to develop and test theory-based treatments to improve outcomes (Jones et al., 2011). Though the model looks at caregiver demands as against the caregiver's background and views these demands as challenges instead, this is just one aspect of the caregiver's need and not the whole picture thus, restricting the model's use in this study.

The Caregiver-Centered Care Competency Framework on the other hand showed there is a gap between what family caregivers need and what they receive from the healthcare system. It aimed at building a better system based on the needs of family caregivers (Parmar et al., 2020a). Caregiver-centered care was seen as a partnership between families and health and social service providers, with professionals aiding family caregivers in their caregiving role, service selection, care management, and advocacy. The older adult's family caregiver was respected and meaningfully involved in the organization and carrying out supportive services under this method. It also identified

and catered to caregivers' needs and preferences, as well as integrated family caregivers as care partners (Hoek et al., 2021; Lilleheie et al., 2020b). Although the Caregiver-centered care competency framework addresses the objectives of this study, it is not without limitations. Healthcare workers have noted a lack of shared understanding and commitment across HCWs and ICGs, as well as a lack of proper education regarding understanding and executing the concept of caregiver-centered care in a practice setting. Additionally, caregiver-centered care has the potential drawback of making ICGs feel as though they are expected to contribute to the sick relative's care in ways that are beyond the scope of their knowledge or skills, or that they are given information that neither the ICG nor the sick relative is prepared to receive. They both might feel more stressed or anxious as a result of this (Mohammadi et al., 2020).

2.1.1 The Caregiver-Centered Care Competency Framework

The development of the Caregiver-Centered Care Competency Framework was a multi-step consensus-building process that ended in a modified Delphi Process with a panel of experts evaluating the competency indicators. The six competency domains which form the main constructs of the model are: Recognizing the Caregiver Role, Communicating with Family Caregivers, Partnering with Family Caregivers, Fostering Resilience in Family Caregivers, Navigating the Health and Social Systems and Accessing Resources, and Enhancing the Culture and Context of Care.



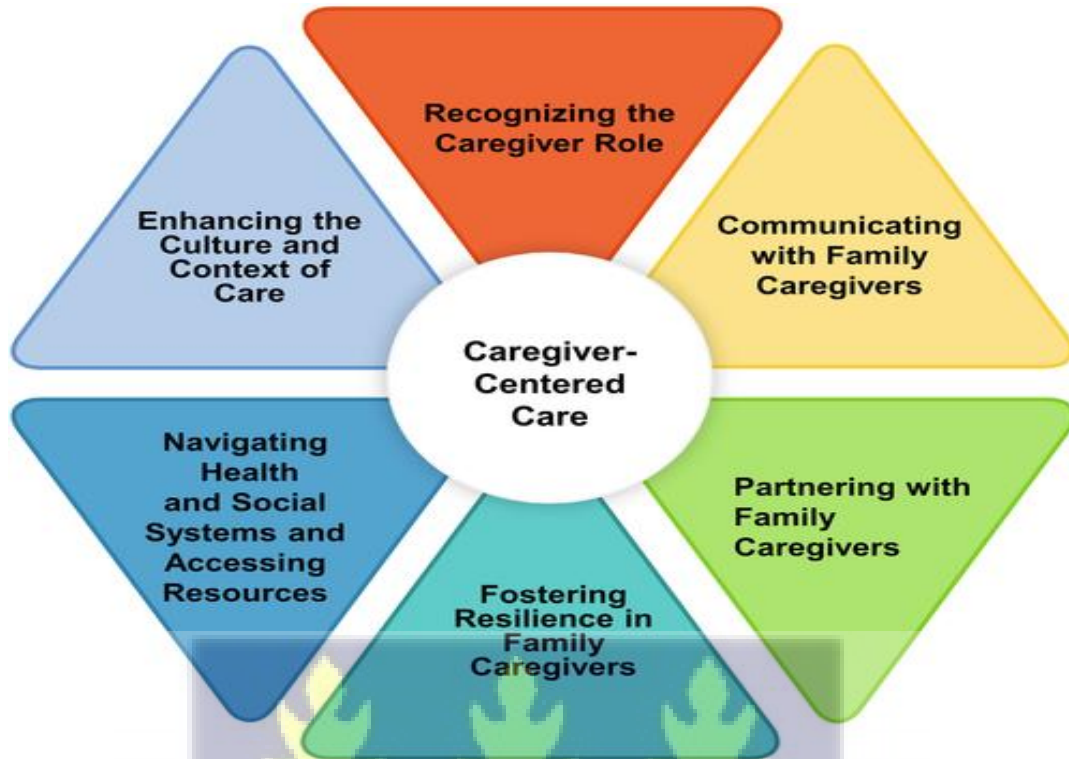


Figure 1: Caregiver-Centered Care Competency Framework

The second (communicating with family caregivers) and third (partnering with family caregivers) constructs of the model are addressed in the first research objective of the study on how healthcare workers (HCW) communicate and partner with ICGs of persons with T2 DM in their caregiving role. The first construct (recognizing the caregiver role) and the fourth construct (fostering resilience in family caregivers) are addressed in the second objective which sought to explore ICGs account of how healthcare professionals recognize their role and help foster resilience in them. The fifth construct (navigating health and social systems and accessing resources) and sixth construct (enhancing culture and context of care) are addressed in the third objective of the study concerning ICGs' experiences of navigating the healthcare system and the culture and context with which care is provided to persons with T2 DM.

2.2 Recognizing the caregiver role

This construct involves valuing the informal caregiver, their knowledge of the consequences of care, their awareness of their role, and the diversity of caregivers (Parmar et al., 2020a). Recognizing the stress that comes with caring for someone with a chronic illness like diabetes is important for the caregiver and the individual who is being looked after. Recognizing the many obligations that caregivers bear, as well as how difficult it is to remember everything that is required to make the most of a doctor's visit, should be valued (Ueshima et al., 2020).

Safe, effective, and high-quality care must be delivered in a team-based, well-coordinated environment. Informal caregivers who report feeling well-supported while engaging with HCWs was due to their role being recognized by HCWs, ICGs that were not recognized in this regard shows the increased ambiguity in clinician responsibilities toward addressing ICG needs (Rosen et al., 2018).

The provision of higher-quality treatment may be aided by treating patients and ICGs as legitimate team members alongside experts. Many HCWs however, fail to recognize the patient or ICG as fully functioning team members and fail to make use of their valuable input. This leads to a sense of exclusion or silence on the part of patients and their ICGs. Therefore, HCWs should strive to better understand and work together with patients and their ICGs by recognizing their positions in the team and acknowledging them as valuable contributors to an interdisciplinary care team who provide critical information that may be useful in directing and tracking advancements in person-centered and family-centered care (Doekhie et al., 2018; Rosen et al., 2018).

Caregivers want the services they provide to be recognized, respected, and appreciated (Anker-Hansen et al., 2018). Recognizing the family caregivers' role ensures that they do not feel alone or isolated in their work; understanding the scope of the load and the factors that contribute to it will aid in the development of interventions.

The process through which people become caregivers is dynamic and time-consuming, especially in cases where the care recipient is dependent on them (Plöthner et al., 2019; Wittenberg et al., 2017). It occurs when a member of the family has symptoms that make it hard for him or her to carry out daily activities, and someone from within or outside his or her family environment assists him or her until the person who takes on the caregiving position recognizes the repercussions and seeks to normalize his or her new function as a caregiver (Law et al., 2021; McDermott & Mendez-Luck, 2018).

Caregivers appeared to struggle the most with the underlying concept of being accountable for everything and this takes a sour turn during the post-discharge period. The quantity of responsibility demanded can quickly lead to emotional overload and role strain (Law et al., 2021). Caregivers must concentrate on the needs and safety of the care recipient twenty-four (24) hours a day while also fulfilling other societal roles: they are spouses, parents, workers, and housekeepers, and must also possess psychiatric, nursing, and therapeutic skills. Professionals in the healthcare field should learn to recognize ICGs as people who require emotional and practical help (Baldwin et al., 2017).

Differences in the relationship between the ICG and the care receiver, together with family norms and history, contribute to shaping the experience of the informal care situation for ICGs and care recipients (Kusi et al., 2020). The healthier the person who has T2 DM is, the lesser the burden of care on the ICG (Kristaningrum et al., 2021).

With patients who are unwell, have poor glycemic control, poor drug adherence or have problems related to diabetes, the intensity of caring and its accompanying psychological and physical suffering increases for the ICG (King et al., 2021; Ogunmodede et al., 2019).

Diabetes mellitus care is demanding for carers, covering emotionally, practically, monetarily, behaviorally, and socially stressful events, and all of these areas of care necessitate a period of adjustment. Caregivers identified the need to be persistent, resilient, resourceful, responsive, and adaptable during the adjustment process (Dhada & Blackbeard, 2019b). Giving care to a sick family member can be seen as a rewarding experience with benefits like personal development, a sense of accomplishment, the strengthening of connections, and a shift in perspective. The advantages of being appreciated for the care one provides serves as a cushion against heavy strain, promotes a positive outlook on life, and provides motivation to continue providing care. A sense of pride, esteem, mastery, and accomplishment is tied to the caretaker role and an existential sense of significance (Sherman, 2019).

The actual effects on particular caregivers, however, vary based on a wide range of personal and environmental factors. Helping the care receivers typically boosts the caregivers' confidence, teaches them how to handle challenging circumstances, makes them feel more connected to the care recipient, and gives them reassurance that the care recipient is being taken care of. It is crucial to remember, too, that these positive impacts can exist alongside the negative repercussions of providing care (Schulz et al., 2016).

Numerous studies have been conducted worldwide on the consequences of informal carers' caregiving roles. Caregivers who provide long hours of care are more likely to

experience adverse effects on their everyday lives and health, such as forced early retirement, fewer working hours, limited free time, greater financial load, and bad health (Jawahir et al., 2021; Sherman, 2019).

2.3 Communicating with family caregivers

This construct involves communicating with the caregiver in a manner that demonstrates respect, empathy, and compassion toward the family caregiver, listening actively and respectfully to family caregivers, providing timely information to family caregivers in ways they will understand, and coordinated care by providing consistent documentation and information amongst providers and family caregivers (Parmar et al., 2020a).

The physical and psychological well-being of person's with T2 DM is impacted by the language used to describe the disease. These words influence how people and society see those who have diabetes or are at risk of developing it. Person's with diabetes, their families, and those at risk for developing diabetes require and deserve communications that are factual and precise, polite and inclusive, and unprejudiced (Nanayakkara et al., 2018).

The caregiver-patient relationship, as well as communication between family members and healthcare personnel, has a substantial impact on the caregiving experience. ICGs play a crucial role in assisting physicians in learning about their patients and promoting information exchange between them and the patient. The quality of life and well-being of caregivers are linked to patients' impressions of their care, particularly communication with clinical personnel and care coordination. Conflict happens between family caregivers and professionals when there is a lack of communication regarding

advance care planning, when words are misconstrued and caregivers perceive the staff has been disrespectful, and when there are divergent understandings about the disease process (Wittenberg et al., 2017). Thus, effective family communication allows healthcare professionals to gain information about the patient's preferences and behavior from the patient's caregivers, perhaps increasing treatment adherence. Sharing information is a quality that stems from the notion that both HCWs and ICGs have special, priceless knowledge and experiences and this has an impact on the involvement of family members in the care process (Jang, 2020; Patel et al., 2018).

The fundamental responsibility of nurses is to the person receiving care if this person is "an individual, a family, a group, or a community." However, in inpatient acute care situations, the needs of ICGs have not received much attention from nurses. Caregivers may feel invisible because all attention is focused on the patient, which is understandable. If the communication needs of patients and their families are not recognized and tackled ahead of time, the accuracy and completeness of the initial evaluation and ongoing management can be jeopardized. This entails understanding how families and persons with T2DM will want to be communicated with throughout the period of hospitalization, communicating in their chosen language and an empathic and courteous manner, valuing what family caregivers have to say as well as their emotions, the importance of timely information, and listening to and addressing their concerns (Lee et al., 2020; Smith et al., 2018). Healthcare professionals who were attentive, sincere, generally focused on patients' and caregivers' experiences, sensitive to unmet information needs, and receptive to patients' and caregivers' possibly varied

communication preferences were valued by caregivers in their communication (Washington et al., 2019).

Clinic consultation, which is a frequent direct meeting with key medical personnel, is a priceless opportunity to assess care and develop treatment strategies. An investigation of parents' consultation experiences and opinions by Dhaba and Blackbeard in 2019 came up with issues parents found worrying whilst interacting with the health care professional. These were the communication styles, complex medical jargon, conflicting advice, variances in practice, anxiety, poor recollection of knowledge with a preference for written instructions, feelings of being questioned and judged leading to non-disclosure, disengagement, and non-attendance. Furthermore, the presence of the child during the consultation was distracting, clinic structure and organizational elements such as time constraints, restricting questioning, and parents wanting and appreciating consistent messaging from health care professionals were also found (Dhaba & Blackbeard, 2019).

In a national study of parents of diabetic children, 43% said care was hampered by a lack of communication and acquiring information (having difficulties discussed and resolved) was an obstacle to therapy for 48% of respondents. These discoveries are concerning since ICGs say they are not able to have the required contact with clinicians to have their inquiries and concerns dealt with. Better communication and retrieval of essential healthcare data occurs when healthcare personnel communicate effectively (such as a clearer description of symptoms) as well as a better grasp of treatment modalities, these improve outcomes and compliance (Patel et al., 2018).

Health workers communicating with caregivers help impact knowledge into them. This knowledge has an impact on caregivers' diabetes management behavior. Previous research found that caregivers with more diabetes knowledge could help persons with T2DM achieve better glycemic control. Furthermore, adolescents with T1DM recognized the importance of ICGs in terms of direction, oversight, and emotional support (Alnaim et al., 2021). Two-thirds of relatives diligently search for information on low blood glucose, with medical professionals and the print media cited as the key indicators of knowledge. Knowledge of therapy was linked to education, past hypoglycemic experience, and information comprehension. Medical education, information searching, and information comprehension were all linked to caregivers' perceptions of hypoglycemic competence. Interventions that encourage caregivers to seek knowledge and enhance their understanding of it should be emphasized (Reifegerste & Hartleib, 2016).

Efficient communication between ICGs, those who benefit from their care and HCWs is capable of minimizing caregiver strain, eliminating uncertainty about care plans, building trust, and reducing errors during the care process. Establishing a consistent connection is dependent on a common understanding of shared views between HCWs and ICGs (Caswell et al., 2015; Hoek et al., 2021; Smith et al., 2018).

Fewer caregivers reported that they were always (21.3%) or usually (6.9%) asked if they needed assistance managing care. However, caregivers reported that healthcare professionals always (70.6%) or usually (18.2%) listened to them and always (54.4%) or usually (17.7%) inquired about their understanding of the treatment regimen. These results underline the necessity of health system efforts to aid family and ICGs who serve

as the primary support system for persons with chronic diseases understand what is happening as far as the care recipient is concerned (Wolff et al., 2020).

Medical personnel frequently try to suppress their emotions to maintain a professional distance with patients. However, patients and family members as well as ICGs constantly perceive a party on the other side of those interactions. They presume the HCW as someone who does not care, is emotionless, essentially dissimilar to them and hides behind a white coat and a degree. HCWs can bridge the gap, reach out, and transform difficult circumstances into occasions for community, purpose, and collective healing by sharing part of their sentiments and their concern for the feelings of ICGs. ICGs place a high value on HCWs being able to empathize with them, and being able to understand the unique care scenario (Wangler & Jansky, 2021; Zaki, 2020).

Disrespectful behavior inhibits collaboration and communication by weakening one's capacity for critical thought, sound decision-making, and assertive communication. Disrespectful conduct is also the cause of challenges in creating team-based strategies for enhancing treatment. The confidence of patients and caregivers is also damaged, which reduces patients' propensity to ask inquiries or supply crucial information (Grissinger, 2017).

2.4 Partnering with family caregivers

This construct involves the benefits of including family caregivers on the care team, establishing a collaborative relationship with ICGs, and incorporating the knowledge of the ICGs in the assessment and care planning of those who benefit from their care (Parmar et al., 2020a). Within modern practice, it is necessary to foster cooperation

between ICGs and HCWs to meet the requirements and desires of persons with T2 DM. As equals in care, these partnerships must emphasize the need for a cordial working relationship between HCWs and ICGs by cultivating mutual respect and honoring each other's significant contributions (Hoek et al., 2021).

Partnering with nurses is viewed by family caregivers as teamwork in which they would be informed frequently and, above all, participate in decision-making (Hagedoorn et al., 2020). ICGs who experience greater levels of teamwork with HCWs especially nurses are also more prepared to provide care at home once the patient is released from the hospital (Hagedoorn et al., 2020). However, despite having a positive outlook on ICGs and being eager to spend time with them, nurses do not appear to view family caregivers as partners in the care. Nurses must work together with family caregivers by including them in the coordination of care during the hospital stay and continuously handing over the care when the patient is about to be sent home to prepare them for more complex and demanding caregiving at home. As a result, nurses can improve the standard and consistency of care (Ellen Ingrid Hagedoorn, 2019).

Each caregiver's requirements and preferences must be considered when providing health care. Interprofessional teams, ICGs and patients working together more effectively is required to provide high-quality healthcare. Caregivers must be more involved in transitions between care and discharge (Lilleheie et al., 2020b). Caregivers want their services to be recognized, respected, and appreciated. Caregivers want their needs and desires for more information, assistance, and training to be taken into account (Anker-Hansen et al., 2018). The healthcare system appears to place insufficient emphasis on ensuring that everyone involved in the care of persons with T2 DM

understand the implications of discharge, treatment, and coordination. Although the service is designed to see individuals holistically, health care providers focus on the conditions of the patients forgetting the caregiver. Patients, caregivers, and the health care team should therefore work together more closely, especially during the transition to the home environment (Lilleheie et al., 2020b).

Involving the family caregiver in the care process fosters a collaborative relationship between patients, nurses, and the family, as well as allows the family caregiver to address any inaccuracies in the patient's medical history. It further decreases their role strain as they know better what to expect from their caregiving role and increases the quality and consistency of care and is linked to their readiness to take on the role of caregiver (Hagedoorn et al., 2020).

Informal caregivers request that each patient's needs and preferences be given more consideration, as well as opportunities for both patients and caregivers to participate in the caregiving process. This translates into the care the person with T2 DM receives upon discharge; some ICGs claimed that they were given insufficient information about the patients' health status, insufficient details about how primary care services are organized, and limited details about who to contact with inquiries regarding the patients' care and health on discharge. They claimed that the health services had left them to handle the practical responsibilities and arrange for the patient's necessary and adequate treatment on their own. The routines of the health services did not consistently include the practice of including patients and their families as well as their ICGs in day-to-day care. Healthcare providers have less time to coordinate services across venues and to

prepare the patients for the home environment. ICGs were thus unsure of who to contact or who was in charge of the patient's medical follow-up (Lilleheie et al., 2020b).

Numerous ICGs expressed unfavorable sentiments toward decision-making and its effects; even years after the decision had been taken. Many of them expressed doubt and remorse, which shows that they were either underprepared for or under-supported during the decision-making process. Other caregivers believed that there was not enough time for decision-making. In addition, caregivers believed they were powerless in the situation (Garvelink et al., 2017). Although a large portion of HCWs are aware of and worried about the health of the caregivers, their preventative care practices were largely inactive. Health care workers should be more proactive and preventive in ensuring the health of caregivers (Biderman et al., 2021).

2.5 Building resilience in family caregivers

This construct involves identifying and recognizing the intricacies of the caregiver-care-recipient connection, developing family caregivers' skills and abilities through education and assistance, boosting the health and wellbeing of family caregivers, and encouraging self-care are all things that should be considered regularly (Parmar et al., 2020a). Resilience is defined as acquiring positive traits during times of stress that are fluid in nature. It is not measured as a specific trait someone has or does not have (Van Breda, 2018). This definition shows that most people can become resilient in some areas of their lives, and this comes about in the face of new challenges or situations (Ghaffari et al., 2019).

Resilience focuses on strengths rather than flaws and is typically understood as a positive outcome despite exposure to adversity or risk. In addition to using their own resources, caregivers engage with their surroundings by using societal and communal resources, which can either support or undermine resilience. Lack of resources could result in subpar results or more difficult caregiving situations. This capacity for adaptation and "bouncing back" in the face of adversity is facilitated by the assets and resources inside the person, their life, and their surroundings. When subjected to different forms of stressors that place high demands on caregivers, caregiver resilience was characterized as having relatively high reported levels of psychological well-being (a "positive outcome") (Joling et al., 2016).

Each caregiver has a unique collection of skills, good habits, positive attitudes, and support systems that they use to overcome barriers and achieve excellent behavioral and health outcomes. Health care professionals can assist caregivers of persons with T2 DM in developing resilience by identifying their talents and figuring out how to use them to help them in their caregiving roles. To promote their health, interventions targeted at decreasing the impact of caregiving on both patients and carers should be designed, assessed, and implemented (Ahn et al., 2020; Romero-Mas et al., 2021).

Caregivers learn to be resilient by sharing their experiences with others and realizing they are not alone. Accepting themselves and others in this light is important to getting past the undesirable effects the caring role comes with. In practice, this is based on the notion that when people feel life events and outcomes are controllable, they avoid learned helplessness and make active attempts to overcome disagreeable conditions, allowing them to move forward and achieve resilience. Resilient individuals can adjust,

resist stress, and maybe prosper during hard times (Palacio et al., 2020). Some programs can help caregivers build resilience, such as training in managing stress and relaxation in the face of adversity (Luo et al., 2021). Receiving financial assistance boosts carers' means for providing care and may alleviate problems that a lack of cash presents. Furthermore, because caregiving causes physical tiredness, frailty, and weariness, receiving assistance in this area eases the load of caregiving (Sanuade & Boatemaa, 2015).

Promoting self-care appears to be another viable strategy for increasing the ability of ICGs of persons living with T2 diabetes to endure burdens. Self-care is deliberately participating in actions that foster total self-health and wellbeing (van Roij et al., 2021). Caregivers who are capable of dealing with the demands and strains of their job are more likely to be resilient. They must have access to the material resources they require, such as skills and knowledge, having their needs and concerns addressed daily as well as assistance and care which are significant invisible resources (Matsopoulos & Luthar, 2020).

The dynamics of the caregiver and care recipient relationship are not a steady one and may require a lot of adjustment as emotions can be displaced on each other more often than not. Family customs and history, all have a role in molding caregivers' and care recipients' experiences in informal care situations (Bjørge et al., 2019). Despite their unpleasant thoughts, informal caregivers experience a sense of success and genuine gratitude for the work they do by adapting, being creative, and forceful in stressful situations (Palacio et al., 2020).

The requirements of the patient are the primary priority of the healthcare team, even if they frequently address the opinions and worries of the family caregiver. Being expected to take on a difficult caring job, the readiness and willingness of the family caregiver are sometimes disregarded. Family caregivers are at high risk for serious health problems and cognitive, emotional, and physical decline, especially as caregiving responsibilities grow more complex over time. This is especially true when they are not mentally, emotionally, or physically capable of providing the care that is needed. Family carers are frequently an at-risk group that is overlooked (Sherman, 2019). Education for caregivers reduced their physical and emotional issues by giving them the confidence to deal with high levels of stress and fostering better interactions between caregivers and HCWs (Ghaffari et al., 2019).

2.6 Navigating the health and social systems and accessing resources

This construct involves collaborating with caregivers to obtain applicable support timeously, interacting with and referring to other providers based on ICG preferences, and working with ICGs to overcome barriers to access services and supports (Parmar et al., 2020a). Patients with T2DM and their caregivers receive support based on their social skills and resources (Slatyer et al., 2019). Caregivers seek a dependable service that takes into account their needs, as well as their desire for additional knowledge, support, referral, and training (Anker-Hansen et al., 2018).

The responders also emphasized the value of targeted referrals to support services and professionals. According to other studies, family carers value family doctors highly

because they seek a dependable, long-lasting contact who can perform advisory and coordination duties (Wangler & Jansky, 2021).

Caregivers and patients with T2DM should be helped to navigate the healthcare system which may be unfamiliar to them and shown resources they can tap into to ensure efficient care. Doing this goes a long way to help the ICG know where to go when help with the caregiving process is needed and whom to talk to. The aim of care was the eventual self-management of the condition by the patient. Thus, there should be minimum interruptions with the flow of care and quick referrals to points of help and resources are key to ensure the caregiver and eventually the person with T2 DM will not feel at a loss as to where to go and what to do to meet their physical, psychosocial and psychological needs (Powers et al., 2016).

Caregivers frequently put in a lot of effort to obtain the resources they require for themselves, their families, or their care recipients. They may need to discover the correct medical practitioner, information, referral resources, financial assistance, or deal with hospitals and insurance companies. In general, the caregivers put a lot of effort into navigating the system and find it difficult at times. Another issue is that those working in the healthcare system do not always readily offer resources (Luke et al., 2020).

A study by Towle et al. in 2020 showed that personal strain is the greatest stress; trying to meet other commitments while unsure of what to do when caring for a loved one. Thus, the ICG's capacity to balance care chores against other life obligations appeared to be negatively impacted by the requirement for support and care of patients. When mediating between the patient and healthcare experts, ICGs expressed concern that the

lack of knowledge and assistance from healthcare services exacerbated their anxiety (Towle et al., 2020).

Almost all primary care physicians believe that primary care teams would help caregivers. The most practical ways are collaborative care models that include physicians, a designated caregiver coordinator or case manager, and groups that help the community. Health and community systems usually work in isolation, making it harder for doctors to refer to different systems and aid caregivers in navigating the diverse services. Caregiving is not considered a medical concern, yet fulfilling the needs of caregivers is complex and time-consuming. Physicians believed they lacked the time to address the challenges that caregivers encounter and felt underpaid for the caregiver care they now provide (Parmar et al., 2020b)

Individualized caregiving training based on individual patient requirements and preferences aided the safe and easy transition of care from the health facility to the house (Towle et al., 2020).

2.7 Enhancing culture and context of care

This construct involves recognizing that social perspectives influence care and caring (e.g., ageism, stigma, discrimination) and participating in self-reflection to improve relationships with ICGs (Parmar et al., 2020a). According to the research, it is crucial to involve patients' families in clinical practice to target family well-being and adherence to diabetes self-management. Family life is where much self-management takes place. Due to the interdependence and mutual impact of family members, it is important to

understand and address the intra-family perspective of supporting and non-supportive interactions (Bennich et al., 2017).

It is important to strike a delicate balance between several aspects to support persons with diabetes in learning and using knowledge, skills, behavioral, problem-solving, and coping techniques. An interaction exists between the person and the environment in which they live, including their clinical status, culture, values, family, and social and communal surroundings (Gregio Neto et al., 2021; Powers et al., 2016). Societal perceptions may impact self-perceptions and caring decisions. A caregiver's psychological load may grow if caregiving is seen negatively or undervalued. The way care is culturally generated in society may influence the value assigned to it (Ng & Indran, 2021).

Similar to African countries that value collectivism; Ghana takes pride in its interdependent, community-focused lifestyle. It is a society in which people's understanding of what it means to be human is based on meaningful interactions. Being human (nipa) in the local languages is seen as being able to relate nicely and care about the well-being of others (Owusu-Ansah, 2015). The culture of reciprocity is ingrained in Ghanaian society, in that parents care for their children and see to their needs in their formative years, and children in turn, cater for their parents in their old age. Taking care of one's parents is seen as a civic responsibility as well as a familial obligation. As a result, in this social setting, caring for the elderly or dependent relative would be seen not merely as a cultural duty, but also as a human responsibility - a noble and humanitarian duty (Owusu-Ansah, 2015).

However, whether this is still the case today is disputed, considering that non-family hired hands care for many aged and dependent parents, and some are mistreated by members of their own family. Collectivism appears to be fading away, especially when it comes to elderly and dependent people care. It appears that domiciliary services for the elderly and dependent have a niche in today's Ghanaian society (Owusu-Ansah, 2015). The lack of geriatric infrastructure in Ghana exacerbates the growing care deficit, which is the result of socio-cultural changes that have weakened the support of the extended family. As a result, people in Ghana may be perceived positively because of their devotion to caring obligations during a period of fast social change (Dovie, 2019; Kusi et al., 2020).

Like the rest of the world, Ghana is fast modernizing and losing some of its ancient systems and customs in favor of modern lifestyles, which have ramifications for care. The perception and concept of family is one example of societal change. Many people nowadays consider family as consisting of a mother, father, and children - a rather nuclear unit. Many years ago, this was not the case; it was usual to live with a large extended family. Everyone was family, and the distinction between true siblings and cousins, nephews, aunts, and uncles was hazy. The extensive family tradition is being lost, which has consequences for care delivery (Owusu-Ansah, 2015).

Another observation is the quantity of freshly built homes that are little occupied and functionally vacant because the majority of adult children in the home have migrated abroad in search of greener pastures. Where adult children remain in the country, they may not live with their parents due to their obligations and busy lifestyles, which make living with or giving sufficient care for aged and dependent parents/relatives difficult.

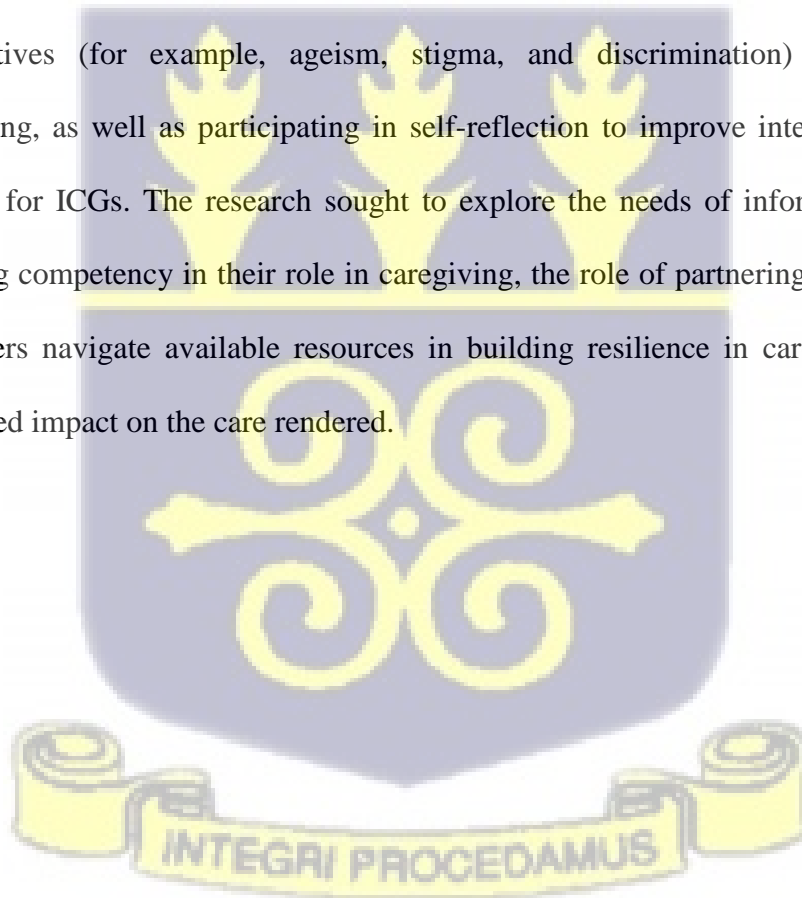
The elderly/dependent parent/relative either lives alone or is primarily cared for by a housekeeper (Owusu-Ansah, 2015). In Ghana, where hospices run by professionals are virtually non-existent, ICGs such as hired help or the members of the family are sought out to give informal care. Caring in these settings is laden with difficulties, including the caregiver's self-care, as well as the absence of support and awareness of how the role and process of caregiving impact a caregiver (Owusu-Ansah, 2015).

2.8 Chapter summary

The Caregiver-Centered Care Competency Framework reveals that there is a gap between what family caregivers need and what the healthcare system offers. It attempts to enhance the system by emphasizing the needs of family caregivers. Recognizing the caregiver role, communicating with ICGs, partnering with ICGs, fostering resilience in ICGs, navigating the health and social systems and accessing resources, and enhancing the culture and context of care are the six competency domains that make up the model's main constructs.

Recognizing the caregiver position entails appreciating the informal caregiver, their understanding of the repercussions of care, their awareness of their role, and caregiver variety. Communicating with family caregivers entails treating the caregiver with respect, empathy, and compassion, listening attentively and politely to ICGs, providing information timeously to ICGs in a manner they can comprehend, and coordinating care by providing consistent documentation and information among providers. Partnering with ICGs entails involving ICGs in the care, building a partnership with ICGs, and using the ICG's understanding of the care in assessments and care planning.

Fostering Resilience in caregivers involves identifying and assessing family caregivers' needs and goals regularly, recognizing the intricacies of the caregiver-recipient relationship, as well as the enhancement of ICGs' skills and talents through education and assistance, and promoting family caregivers' health and wellbeing while encouraging self-care. Collaborating with caregivers to quickly access appropriate supports, communicating with and making referrals based on their preferences to other providers, and working with ICGs to overcome hurdles to accessing services and supports are all part of navigating the health and social systems and accessing resources. Finally, improving the culture and context of care entails acknowledging how societal perspectives (for example, ageism, stigma, and discrimination) affect care and caregiving, as well as participating in self-reflection to improve interactions with and support for ICGs. The research sought to explore the needs of informal caregivers in attaining competency in their role in caregiving, the role of partnering with and helping caregivers navigate available resources in building resilience in caregivers, and their combined impact on the care rendered.



CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

The methodologies employed in this research are explained in this chapter. This included the study design, setting, population, eligibility criteria, sample size, sampling method, data collection procedure, quality control, and analysis of data.

3.1 Research design

In this research, an exploratory- descriptive qualitative research design was applied. Exploratory research is the investigation of a topic that has never been properly examined or studied before (Bohari et al., 2019). This was utilized to get a deeper grasp of a current event and gain new insights into it to produce a more precise problem. It began with a broad notion and used research findings to explore related concerns to the research topic (Bohari et al., 2019). Descriptive research attempts to characterize a population, situation, or phenomenon systematically and exactly. It can answer what, where, when, and how questions but not why (Silva, 2017). An exploratory-descriptive design, which was often field research in natural settings, has the least control over variables. The information gathered helped to create theories or explain phenomena from the point of view of the people being examined (Scheuer et al., 2018).

This design was used to collect feedback from ICGs of persons with T2DM to better prepare them for their role and the implications that came with it. The qualitative descriptive exploratory design was chosen as the best fit for this research since it

enabled the researcher to speak with the participants for longer periods. As a result, a thorough grasp of the phenomenon under investigation was gained (Potvin et al., 2019).

3.2 Research setting

The 37 Military Hospital, Neghelli Barracks, served as the setting for the study. This institution was found in Ghana's Greater Accra Region, in the Ayawaso East district. The facility is a teaching hospital with wards and departments including the Surgical, Medical, Paediatrics, Obstetrics, Gynecology, Accident and Emergency, Public Health, Dental, Pathology, Pharmacy, Physiotherapy, Radiology, the Polyclinic, and Veterinary units. The hospital's educational institutions include the Nursing and Midwifery Training School (NMTC), School of Anesthesia, Emergency Medical Technician School, and a Postgraduate Medical College. The 37 Military hospital is a 400-bed institution that delivers high-quality healthcare to service members, ex-service members, Ministry of Defense civilian employees, their families, and the general public. It also acts as a health facility for the National Disaster and Emergency Response.

The ward from which participants were recruited were the female medical (Opoku ward), male medical (Bandoh ward), and the surgical (Tamakloe) wards of the hospital. The female ward has a ward capacity of 35 and staff strength of about 40 whilst the male medical ward has a ward capacity of 28 and staff strength of about 30. Together, both wards rendered medical nursing and medical management to patients above the age of 12 with conditions such as diabetes mellitus, pleural effusion, diabetic ulcer, hypertension, pneumonia, chronic kidney disease, ischemic and hemorrhagic stroke to name a few. A patient's gender determined which ward the patient would be admitted into.

The surgical ward on the other hand has a ward capacity of about 60 beds and a staff strength of about 55 personnel. It is divided into the male and female sections with a high dependency unit close to the nurses' station for monitoring of patients immediately after surgery. Conditions managed on the ward are appendicitis, acute abdomen, diverticular disease, thyroiditis, and urinary retention, just to name a few.

3.3 Population

The target population pertained to the category of participants who had particular characteristics that the researcher was looking for (Asiamah et al., 2017). The target population in this study was ICGs in the medical (male and female) and surgical wards of the 37 Military Hospital.

3.4 Inclusion Criteria

1. Informal caregivers who were 18 years and above
2. ICGs who had a minimum of three months of caregiving experience
3. ICGs who attended the 37 Military Hospital (medical and surgical wards)
4. ICGs whose patients were persons with Type 2 DM
5. ICGs who were willing to sign the study consent form

3.5 Exclusion Criteria

1. Informal caregivers who were unwilling to partake in the study
2. ICGs who were not on the medical and surgical wards

3.6 Sample Size and Sampling Technique

Data saturation determined the sample size. Data saturation was observed on the twentieth participant. This was when no new information emerged in the interview.

Therefore, 20 ICGs were selected as the sample size to represent the target population for the study.

To recruit participants for the study, the purposive sampling strategy was utilized. The purposive sampling technique is a non-probability strategy that is employed in the choosing of study participants. The researcher selects the participants with care, and this selection is in line with the study's aims. This is to guarantee that the information gathered is relevant to the topic at hand (Ames et al., 2019).

For this study, the purposive sampling method was suitable because the ICGs of persons with T2DM at the designated wards of the 37 Military Hospital, were considered to be the ones who would provide these pertinent responses concerning their experience with providing informal care to persons with T2DM. Therefore, ICGs of persons with T2DM were identified purposively with the help of the nurses on the selected wards and invited to take part in the study by the researcher.

Therefore, following permission from the hospital authorities (Appendix IV), the researcher went to the wards during their morning meeting to explain the research's purpose and objectives to the nurse manager and staff, and to be introduced to ICGs of persons with T2DM by the nurse manager or shift in-charge. Caregivers who matched the inclusion criteria were invited to take part in the study by the researcher. Only those who agreed and showed willingness to take part in the study were recruited for the study.

3.7 Tool for Data Collection

A semi-structured interview guide was used to collect data for the study (Appendix III). According to the study's objectives, a set of guided open-ended questions were developed. The purpose of this tool was to elicit detailed accounts from the study participants that address the research questions adequately. The portions of the interview guide were captured in sections; from A to E. Section A consisted of questions designed to collect demographic information from participants such as their age, gender, years of caregiving, level of education and relationship with patient. Participants were asked open-ended questions in Sections B to E that were directed by the study's specific aims. Section B consisted of open-ended questions aimed at exploring the nature of communication between ICGs of persons with T2 DM and healthcare personnel. Section C comprised questions on the extent of HCWs partner and help ICGs of patients with diabetes. Section D looked at culture and context of care and questions in Section E explored ICG experience of attaining competency.

The data collecting instrument was pretested with four family caregivers from the Greater Accra Regional hospital (formally Ridge hospital) who met the inclusion criteria and agreed to partake in the study. To guarantee that the instrument fulfilled its intended purpose, all necessary changes based on the responses were addressed. The information gathered during the pre-testing phase was not included in the study's findings.

3.8 Procedure for data Collection

After obtaining ethical approval (Appendix V), permission was sought from the Chief Nursing Officer of the 37 Military Hospital to collect data from the facility. The nurse

managers of the medical and surgical wards helped introduce the researcher to caregivers of persons with T2DM on their wards. The study's goal was explained to the ICGs and they were invited to participate voluntarily. Participants were contacted to schedule a suitable time and location for the interviews. The chosen family caregivers were interviewed for a maximum of 45 minutes using an interview guide at a convenient location with minimal interruption. In a one-on-one interview, each participant was asked to share his or her thoughts on their preparation needs as caregivers of persons with T2DM. This was followed by probes based on their responses.

All COVID-19 protocols were also duly observed. These included wearing of face masks, hand hygiene and social distancing. Only with the participants' permission were the interviews recorded. Field notes were also taken, with the permission of participants, to provide additional information on observations made on the field. When data saturation was reached, the interviews came to an end.

3.9 Data management

The term research data management (RDM) refers to the collection, storage, preservation, and interchange of data utilized in a study. It requires managing research data daily throughout the course of the project. It also includes deciding how data will be saved and shared after the project is completed (Chigwada, 2021). Data management is concerned with maintaining the integrity and completeness of the information gathered from participants. All study-related records, including individual permission forms, demographic data, field notes and other pertinent materials were properly filed and kept under lock and key. The researcher labeled the audio recordings and transcripts, archived them electronically, and kept them safe on a computer with

password protection. The data was accessible only to the researcher and her supervision team. After five years, all the stored data would be destroyed.

3.10 Data Analysis

Data analysis in qualitative research is the act of meticulously searching and organizing transcripts of interviews, notes taken during the interviews, and other resources, other than text the researcher gathered, to gain a better grasp of the situation at hand (Ravindran, 2019). To analyze the data gathered, the thematic content analysis approach was employed in this study. Thematic analysis is a qualitative research method that can be used in a variety of themes and epistemologies. It is a technique for finding, evaluating, arranging, summarizing, and reporting themes in a collection of data (Nowell et al., 2017). Participants' data were transcribed directly from audio to text. Concurrently, thematic content analysis was used to analyze the data.

With thematic content analysis, when major themes emerge inductively from the texts, the investigator builds codes during a careful analysis of the texts, presuming that the recorded communications themselves (i.e., the texts) form the data. Typically, these codes are composed of phrases or short sentences that symbolically assign an "essence-capturing" trait (Javadi & Zarea, 2016).

In this study, the transcripts were reviewed by the researcher numerous times to obtain a thorough comprehension of what the participants had to say. Then, based on the meanings of the sentences, codes were assigned to them (coding). Similar codes were then combined to make sub-themes. The sub-themes were then which were then grouped under the pre-determined constructs of the Caregiver-Centered Care

Competency Framework (Parmar et al., 2020a) as the major themes. Findings were then presented in the form of themes and sub-themes and, these were supported by verbatim quotes from the participants.

3.11 Methodological Rigour

Methodological rigour refers to applying the scientific method's highest standards and best practices to one's research. It is all about getting to the bottom of things. When it comes to subject selection and data processing, scientific rigour entails minimizing prejudice (Maher et al., 2018). The trustworthiness criteria recommended by Lincoln and Guba (1985) was employed in this study in order to ensure methodological rigor. This includes credibility, transferability, dependability and confirmability.

It is regarded to be credible when the research findings reflect the perspectives of those being investigated. Credibility in qualitative research refers to the data's dependability (Korstjens & Moser, 2018). In this study; longer interactions with participants, member checks, actively recruiting individuals who fulfilled the study's inclusion criteria and triangulation of data helped to ensure trustworthiness.

Triangulation means mixing ideas, techniques, or observers to ensure that underlying biases caused by the usage of a single method or observer are mitigated (Noble & Heale, 2019). Triangulation of data was ensured by synthesizing data transcribed and field notes made during fieldwork to paint a clear picture of what the participants said.

Transferability is the degree to which discoveries from research may be put into practice in a variety of contexts or settings with a variety of participants (Korstjens & Moser, 2018). By thoroughly detailing the study's setting and overall design as an audit trail so

that it can be duplicated by other researchers in different situations, transferability was ensured.

The constancy of results throughout time is referred to as dependability. This entails participants' evaluations of the study's findings, interpretations, and suggestions, all of which are backed up by data received from study participants (Korstjens & Moser, 2018). Dependability was ensured through an external audit by the second supervisor and since he is an expert in this field, his inputs ensured a high level of dependability. Another technique to assure dependability was to conduct interviews with all participants using the same interview guide.

Finally, the goal of confirmability was to show that the data and interpretations of the findings were obtained from the data and not the result of the inquirer's imagination (Korstjens & Moser, 2018). Confirmability was guaranteed by keeping a field diary and accurate record keeping for an audit trail.

3.12 Ethical Considerations

Research ethics are principles that guide researchers in doing and reporting research without deception or with the objective of harming participants of the research or society as a whole, whether intentionally or accidentally (Žukauskas et al., 2018). To ensure the validity of findings, it is vital to follow ethical norms when doing and reporting research (Levine, 1979).

Ethical clearance was sought from the 37 Military Hospital Institutional Review Board (37MH-IRB/UG/IPN/607/2022). The Chief Nursing Officer (matron) of the 37 Military Hospital was also informed about the study and permission sought from her to collect

data for the research. Study participants were briefed on the study's purpose as well as the part they would play in it using the participant information sheet (Appendix I). Informal Caregivers who agreed to take part in the study were asked to sign a consent form indicating their desire to participate in the study (Appendix II). Participants were recruited only when they gave their full consent to be a part of the study. They were told that they could withdraw from the study at any moment and would not face any consequences if they did so.

Permission was sought from participants to record the interviews. To protect the participants' anonymity, no personally identifiable information was collected. The interviews took place in a calm, private setting with only the researcher and one participant at a time. This was to protect the participants' privacy and make them feel at ease so they may fully participate in the interviews. The audiotapes and transcripts were accessible only to the researcher and her supervisors.

Participants participation was treated with the utmost discretion, as well as the confidentiality of the information supplied, and all data and recordings relevant were kept as private, safe and secure as possible. Codes were used to replace all names to ensure anonymity.

All participant information was utilized for academic purposes, including publishing. The records may be viewed by members of the School of Nursing and Midwifery, Graduate School, and Professional Nursing Bodies from time to time, but participants can rest confident that they would never know who said what. The researcher would preserve all data and recordings for five (5) years before destroying them. An Ethics Committee would be consulted if the data is needed in the near future.

All COVID-19 protocols were also duly observed. A face mask was worn by the researcher and each participant. Hand washing or sanitizing of hands was ensured before and after each interview. The researcher and the participants were seated at least 2 meters from each other to ensure social distancing.



CHAPTER FOUR

RESULTS

4.0 Introduction

The results of the study are discussed in this chapter. The objectives of the study were to (a) explore how ICGs of persons with T2 DM communicate with HCWs and partner with them to provide care; (b) ascertain ICGs account of how HCWs recognize their caregiving roles and help foster their resilience as caregivers and (c) describe ICGs experiences of navigating the healthcare system as well as the culture and context with which they provide care to persons with T2 DM. Data was analysed using thematic content analysis. The results have been presented according to the themes and subthemes from the data. Findings from the study are also supported with verbatim quotations from participants.

4.1 Demographic Characteristics of Participants

A total of twenty (20) participants were interviewed for the study. Code names have been assigned to each participant; from the first (P-1) and second participant (P-2) through to the twentieth participant (P-20). Characteristics obtained included gender, age, relationship with the patient, level of education and duration of caregiving. Fourteen (14) of the participants were females and six (6) were males. Among the 14 females who participated in the study; eight (8) were daughters of persons with T2 DM, four (4) were sisters of persons with T2 DM and two (2) were wives of persons with T2

DM. Among the 6 males who participated; four (4) were husbands of persons with T2 DM, one (1) was a nephew and another one (1) was a son; both of persons with T2 DM.

The age range of the participants was from twenty-two (22) years to seventy (70) years. Ten (10) of the participants had a tertiary level of education, eight (8) had a secondary level of education and two (2) of the participants had a basic level of education. Five (5) of the participants have been engaged in caregiving of patients with T2 DM for more than 5 years and the remaining fifteen (15) have been providing care for 5 years or less. The least period of caring for persons with T2 DM among the participants was one (1) year by a fifty-five (55) year-old husband of a patient with T2 DM. The longest duration of caregiving was seventeen (17) years by a forty (40) year-old daughter of a patient with T2 DM. The demographic data of the participants are presented in Table 4.1.

Table 4.1: Participant's Demographic Data

Number	Code name	Gender	Age	Relationship with the patient	Level of education	Duration of caregiving
1	P-1	F	22	Daughter	Secondary	2 ^{1/2} years
2	P-2	M	70	Husband	Tertiary	9 years
3	P-3	F	54	Sister	Tertiary	4 months
4	P-4	M	55	Husband	Tertiary	1 year
5	P-5	F	36	Daughter	Tertiary	10 years
6	P-6	F	51	Wife	Secondary	1 year
7	P-7	F	33	Daughter	Diploma	1 ^{1/2} years
8	P-8	F	38	Daughter	Tertiary	1 year
9	P-9	M	40	Nephew	Tertiary	5 years

Number	Code name	Gender	Age	Relationship with the patient	Level of education	Duration of caregiving
10	P-10	F	38	Daughter	Secondary	6 ^{1/2} years
11	P-11	M	61	Husband	Secondary	6 years
12	P-12	F	40	Daughter	Secondary	17 years
13	P-13	M	38	Son	Tertiary	2 years
14	P-14	F	28	Daughter	Tertiary	3 years
15	P-15	F	58	Wife	Basic	5 years
16	P-16	F	40	Sister	Secondary	1 year
17	P-17	F	34	Sister	Basic	4 years
18	P-18	F	40	Sister	Secondary	2 years
19	P-19	M	67	Husband	Secondary	5 years
20	P-20	F	38	Daughter	Diploma	3 years

4.2 Organization of Themes and Sub-themes

Six (6) main themes with fourteen (14) corresponding sub-themes were identified from the data. The main themes were identified based on the constructs of the Caregiver-Centered Care Competency Framework (Parmar et al., 2020a). The themes were: (1) “Communication between HCWs and ICGs”, (2) “Partnership with HCWs”, (3) “Recognition of the role of the ICG”, (4) “Building resilience in ICGs”, (5) “Navigating the health care system”, and (6) “Culture and context of care”. Details of the themes and sub-themes are presented in Table 4.2.

Table 4.2: Main themes, Sub-themes and Categories

Themes	Sub-themes
1. Communication between HCWs and ICGS	Clarity of communication
	Sharing of information
	Follow-up phone calls
2. Partnership with HCWs	Collaboration with HCWs
	Accessibility to HCWs
	Attitude of HCW (Positive/ Negative)
3. Recognition of the role of the ICG	Awareness of the role of ICG
	Acknowledgment of ICGs
4. Building resilience in ICGs	Education from HCWs
	Concern about welfare (Health Promotion)
5. Navigating the healthcare system	Direction from HCWs
	Referral from HCWs
6. Culture and context of care	Duty to care
	Support system

4.3 Communication between HCWs and ICGS

The first research objective was aimed at exploring how HCWs communicate with informal caregivers (ICGs) in providing care for persons with T2DM. The theme “Communication between HCWs and ICGs” refers to how ICGs and HCWs interact with each other to provide care for persons with T2 DM. Participants were of the view

that communication with HCWs is an important resource for carrying out their caregiving role for persons with T2 DM. This enabled the ICG to know and understand what was going on as far as the care of persons with T2 DM is concerned. Exploring the theme “Communication between HCWs and ICGs” involves clarity of information shared between HCWs and ICGs and follow-up calls by HCWs to check on patients with T2 DM at home through their ICGs. Three (3) sub-themes emerged namely: “Clarity of communication”, “sharing of information” and “follow-up phone calls”.

4.3.1 Clarity of communication

The first sub-theme “clarity of communication” refers to the use of easily understandable language by HCWs in communicating with ICGs of persons with T2 DM. Participants appreciated the use of simple and easily understandable terms in communicating with HCWs whilst interacting with them.

Easily understandable language

In this study, the HCWs reportedly communicate to ICGs of persons with T2 DM in languages that they easily understand. According to the participants, HCWs do well to communicate with them in a language that they understand.

“...communication is done in a language I understand That is the language they (HCWs) used”. (P-2)

“Explanation into her (person with T2 DM) condition was done in a language I understood with no jargon”. (P-8)

“They (HCWs) indeed explained her (person with T2 DM) diabetes to me to the best of my understanding”. (P-13)

To make communication easier and easily understandable, HCWs even do well to speak with ICGs in vernacular to ensure that messages carried out to ICGs are clear and easily understood. A fifty-one-year-old female informal caregiver explained that one doctor had to speak with her in “Twi” (a common vernacular in Ghana) whilst explaining the diagnosis of her husband to her.

“...When his (patient with T2DM) diagnosis was being explained to me (ICG of a person with T2 DM), he (the doctor) spoke “Twi” so I (the ICG) understood what he was saying”. (P-6)

Complex terms

Participants explained that in instances where medical terms and jargon were used, the HCW will break it down to ensure they understood what was being communicated. This was to ensure clarity in communication with ICGs. They tried doing this by avoiding big grammar. Secondly, in instances where some complex English terms are used, the nurses and doctors try to explain to the ICGs what they mean to say;

“The nurses and doctors do not use big grammar and they try to come down to our (ICGs) level”. (P-3)

“The last time I (ICG of a person with T2 DM) interacted with a HCW, a term was used in the discussion I did not understand. I asked the doctor and he explained the meaning of it meant and I was okay”. (P-3)

“When he (the doctor) had to use an English term, he explained later what the English term meant”. (P-6)

4.3.2 Sharing of information

The second sub-theme “sharing of information” refers to the passing of information from one entity to the other. Information exchange between the ICG of the person with T2 DM and HCWs was deemed one of the important components of the interaction. This is because it allowed the HCW to envision the state of the patient with T2 DM and what could account for their ill state. It also allowed the HCW to ask follow-up questions in areas of the life of the person with T2 DM that they did not understand. Such interaction also helps the ICG to build rapport with the HCW and for them to understand the condition of their relative and the cause of T2 DM.

Although some HCWs shared information with ICGs, others chose to withhold information from ICGs. Withholding information was seen to have a negative impact on the care of the person with T2 DM. ICGs who experienced HCWs withholding information from them decided not to follow up on the care and progress of their relative with T2 DM. They rather chose to believe that HCWs know what is best for their relative with T2 DM.

Sharing information

In this study, some participants said HCWs voluntarily shared information with them and informed them when they brought their relative with T2 DM to the hospital what the condition was and the way forward.

Participants added that this gave them insight into what was wrong with their relative, the plan of action to be taken by HCWs to make their relative better and eased their anxiety/worry. A fifty-five year old husband of a person with T2 DM had this to say:

“...the doctor at the medical emergency called me (the ICG) and explained to my wife and me what was wrong; the chronic nature of T2 DM, medications and management involved and asked us not to worry”.

(P-4)

A fifty-five year old husband of a person with T2 DM also recounted that the nurses on the ward did not hide any information from him and his wife. The nurses went on to explain the treatment modalities to them including how many times a day they will check the random blood sugar of his wife (a patient with T2 DM).

“...the nurses did not hide any information from us (husband of a person with T2 DM together with his wife). They explained the course of the treatment to us and encouraged us to get our own glucometer strips as they will be checking it every thirty minutes because her RBS was high”.

(P-4)

A fifty-one (51) year old wife of a patient with T2 DM also added that the doctor gave her his number to call when she needed any further explanation of her husband's condition or had any concern.

“...he (the doctor) gave me (the wife of a patient with T2 DM) his phone number to call when I need any explanation or I have any concerns”. (P-

6)

Withholding information

A fifty-four year old sister of a person with T2 DM recounted that some HCWs withhold information about the condition of their relative with T2DM. This occurred in many forms including the unwillingness of HCWs to provide information or to answer questions of ICGs concerning the diagnosis and treatment of their relative with T2DM under their care.

“When I (a relative of a person with T2 DM)) ask them (HCWs) questions, they are not willing to provide me with answers.” (P-3)

Others recounted that HCWs deliberately hide bad news or any unpleasant information about the condition of the person with T2DM from their ICGs. However, ICGs were not pleased with that.

“...if there is something wrong with the results, I (ICG of a person with T2 DM) think they (HCWs) should be forthright with the caregiver for us to know what is going on. HCWs like to hide the bad news from us the caregivers which is not good for us”. (P-10)

Not chasing information

Some ICGs however, due to the trust they have in HCWs do not bother to follow them up for information concerning the diagnosis and treatment of their relative with T2DM under their care. To them, they trust that HCWs know best and are in a better position to make an informed decision on their behalf without their direct knowledge and contribution.

A sixty-one year old husband of a person with T2 DM had this to say:

“HCWs are the ones with knowledge in this field so whichever way they think they can help and educate us, we are prepared to listen and abide by their instructions”. (P-11)

Chasing for information

A few of the participants had to chase HCWs for information regarding the diagnosis and treatment of their relative’s condition. A thirty-eight-year-old daughter of a patient with T2DM who was asked to go for echocardiogram recounted that she had to physically follow a doctor round the hospital premises before he paid attention to her and explain to her what the test was about.

“...I (daughter of a patient with T2 DM) had to follow the doctor around to ask why the echocardiogram was requested, what it is about and what to expect; I followed the doctor from the emergency to almost the theatre before he pulled me aside to explain that the echocardiogram is to look at her heart and to know how it is functioning”. (P-10)

4.3.3 Follow-up phone calls

“Follow-up phone calls” emerged as the third sub-theme under communication between HCWs and ICGs. Most participants would appreciate it if HCWs have their phone numbers and make follow-up calls post-discharge to check on the health and well-being of their patients with T2DM.

This is to give them some comfort and assurance that HCWs still monitor them even when they are outside the hospital and at home.

“I (ICG of a person with T2 DM) wish maybe every once in a while, the hospital can at least call to check up on her.” (P-9)

“...HCWs should also know the phone numbers of caregivers of their patients to check up on them and the patients to know how they are faring.” (P-10)

A forty (40) year-old nephew of a person with T2 DM added that persons with T2 DM and their relatives should be followed up on intermittently aside from their scheduled review dates. This is to keep HCWs abreast with the state of the person with T2 DM post-discharge and post-review to know how the person with T2 DM is faring.

“So far as it is your (HCW’s) patient, it should not be about only the review dates before the HCW gets to know what is up with the patient (person with T2 DM)”. (P-9)

A forty (40) year-old nephew to a T2 DM patient said such phone calls will be helpful as they will help address any question he may have concerning the care of the person with T2 DM. This according to him would help clear any doubt or concerns they may have with a medication dosage, food or a certain line of action they may want to take.

“There may be something about her (person with T2 DM) medication or diet that I wish I (ICG) could talk to a HCW about for which I do not

have to drive all the way from Akuse to the hospital (37 Military hospital)”. (P-9)

“Maybe at that time, something may have happened and the HCW can advise the caregiver as to what to do” (P-10)

4.4 Partnership with HCWs

The theme “Partnership with HCWs” refers to a situation where HCWs and ICGs work together over a reasonable period to achieve a common aim. During the partnership between HCWs and ICGs, mutual understanding is built between the two parties and each other’s valuable contribution is acknowledged. Participants were of the view that partnership with HCWs was critical in their caregiving role. They explained that partnership with HCWs enabled them to be involved in the care and decision-making process. They further added that partnership affords them the chance to share what they know about T2 DM and caring for persons with the condition with HCWs; this affords them the chance to have myths and misconceptions corrected. Exploring the theme “Partnership with HCWs” involves accessibility to HCWs which creates an avenue for ICGs to collaborate with HCWs. Participants however noted that the attitude of HCWs impacted the quality of the partnership formed between ICGs and HCWs and this in the long run affected care decisions and the degree of involvement in the management of the condition of their relatives with T2 DM. Three (3) sub-themes emerged after exploring the theme “partnership with HCWs” namely; collaboration with HCWs, accessibility to HCWs and attitude of HCWs.

4.4.1 Collaboration with HCWs

The first sub-theme “collaboration with HCWs” refers to HCWs teaming up with ICGs of persons with T2 DM to achieve a goal. Participants appreciated being collaborated with by HCWs directly involved in the management of their relative with T2 DM. Partnership with HCWs affords them the chance to work hand in hand with HCWs, feel part of the healthcare team and be involved in the care management of their relative with T2 DM.

Involving the ICG

In this study, HCWs reportedly involve ICGs of persons with T2 DM in the management of the condition of their relatives. Participants were of the view that HCWs involve them in decision-making concerning their relative with T2 DM making the care process all-inclusive, thus all stakeholders (HCWs and ICGs) in the healthcare continuum were involved. They added that in some instances, HCWs discussed with them treatment plans as well as discharge treatment of their patients with T2 DM before they were effected.

“The care is all-inclusive; we (the family of a person with T2 DM) are informed and involved in making decisions”. (P-3)

“I (a relative of a person with T2 DM) am involved in the planning of her care and if there is any treatment plan to be instituted, I am told about it”. (P-9)

“...They (HCWs) even involved me (relative of person with T2 DM) in her discharge planning; letting me know what to do to help regulate the sugar levels”. (P-4)

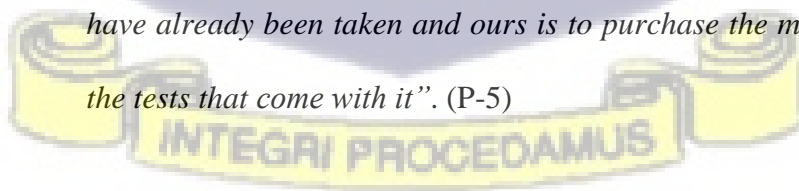
Uncoordinated care

Not all participants were involved in the care of their relatives with T2 DM. In instances where ICGs were not involved in the care of their relative with T2 DM, they described the care being rendered as uncoordinated with HCWs on one side and the ICG on the other with each doing what they think is best for the person with T2 DM independently. They however added that the role they play in this instance of uncoordinated care is to buy medications and do investigations HCWs request.

“It feels like HCWs are doing the part of the job required of them and we (ICGs) are also doing our part, thus, the care is uncoordinated”. (P-5)

“For collaboration and being involved in the planning of care; we (the family of a person with T2 DM) are not involved. By the time you (the ICG) come, the treatment plan is written in the form of tests and medications”. (P-13)

“By the time we (relatives of a person with T2 DM) come, the plan would have already been taken and ours is to purchase the medications and do the tests that come with it”. (P-5)



4.4.2 Accessibility to the HCWs

The second sub-theme “accessibility to HCWs” refers to the quality of being easy to reach. Accessibility to HCWs influences the degree of collaboration that occurs between ICGs and HCWs. Thus, the availability or otherwise of HCWs to ICGs influenced how collaboration between the two stakeholders was established. Accessibility to HCWs allows the ICG to easily reach HCWs involved in the care of the person with T2 DM to get any concerns or questions they may have addressed.

Participants had varied responses with regard to accessibility; some participants were of the view that HCWs were easily accessible to the ICG whilst others said accessibility to HCWs was difficult. In exploring this concept, two sub-themes namely; “easy access to HCWs” and “difficulty with access” emerged.

Easy access to HCWs

In this study, accessibility to HCWs by ICGs was reportedly easy. Participants explained that nurses were more accessible to ICGs of persons with T2 DM than doctors. They added that nurses were stationed on specific wards as opposed to doctors who had more than one ward under their care and as such, nurses were easier to find. They however added that accessibility to HCWs was also dependent on how busy or otherwise the HCW was.

They further added that accessibility depends on the schedule and workload of the HCW. Some said that they either had to wait for the HCW who was busy to be done with the responsibilities they have at hand or were directed to someone else to have their issue addressed.

“It is easier to get access to a nurse than a doctor. The nurses are stationed on the ward whilst the doctors move from one ward to the other”. (P-19)

“When I (ICG of a person with T2 DM) have a concern, I can easily go to the nurses’ station and speak to any nurse there about it”. (P-6)

“Sometimes when the nurses or doctors are busy, you have to wait around for them or the ICG is directed to another person who can help”.
(P-8)

Difficulty with access

Other participants however recounted that access to HCWs was difficult. Participants explained that doctors may be accessible during certain times of the day and if a caregiver can come early in the morning, they may meet the doctor but at other times, the doctor may be unavailable and they are asked to wait till a later time. In instances where doctors were unavailable, ICGs channelled the concerns they have to the nurses on duty.

“I (ICG) have to wait around for the doctor to come. If you (a relative of a person with T2 DM) come early, you will meet a doctor to have your concerns addressed. But in the afternoon, they (doctors) may have come

and gone or you (a relative of a person with T2 DM) can wait for them in the evening". (P-8)

"I (ICG) don't get to see the doctors all the time because I come during the visiting times". (P-15)

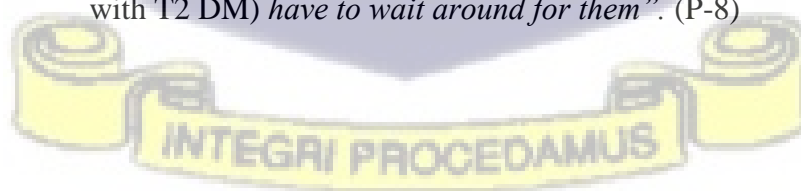
"You (a relative of a person with T2 DM) don't see the doctors around as much as you see the nurses so they (nurses) are the ones we channel our concerns to". (P-16)

Some participants however acknowledged the busy nature of HCWs and noted that when doctors and nurses are busy with other patients, they do not have much of a choice but to wait for them to be free. Others added that doctors who may be unavailable left pertinent information with the nurses to be relayed to relatives of persons with T2 DM.

"...So difficulty with accessing HCWs depends on whether they (HCWs) are busy or not". (P-13)

"...Sometimes if there is any information to be given, they (doctors) write it down and when we (relatives of persons with T2 DM) come, it is relayed to us by the nurses on the shift". (P-8)

"...Sometimes when the nurses or doctors are busy, you (ICGs of persons with T2 DM) have to wait around for them". (P-8)



4.4.3 Attitude of HCWs

“Attitude of HCWs” emerged as the third sub-theme under partnership with HCWs. Attitude refers to a particular feeling or way of behaving about something. The attitude of HCWs and ICGs impacts the relationship built during the interaction of both parties and determines to a large extent how fruitful the partnership between ICGs and HCWs will be. Participants held the view that the attitude of HCW has positive and negative aspects.

Positive aspects included times when the HCW was approachable, ready to listen, had empathy for the ICG’s situation and were patient with the ICG.

Participants explained that some HCWs were easily approachable and ready to listen to their concerns and attend to their needs. When they needed someone to come to the bedside of the patient with T2 DM during visiting hours to see what the particular concern of ICGs was about, HCWs especially nurses quickly obliged. They however added that doctors had a listening ear as compared to nurses. They further added that some HCWs were empathetic to the plight of the ICG and could tell when the condition of the person with T2 DM was having a toll on the ICG.

Nurses in this instance offered to help them in carrying out some of their roles such as the grooming of the person with T2 DM.

“When I (ICG of a person with T2 DM) have a concern, I can easily go to the nurses’ station and speak to a nurse there about it or ask them to come and see something at his (a person with T2 DM) bedside and they readily oblige”. (P-6)

“...Compared to some nurses, the doctors really have a listening ear”.

(P-8)

“Nurses are also empathetic towards us the caregivers and can tell when the ailment of our relative (person with T2 DM) is also having a toll on us. Some lend a helping hand to continue grooming needs or whatever needs we have”. (P-6)

Whilst the role of the HCW was deeply appreciated by most ICGs, the ICGs were of the view that HCWs should be patient with them when it comes to healthcare situations. They attributed any altercation that may occur on their part to the stress of caregiving.

“... A bit of patience with the caregiver is needed. Caregiving is not easy, we (ICGs) are not saying pamper us but we want a bit of patience to be exercised when dealing with us”. (P-19)

Negative aspects of the HCWs attitude according to ICGs involved negative demeanour and reactions to questions such as anger or displeasure, rude HCWs, HCWs not being empathetic and situations where the ICG was blamed for the state of the person with T2 DM. Participants were of the view that HCWs exhibited displeasure when they asked them certain questions. They said they did not know if HCWs did not know what they were asking about. A fifty-four-year-old sister of a person with T2 DM had this to say:

“When I (ICG of a person with T2 DM) ask them (HCWs) questions ...I do not know if they do not know about what I am asking. Some of them become annoyed”. (P-3)

Some participants added that the demeanour of HCWs sometimes makes ICGs of persons with T2 DM regret asking them certain questions and in some cases; HCWs were rude to them by speaking to them in a harsh manner.

“...how some (HCWs) will respond to your (the ICG) questions and their demeanour will make you regret asking the questions”. (P-12)

“Sometimes someone (a HCW) can speak to you (ICG of a person with T2 DM) so harshly and it is terrible because this person is being rude to you but that is not how HCWs are supposed to behave”. (P-10)

They further added that some HCWs were not empathetic to their situation. They explained that the role of the HCW was to tell the ICG or relative of the person with T2 DM what pertains to the condition of the patient. It was not the job of HCWs however to empathize with the ICG.

“...it feels like HCWs (of persons with T2 DM) are doing their work so there is no need or room for empathy”. (P-1)

“...HCWs are not empathetic, theirs is to tell you (ICG) what the situation is and what can and cannot be done to solve it”. (P-13)

Some participants added that in situations where the person with T2 DM was brought to the hospital in an ill state, HCWs blamed them for the state of the patient. A thirty-six year old daughter of a person with T2 DM had this to say:

“...So when we (relatives of a person with T2 DM) came to the medical emergency, she (a person with T2 DM) was unconscious and the nurse

talked a lot expressing displeasure. This made me (relative of a person with T2 DM) feel so bad. Up till now, I haven't gotten over it. It was as though we were not taking care of her and brought her in a bad state".

(P-5)

4.5 Recognition of the role of the ICG

The second research objective was aimed at ascertaining ICGs account of how HCWs recognize their caregiving role and help build their resilience. The theme “recognition of the role of the ICG” refers to the ways HCWs acknowledge the role and contributions of its ICGs in the caregiving of persons with T2 DM. Participants were of the view that knowing their role and same the roles being acknowledged by HCWs went a long way to encouraging them during the performance of their caregiving role. It further urged them to go on even when caregiving for persons with T2 DM was difficult.

Exploring the theme “recognition of the role of the ICG” involves awareness of the role they are expected to play in rendering care to persons with T2 DM and acknowledgment of the input of ICGs. Two (2) sub-themes emerged namely; “awareness of the role of the ICG” and “acknowledgment of ICGs”.

4.5.1 Awareness of the role of the ICG

The first sub-theme “awareness of the role of the ICG” refers to being knowledgeable of the responsibilities expected of ICG with regard to caring for persons with T2 DM. Participants added that being aware of what was expected of them gave them foresight into what the caregiving process for persons with T2 DM was like. They added that they

were aware of the role they play in contributing to the health and well-being of persons with T2 DM.

Dependence for activities of daily living (ADL)

Dependence refers to the state of relying on someone for support to complete ADL. In this study, ICGs of persons with T2 DM were reportedly aware of the roles expected of them in caregiving. They explained that such roles included dependence on them to complete the activities of daily living for persons with T2 DM and helping them to keep to the dietary plan and medications given to them by HCWs as well as helping them honor their review appointments with the HCW.

The majority of participants stated that they provided little assistance to their relative with T2 DM. This was because persons with T2 DM did not depend on them to complete their ADL. As a result, they played a supportive role and ensured that persons with T2 DM were eating according to the diet plan given, taking their medications as they should and honoring their review dates with the doctor.

“...My mum has been carrying out her ADL on her own; takes her medications herself and cooks for herself. She only needs help with honoring her review dates...” (P-5)

“I (husband of a person with T2 DM) ensure she does not eat anyhow and sticks to what she has been told to eat”. (P-4)

“I (the son of a person with T2 DM) make sure she does not run out of her medications and she attends her scheduled appointments. She does

not rely on me (the son of a person with T2 DM) to take care of her, she attends to her ADL on her own". (P-13)

Some participants however said the degree of dependence changed when their relative with T2 DM became ill as they took over completing the ADL for them and attending to any needs they had in between.

"...but since she (person with T2DM) became weak, I see to her grooming needs, cook her meals for her and ensure that she has taken her medications. I cater for any concerns in-between". (P-5)

"Before her condition took an ill turn, she could carry out most ADL on her own; all we (relatives of a person with T2 DM) needed to do was to carry her water to the bathroom and she baths on her own. However, when her condition took an ill turn, we had to carry out her ADL, bath and feed her and change her diaper and attend to whatever needs she may have in between". (P-1)

4.5.2 Acknowledging the ICG

The second sub-theme "acknowledging the ICG" refers to ICGs being recognized for the work they are doing by HCWs. Participants were of the view that they were adequately recognized and appreciated for the role they play in the caregiving continuum by HCWs. Being appreciated served as a source of encouragement for them to forge on in the journey of caregiving.

Recognizing the ICG

Participants recounted that recognizing them was done through calling the mobile phone numbers they provided during the folder registration process and those taken by the admitting nurse when they presented to the ward from the medical emergency for the further management of their relative with T2 DM. After ascertaining how they are related to the person with T2 DM, the HCW goes on to say the reason they called.

A forty (40) year old sister of a person with T2 DM had this to say:

“We (relatives of a person with T2 DM) provided our phone numbers during the registration process for a folder and the nurses took the same from us when we got here (the ward) so we are called when there is a need”. (P-18)

Some HCWs recognized ICGs by having the contact number of ICGs and calling them when there was a prescription written or investigations to be done.

“...one of his (person with T2 DM) doctors has my (ICG) number so when they write a prescription for him and I am not around, he calls me that he has left a prescription for me at the ward so I should go for it and buy the drugs when I come around”. (P-6)

“...I (the ICG) sometimes get a call from the doctor when for a test or medication to be done or purchased and I am not around. That is how I am recognized as a caregiver”. (P-17)

Additionally, the nurses on the ward took notice of who usually cares for a particular patient and hence easily recognizes who the ICG is related to. A fifty-four year old sister of a person with T2 DM had this to say:

“I am acknowledged as a caregiver and the nurses know that I am the one who is usually around to take care of her”. (P-3)

Appreciating the role

Participants were reportedly appreciated by HCWs when they purchased all the prescribed medications and did all the tests requested by HCWs for their relatives with T2 DM.

“When HCWs come and I (ICG) have bought the medications and done the tests required, they appreciate my input in getting them done”. (P-13)

“They (HCWs) are particularly happy if he (a person with T2 DM) has not run out his medications and has done all requested tests”. (P-14)

In other instances, other family members and friends appreciated the ICG when the person with T2 DM appeared neatly groomed in bed. Participants appeared happy when they were commended in this regard.

“When other visitors or family members come and he (a person with T2 DM) is neatly groomed in bed, they appreciate the effort I have put in”.

(P-15)

“The nurses appreciate how we (relatives of a person with T2 DM) always come to visit her (a person with T2 DM) and ensure she is well groomed and has everything she needs”. (P-19)

Acknowledgment from HCWs, other family members and friends had positive effects on the ICGs of persons with T2 DM as they saw it as a way of others appreciating their efforts and urging them to continue their good work when the going was tough and they wanted to give up. Some ICGs said acknowledging their efforts meant their services were appreciated and not in vain.

“It makes me (ICG) feel good that someone (other family members or friends) is at least appreciating the time and money I have spent. It also helps me carry on even when I want to give up”. (P-16)

“It makes me feel like sacrificing my time is being appreciated and not in vain”. (P-18)

“Appreciation like that keeps you (the ICG) going even when the going is tough. You know that you are doing something to help and it’s acknowledged by those who matter”. (P-17)

A sixty-seven (67) year old husband however added that though being appreciated is essential; he will still care for his wife with T2 DM whether he was appreciated or not as his wife will do the same for him if he were to be the sick one.

“When we (family of a person with T2 DM) are appreciated, we feel happy that our effort is recognized but without it, we still go about doing

what is expected of us because my wife will do that if she were in our shoes". (P-19)

4.6 Building resilience in ICGs

The theme “building resilience in ICGs” refers to the ability of ICGs to recover quickly from difficult situations through education and improving their skill set when it comes to caring for persons with T2 DM. It involves having the know-how to deal with situations that come up during the caregiving journey of a person with T2 DM. Thus for ICGs to build resilience; there is the need for them to be equipped with the needed knowledge and skills required for the caregiving role.

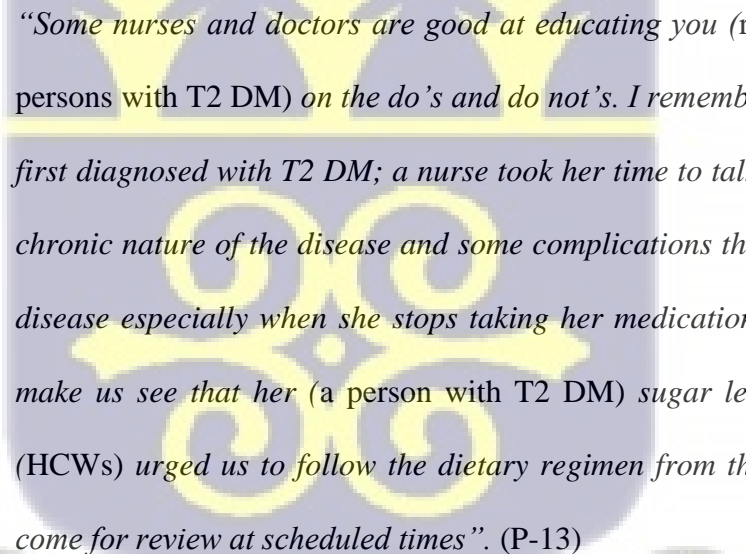
Exploring the theme “building resilience in ICGs” involves HCWs educating ICGs of persons with T2 DM on care regimens such as diet, medications, do’s and do not’s and teaching ICGs what to expect as far as the condition is concerned. This prepares them on what to expect at home post-discharge and what to do in dicey care situations. Participations reportedly found educating them a great resource during caregiving.

“Building resilience” also involves caring for the well-being of ICGs of persons with T2 DM. Caring for the well-being of ICGs of persons with T2 DM entails health promotion practices with the intending to ensure the good health of ICGs which inadvertently translates into the care of persons with T2 DM. The need to find rest periods and rotate care between ICGs of persons with T2 DM is emphasized. Two (2) sub-themes namely “education from HCWs” and “concern about the welfare” (health promotion) of ICGs emerged.

4.6.1 Education from HCWs

The first sub-theme “education from HCWs” refers to the process where ICGs receive care instructions from HCWs and acquire skills to take care of persons with T2 DM. Education serves as an avenue for ICGs to gain the needed skill set and confidence required on the long journey of caregiving.

Many of the participants were of the view that some HCWs were good at educating them on what to do and not do regarding caring for the person with T2 DM, the nature of T2 DM, its complications, consequences of non-compliance with drugs given, dietary and scheduled review appointments, signs and symptoms of hypoglycemic episodes and reinforced dietary compliance.



“Some nurses and doctors are good at educating you (relatives/ICGs of persons with T2 DM) on the do’s and do not’s. I remember when she was first diagnosed with T2 DM; a nurse took her time to talk to us about the chronic nature of the disease and some complications that come with the disease especially when she stops taking her medications and what will make us see that her (a person with T2 DM) sugar level is low. They (HCWs) urged us to follow the dietary regimen from the dieticians and come for review at scheduled times”. (P-13)

“They (HCWs) taught me...the kinds of food she (person with T2 DM) has to eat. The dieticians also came to talk to her and reinforce the do and do not’s concerning her diet to help regulate the sugar levels”. (P-4)

Participants added that they were educated on the use of the glucometer, the kinds and quantity of food to give to the person with T2 DM, what to expect whilst at home and what to do in cases of a health emergency.

“They (HCWs) taught me (ICG of a person with T2 DM) how to use the glucometer...the kinds of food to eat and the quantity she (a person with T2 DM) to consume. (P-4)

“HCWs taught us (family of a person with T2 DM) ...what to expect whilst at home and what to do in those circumstances”. (P-14)

4.6.2 Health promotion (Concern about welfare)

ICGs are pseudo-patients who require the care and attention of HCWs. A special interest needs to be taken in persons who are responsible for the post-discharge care of persons with T2 DM. This goes a long way to ensure good health and better condition outcomes for both persons with T2 DM and their ICGs. Caregiving is stressful and ICGs bear the brunt of it as they have to care for the person with T2 DM who may in some circumstances be dependent on them to complete their activities of daily living and somehow still maintain their personal work-life balance. This coupled with personal problems/challenges the ICG may have can take a toll on ICGs and it is the responsibility of HCWs to be interested in these persons to ensure they are in the best of health as their health outcomes inadvertently affect the health of the person with T2 DM.

“She (a person with T2 DM) has been falling sick but this current episode is a little more serious than previously so it is challenging and

very stressful. It is not easy to take care of a sick person. If you (the ICG of a person with T2 DM) do not take care; you may end up falling sick after the admission period is over". (P-7)

"Caregiving is not easy...when the ICG (of persons with T2 DM) is stressed; they stress the patient as well". (P-16)

"...some ICGs (of persons with T2 DM) may be anxious about the condition of their relative with T2 DM or have a particular problem/challenge personally coupled with the illness. This affects their wellbeing". (P-12)

All of the participants of the study said that HCWs do not show concern for their welfare. They were of the view that HCWs were concerned about the person with T2 DM and the job of the HCW is to tell the ICG what pertains to the condition of the person with T2 DM. How the ICG of persons with T2 DM achieves the "role-life balance" is not their duty. Participants added that HCWs were not concerned about where they slept if they did not go home, how they are faring or if they had eaten.

"Their (HCWs) main concern is with the sick person (a person with T2 DM) and not you (the ICG). How you get by is up to you". (P-16)

"No one (no HCW) asks how we (ICGs of persons with T2 DM) are truly faring and how we are balancing coming here all the time with our personal lives". (P-3)

“Mostly the attention is on the person who is on admission (a patient with T2 DM), about 99.9% of the time. Hardly will you (the ICG) get anyone (HCWs) asking if you have eaten and where you sleep if you do not go home”. (P-1)

It is imperative therefore that HCWs teach ICGs how to take care of themselves so they give off their best to the person with T2 DM. Self-care and health promotion techniques take various forms such as getting other people/ family members involved in the care so each one takes turns in caring for the person with T2 DM so the other person can get some rest. A thirty-six (36) year old daughter of a person with T2 DM had this to say:

“My sister and I take turns in caring for our mother, she comes in the morning and I come in the afternoon”. (P-16)

4.7 Navigating the healthcare system

The third research objective was aimed at describing ICGs experience of navigating the healthcare system as well as the culture and context in which they provide care to persons with T2 DM. The theme “navigating the system” refers to how ICGs of persons with T2 DM find their way to a specific place or department in the hospital to access their services. Such departments in the hospital include radiology, pharmacy, dietetics and laboratory. Participants were of the view that navigating the system came in the form of directions from HCWs to the departments aforementioned where certain services were rendered. It also involves referral from the HCWs to facilities closer to the ICG of persons with T2 DM or one of the choosing of the ICG. In exploring the theme

“navigating the system”, two sub-themes emerged namely “direction from HCWs” and “referral from HCWs”.

4.7.1 Direction from HCWs

The first sub-theme “direction from HCWs” refers to HCWs guiding ICGs to a specific department where certain services they require are rendered. The majority of participants said HCWs willingly provided directions to facilities where services are rendered in the hospital and showed ICGs where to go for review on discharge. Direction to departments in the hospital ensures that the services provided to persons with T2 DM and their ICGs appear seamless.

Direction to facilities where services are rendered

HCWs reportedly directed ICGs of persons with T2 DM to departments such as the laboratory, pharmacy, radiology and dietetics. Participants appreciated that such directions were given willingly by HCWs when asked. ICGs and relatives of persons with T2 DM were willingly directed to these departments by HCWs who required services such as laboratory tests and x-rays done as well as medications to be purchased. This experience was the same for those who were new to the system of the hospital and those who were already familiar with the system. ICGs were also directed to the dietetics department where they sort the services of dieticians in planning meals for their relatives with T2 DM.

“...I (ICG) was shown where the pharmacy was. Because this is our first time coming here (the 37 military hospital), I asked for where the

pharmacy and the laboratory and I was shown the place. We were shown the x-ray department too”. (P-7)

“...they (HCWs) showed us where the pharmacy and the laboratory are. They showed me (a relative of a person with T2 DM) two different pharmacies in the hospital and that when I do not get the medications at one point, I can go to the other and check to see if they have what I am looking for”. (P-6)

“We (relatives of persons with T2 DM) were given directions to the dietetics department for which we are most grateful”. (P-15)

A seventy-year-old husband of a person with T2 DM added that they were shown which part of the Out-patient’s department (OPD) to go to when it was time for the review appointment post-discharge.

“We (relatives of persons with T2 DM) were shown which part of the OPD to go to and when to go to for review”. (P-2)

4.7.2 Referral from HCWs

The second sub-theme “referral from HCWs” to other facilities refers to situations where ICGs prefer to continue care at a facility closer to them or at a facility based on a personal preference or that of the family of the person with T2 DM. Many reasons could account for a referral and it is in the right direction for an ICG to ask the HCW for one. Some of the reasons cited are distance, financial constraints and personal/ family doctors to continue with the care. It is therefore important that HCWs assist ICGs who may

request such to ensure the smooth transition of the person with T2 DM to another provider.

Referral to closer facilities

In this study, participants were of the view that referrals could be made to closer facilities to ensure continuous care. Referral to the dietician was on the list of referrals to other providers. The aim of such a referral was to collaborate with ICGs of persons with T2 DM to make a well-structured meal plan for the person with T2 DM to help with the overall aim of good glycemic control. Diabetes presents with many complications and as such, based on the symptoms the person with T2 DM presents with, the HCW can call into other providers to weigh in on the management of the condition. One such provider is the dietician.

“We (relatives of a person with T2 DM) were referred to a dietician to help plan his diet”. (P-15)

“We were also informed the dieticians will come and see her today”. (P-7)

“We were asked to see the dietician to be taught what food she has to eat”. (P-1)



Direction to preferred facilities

A fifty-one year old wife of a person with T2 DM added that she would prefer to be referred to a facility closer to her home. She explained that distance from her home to the 37 Military hospital was a constraint as she had to sit in long hours of traffic with her husband who is ill before they can get to the hospital. Hence a referral to a facility closer to her home will be much more helpful.

“When we are discharged, I hope to get a hospital in Kasoa where they (HCWs) can take care of him expertly like HCWs do here (in 37 military hospital) and go for review appointments there. This is because of where we live and the hours we spend in traffic just to get here (37 military hospital)”. (P-6)

4.8 Culture and context of care

The theme “culture and context of care” refers to the environment in which care is rendered. The culture an informal caregiver belongs to and the context (situational/familial) in which the ICG finds him or herself influences whose responsibility it is to care for the person with T2 DM. It also informs the kind of support such a caregiver is likely to have and receive. Exploring the theme “culture and context of care” involve whose responsibility it is to care for the person with T2 DM and the support system such an ICG has at his or her disposal. Two (2) sub-themes namely “duty to care” and “support system” emerged.

4.8.1 Duty to care

The first sub-theme “duty to care” refers to whose responsibility it is to care for the person with T2 DM. Participants were of the view that the immediate family of the person with T2 DM was responsible for his or her care with the extended family playing a supporting role.

Responsibility for care

Participants said it was the duty of the immediate family of the person with T2 DM to take care of them, thus, his or her wife, husband and children. They however added that the extended family should be informed about the condition. They added that everyone now had a family and it was not right to burden someone else with the care of a relative with T2 DM.

“...the family is responsible for the sick person (person with T2 DM), especially the sick person’s spouse and children”. (P-17)

“It is the nuclear family first and foremost but the extended family has to be informed. They can assist if they want to”. (P-15) *“Currently, everyone has their family so no one depends on those outside the family much, unless you (members of the nuclear family) want the extended family to know about the ill health of a member so they can offer assistance if any.*

When one is sick, his or her immediate family members take care of him or her. We (relatives of a person with T2 DM) do not burden anyone (other relatives outside the nuclear family)”. (P-5)

Other participants were of the view that if the person with T2 DM did not have any family of their own (i.e. husband, wife and children) and in instances where the person with T2 DM had children but they were younger or not financially capable of taking care of the person with T2 DM; then the responsibility lies with the family of the person with T2 DM to take care of such a person.

“If the person with T2 DM has no children; his or her siblings or extended family takes over the care”. (P-14)

“Maybe the children of the person with T2 DM are not well to do or at not up to the stage where they can take care of someone else (a person with T2 DM), the siblings step in and take up that role”. (P-3)

A thirty-four year old sister of a person with T2 DM also added that in instances where the children of a person with T2 DM were not geographically located in Ghana, then it was the duty of the family of the person with T2 DM to take care of him or her.

“...the family is responsible for the care of the person with T2 DM, especially one’s spouse and children but because her (the person with T2 DM) children are not in the country, I take care of her. Her children send me money to ensure everything needed is purchased”. (P-17)

4.8.2 Support system

The second sub-theme “support system” refers to a network of people who provide emotional and physical support to the ICG of a person with T2 DM. Support systems

came in varied forms according to participants and involves the extended family, siblings, hired hands and friends of persons with T2 DM. The purpose of a support system is to make the burden of caregiving for persons with T2 DM lighter and more bearable.

Helping hand

The extended family served as a major support system for the majority of ICGs and they were complemented by hired hands and friends for support. These persons lent a helping hand to ICGs during the performance of their caregiving role. Help from the extended family, hired hands and friends in any form made the person with T2 DM glad.

“Both of our (ICG and the person with T2 DM) families help out. We have some friends in our neighborhood who have been helping with the cooking of her meals whilst she is on admission”. (P-4)

“...His siblings and other family members come around to visit which is good. I am sure he (the person with T2 DM) gets happy to see family and friends during visiting hours”. (P-15)

“We (ICG and the person with T2 DM) also have a home care nurse who helps with the care”. (P-11)



Form of help

Support from family, friends and hired hands came in various forms; physical, financial, emotional and spiritual. Some prayed with the person with T2 DM and their ICG whilst others offered money to augment the expenses involved in the care and helped with wound care. These forms of help shed some of the load off the ICG of persons with T2 DM.

“They (support system) pray with us (ICG and person with T2 DM) and offer us emotional and psychological support”. (P-15)

“I (ICG of person with T2 DM) mostly foot the bills for her medical care, sometimes I get support financially from my cousin and uncle”. (P-9)

Others also helped with wound care in persons with T2 DM who had a wound.

“We (ICG and person with T2 DM) also have a home care nurse who comes to do the dressing of her (person with T2 DM) wound every time”. (P-11)

4.9 Summary of chapter

The study focused on exploring preparation needs of informal caregivers of persons with T2 DM at the 37 Military Hospital. The perceptions of twenty participants were obtained using a semi-structured interview guide and their responses were analyzed by the thematic content analysis approach. The key findings of the study are as follows:

1. HCWs reportedly communicate to ICGs of persons with T2 DM in languages that they easily understand and, in some instances, resort to the using of vernacular. Complex terms were also explained to them to aid understanding into the condition. Some participants were partnered with by HCWs in the care management whilst others were not. In instances where ICGs were not partnered with, they described the care as uncoordinated
2. ICGs were aware of their role in the caring of persons with T2 DM and appreciated being recognized by HCWs and other family members.
3. Resilience was built in ICGs when HCWs educated them on what to do and not do regarding care, the nature of T2 DM, its complications, consequences of non-compliance with drugs given, dietary and scheduled review appointments, signs and symptoms of hypoglycemic episodes and reinforced dietary compliance
4. HCWs willingly directed them to departments where services were rendered such as the laboratory, pharmacy, radiology and dietetics. They also referred them to other providers with particular mention of dietitians. Some preferred referral to facilities closer to their homes as the time spent in traffic to get to the hospital was a constraint.
5. It was the responsibility of the immediate family of a person with T2 DM to take care of him or her but the extended family has to be informed and offer support when necessary. Other forms of support the ICG had were from friends and hired hands who helped emotionally, physically and psychologically.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

This chapter draws a relation between the existing literature and the findings of this study. The study sought to explore the preparation needs of informal caregivers of persons with T2 DM at the 37 Military hospital. The chapter is discussed in the order of the major themes developed in the study. The themes that emerged from the study included communication between HCWs and ICGs, partnership with HCWs, recognition of the role of the ICG, building resilience in ICGs, navigating the healthcare system and culture and context of care. The Caregiver-centered care competency model by Parmar et al. (2020a) also guided the study. The demographic characteristics of the participants are presented first and subsequently the themes and sub-themes.

5.1 Demographic characteristics of Participants

The ages of the participants ranged from twenty-two (22) to seventy (70) years indicating that all participants involved in the study were adults. This showed they were mature enough to take up the caregiving role and were likely to have resources to help them in their process of caregiving (Dang et al., 2022; Lin & Wolf, 2020). Fourteen (14) of the participants were females and six (6) were males indicating more females tend to take up a role in caregiving as compared to their male counterparts. Females are seen as having the wherewithal to care for others than males (Dixe et al., 2019; Jacobs et al., 2017; Sharma et al., 2016).

Fifteen (15) of the participants were from the immediate family of the person with T2 DM. They comprised 8 daughters, 4 husbands, 2 wives and a son. This showed that people constituting the immediate family members of the person with T2 DM especially the children were involved in taking care of one of their parents (Dixe et al., 2019; Lin & Wolf, 2020). Five (5) of them were extended family and took the form of a sister and a nephew. This showed that the duty of care for the person with T2 DM was the primary responsibility of the immediate family and members of the extended family played a supportive role (Dixe et al., 2019; Eriksson et al., 2021).

Furthermore, the participants were all educated with 2 of them having a basic level of education and eight having tertiary education. This showed that they could understand the treatment regimen, the impact of caregiving as well as the critical role they play in partnership with HCWs. This boosted the confidence of ICGs in approaching HCWs to address their concerns, understand treatment regimen communicated and make informed decisions (Dauvrin et al., 2017; Williams, 2017). Five (5) among the participants have been engaged in caregiving of patients with T2 DM for more than 5 years and the remaining fifteen (15) have been providing care for 5 years or less, with the least period of care being one year. This showed that the ICGs of persons with T2 DM had a fair idea of what the disease condition was, their roles, the consequences of care and how to take care of their relatives (Quinn & Toms, 2019; Sacco et al., 2022).

5.2 Communicating between HCWs and ICGs

The theme of communication between HCWs and ICGs comprised of the nature of communication between the two parties and it included clarity of communication,

sharing of information and follow-up phone calls between HCWs and ICGs. These were explored during the interviews to gain an understanding of the nature of communication from the perspective of the ICG.

In exploring the perception of ICGs on how they are communicated with by HCWs, the findings of the study suggested that participants had a positive perception of the concept and deemed communication an important resource in the performance of their caregiving role to persons with T2 DM. Participants explained that they valued interactions with HCWs especially when clear language was used in communication and they were spoken to in a language they understand with no complex terms. Additionally, participants said that where medical jargons and phrases were used, the HCW ensured that ICGs understood what was being said by explaining what the jargon or phrase meant. Communication with simple language devoid of complex terms builds trust between HCWs and ICGs and gives ICGs the confidence to approach the HCW with concerns or situations they did not understand (Galante et al., 2021).

Communication should be devoid of complex jargon to ensure understanding. Persons with T2 DM, their families, their caregivers and those at risk for developing diabetes require and deserve communications that are factual, inclusive and concise to aid understanding. These findings are consistent with studies that explored the nature of communication between ICGs and HCWs (Galante et al., 2021; Nanayakkara et al., 2018; Wolff et al., 2020).

Participants were of the view that when providing care for persons with T2 DM, communication is crucial because it allows the ICG to be aware of and comprehend

what is going on with the care recipient (the person with T2 DM). Being communicated with by HCWs also affords them the opportunity to be part of the health care team through information sharing. The quality of caregiving is significantly impacted by communication between the caregiver and patient, family, and HCWs, and serves as a means of information sharing between the ICG and the HCW. Sharing information is a quality that stems from the notion that both HCWs and ICGs have special, priceless knowledge and experiences (Jang, 2020; Wittenberg et al., 2017).

Participants had varied responses to information sharing with HCWs. Some narrated that information sharing between HCWs and ICGs was done voluntarily whilst others were of the view that information was not shared willingly and as such the ICG had to chase the HCW for explanations into tests requested and the outcome of tests done. They added that they were not told the reason behind the investigations requested and even when the investigations were carried out, they still had to press the HCW to tell them the outcome of the test and what it meant going forward. At other times, drugs and investigations were requested without explaining the reason for them to the ICG.

Caregivers have needs and desire for more information, assistance, and education during interaction with HCWs. The healthcare system appears to place insufficient emphasis on ensuring that everyone involved in patient care understands the meaning and implications of treatment and coordination. Although the service is designed to see individuals holistically, healthcare providers focus on the conditions of the patients forgetting the ICG leading in some circumstances to altercations (Anker-Hansen et al., 2018; Lilleheie et al., 2020a).

Altercations happened between ICGs and HCWs when ICGs felt they were misunderstood, did not know what was going on with the care recipient and they did not understand what was being communicated. Additionally, when there was a lack of communication regarding advance care planning, when words were misconstrued and ICGs felt HCWs were being dismissive, and when there were differences in how the disease process is understood, HCWs and ICGs found themselves misunderstood (Wittenberg et al., 2017).

Furthermore, ICGs added that follow-up calls to check on them and the person with T2 DM would go a long way to help them in their caregiving journey. Intermittent follow-up calls were preferred by some ICGs whilst others preferred a reference number to call in case they had questions or were unsure of what to do in a situation involving the person with T2 DM. The ICGs however appreciated the busy nature of the work of HCWs and the number of patients the HCW may have to see at any given time which may have an impact on the tendency to follow -up on each of them through calls. However, follow-up checks on patients post-discharge reduced the frequency of readmission and increased the length of time outside of the hospital (Mwachiro et al., 2019). This underscores the need for HCWs to place priority on following up ICGs and their patients with T2DM.

Lastly, some ICGS said the unwillingness of some HCWs to share information made them decide not to follow up on HCWs for information. These ICGs rather trusted that HCWs were knowledgeable in their field and know what was best for their relative with T2 DM hence leaving the decision-making to them. They thus trusted that HCWs know what they are about and will ensure that their care recipient gets the best of care hence

whatever decision is taken by HCWs is the right one. This led to learned helplessness on the part of ICGs where they saw themselves as powerless in the healthcare continuum and as such trusted that HCWs will take the right decisions for their relatives in their care and were okay to not get involved in the decision-making (Garvelink et al., 2017).

It is therefore imperative that HCWs remember all the facets of communication (verbal and non-verbal) and strive to inculcate these whilst interacting with ICGs of T2 DM. Communicating in clear languages without the use of complex terms and where such terms are used, they are explained to the ICG providing them the avenue to understand the complex nature of the caregiving process. The act of sharing information and following up on ICGs and persons with T2 DM outside of their scheduled review appointments through calls also plays an important role in management of patients with T2DM.

5.2 Partnering with HCWs

The theme partnership with HCWs focused on the degree to which HCWs involved ICGs in the caregiving process and included collaboration with HCWs, accessibility to HCWs and the attitude (positive and negative) of HCWs. In exploring the extent to which ICGs are involved by HCWs in the caregiving role whilst in the hospital setting, the participants had varied responses. In general, ICGs valued being partnered with by HCWs in providing care although not all of them experienced such partnerships. They bemoaned the relegation of such an important role in the caregiving continuum to just buying medications and doing tests. To meet the needs and preferences of persons with T2 DM, collaboration between ICGs and HCWs must be encouraged in modern

practice. These collaborations must emphasize the necessity for a friendly working relationship between HCWs and ICGs by building mutual respect and recognizing each other's valuable contributions as equals in care (Hoek et al., 2021).

In exploring how much ICGs were involved in the care management by HCWs; some participants were of the view that they were involved every step of the way in the management of the condition of their relative with T2 DM. They explained that HCWs involved them in every step of the way through various means. Such means included; first HCWs speaking to them before certain key decisions in the caregiving process were taken. Secondly, the expect HCWs to have a meeting with them to explain to them the condition, prognosis, way forward and alternatives involved in the management of the person with T2 DM as well as allowing them to choose the route to be taken as far as management of the person with T2 DM was concerned. In instances where ICGs could not arrive at a decision immediately or had to consult with other family members to arrive at a decision, HCWs gave them ample time to do that. Partnership with HCWs is teamwork in which informal caregivers would be informed frequently and, above all, participate in decision-making (Hagedoorn et al., 2020).

On the contrary, other participants were of the view that they were not involved by HCWs in the care management of their relative with T2 DM. They said decisions involving the care management of their relative were usually taken by the team of doctors responsible for the care. They added that the part ICGs played in such instances was to make funds available to ensure the plans proposed by HCWs were executed. Thus, they were not involved in arriving at the plan but were rather told what the plan was and how it was going to be executed in the form of investigations and purchasing

the needed drugs. In other instances where ICGs were not told the plan but medications were prescribed and tests were written for them to do, they described the care as uncoordinated with ICGs on one side and HCWs on the other. Similarly, Garvelink et al. (2017) found that numerous ICGs expressed unfavorable sentiments toward decision-making and its effects; even years after the decision had been taken. Many of them expressed doubt and remorse, which shows that they were either underprepared for or under-supported during the decision-making process. Other caregivers believed that there was not enough time for decision-making. In addition, caregivers believed they were powerless in the situation (Garvelink et al., 2017).

Accessibility to HCWs played a huge role in collaboration with ICGs in the caregiving process. The easier or otherwise it was for ICGs to have access to HCWs, the better or otherwise the partnership. Participants in expressing their views on accessibility to HCWs said that some HCWs were more accessible than others. They explained that nurses were more accessible than doctors and they based this on the nature of the job of these two HCWs and how nurses outnumber doctors in any hospital setting. They added that there were nurses always available at the nurses' station to speak to as opposed to the doctors who were not stationed on a particular ward. Thus in most countries, nurses outnumber doctors, with an average of three nurses for every doctor (Karan et al., 2021).

The attitude of HCWs also affected the partnership formed between them and ICGs. Participants were of the view that some HCWs were friendly, had a welcoming nature and were always ready to listen to and address concerns ICGs of persons with T2 DM had. Some HCWs went further to give ICGs their phone numbers whilst on the other hand, some were rude, spoke harshly to ICGs, blamed the ICG for the state the person

with T2 DM was in and sometimes appeared to be annoyed when they were asked questions concerning the person with T2 DM. HCWs who were approachable, friendly and receptive to patients were valued by ICGs. Such HCWs were easily approached by ICGs and shared their concerns with them. Developing team-based solutions for improving care management of persons with T2 DM between ICGs and HCWs can be difficult as a result of disrespectful behavior. Persons with T2 DM and their ICGs are less likely to ask questions or provide important information when their confidence and that of caregivers are undermined (Grissinger, 2017; Washington et al., 2019).

Some participants however said when they shared their concerns or asked some HCWs questions, these HCWs were of the view that ICGs of T2 DM patients should be informed of what to do and appeared irritated. Participants added that these HCWs worked with the presumption that, the ICG ought to know the answer to the question they are asking considering their duration of caregiving. Disrespectful and nonchalant behavior inhibits collaboration and communication between ICGs and HCWs by weakening the capacity for critical thought, sound decision-making, and assertive communication. Disrespectful conduct is also the cause of challenges in creating team-based strategies for enhancing the treatment and care management of persons with T2 DM. The confidence of patients and caregivers is also damaged, which reduces their propensity to ask inquiries or supply crucial information (Grissinger, 2017).

Participants however added that they were blamed by the HCW for the state the care recipient was in especially when the person with T2 DM presented with high glucose readings, an infected wound, a poor state and non-compliance with scheduled reviews. This was found to be disruptive to the caregiving role and increased the burden of

caregiving. These views were supported by Doss and Popejoy (2022) where the researchers posited that guilt, anxiety and helplessness were part of the caregiving experience. However, the burden of care on ICGs of persons with T2 DM increased significantly when they were made to feel guilty for the poor state of the care recipient and when the person with T2 DM had a poor wound appearance (Doss & Popejoy, 2022).

Some participants added that their interaction with HCWs lacked empathy for their situation. They explained that HCWs did not form any personal relationship with them and kept the relationship formal; limiting the interaction to telling them what pertained to the care recipient's condition. How ICGs fared with the information provided by HCWs and the cost of care management was not the concern of HCWs. The role of HCWs was to tell the ICG what was wrong and the monetary obligation required; the psychological, physical and financial impact was left for the ICG to bear alone. These views are consistent with studies exploring the degree of empathy in the ICG-HCW interaction. The studies posited that ICGs placed a high value on HCWs being able to empathize with them, and being able to understand the unique care scenario. HCWs however on observation often suppressed their emotions when dealing with patients and caregivers and maintained a professional distance. When this was done, patients and ICGs perceived an emotionless person on the other side of the interaction. ICGs presumed the HCW does not care and see themselves as dissimilar to them; hiding behind a white coat and a degree (Wangler & Jansky, 2021; Zaki, 2020).

Courtesy and respect varied depending on the HCW's personality, level of stress, and other factors, which affected how the concerns of ICGs were handled and how they

were communicated with. In general, while some HCWs were kind and courteous to ICGs, others were not. HCWs who were attentive, sincere, generally focused on patients' and caregivers' experiences, sensitive to unmet information needs, and receptive to patients' and caregivers' possibly varied preferences were valued by caregivers of such patients (Washington et al., 2019).

Whilst the role of the HCW was deeply appreciated by most ICGs, they asked that HCWs be patient with them and tolerate their naivety when it comes to healthcare situations. They attributed any altercation that may occur on their part to the stress of caregiving and verbalized patience with them gives them the chance to approach the HCW with questions they have which can better prepare them to care for the person with T2 DM.

5.3 Recognition of the role of the ICG

The theme recognition of the role of the ICG comprised exploring whether ICGs were aware of the role they play in caring for a person with T2 DM and the impact of such recognition and acknowledgment. It involved an awareness of the role played in the caregiving process and acknowledgment of such roles. In exploring the concept of recognizing the ICG, the majority of the participants were of the view that they were adequately recognized by HCWs for the role they play in the healthcare continuum and this made them feel like they are part of the team. This is consistent with the study findings of Plöthner et al (2019) which stated that acknowledging the ICG's role ensures that they do not feel alone or isolated in their work (Plöthner et al., 2019).

Participants narrated that recognition was done through calling the mobile phone numbers they provided during the folder registration process and those taken by the admitting nurse when they presented to the ward for the further management of their relative with T2 DM. After ascertaining how the ICG was related to the person with T2 DM during the call, the HCW then went on to say the reason they called. This is supported by a study that explored the recognition of the ICG. The study findings suggested that ICGs who reported feeling well-supported while engaging with HCWs were due to their role being recognized and supported by HCWs. These results have a direct bearing on the trend to acknowledge ICGs as valuable contributors to an interdisciplinary care team who provide critical information that may be useful in directing and tracking advancements in person-centered and family-centered care (Rosen et al., 2018).

When asked how what their roles are and how they assist the person with T2 DM in completing their activities of daily living (ADL); the majority of participants stated that generally, they provided little assistance to their relatives with T2 DM when they were in a healthy state and there were no co-morbidities. This is because in a healthy state, persons with T2 DM did not depend on them to complete their ADL. Thus the role of the ICG in caring for such persons with T2 DM was to provide support, ensure they eat according to the diet plan given, take their medications, and honor their review dates. This is in line with a study on the burden of care on the ICG depending on the health of the care recipient. The study findings showed that the healthier the person who has T2 DM, the lesser the burden of care on the ICG (Kristaningrum et al., 2021). Participants however said the degree of dependence changed when their relative with T2 DM

became ill and had other co-morbidities as they took over completing their ADL for them and attending to any needs they had in between. This view was supported by research done on the intensity and impact of care of an ill care recipient on the ICG. The findings of both research posited that the intensity of caregiving with its associated psychological and physical distress increased with persons with T2 DM who were ill, had bad glycemic control, low adherence to medications and had diabetes-associated complications (King et al., 2021; Ogunmodede et al., 2019).

Another important component of recognizing the ICG of persons with T2 DM was the element of appreciating them for the care they provide. Appreciation from HCWs and other family members and friends was a big deal for the ICG. Participants explained they were appreciated by HCWs when their relatives with T2 DM had all their medications available and their tests were done as requested. In instances where the tests were not done and medications had not been purchased, HCWs registered their displeasure and stressed the need to get them to make progress with care management. Acknowledgment from HCWs, other family members and friends had a positive effect on ICGs of persons with T2 DM as this component was seen as a way of others appreciating their efforts and urging them to continue their good work. The advantages of being appreciated for the care one provides may serve as a cushion against heavy strain, promote a positive outlook on life, and provide motivation to continue providing care. This leads to a sense of pride, esteem, mastery, and accomplishment tied to the caregiver role and an existential sense of significance (Sherman, 2019).

5.4 Building resilience in ICGs

In exploring the term building resilience in ICGs, the focus was on HCWs preparing the ICG for the role of caregiving and being concerned for their wellbeing. It involved educating ICGs on the nature and care management of the person with T2 DM and teaching them health promotion strategies.

In contrast to claims that ICGs serve as a source of encouragement for persons with T2 DM to adhere to treatment regimens, ICGs were usually unprepared to fulfill this role. They did not know what to do during emergencies and some could not identify hypoglycemic symptoms. Thus more effort is required to make sure ICGs are educated and their skill set is built to ensure caregiving is successfully done (Waller & Fox, 2020).

Participants in answering how HCWs helped build resilience in them for the caregiving role, participants were of the view that HCWs educated them on what to expect with T2 DM whilst at home, the do's and do not especially with diet, emphasis on drug and review date adherence, the use of a glucometer and how to care for the person with T2 DM during an emergency as a result of T2 DM.

In exploring the concept of building resilience in ICGs, many of the participants agreed that HCWs assisted them in diverse ways in their caregiving role with particular mention of educating them on the diet of the person with T2 DM, signs and symptoms of hypoglycemia, medication and review adherence, explaining the condition to them and what can be done to make their relative with T2 DM better, the use of a glucometer and telling them the do's and do not's related to caring for persons with T2 DM. Such

education helped them build their confidence in meeting the demands of the person with T2 DM and develop a sense of being in control of management regimens through their skill set. These views were supported by research done on the role education of ICGs played in the caregiving process. The findings of the researchers asserted that the education of caregivers of persons with T2 DM reduced their physical and emotional issues in the performance of their caregiving role. Education gave them the confidence to deal with high levels of stress, feel at ease, resolve any challenges as their skills improved and fostered better interactions between caregivers and HCWs (B. L. Dhada & Blackbeard, 2019; Ghaffari et al., 2019). On the contrary, Schulz et al (2016) found that the education demands of caregivers of persons with T2 DM were not consistently met, and at best, there is inconsistent training of such caregivers in the performance of caregiving responsibilities (Schulz et al., 2016). It is therefore important that HCWs factor in the education of ICGs of persons with T2 DM, strive to build their skill set and fill the gaps in these areas prior to discharge to ensure that ICGs were well prepared for their role in the care management of persons with T2 DM.

All of the study participants said that HCWs do not show concern for their well-being and did not teach them health promotion practices that will help them balance caring for persons with T2 DM and their personal lives. They were of the view that the job of the HCW was to tell the ICG what was wrong with the person with T2 DM but how the ICG achieves “role-life balance” is not their duty. This was supported by a study by Sherman (2019) where findings suggested that the requirements of the person with T2 DM are the primary priority of the healthcare team, even if they frequently address the opinions and worries of the ICG. ICGs are at high risk for serious health problems and

cognitive, emotional, and physical decline, especially as caregiving responsibilities grow more complex over time. This is especially true when they are not mentally, emotionally, or physically capable of providing the care that is needed. Informal caregivers are frequently an at-risk group that is overlooked (Sherman, 2019).

Caring for the well-being of ICGs and teaching them health promotion strategies will ensure that ICGs are in the best state of health and able to care for persons with T2 DM. It also brings into sharp focus the need to be concerned not only for the person with T2 DM but also for whom the care is handed over to post-discharge. It is also imperative for HCWs to determine the degree of preparedness of ICGs of persons with T2 DM and fill the gaps identified using a standard measure of assessment.

5.5 Navigating the healthcare system

In exploring the concept of navigating healthcare systems, the focus was on how ICGs of persons with T2 DM moved from one department to the other to access services provided by such entities and the smooth transition from one department to the other. It involved directions and referrals from HCWs to other providers.

The majority of participants said assistance from HCWs came mainly in the form of directions to facilities where services are rendered in the hospital such as the pharmacy, the laboratory, the dietetics and the radiology departments. HCWs were described as very welcoming when asked for such directions and readily and willingly assisted the ICG with such information. ICGs of persons with T2 DM should be helped to navigate the healthcare system which may be unfamiliar to them and shown resources they can tap into to ensure efficient care. Doing this goes a long way to help the ICG know where

to go when help with the caregiving process is needed and whom to talk to (Powers et al., 2016; Wangler & Jansky, 2021).

Other ways HCWs assisted the ICG were to show ICGs where to go for review on discharge, referral to facilities close to where they reside and other providers in the care management of persons with T2 DM. This is supported by research on the flow of care between providers. The findings of the research posited that the aim of care was the eventual self-management of the condition by the person with T2 DM. Thus, there should be minimum interruptions with the flow of care, quick referrals to points of help and resources are key to ensure the caregiver and eventually, the person with T2 DM will not feel at a loss as to where to go and what to do to meet their physical, psychosocial and psychological needs (Powers et al., 2016).

5.6 Culture and context of care

In exploring the theme culture and context of care, the focus was mainly on whose responsibility it was for the care of the person with T2 DM and the support system such an ICG had at his or her disposal. The majority of participants said it was the duty of the immediate family of the person with T2 DM to take care of them; however, the extended family should be informed about the condition. Powers et al (2016) agreed with this view in their study where they asserted that it was important to strike a delicate balance between several factors to support persons with T2 DM. An interaction exists between the person and the environment in which they live, including their clinical status, culture, values, family, social and communal surroundings (Powers et al., 2016).

The extended family served as a support system for the majority of ICGs whilst others had hired hands and friends for support. Support came in various forms; physical, financial, emotional and spiritual. This was consistent with studies by Bennich et al (2017) and Sousa-Munoz (2020) who asserted that it is crucial to involve patients' families in clinical practice to target family well-being and adherence to diabetes self-management. Family life is where much self-management takes place. Due to the interdependence and mutual impact of family members and friends, it is important to understand and address the intra-family perspective of supporting and non-supportive interactions. Family members often have a substantial impact on the person with T2 DM's psychological well-being, the decision to follow medical treatment recommendations, and the ability to initiate and maintain dietary and exercise modifications through their communication and attitude (Bennich et al., 2017; Sousa-Munoz & Sá, 2020). However, in Ghana, where hospices run by professionals are virtually non-existent, ICGs such as hired help or the members of the family are sought out to give informal care. Due to obligations and busy lifestyles, primary relatives may not live with persons with T2 DM and in these cases, they are primarily cared for by a housekeeper (Owusu-Ansah, 2015).

5.8 Summary of discussion

In summary, the study identified that participants were of the view that communication between them and HCWs was crucial to the caregiving process. The participants in their narration held the opinion that it enabled the ICG to be aware of and understand what is happening with the person with T2 DM. Participants valued when they were interacted with in a language they understand and medical jargon was explained to them. They

added that follow-up calls to check on ICGs and persons with T2 DM were very essential.

Participants valued being partnered with by HCWs in providing care for persons with T2 DM although not all of them experienced it. They bemoaned the relegation of such an important element to just buying medications and doing tests. Participants appreciated being adequately recognized by HCWs for the role they play in the caregiving process and this made them feel like they are part of the team. They further added that they developed resilience when the HCW educated them on what to expect in the condition, what can be done to make their relative better and telling them the do's and do not related to caring for persons with T2 DM.

Furthermore, participants said assistance from HCWs in navigating the healthcare system came mainly in the form of directions to facilities where services are rendered in the hospital such as the pharmacy, the laboratory, the dietetics and the radiology departments and referral to other HCWs and providers based on the ICGs preference. The majority of participants said it was the duty of the immediate family of the person with T2 DM to take care of them; however, the extended family should be informed about the condition. The ICGs however, felt prepared for the caregiving role when they were educated on what to expect with T2 DM whilst at home. Thus, especially with regard to diet as well as having a reference number to call in case they have any questions and if HCWs will check up on them intermittently aside their scheduled review dates.

CHAPTER SIX
SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND
RECOMMENDATIONS

6.0 Introduction

This chapter provides a summary of the study and discusses how the research findings can be used in nursing practice, education, administration and research. The researcher's insight from the study, as well as its limitations, conclusions, and recommendations are further outlined in the chapter.

6.1 Summary of the study

The purpose of this study was to explore the preparation needs of informal caregivers (ICGs) of persons with type 2 diabetes mellitus (T2 DM) at the 37 Military Hospital. The caregiver-centered care competency model was adapted and this was used to guide the formulation of the research objectives of the study. This conceptual framework explained a collaborative working relationship between relatives/families of persons with T2 DM and HCWs. The literature review showed that there is a deficiency in the training of ICGs for their role in caring for persons with T2 DM. This deficiency makes ICGs feel inadequately prepared for their caregiving role which contributes to their stress, affects the care they render and the subsequent poor health outcomes of persons with T2 DM.

This study was guided by the exploratory-descriptive qualitative design. Specifically, the study sought to explore the concepts of communication between ICGs and HCWs, partnership with HCWs, recognition of the role of the ICG, building resilience in ICGs,

navigating the healthcare system and culture and context of care. A total of twenty study participants who were ICGs of persons with T2 DM with a minimum of 3 months of caregiving experience were involved in the study. To elicit responses from participants, a semi-structured interview guide with open-ended questions, based on the caregiver-centered care competency model and the study's objectives, was designed.

The findings of the study indicated that communication and partnership were important resources in the performance of the caregiving role by ICGs of persons with T2 DM. Participants explained that being recognized and appreciated for their role served as an encouragement for them in their caregiving journey. They added that building their skill set and confidence by educating them on what to do and not do, how to identify hypoglycemic episodes, medication and review appointment adherence went a long way to building resilience in them and preparing them for the role of caregiving of persons with T2 DM. Participants appreciated how willing HCWs directed them to departments in and outside the hospital where services such as radiology, dietetics, pharmacy and laboratory services could be accessed. Lastly, they emphasized the important role culture and context plays in their caregiving. Culture and context determined whose responsibility it was to care for the person with T2 DM and the support system such an ICG had at his or her disposal. The caregiver-centered care competency model was appropriate in exploring and describing ICGs account of what they experienced from HCWs in caring for their relatives with T2 DM as opposed to what an ideal situation presents.

6.2 Implications for Nursing

6.2.1 Practice

It is clear from the study that how well HCWs prepare ICGs of people with T2 DM has a direct bearing on the efficiency of their performance in the caregiving duties and, ultimately, how well people with T2 DM fare in terms of health. It may be possible to increase ICGs' capacity to provide care and enhance their health and well-being by integrating ICGs into the healthcare system through partnerships with HCWs and providing them with the needed training and assistance. This will help define a broader role for ICGs and highlight how crucial ICG health and well-being are. Lastly, it will help HCWs recognize, understand and assess informal caregiving situations. This will lead to the use of relevant tools to determine the ICGs preparedness for the role and integrate both the care recipient (person with T2 DM) and the ICG in the decision-making process.

6.2.2 Education

Nurse educators need to consider the development of curricula to enhance HCWs' knowledge and abilities to involve ICGs in the caregiving process. Thus, the massive role played by ICGs should be the focus of clinical education programs. This will bring into sharp focus the foundational knowledge needed by HCWs to understand the complexity of informal caregiving, i.e., the positive and negative consequences of caregiving on the ICG, care recipient, the family of the care recipient, the influence of unconscious biases on care as well as the sociocultural variables that impact informal caregiving.

6.2.3 Administration

Nursing administrators must establish a needs assessment of ICGs of people with T2 DM as a required learning activity on the ward and create a precise, consistent policy for its execution. Ward in-charges and shift heads should take it upon themselves to regularly evaluate the needs of ICGs to spot and close gaps that could potentially affect the ICG's effectiveness in their caregiving role. As they do this, ward in-charges and shift heads should keep in mind that communication and approachability of HCWs are essential to ensure ICGs feel comfortable to express their concerns to the HCW.

6.2.4 Research

This study explored the concept of preparation needs of ICGs of persons with T2 DM at the 37 Military hospital. However further studies can be done to ensure needs assessment is also incorporated into discharge planning and discharge education of persons with T2 DM and their ICGs to ensure that any need missed at the beginning of the interaction between ICGs and HCWs is addressed. Studies can also be done into the specific role culture plays on whose duty it is to care for the sick and how it informs the support such an ICG has at their disposal.

6.3 Limitations

The qualitative design used for the study makes the findings unique to the selected setting and the population sample used as such, the findings are not generalizable. Secondly, the study focused only on only ICGs directly involved in the care of patients with T2DM but, who may not only be the ones involved in the informal care of patients with T2DM.

6.4 Insight gained

The researcher has learned a lot about the research process from problem identification and proposal development to the conclusion of the study. Using a model as the foundation for any study was highly enlightening because it aided in determining the objectives, examining the literature, and discussing the findings. Additionally, the researcher has gained a great deal of knowledge about interpreting and reporting qualitative data. The researcher has also learned a lot about the topic under study, and this has been an eye-opening experience.

6.5 Conclusion

In conclusion, the sub-themes that emerged from the study explained the themes Communication between HCWs and ICGs, Partnership with HCWs, Recognition of the role of the ICG, Building resilience in ICGs, Navigating the health care system, Culture and context of care; and this provided a good representation of the context of the Caregiver-Centered Care Competency Framework that was used to guide the study. It was evident that communication and partnership were important resources in the performance of the caregiving role by ICGs of persons with T2 DM. The development of their skills and confidence through education from HCWs on how to care for patients with T2DM at home in terms of their nutrition, medication and review appointment, built resilience in them. However, the HCWs lacked empathy in their interactions with the ICGs of patients with T2DM.

6.6 Recommendations

The following recommendations were made based on the findings of the study:

1. HCWs must continually communicate with ICGs in an easily understandable language and if need be, explain terms using vernacular.
2. Hospital management should encourage and ensure that HCWs continue to develop proper partnerships with ICGs to ensure they understand the treatment process and involved them in decision-making concerning their relatives with T2 DM.
3. Regular in-service training by the in-service training unit coordinator should focus on customer care issues and sensitize HCWs on the need to and also how to recognize the all-important role ICGs play as a part of the treatment team in order to engage them properly for the benefit of patients with T2DM.
4. Patient relatives and friends need to recognize and appreciate the effort ICGs put into caring for the person with T2 DM so as to encourage, motivate and support them in caring for patients with T2DM.
5. Resilience is built when the skill set of ICGs is developed. HCWs should teach ICGs what to do and not do, how to handle the person with T2 DM in case of emergencies, how to identify signs and symptoms of hypoglycemia as well as diet, review appointments and treatment adherence.
6. HCWs should continue to help ICG navigate the healthcare system and promptly refer them to other providers if need be
7. HCWs should recognize and understand that culture and context play a huge role in the performance of their caregiving duties as it determines whose

responsibility it is to care and the support system available for supporting patients with T2DM and their ICGs.



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APPENDIX I: PARTICIPANT INFORMATION SHEET

Title: Exploring preparation needs of informal caregivers of diabetic patients at the 37 military Hospital

Principal investigator: Gloria Efa Kissi

Address: University of Ghana
College of Health Sciences
School of Nursing and Midwifery
Legon

Phone: 0507323672

Email: ge@st.ug.edu.gh

General Information about Research

You are cordially invited to take part in a research project at the 37 Military Hospital that will look into the needs of informal caregivers of diabetic patients. Informal caregivers of diabetes patients who have been caring for them for at least three months will be recruited. If you accept to participate in the study after reading this general information, you will be interviewed to tell us about your diabetic patient caregiving experience. The researcher will ask you questions in English and refocus you whenever you are out of context. You should also keep in mind that the interview will take place at your leisure and could run anywhere between 45 and 60 minutes. Based on your consent, the entire interview will be taped. Please keep in mind that your participation in this study is completely voluntary, and you can opt out at any time if you don't want to.

Possible Risks and Discomfort

There is very little (minimal) risk or discomfort associated with your participation in this study on a physical, social, or psychological level.

Possible Benefits

The findings of this study are expected to improve how caregivers of type 2 diabetics are interacted with by nurses to help them achieve competency and be prepared in their caregiving role.

Confidentiality

Your participation will be treated with the utmost discretion, and all data and recordings pertaining to you will be safeguarded to the best of our abilities. During data analysis, you will not be named in any report; all names will be substituted with alphabets. Any publication resulting from the research will not include personal identifiers or identifying codes. All information gathered from research participants will be utilized for academic purposes, including publishing. Some members of the School of Nursing and Midwifery, Graduate School, Legon, and Professional Nursing Bodies may peek at your research records from time to time, but you may be assured that they will not be able to know who said what. All data and recordings will be stored by the researcher and then destroyed five (5) years after the research is completed by deletion of electronic files, shredding, and secure destruction of paper files. An Ethics Committee will be consulted whenever it is necessary to use the data in the near future.

Compensation

Participants will not be compensated for their participation in the study but will get a bottle of water and a soft drink after the interview.

Additional Costs

You will not incur any financial cost in participating in the research.

Voluntary Participation and Right to Leave the Research

Your participation in the study is completely voluntary. You only need to inform the researcher if you choose to stop participating in the study before it is completed. Any contribution provided can be withdrawn at any time throughout the study if you so desire.

Contact of Additional Information

If you have any questions or concerns about this study, please contact the people listed below:

- 1) Gloria Efa Kissi (Principal Investigator) - 0507323672
- 2) Dr. David Atsu Deegbe (Faculty/Supervisor, School of Nursing and Midwifery, University of Ghana) – 0243758359



APPENDIX II: PARTICIPANT CONSENT FORM

The above document describing the research title's benefit, risk, and processes (Exploring preparation needs of informal caregivers of diabetic patients: a study at the 37 Military Hospital) has been read and explained to me. I have been offered the option of having any question I have answered to my satisfaction.

.....

.....

Date

Name and signature or mark of volunteer

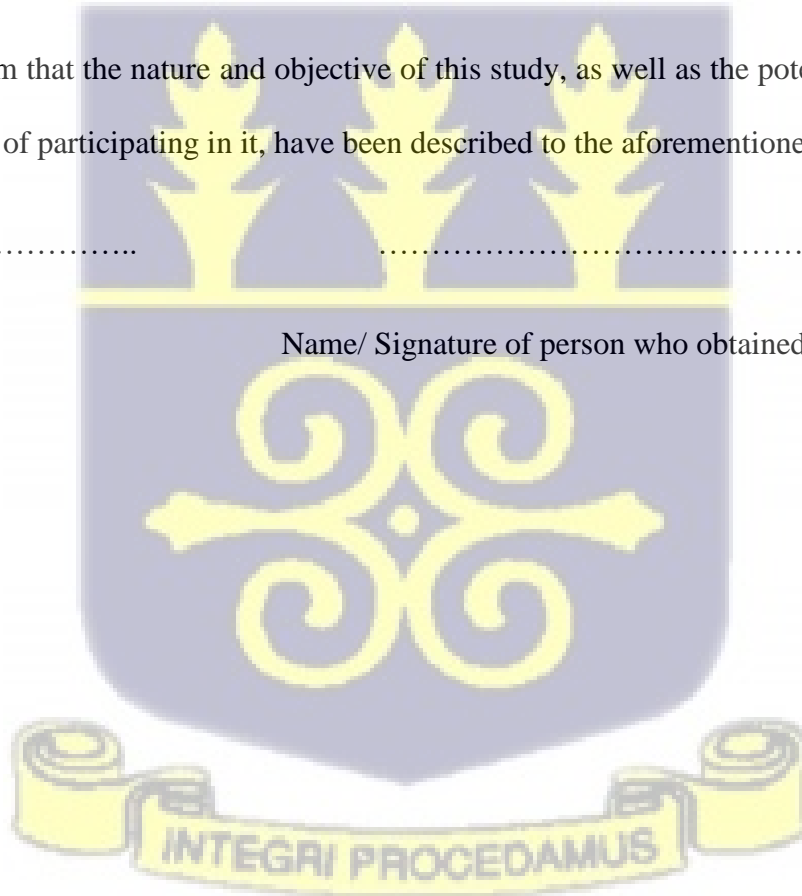
I confirm that the nature and objective of this study, as well as the potential benefits and hazards of participating in it, have been described to the aforementioned individual.

.....

.....

Date

Name/ Signature of person who obtained the consent



APPENDIX III: SEMI-STRUCTURED INTERVIEW GUIDE

Section A: Demographic data

Gender Male [] Female [] Other (specify): _____

Age: _____

What is your relationship with the patient? _____

What is your level of education? _____

How long have you been providing care for this sick person?

Section B: Supportive care for informal caregivers

How ICGs of T2 DM communicate with healthcare workers and partner with them to provide care

1. Tell me about your roles as a caregiver?
2. How would you describe how healthcare professionals communicate with you?
 - i. In a language you understand
 - ii. With respect and empathy
 - iii. With patience
 - iv. Providing information (adequacy/ timeliness of information)
 - v. Provision of listening ear
 - vi. Respectful and empathetic
 - vii. Timely response to questions/ concerns
 - viii. Difficulty in getting access to information from health care workers.

Ascertain ICGs account of how healthcare professionals recognize their caregiving roles

3. What does a typical day of providing care entail?
4. In what ways do health care workers recognize the role you play in caring for your sick relative?
 - i. Others (family members, friends)
5. How do health care workers appreciate and respect the role you play in caring for your sick relative?
 - i. Others (family members, friends)
6. How does being recognized for your role as a caregiver impact your caregiving ability?

How ICGs of T2 DM partner with health care workers to provide care

1. How will you describe working with the health professionals who attend to your sick relative?
2. Tell me about how health care workers involve you in the care of your sick relative.
 - a. Collaboration
 - b. Seeking your opinion
 - c. Involvement in decision making.
 - d. Seeking your help/ assistance.
 - e. Providing you direction on how to care for your sick relative.

Ascertain ICGs account of how healthcare professionals help foster their resilience as caregivers

3. Tell me about assistance you receive from the health care professionals
4. Describe how health care workers show concern about your needs
 - a. Health/ Wellbeing/ Self-care
5. How do health care workers help promote your skills and abilities in caring for your sick relative?
 - a. Education/ Support/ Direction

Describe ICGs experiences of navigating the healthcare system

6. Describe how health workers assist you in accessing health care for your sick relative
 - a. Information/ Support/ Direction/ Referrals
7. Describe the attitude of health workers towards you when you go with your sick relative to the hospital for health care.
 - a. Acceptance/ Assistance in difficult situations

Describe the culture and context with which ICGs provide care to persons with T2 DM

8. In your culture, describe the caregiving role and whose duty it is?
9. What are some of your support systems and how do they help?

APPENDIX IV: INTRODUCTORY LETTER



UNIVERSITY OF GHANA
SCHOOL OF NURSING AND MIDWIFERY

Ref. No.:

14th March, 2022

Institutional Review Board

37 Military Hospital

Neghelli Barracks

ACCRA

Tel: 059 1759506

Email: irbmilhosp@gmail.com

Dear Sir/ Madam,

INTRODUCTORY LETTER (GLORIA EFA KISSI: 10280644)


The bearer of this letter is a Master of Philosophy student at the School of Nursing and Midwifery, University of Ghana, Legon. She is conducting a study on the topic “EXPLORING PREPARATION NEEDS OF INFORMAL CAREGIVERS OF TYPE 2 DIABETIC PATIENTS: A STUDY AT THE 37 MILITARY HOSPITAL”.

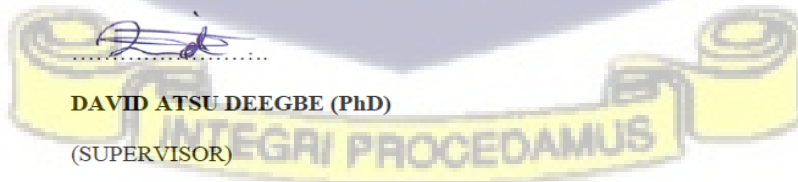
I would be grateful if you could accord her the needed support she may require.

You may contact me or her on phone numbers +233 243 758 359 and +233246593727, respectively.

Thank you.

Yours faithfully,


.....
DAVID ATSU DEEGBE (PhD)
(SUPERVISOR)



APPENDIX V: ETHICAL CLEARANCE CERTIFICATE



Institutional Review Board
37 Military Hospital
Neghelli Barracks
ACCRA

Tel: 059 1759506
Email: irbmilhosp@gmail.com

01 April 2022

ETHICAL CLEARANCE

37MH-IRB/UG/IPN/607/2022

On 01 April 2022 the 37 Military Hospital (37MH) Institutional Review Board (IRB) approved your protocol.

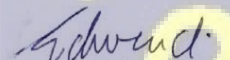
TITLE OF PROTOCOL: Exploring preparation needs of informal caregivers of Type 2 Diabetic patients: A study at the 37 Military Hospital

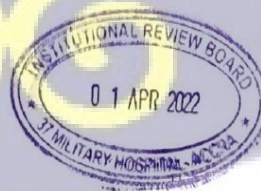
PRINCIPAL INVESTIGATOR(s): GLORIA EFA KISSI

Please note that a final review report must be submitted to the Board at the completion of the study.

Please report all serious adverse events related to this study to 37MH-IRB within seven (7) days verbally and fourteen (14) days in writing.

This certificate is valid till 31 March 2023.


DR EDWARD ASUMANU
(37MH-IRB, Vice Chairman)



Cc: Brig Gen NA Obodai
Commander, 37 Military Hospital

INTEGRI PROCEDAMUS