UNIVERSITY OF CAPE COAST

RELATIONSHIP BETWEEN FORMAL AND INFORMAL CAREGIVERS AT THE PAEDIATRIC WARD OF THE CAPE COAST TEACHING HOSPITAL

DORINDA NPOINDEN NYALA

Thesis submitted to the Department of Integrated Development Studies of the School for Development Studies, College of Humanities and Legal Studies, University of Cape Coast, in partial fulfillment of the requirements for the award of Master of Philosophy Degree in Development Studies

MAY 2021

DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it h2as been presented for another degree in this university or elsewhere.

Candida	te's Signature Date:
Supervi	sors' Declaration
We here	eby declare that the preparation and presentation of the thesis were
supervis	ed in accordance with the guidelines on supervision of thesis laid
down by	the University of Cape Coast.
Principa	1 Supervisor's Signature Date:
Name: .	
G G	NOBIS
Co-Supe	ervisor's Signature
Name: .	

ABSTRACT

Relationships between caregivers could be coordinated or conflicted in the caregiving process. Coordinated relationships have been found to improve health outcomes, reduce stress attached to caregiving and improve patient satisfaction of health care quality. The Cape Coast Teaching Hospital has taken a step in boosting coordination between formal and informal caregivers by incorporating informal caregivers in the care delivery process by providing a mothers' hostel. This study sought to explore the relationship between formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. The interpretivist paradigm was used and interviews and observation were used to explore how formal and informal caregivers relate at the Paediatric Ward of the Cape Coast Teaching Hospital. Based on the conceptual framework of this study, the emerging trends from the data gathered were organised into three main themes namely: the caregiving activities of formal and informal caregivers; communication between formal and informal caregivers; and the role expectations and perceptions of formal and informal caregivers. The study found that the caregiving activities of formal and informal caregivers, their communication and their role expectations and perceptions determined both coordination and conflict between them. Interventions by health institutions, health professionals and individuals need to be directed towards boosting coordination between formal and informal caregivers at the hospitals.

KEY WORDS

Caregiving activities

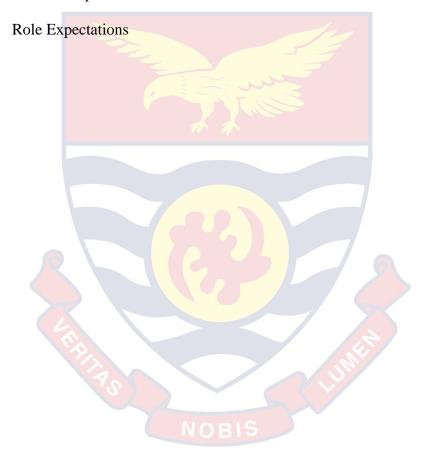
Communication

Conflicts

Coordination

Perceptions

Relationship



ACKNOWLEDGEMENTS

I am grateful to my supervisors, Prof. Akua O. Britwum of the Department of Labour and Human Resource Studies and Dr. Nana Amma Anokye of the Department of Environment, Governance and Sustainable Development, School for Development Studies, for their direction and support in various ways throughout my study period.

I also extend my gratitude to the lecturers of the School for Development Studies for their support during my period of study and the Cape Coast Teaching Hospital for its approval which enabled me to commence data collection at the hospital. In addition, I thank the patients, doctors and nurses at the Paediatric Ward of the Cape Coast Teaching Hospital who provided a great deal of information for the study as well as the patients and their parents for sharing their stories and experiences during the data collection process. To Dr. Alfred Yaw Kaitoo, Ms. Rita Adwoa Ghartey, I say thank you for supporting the data collection process. To Dr. Obeng, Mr. Carl Nii Amartey Armah and my course mates; The late Ms. Afia Dentaa Dankwah, Ms.Vida Opoku Boakye and all other individuals who encouraged, supported and advised me during my study period, I am extremely grateful.

NOBIS

DEDICATION

This thesis is dedicated to my parents, Dr. Joseph Issah Nyala and Mrs.

Margaret Gantier Nyala and my siblings, Dorcas Nyulnye Nyala and Veronica

Marjorie Nyala.



TABLE OF CONTENTS

	Page
DECLARATION	ii
ABSTRACT	iii
KEY WORDS	iv
ACKNOWLEDGEMENTS	v
DEDICATION	vi
TABLE OF CONTENTS	vii
LIST OF TABLES	xii
LIST OF FIGURES	xiii
LIST OF ACRONYMS	xiv
CHAPTER ONE	1
INTRODUCTION	1
Background of the Study	1
Problem Statement	8
Research Objectives	11
Significance of the Study	12
Delimitation	12
Limitations of the Study	13
Definition of Terms	13
Organisation of the Study	14

CHAPTER TWO	16
LITERATURE REVIEW	16
Introduction	16
Caregiving	16
Activities of Caregivers	18
Formal Care	19
Informal Care	20
Relationships Between Formal and Informal Caregivers	21
Coordination of Caregiving Activities Between Formal and Informal	
Caregivers	23
Conflicts in Caregiving Activities Between Formal and Informal	
Caregivers Role Expectations and Perceptions of Performance of Formal and	24
Informal Caregivers	26
Communication Between Formal and Informal Caregivers	27
Theoretical Framework	30
The Task-Specific Theory (Litwak 1985)	31
Relational Coordination Theory	32
Empirical Review	34
Lessons Learnt from the Empirical Review	42
Conceptual Framework	43
CHAPTER THREE	46

METHODOLOGY	46
Introduction	
Research Design	46
Study Area	48
Study Population	49
Sampling Procedure	50
Data Collection Procedures	51
Actual Field Work	52
Data Processing and Analysis	53
Ethical Considerations	54
Validity and Reliability	55
Chapter Summary	56
CHAPTER FOUR	57
RESULTS AND DISCUSSIONS	57
Introduction	57
Background Characteristics of Participants	57
Caregiving Activities of Formal and Informal Caregivers	59
Activities of Daily Living, Instrumental Activities of Daily Living and	
Medical Caregiving Activities	61
Communication between Formal and Informal Caregivers	69
Quality of Information Shared by Formal and Informal Caregivers	70
Channelling of Information Shared	76

Meaning Made of Information Shared between Formal and Information	mal
Caregivers	80
Meaning Made of Information Shared by Formal and Informal	
Caregivers	80
Role Expectations and Perceptions of Formal and Informal Care	givers
	83
Formal and Informal Caregivers' Perceptions of Caregiving Task	k s 89
Chapter Summary	92
CHAPTER FIVE	94
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	94
Overview	94
Summary	94
Key Findings	94
Conclusions	97
Recommendations	99
Suggestions for Further Research	100
NOBIS REFERENCES	101
APPENDIX A	113
Interview Guide for Informal Caregivers	113
APPENDIX B	116
Interview Guide for Formal Caregivers	116
APPENDIX C	119

Interview Guide for In-Patients	119
APPENDIX D	121
Observation Guide	121



LIST OF TABLES

Table	I	Page
1	Activities of Daily Living	62
2	Instrumental Activities of Daily Living	62
3	Medical Caregiving Activities	63
4	Quality of Information Shared Between Formal and Informal	
	Caregivers	71
5	Role Expectations Formal Caregivers have of Informal Caregivers	84
6	Role Expectations Formal Caregivers have of Informal Caregivers	88

LIST OF FIGURES

Figure

Page

1 Conceptual Framework showing the Relationship between formal and informal caregivers.

45



LIST OF ACRONYMS

Acronym Meaning

ADL: Activities of Daily Living

AHRQ: Agency for Health Care Research and Quality

FPDR: Family Presence During Resuscitation

IADL: Instrumental Activities of Daily Living

ICU: Intensive Care Unit

IFA: International Federation on Aging

NICHE: Nurses Improving Care for Health-system

PWD: People with Dementia

SHARE: Survey of Health, Ageing and Retirement in Europe

WHO: The World Health Organisation

NOBIS

CHAPTER ONE

INTRODUCTION

Background of the Study

"Health is wealth" remains, primarily an intuition out of proposition (Husain, 2010, p 1). Many researchers rather present empirical and theoretical arguments of the converse proposition, "wealth is health" (Husain, 2010, p 1). However, recent literature shows changes in the views that improvement of longevity and health are no more seen as mere end-products or by-products of socio-economic development. Longevity and health are now seen as the major determinants of socio-economic development and poverty reduction (Husain, 2009).

The provision of health care or caregiving therefore must be a vital part of a country's strategies to socio-economic development as it reduces losses during production as a result sick workers and enhances productivity. Health care provision also reduces the rates of absenteeism and positively affects peoples' future incomes by improving school childrens' learning (Lustig, 2007). Alsan, Bloom and Canning (2006) also argue that steps to provide healthy childhoods for children, improve life expectancy, decrease the problem of disease etc will contribute to the creation of wealthier economies.

The providers of care (formal and informal caregivers) tend to have relationships that have a significant impact on the health of those they care for (Litwin & Attias Donfut, 2009). Relationships that exist between caregivers are formed within or outside care institutions and they affect the mental, emotional, health, psychological and social aspects of the lives of care

recipients. These relationships have been increasingly emphasised over the years (Büscher, Astedt-Kurki, Paavilainen, & Schnepp, 2011; Toscan, Mairs, Hinton, & Stolee, 2012; Orpin, Stirling, Hetherington & Robinson, 2014).

The relationships formed between formal and informal caregivers occur through the involvement of informal caregivers in the formal care delivery process. In Ghana, formal care is categorized according into four main delivery systems which are the private-for-profit, public, traditional systems and private-not-for-profit systems (Abor, Abekah-Nkrumah & Abor, 2008). The use of formal care has become predominant these days (Salisu & Prinz, 2009). This has made it easier for more individuals and families to patronize formal health care services (Barimah and Mensah, 2013).

The involvement of informal caregivers in the formal care delivery process is due to social obligations (Li, 2005) and the poor perceptions Ghanaians have of the quality of health care being provided at the hospitals (Agbelie, 2017). Studies on patient satisfaction in Ghana over the years show that patients and formal caregivers report of poor health care quality delivery (GHS, 2008; MOH, 2007) which include long waiting hours at the Out-patient Department, poor hospital environments, poor attitudes of formal caregivers towards patients and poor communication amongst formal caregivers (Turkson, 2009; Atinga, Abekah-Nkrumah, & Domfeh 2011).

According to the Agency for Health Care Research and Quality (ARHQ), the involvement of informal caregivers in patient care speeds up the recovery process and patient safety while ensuring effective health care quality delivery through effective communication. However, the AHRQ found that a

break in communication between caregivers contributed to 70 percent of medical errors. This can be avoided by informing and engaging patients and informal caregivers to improve patients' safety through informed choices, infection control initiatives, safe medication use, observation of care processes, practicing self-management and reporting complications (Loghmani et al., 2014).

The relationship between formal and informal caregivers has been studied and defined differently by many authors. Formal caregivers, on the one hand, are seen as individuals who provide care and receive remuneration in return (Lai, 2003); are registered (Sudhinaraset, Ingram, Lofthouse, & Montagu, 2013); are institutionalised (Byrne, Goeree, Hiedemann, & Stern, 2009); are trained (Baskin Dalal, Das, Goyal, Harkins, Nanda, Nanda, Silberstein, Singh, Singh, Singh & Svenson, 2016) and skilled in the area of health care (Egan & Labyak, 2006). On the other hand, informal caregiversare are those who provide unspecialised care and do not receive remuneration in return (Lai, 2003); unregistered (Sudhinaraset, et al., 2013); who are uninstitutionalised (Byrne et al., 2009); untrained (Baskin et al., 2016) and unskilled in health care delivery (Egan & Labyak, 2006).

The above definitions of formal and informal caregivers overlap to some extent. For instance, some studies reveal instances where informal caregivers are paid (IFA, 2014; Heitmueller, & Inglis, 2007) and other studies show that informal caregivers have some skills (Smith, Lawrence, Kerr, Langhorne, & Lees, 2004). Such situations make it difficult to have clear cut distinctions between formal and informal caregivers. This study operationalises formal caregivers as people who are trained in public health

and employed at the Cape Coast Teaching Hospital to enhance the health of patients. Informal caregivers are defined in this study as relatives, friends, neighbours and other non-hospital staff who are unskilled and unpaid in the area of health care delivery.

Attempts to explain the relationship between formal and informal caregivers usually adopt theories such as the substitution theory, supplementation theory, hierarchical compensatory theory and the task specific theory (Cantor, 1975; Edelman, 1986; Greene, 1983; Litwak, 1985). According to Greene's (1983) substitution theory, most informal caregivers are likely to substitute the care they provide with formal care when given the option. Edelman's (1986) supplementation theory proposes that formal care merely supplements the care that informal caregivers provide to save time and minimise stress, while Cantor's (1975) hierarchical compensatory theory asserts that care recipients choose their caregivers based on their preferences which are based on the closeness, accessibility and availability of caregivers (Litwin & Attias-Donfut, 2009). The task specific theory (Litwak, 1985) which underpins this study also postulates that formal and informal caregiving tasks are distinct based on the type of assistance needed and the caregivers' ability to perform certain tasks (Luong, 2000). The task specific theory thus encompasses the concepts of caregiving tasks, coordination and conflicts that characterise relationships between formal and informal caregivers. These concepts form the focus of this study.

The knowledge, skills and specialisations of formal caregivers on one side of the divide allow them to perform caregiving tasks that informal caregivers are sometimes legally barred from performing due to their lack of

skills and specialisation. Informal caregivers on the other side of the divide perform caregiving tasks based on the knowledge they acquire through everyday socialisation and familiarity with care recipients. Informal caregivers might have certain information such as the preference and health history of the care receiver which formal caregivers lack. As a result, formal and informal caregivers are best equipped to perform different tasks that are relevant to the care needs of the care recipient (Litwak, 1985). Hence, the caregiving tasks performed by formal and informal caregivers need to be harmonised to provide holistic care to recipients through coordination.

Relationships that exist between formal and informal caregivers are usually characterised by coordination or conflicts. This study defines coordination as the ability of both forms of caregivers to work together in harmony for the common goal of providing care to recipients (Care, 2014). Thus, how formal and informal caregivers can use the connection or linkages between them in the provision of care to in-patients. This study also defines conflicts in this content as disagreements between caregivers that affect how they work together (Kumpers, Mur, Maarse, & van Raak, 2005; Sicotte, D'Amour, & Moreault, 2002).

A coordinated or conflicted relationship in the hospital is determined by communication between formal and informal caregivers which is explained by the relational coordination theory (Gittell, 2015). According to the relational coordination theory, communication forms a vital part of the process of coordinating caregiving activities. It becomes necessary to communicate when matters concerning the health of the patients needs to be addressed between formal and informal caregivers. Coordination between formal and

informal caregivers can be achieved when communication between formal and informal caregivers consists of the dissemination of relevant, timely, adequate, accurate and comprehensible information (Toscan, Mairs, Hinton, & Stolee, 2012). Thus, the nature and the understanding of the information shared between formal and informal caregivers can affect their relationship and hence the health of care recipients (Wanjau, Muiruri, & Ayodo, 2012). The use of comprehensible language in communication can facilitate understanding which prevents miscommunication of information and conflicts. In this light, Jansen et al. (2009) suggested that formal caregivers need to explain terminologies unknown to informal caregivers.

The relational coordination theory also posits that coordination between formal and informal caregivers is influenced by their role expectations and perceptions of care provided based on whether caregiving activities are performed to their satisfaction (Girmay, Marye, Haftu, Brhanu, & Gerensea, 2018). At the hospitals, formal and informal caregivers expect the performance of caregiving tasks from one another (Bostan, Acuner & Yilmaz, 2007). They also expect that these tasks being performed meet the care needs of patients. Formal caregivers expect informal caregivers to perform certain caregiving tasks which are usually unspecialised in caring for the in-patient while informal caregivers expect formal caregivers to perform specialised tasks.

Formal and informal caregivers' low level of satisfaction with care provided to in-patients results in conflicts out of disappointment and despair between them. These conflicts suggest that the perceptions of formal and informal caregivers play a role in their relationships. Therefore, care delivery

must meet the expectations of caregivers to achieve coordination (Salin, Kaunonen, & Åstedt-Kurki, 2013).

A lot of research work has been done on the relationship between formal and informal caregivers. Aêstedt-Kurki, Paavilainen, Tammentie and Paunonen-Ilmonen, (2001) conducted a study on how adult patients' families interact with the hospital staff from the staffs' perspective in Finland. Armi, Guilley and Lalive D'Epinay (2008) also investigated the interface between formal and informal support in Switzerland. Another study done by Litwin and Attias-Donfut (2009) examined the relationship between formal and informal care delivered to elderly homes in France and Israel, among many other studies. The studies on relationships that exist between formal and informal caregivers have different findings. Some studies found that the relationship between them was coordinated (Armi et al., 2008; Litwin & Attias-Donfut, 2009). Others found conflicts within the relationship (Kumpers et al., 2005; Sicotte et al., 2002; Victor, Healy, Thomas, & Sergeant, 2000) while others found both coordination and conflicts (Aêstedt-Kurki, et al., 2001) within their various study areas.

Armi et al. (2008) found that there was coordination between formal and informal caregivers using activities as indicators. According to Armi et al. (2008), as the activities of one form of a caregiver increased, the activities of the other also increased which was an indication of a coordinated relationship. Litwin and Attias-Donfut (2009) found that the co-existence of formal and informal caregivers usually resulted in coordination between them. Studies by Sicotte et al. (2002), Kumpers et al. (2005) and Victor, Healy, Thomas and Sergeant, (2000), however, showed a failure in the coordination between

formal and informal caregivers while Aêstedt-Kurki et al, (2001) found both coordination and conflicts in the relationship between formal and informal caregivers.

This study raises the question of how communication consisting of comprehensible, timely, adequate and accurate information between formal and informal caregivers aids in determing coordination between them.

This study also raises the question of how the levels of satisfaction of formal and informal caregivers with the performance of caregiving tasks affect their pereptions of how caregiving activities are performed and how this determines coordination in the performance of their caregiving activities. The study seeks to explore the relationship between formal and informal caregivers based on the above propositions.

Problem Statement

Relationships that exist between formal and informal caregivers seem pivotal in the delivery of care to the sick. These relationships between caregivers are formed in health care institutions due to the inclusion of informal caregivers in the care delivery process to provide collaborative care. Collaborative care provision between formal and informal caregivers their coordination to provide holistic care to care recipients. The coordination between caregivers in in-patients care aids in speeding up the in-patients recovery process and patient safety while ensuring health care quality delivery through effective communication and the performance of caregiving activities. Collaborative care also allows for efficiency amongst formal and informal caregivers whiles encouraging families to be active in the care process. However, the AHRQ found that a break in communication among caregivers

can lead to conflicts thereby contributing to medical errors posing a threat to the care of care recipients (Kumpers et al., 2005; Sicotte et al., 2002; Victor et al., 2000).

Many studies have discussed the relationship between formal and informal caregivers and found that caregiving roles, communication and role expectations and perceptions of formal and informal caregivers determine coordination in the relationship between them. Studies have also found that when communication between formal and informal caregivers consists of the dissemination of relevant, timely, adequate, accurate and comprehensible information, a good relationship is created between them (Toscan et al., 2012). Lastly, studies also point out that when the formal and informal caregivers are satisfied with the performance of expected caregiving activities they have high perceptions of the performance of caregiving tasks which positively affects how they relate with one another (Moyer et al., 2014). However, a conflictual relationship between formal and informal caregivers can arise when coordination in the performance of caregiving activities and communication fail. A conflictual relationship can also arise between formal and informal caregivers when the performance of caregiving tasks is not up to their expectations resulting in low perceptions of formal and informal caregivers.

There can be overlaps in the performance of specialised and unspecialised tasks by formal and informal caregivers. The overlaps in the performance of specialised and unspecialised caregiving tasks are not systematic for every patient. Thus, the reasons for the overlaps in the performance of specialised and unspecialised caregiving tasks might vary. Overlaps in the performance of caregiving tasks are found to cause conflicts

between formal and informal caregivers. Hence, the need for coordination in the performance of caregiving tasks between formal and informal caregivers (Covinsky et al., 2013).

A lot of studies on the relationship between formal and informal caregivers in the provision of care are concerned with the elderly and those with specific diseases like dementia (Orpin, Stirling, Hetherington & Robinson, 2014), Alzheimer (Carpentier, 2008) and Delirium (Hagerling, 2015) who might not be necessarily hospitalised. The Cape Coast Teaching Hospital in Ghana can be said to have realised the importance of the relationship between formal and informal caregivers by providing a hostel for mothers at the Paediatric Ward to encourage and enhance coordination. It is however, not clear whether there is coordination or conflict in the relationship between formal and informal.

This study is relevant because formal and informal caregivers tend to have relationships that have a significant impact on the health of those they care for (Litwin & Attias Donfut, 2009). Studies on the relationship between formal and informal caregivers for children are fewer. However, an assessment of care provided by the hospitals for children in Ghana revealed that the care quality did not match the WHO recommended standards. This study might improve the understanding of how quality of care provided to children is affected by the relationship between formal and informal caregivers (Abuosi, Domfeh, Abor, & Nketiah-Amponsah, 2016).

The relationships between formal and informal caregivers are

relevant for various categories of people whether old or young and affect the mental

and emotional health of the patients regardless of their age (Silver, 2015). Children are found to demand and receive more care as compared to adults, therefore, understanding the interface between formal and informal caregivers in care provision and how it affects the quality of health care delivery is of much importance [Evagelou, Lordanou, Lemonidou, Patiraki, Kyritsi, & Bellou, 2003; Kelly, Wells, Chen, Reeves, Mass, Camitta, & Hinds, 2014]. To address the identified gap in knowledge the study sought to answer the question: how does the performance of caregiving roles by formal and informal caregivers, their communication with one another as well as the role expectations and perceptions of the performance of their caregiving activities affect their relationship at the Paediatric Ward of the Cape Coast Teaching Hospital?

Research Objectives

The general objective of this study was to explore the relationship between formal and informal caregivers at the Cape Coast Teaching Hospital.

Given the general objective stated above, the specific objectives were to:

- 1. Examine the task specifics of formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital;
- 2. Describe the communication between formal and informal caregivers in the performance of their caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital;
- 3. Investigate the role expectations and perceptions of formal and informal caregivers regarding the performance of caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital; and

Research Questions

The study was based on the following research questions:

- 1. What are the task specifics of formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital?
- 2. How do formal and informal caregivers communicate in the performance of their caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital?
- 3. What are the role expectations and perceptions of formal and informal caregivers regarding the performance of caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital?

Significance of the Study

This study contributes to the theoretical and empirical discourse on the relationship between formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. The study brings to light the issues of formal and informal caregiver relationships in Ghana as they affect the health outcomes of patients. The findings make knowledge available to health sector workers, policymakers and the general public at large in the area of improving the interactions between formal and informal caregivers to enhance the quality of care for patients.

Delimitation

The study focused on exploring the views, meanings, opinions and reasoning behind the caregiving activities performed by formal and informal caregivers, their expectations and perceptions of the performance of caregiving tasks and also how they communicate with one another as they perform their caregiving tasks.

The Cape Coast Teaching Hospital is one of the four teaching hospitals in Ghana, with the rest being the Korle Bu, Tamale Teaching Hospital and the Komfo Anokye Teaching Hospitals. The hospital was used in this study because it is the only referral hospital in the region and provides an all-inclusive range of specialist health care services to the Central Region, Western Region and parts of the Greater Accra and the Eastern Region.

Limitations of the Study

A limitation of this study was the inability of the researcher to stay for longer periods at the Paediatric Ward to gather data on issues relevant to the study. This was due to COVID 19 which made interactions unsafe for participants and the researcher as well.

Definition of Terms

Various terms have been defined for this study and they include:

Caregiver: A caregiver in this study refers to one who gives care to a person in need of it, for instance, the aged, the sick, a child, a relative, a husband or wife, a friend, or a neighbour.

Formal caregiver: A formal caregiver is defined in this study as one who is trained in public health and employed to enhance the health of patients at the Cape Coast Teaching Hospital.

Informal caregiver: An informal caregiver is defined as a relative, friend, neighbour and non-hospital staff who is unskilled and unpaid in the area of health care.

Relationship: A relationship is a continuous association between people.

Conflicts: Conflicts are defined as disagreements between formal and informal caregivers that affect how they work together.

Coordination: Coordination refers to the ability of caregivers to work together harmoniously for the common goal of providing care to recipients.

Communication: Communication is defined as the process of conveying information and mutual understanding from a person to another.

Role Expectations: Role expectation is where roles are constructed by people according to what they preconceive the roles to entail.

Perceptions: Perceptions refer to how one cognises the performance of caregiving activities.

Activities of Daily Living: Activities of Daily Living refer to those basic activities people perform to take care of themselves.

Instrumental Activities of Daily Living: refer to the complex activities that reflect how a person thrives and lives independently.

Organisation of the Study

This research is organised into five chapters. The first chapter presents the introduction which focuses on the background of the study, problem statement, research objectives and the research questions. The chapter also discusses the significance as well as the delimitations and limitations of the study. Chapter Two centres on literature related to the study and, it looks at the theories and concepts used in the study. The third chapter focuses on the various methods, techniques and procedures adopted in this study. Chapter Four presents the results and discussion of issues on caregiving activities, communication between formal and informal caregivers and their role expectations and perceptions of the performance of their caregiving tasks. The final chapter, which is Chapter Five of this study, covers the summary,

conclusions and recommendations. It also offers suggestions for further studies.



CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter focuses on a review of related literature on the relationship between formal and informal care in a hospital environment. Specifically, the chapter presents a review of the theories (task specific and relational coordination theories) and concepts (formal and informal caregivers, relationships, caregiving tasks, role expectations, perceptions, coordination, conflicts and communication). The review of theories and concepts gives a structure for an understanding of the phenomenon being studied. Some related empirical studies were also reviewed to help situate the study within the broader existing knowledge on the relationship between formal and informal caregivers. Thus, the reiew of empirical studies provided the basis for the identification of the gaps in the literature and the choice of research methods that were deployed to carry out this study.

Caregiving

Caregiving is defined as the provision of support to an ill person, a disabled or one needing assistance with everyday activities such as an elderly person or an infant (Byrne, Goeree, Hiedemann, & Stern, 2009). According to Greenlee and Scharlach, (2001) caregiving usually requires that one receives mental, physical, psychological and social attention for their well-being. Caregiving may also involve looking after one's well-being emotionally or taking care of one's physical health needs (Greenlee & Scharlach, 2001). Generally, caregiving describes a variety of circumstances or experiences. It may involve caring for a person in the home of the caregiver or the home of

the one receiving care or in an institution. Usually, individuals may receive care for long-term physical disabilities or chronic illnesses, or they may receive care for intermittent and periodic illnesses. This study adopts the definition of a caregiver provided by Hermanns and Mastel-Smith (2012) as one who looks after a person and provides their needs, for instance, the aged, the sick, a child, relative, husband or a wife, a friend or a neighbour. Caregiving can either be formal or informal, and is usually concerned with assisting the sick and the aged with the Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL) of the care recipient.

Activities of Daily Living and Instrumental Activities of Daily Living

Activities of daily living (ADL) and Instrumental Activities of Daily Living (IADL) are both crucial for individuals to function each day with comfort and ease. ADL is a term used in health care to refer to those basic self-care activities people perform to live independently. The concept was proposed originally by Sidney Katz together with his team in the 1950s and is normally used to measure the functional condition of a person. It is the ability or inability of most people with post injuries, the elderly, the disabled and children to perform ADL since they cannot be independent without assistance. The ADL include bathing, eating, mobility, grooming, dressing and toileting (Noelker & Browdie, 2013). The help needed for each ADL varies from person to person and could range from little activities such as reminders to full dependency on others to perform those tasks (Mlinac & Feng, 2016).

The complex activities that reflect how a person thrives and lives independently within a community are referred to as the Instrumental Activities of Daily Living (Noelker & Browdie, 2013). Thus, IADL require

more complex organisational and thinking skills in performing caregiving activities and does not necessarily involve personal caregiving activities as compared to ADL. IADL include financial management, communication management, washing of clothes, community mobility, shopping, maintenance of the home, medication management and meal preparation (Noelker & Browdie, 2013).

Activities of Caregivers

Due to the family system, care recipients are likely to get care from their kin, performing personal caregiving activities such as taking out the trash, cooking and washing since these family members live with them, live nearby and have commitments to them. Care recipients are also likely to get help from their kin due to their motivation to provide help and because they share a common lifestyle. Spouses and adult children also take care of the finances of their sick relatives because of their closeness and commitments to them (Penning & Keating, 2000). These activities of caregiving support the activities of formal caregivers and help them provide care to recipients.

In formal care settings such as hospitals, formal services including diagnosis, prescription of drugs and medical procedures that can only be provided by practitioners and professionals (Paulus et al., 2005) are expected. However, in hospitals where the presence and activities of informal caregivers are accepted, support is provided to care recipients by informal caregivers with activities such as feeding, bathing and toileting based on their daily experiences and intimacy with the patient and their localities (Hudson, Aranda & Kristjanson, 2004).

The caregiving activities of formal caregivers usually follow scientific principles (Hudson, et al., 2004), while the caregiving activities of informal caregivers require knowledge from familiarity and socialisation with the care recipient. Hence the activities performed by the doctors and nurses cannot be performed by the patient's family, friends, or neighbours who lack these skills. However, they can be trained and well informed by formal caregivers to perform certain tasks at the hospital. Informal caregivers can be informed and trained on patient preparation, care recommendations and disease processes for implementing care techniques such as bandaging and assisting with special diets (Loghmani, Borhani & Abbaszadeh, 2014).

Hospitals are institutions that have policies governing their daily activities. Some of these policies sometimes do not favour the presence and activities of informal caregivers that might lead to disagreements. The family, however, can satisfy the basic needs of the patient in the hospital to a large extent and also help patients reduce stress while encouraging them to correspond effectively to therapeutic forms. The family also directs patients in self-care activities and supports them in overcoming complications associated with their illnesses (Badr, Smith, Goldstein, Gomez, & Redd, 2015).

Formal Care

Timonen (2009) used the term "formal care" to describe care that is provided by a trained individual or an institution to a person or a group of people who need it. Litwin and Attias-Donfut (2009) defined formal care as formal services that range from personal care delivered at home, day-care facilities, then to residential institutions. Formal care was also used by Litwin and Attias-Donfut, (2009) as professional assistance for the elderly. This

study, however, defines formal care as care given by those that are educated and employed in public health or an associated discipline to enhance the health of patients. Formal care may be provided by volunteers from non-profit organisations or governments as well as private groups such as companies through health institutions (Salisu & Prinz, 2009). Formal caregivers have training from an institution (Sudhinaraset, et al., 2013) and may be found in institutions, homes or communities. Some are paid through social security and taxes while others take cash in hand (Timonen, 2009). Formal caregivers are also usually registered with a government regulatory body and operate with the regulations and purview of the government and within social-care and institutionalised systems (Sudhinaraset et al., 2013).

Informal Care

According to the International Federation on Aging (2014), informal care is unpaid care that is provided by friends, family and any other unpaid helpers due to a social connection or relationship between the caregiver and the care receiver. The IFA also defined it as duties that receive payment less than the market price (IFA, 2014). Informal care involves a range of instrumental and emotional assistance that makes people feel at home (Lum, 2011). Informal caregiving is concerned with the assistance of an adult with not less than two useful daily activities such as transportation, shopping, home maintenance, toileting and bathing, (Covinsky, Palmer, Fortinsky, Counsell, Stewart, Coyne, Murphy, Costello, O'Neill, & Donnellan,, 2013). Informal caregiving further centres on formal service management and coordination. This includes the navigation of formal health structures, connecting people to amenities and organising numerous services from various caregivers for

people in need of care (Covinsky et al., 2013). Lastly, informal care looks at the provision of assistance on a short-term basis such as care provided after surgery, or provision of assistance on a long-term basis for persons with weakening physical and/or mental abilities or other prolonged health conditions (Lum, 2011). This study, however, looks at informal care as care that is given by relatives, friends, neighbours and non-hospital staff who are unskilled and unpaid in the area of health.

Relationships Between Formal and Informal Caregivers

A relationship is defined by Reis and Collins (2004) as a continuous association between people. It is the linkage or connection between two or more phenomena or entities. Formal and informal caregivers form relationships based on the care they provide to those in need of it. These relationships are widely studied and are often understood in various ways. In some researches, formal caregivers view their relationship with informal caregivers as one between specialists (formal caregivers) and surrogates (informal caregivers) for patients, performing the roles a patient is supposed to perform. In such cases, the informal caregiver provides information needed by formal caregivers on the patient's behalf which indicates a partnership in the relationships that exist between formal and informal caregivers (Agbenyefia, 2017).

In other studies, informal caregivers view their relationship with formal caregivers as one between two specialists. Informal caregivers view their relationship with formal caregivers as one between themselves as primary health providers who provide useful information about care receivers due to the experiences they have in monitoring the symptoms of the latter's

ailments and making adjustments to treatments and formal caregivers as resources. Informal caregivers perceive formal caregivers as resources in sharing suggestions for diagnosis and treatment plans and also getting guidance on care delivery (Ward-Griffin & Mckeever, 2000). The relationship between formal and informal caregivers is also sometimes perceived by formal caregivers as one between health professionals and informal caregivers as second patients, with health conditions and also needing care. Thus, informal caregivers are rarely seen as partners in care provision with whom negotiations and knowledge exchange are made.

Ward-Griffin and Mckeever (2000) also found four different relations between formal and informal caregivers and these are the nurse-helper, worker-worker, manager-worker and the nurse-patient relationships. The relationship between formal and informal caregivers can be seen as a nursehelper relationship where formal caregivers provide much of the care and informal caregivers perform the supportive role. The formal-informal caregiver relationship can be seen as a worker-worker relationship where formal caregivers recognise the role informal caregivers play in the care of care recipients and hence work in a team. The formal-informal caregiver relationship can also be seen as a manager-worker relationship, where formal caregivers transfer most of their roles to informal caregivers gradually over time while taking supervisory roles. The formal-informal caregiver relationship can also be seen as a nurse-patient relationship where the formal caregivers see informal caregivers as patients that also need care in their own right. These relationships hinge on the coordination or conflicts between formal and informal caregivers.

Coordination of Caregiving Activities Between Formal and Informal Caregivers

Coordination is where two or more people work together in agreement to achieve their aim (Griffin & Moorhead, 2007). This definition implies that coordination can be seen between two individuals or two organisations, or between individuals and organisations and between organisations. Coordination determines how formal and informal caregivers relate with one another in the provision of care to recipients. The ability of formal and informal caregivers to work together in the provision of care results from how they communicate with one another and whether caregiving activities are performed to their expectations or not and the perceptions they have thereof.

Coordination of the caregiving activities, according to Armi, Guilley and Lalive D'Epinay, (2008), usually involves situations where formal caregivers provide much of the care needed by recipients while informal caregivers play the supportive role in some instances (Armi, Guilley, & Lalive D'Epinay, 2008). In other instances, informal caregivers provide care to recipients while formal caregivers support informal caregivers in caregiving activities. (Jacobs, Broese, & Deeg, 2014). Other instances show partnerships between formal and informal caregivers where both roles are recognised as equal in the care delivery process (Hengelaar et al., 2018; Ward-Griffin and Mckeever, 2000).

Both caregivers and care recipients benefit from the coordination between formal and informal caregivers. For caregivers, the stress attached to caregiving can be reduced as they communicate about caregiving tasks and also when each form of caregiver performs his/her roles as expected. For care recipients, coordination between formal and informal caregivers can help improve their health outcomes. Coordination also increases the satisfaction of patients and their informal caregivers with the quality of care provided by improving the safety of patients (Jansen et al., 2009).

Conflicts in Caregiving Activities of Formal and Informal Caregivers

Ward-Griffin and McKeever (2000) explained that the failure of formal caregivers to recognise the knowledge and expertise of informal caregivers in health care institutions is reportedly a cause of conflict in relationships between formal and informal caregivers. Kirk (2001) posited that formal and informal caregivers have a more conflicting than coordinated relationship. Much of the conflict between formal and informal caregivers is due to the lack of recognition of knowledge and expertise from both sides. Conflicts between formal and informal caregivers, according to Hudson et al. (2004), on one hand, results from the rejection of the support and advice from formal caregivers by informal. The advice given by formal caregivers might be perceived as inappropriate by the informal caregivers based on certain factors such as their religion and knowledge they have about the care receiver and, thus, may choose not to recognise the knowledge and skills of formal caregivers. On the other hand, formal caregivers do not recognise the informal caregivers as partners in the provision of care (Wittenberg, Kwekkeboom & de Boer, 2012: de Boer & de Klerk, 2013). Informal caregivers claimed they rarely or never got the opportunity to participate in decisions or share their concerns with formal caregivers (de Klerk, de Boer, Plaisier, Schyns & Kooiker, 2015).

The World Health Organisation (2018) recommended that the views of individuals, families and communities should be adopted and that they should be recognised as beneficiaries and partners of a health system that is trustworthy and considers their needs and preferences in humane and holistic ways.

Also, according to Carpentier, Ducharme, Kergoat and Bergman (2008), the conflict between formal and informal caregivers can be caused by informal caregivers' hesitation to disclose information on care recipients in their interactions with formal caregivers. Hesitation to disclose information by informal caregivers is due to family tension, different values and beliefs of members within the same families, stigmatisation attached to illness and the emotional dependence on the identity of the caregiver (Carpentier, Ducharme, Kergoat & Bergman, 2008). All these mentioned factors weaken the ability of informal caregivers to act in coordination with formal caregivers. It can be said then that the rationale for making decisions and the understanding of social actors (families, professional caregivers and or community groups) may be wildly varied and can aggravate and complicate their relationships (Carpentier, 2008).

Conflicts between formal and informal caregivers are reported by Loghmani, et al. (2014) to be caused by informal caregivers not observing visiting hours, thereby going against the policy of the hospital. According to Loghmani et al.'s findings, visiting in-patients outside of specified visiting hours caused disruptions to the activities of hospital staff, disturbed other patients and invaded their privacy. The Intensive Care Unit (ICU) has a greater occurrence of this problem because of the initial structure and idea of

units of such kind which have limited informal caregiver presence and highly restricted visits. The mentality was that informal caregivers added to the risk of a patient's infection, interrupting patients' rest and inducing physiological changes (Marco et al., 2006).

Families should be approached more gently and not forced into observing hospital policies. The use of force by formal caregivers to get informal caregivers to comply with instructions and hospital policies can also bring about conflicts. This is because in the hospital setting, formal caregivers are perceived as more powerful as compared to the families, even though the informal caregivers have much say in the care of the in-patient. This power play between formal and informal caregivers affects their relationship negatively (Covinsky et al., 2013).

Role Expectations and Perceptions of Performance of Formal and Informal Caregivers

Role expectations, according to Edwards and Chapman (2004), is where roles are constructed by people, according to what they preconceive the roles to entail. Thus, the relationship between formal and informal caregivers is likely to be determined by the expectations of each party concerning what the respective roles demand. For example, the formal caregiver who expects bathing and feeding in-patients to be the domain of informal caregivers and drug administration and laboratory investigations to be the province of formal caregivers is likely to work in coordination with informal caregivers who rightly meet his/her expectations. When caregiving activities are not performed to the expectations of formal and informal caregivers, feelings of anger, frustration, powerlessness, shame, self-blame or despair are brought up

(Siassi, 2007). These emotions of informal caregivers are understandable because they provide care to those close to them. They are also understandable for formal caregivers because they have the aim of providing the best quality care to recipients (Janzen et al., 2006).

Role expectations of formal and informal caregivers influence the perceptions they have of the quality of care delivered to care recipients. Perceptions are defined by McDonald (2011) as to how one cognises the world, thus, the way a phenomenon is understood, regarded and interpreted. Perceptions of the care delivered to care recipients could be high or low based on whether or not caregiving activities were performed to expectations. When low perceptions are formed as a result of caregiving activities not being performed up to expectations, conflicts could arise between formal and informal caregivers, thereby hindering coordination between them (Bostan et al., 2007).

Communication Between Formal and Informal Caregivers

Communication is defined by Lunenberg (2010) as the process of conveying information and mutual understanding from one person to another. Caring for patients involves individuals who need to communicate information on patients. Coordinating the caregiving activities of formal and informal caregivers relies on their ability to communicate by sharing information and the mutual understanding of the information shared (Coiera, 2006). Understanding of information implies the interpretation of the information according to its intended meaning. Communication among formal and informal caregivers can improve their relationships which will, in turn, ensure the good health and safety of patients. The inability of formal and informal

caregivers to share information and understand the information being shared can lead to bad health outcomes such as a decline in health condition or death of care recipients (Lunenberg, 2010).

Information sharing incorporates giving others information and the receipt of information given by the one providing the information. Thus, information sharing implies activities that are involved in the provision of information to others proactively or when requested. The information that is shared impacts other people's perception of the world and creates a working understanding of the world that is mutually compatible (Reijo, 2017). The sharing of information includes interpersonal interaction such as telephone calls, emails, face-to-face conversations, computer systems and letters. In health care institutions formal and informal caregivers usually share information through face-to-face conversation. Information shared between formal and informal caregivers can be knowledge which is obtained by informal caregivers on one hand based on their everyday life experiences with people and localities and hence respond to the needs of these people and localities as such (Shih, Lai, & Cheng, 2015). Thus, informal caregivers assess their relatives based on intimate and more comprehensive cues. Formal caregivers, on the other hand, have scientific knowledge and, hence respond to hospital situations with scientific principles and assess complex health situations in short encounters (Hudson et al., 2004). Hence, caregivers can coordinate their activities when the knowledge they both possess is communicated between them. According to Bellou and Gerogianna, (2007), communication will enable the informal caregivers participate more effectively in care provision since they will be informed about the condition of patients and educated on how to provide them with psychological, emotional and financial, support (Bellou & Gerogianni, 2007).

Since communication affects information transactions and also forms a huge part of clinical outcomes or events (Coiera, 2006) as well as the well-being of the patient (Loghmani et al., 2014), the Agency for Health care Research and Quality (AHRQ) identified effective communication as a strategy for health care quality. Effective communicative behaviour between formal caregivers and the family allows for partnership during the period of stay of the patient at the hospital (US Department of Health and Human Services, 2006). To achieve effective communication, the AHRQ has come out with four tools and they are as follows:

- i. Making patients and family full partakers of the health care team before admission for the entire period of stay of in-patients and their informal caregivers in the hospital. This makes them a part of a multidisciplinary team in an open family presence policy to support in in-patient care. This multidisciplinary team comprises of physicians, hospital leaders, nurses, patient and family advisors, other key management and clinical staff. An open family policy outlines the guidelines for visitors to ensure patients' safety and well-being (US Department of Health and Human Services, 2006).
- ii. Keeping the patients and family informed about the background of the hospital environment.
- iii. Letting the patients and family know the acceptable behaviours that can be demonstrated as part of the team.

iv. Describing detailed, appropriate and effective patterns of communication where clinicians can support and invite the families and patients as part of the health care team.

According to the ARHQ, involving informal caregivers in the process of care delivery to in-patients helps to shorten their duration of admission in the hospital by speeding up their recovery process. The involvement of informal caregivers in the care delivery process also enhances good quality health care quality delivery by ensuring patient safety through effective communication between formal and informal caregivers. However, the AHRQ found that a break in communication among caregivers can contribute to medical errors. This can be avoided by informing and engaging patients and family to improve patients' safety through informed choices, infection control initiatives, safe medication use, observation of care processes, practising self-management and reporting complications.

Theoretical Framework

Theories such as the substitution, complementation, supplementation, hierarchical compensatory, the task specific theory and the relational coordination Theory usually underpin the relationship between formal and informal caregivers. According to the substitution theory, some aspects of formal care services are replaced by informal caregiving services. The complementation theory hypothesises that a task to be performed is shared by both formal and informal caregivers, while the supplementation theory hypothesises that some care activities are performed by both support groups and others are specially performed by one support group or the other. The task

specific theory and the relational coordination theory are the theories used in this study.

The Task-Specific Theory (Litwak 1985)

The theory underpinning this study is the task specific theory as it focused on the relationship between formal and informal caregivers based on the different caregiving activities they perform. The task-specific theory places social network groups into two categories, thus formal and informal (Litwak, 1985). This theory postulates that the various social networks are different and due to these differences, each social network group can best manage different tasks. The differences in these two groups are due to their specialisation, training and payment for services rendered. People have different care needs which demand that both the formal and informal caregivers work together to provide care to them bringing on board their various skills, knowledge and training (Paulus et al., 2005).

According to the Task-Specific Theory, both formal and informal caregivers need to coordinate each other's caregiving roles which will help reduce stress attached to caregiving and also reduce negative caregiving results by providing caregivers with relief from labour-intensive duties (Bruhn, 2016). Zhang (2020) postulates that this theory may hence reduce the potential for conflict by clearly separating responsibilities among caregivers. The theory is used in this study because it helps explain why both formal and informal caregivers are seen to cater for in-patients given that they both perform different roles.

This theory is therefore in line with the first objective of this study which seeks to examine the task specifics of formal and informal caregivers.

As a result of the differences in roles, skills and abilities of caregivers, there are likely to be disagreements between formal and informal caregivers over care provided to patients such as the kinds of medical treatment the patient receives in the process of care provision. Since formal and informal caregivers find themselves around each other more often due to their caregiving roles a relationship is established (Zhang, 2020) and this research seeks to explore whether their relationship is coordinated or conflicted.

However, this theory is deficient in entirely explaining the relationship between formal and informal caregivers. The task specific theory is silent in the area of role expectations of formal and informal caregivers and the perceptions they derive from how the roles are performed as well as communication between formal and informal caregivers which influences the relationship between them. This study makes up for this gap by using the relational coordination theory (Gittell, 2015).

Relational Coordination Theory

The relational coordination theory also posits that coordination between formal and informal caregivers is influenced by their role expectations and perceptions of one another (Girmay, Marye, Haftu, Brhanu, & Gerensea, 2018). At the hospitals, formal and informal caregivers expect the performance of caregiving tasks from one another. They also expect that these tasks being performed meet the care needs of patients. Formal caregivers expect informal caregivers to perform certain caregiving tasks which are usually unspecialised in caring for the in-patient while informal caregivers also expect that formal caregivers perform specialised tasks. Specialised and unspecialised caregiving tasks might not always be performed to the

satisfaction of both parties as a result of unclear roles and overlap in certain caregiving tasks which can adversely affect the relationship between formal and informal caregivers (Bostan, Acuner & Yilmaz, 2007).

The perceptions of formal and informal caregivers are derived from their satisfaction with how caregiving activities are performed. The satisfaction of formal and informal caregivers with the performance of caregiving roles also plays a role in how they relate with one another either negatively or positively (Moyer et al., 2014). When the perceptions of care provided are lower than the caregivers' expectations of the quality of care required and health outcomes, they might tend to vent at each other out of disappointment and despair. This suggests that perceptions of care provided must meet expectations of care provided to have coordination between formal and informal caregivers without which there could be conflicts (Salin, Kaunonen, & Åstedt-Kurki, 2013). These dimensions of relationships improve work performance thereby improving the relationship between health professionals who perform various roles thereby improving communication and vice versa. The interdependencies of tasks are then managed in a seamless and more direct way with less lapses, redundancies, delays and errors.

The relational coordination theory makes up for the gaps in the Task specific theory in explaining the relationship between formal and informal caregivers by incorporating the element of communication which determines coordination or conflict in the relationship between formal and informal caregivers. This theory is, therefore, used to address the second objective of this study which is to describe the communication between formal and informal caregivers in the performance of their caregiving. The relational

coordination theory also encompasses the elements of role expectations and perceptions determining coordination and conflicts in the relationships between formal and informal caregivers. Hence, the relational coordination theory is used in this study to also address objective three of this study which is to investigate the role expectations and perceptions of formal and informal caregivers regarding the performance of caregiving.

Empirical Review

This section looks at the methods as well as the theories used by other authors in studying the relationship between formal and informal caregivers.

The empirical review was used to determine the gaps that exist in the literature concerning relationships between formal and informal caregivers.

Agbelie (2017) assessed the perceptions of formal and informal caregivers on health care quality at the Princess Marie Children's Hospital's Out-Patient Department in Ghana. The author employed a quantitative research approach that allowed for a descriptive cross-sectional study design with questionnaire administration as the data collection method. The quantitative research approach was used because the study had the aim of quantifying and analysing numeric data on the quality of care provided at the Princess Marie Children's Hospital's Out-Patient Department. With the quantitative research approach used, the results of Agbelie's (2017) study can be generalised for other groups. The descriptive cross-sectional study design was suitable as this study focused on health-related issues. Chi-square was used to assess categorical predictors related to the quality of care while analysis was done using ordinal logistic regression to assess the factors linked

to the outcome variables. The results of the study indicated that perceptions of the quality of care in the five areas of service quality which included assurance, tangibility, responsiveness, empathy and reliability of care were lower than the quality of care expected. This was the reason for the dissatisfaction of formal and informal caregivers with the quality of health care provided. The study concluded that the expectations of formal and informal caregivers were not met adequately and hence, the quality of care was moderate. The study, then, recommended that there be policies at health institutions that always monitor and evaluate the care quality to suit the expectations of formal and informal caregivers (Agbelie, 2017).

A study by Orpin et al., (2014) explored the patterns of how formal and informal care were utilised by persons with dementia (PWD) in communities in Australia. In contrast to Agbelie's (2017) study, Orpin et al., (2014) used a qualitative research approach instead of a quantitative research approach. This was because, as against generalisation of results in Agbelie's study, Orpin et al., were interested in gathering in-depth knowledge to comprehend the experiences and opinions of the use of formal and informal care, an area that had not seen much research for PWD in Australia. A sample of 18 primary carers of People with Dementia (PWD) were selected using convenient sampling. The results of this study showed an overall dissatisfaction among informal caregivers regarding their relationship with formal care providers. Informal caregivers felt their contributions were unseen and unrecognised by the formal care providers and that the activities of formal care providers excluded family and friends. Hence, no attention was paid to

family and friends of the sick and that their needs and concerns were ignored and their ability to provide care underestimated Orpin et al., (2014)

Armi, Guilley and Lalive D'Epinay (2008) also investigated the interface between informal and formal support in Switzerland. Armi et al. were interested in the elderly who increasingly needed care but faced a decrease in the number of informal caregivers available to provide informal care to them. A sample of 323 was used with descriptive analysis to determine whether informal and formal services were coordinating or substituting each other. Armi et al. used the complementation, supplementation, substitution, task-specific and the hierarchical compensatory theories to explain the complementary and supplementary nature of the interface between formal and informal care. These theories were also used to analyse the amount of care received by each social network group and the difference in the utilisation of caregivers among individuals respectively. It was found that as formal services increased, there was also a significant increase in informal services. This was an indication that the formal and informal networks coordinated with each other. Also, in 21.2 percent of the cases analysed, formal care substituted partly for informal care and in only 6.4 percent of the cases, informal support stopped after there was an increase in formal support and thus, it could not prove the assertions that family and friends will be more ready to provide care with the institution of formal services.

Litwin and Attias-Donfut (2009) examined the relationship between formal and informal care delivered to elderly homes in France and Israel. This study is similar to Armi et al's., (2008) study on the interface between informal and formal support in Switzerland because they were both centred on the

Attias-Donfut (2009) used France and Isreal as their study areas because these countries have similar family welfare systems but are different in history, religion and culture. Litwin and Attias-Donfut sought to establish whether formal care substituted for or coordinated informal care services. Similar to Armi et al., (2008), Litwin and Attias-Donfut (2009) also used the substitution, complementation and supplementation theories to investigate coordination or substitution of formal and informal care. A quantitative research approach was also utilised in both studies. The quantitative research approach was used in Litwin and Attias-Donfut' study to allow for generalisation of results for both France and Israel. Litwin and Attias-Donfut sampled participants of age 75 and above.

Data for the study were from both secondary [Survey of Health, Ageing and Retirement in Europe (SHARE)] and primary sources. Regression analysis was done on forms of care from outside the household which is formal support only, informal support only and both formal and informal support. The predictor variable was whether informal support was received from a family member staying in the household or not. The study had similar results as the study conducted by Armi et al., (2008). From Litwin and Attias-Donfut's (2009) study results, it was clear that the existence of both forms of care commonly results in coordination. The results also showed that the combination of both forms of care mostly happen when there is a greater need for care and that caregivers who were spouses had less formal help as compared to children from the same household or other family members. Regardless of this, spouses, children and other family members still had a

considerable amount of help from formal services (Litwin & Attias-Donfut, 2009).

Paulus, Keijzer and Raak (2005) also analysed the relationships between formal and informal caregivers. Their study however, was conducted in residential areas, specifically nursing homes, in the Netherlands as compared to the study areas used by Armi et al's., (Switzerland) and Litwin and Attias-Donfut's study (France and Israel). Paulus et al., (2005) sought to determine whether or not the introduction of integrated care, could result in changes occurring in the relationships between formal and informal caregivers at the nursing homes. Contrary to Armi et al (2008) and Litwin and Attias-Donfut's (2009) complementation, substitution and supplementation theories adopted, Paulus et al., (2005) used the Noelker and Bass Theory. The Noelker and Bass theory was used to determine the rates of contribution and the ratios of formal and informal care for 14 activities as against seeking to establish coordination in formal and informal caregiving relationships by Armi et al (2008) and Litwin and Attias-Donfut (2009).

Paulus et al. used a quasi-experimental design in their study since it was impossible to select individual nursing homes at random. Two nursing homes were selected purposively to suit the criteria of the study which included a working environment that is stable, comparability of size and those who were motivated to make contributions to the research (Paulus et al., 2005). The results of the study indicated that integrated care did not lead to major changes in the relationships between formal and informal caregivers at nursing homes in the Netherlands. Formal care was substituted with informal care minimally with little changes in how formal and informal caregivers

performed different activities in dual specialisation. In contrast to Paulus et al's findings, Armi et al., found that informal care was substituted with formal care and in 21.2 percent of the analysed cases. Paulus et al., found that relationships were seen to change with time and this caused complexities in how separate activities are linked. The study concluded that informal caregivers make contributions to a lot of activities. However, integrated care impacted involvement moderately (Paulus et al., 2005).

Loghmani, Borhani and Abbaszadeh (2014) studied the factors influencing the communication between informal caregivers and nurses in Kerman's Intensive Care Unit in Iran. The study was done qualitatively using content analysis. Eight nurses and ten informal caregivers of patients were interviewed. Participants were initially purposively sampled. However, data were later collected using theoretical sampling. Results from this study showed that factors that facilitated communication between nurses and informal caregivers included emotional support, spiritual care, participation, consultation and notification. It was also found that the barriers to communication included patient and job difficulties and misunderstandings in treatment.

The study concluded that effective communication could be achieved by identifying the facilitators and barriers of communication, setting up new rules, employing creative ways of educating and establishing ICU team communication. This should be done while considering the patient-based approach to improve the adequacy of communication. When communication from formal caregivers is inadequate, information received by informal

caregivers can be conflicting and potentially increase stressful situations (Loghmani et al., 2014).

Brand, Slee, Chang, Cheng, Lipinski, Arnold and Traub (2015) conducted an action research on Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) training. This study accesses whether TeamSTEPPS training was going to improve communication between nurses and physicians and between physicians. The study was also conducted to assess whether TeamSTEPPS would improve the perceptions of patients about the teamwork of the emergency department at the Tertiary Care Hospital Emergency Department. Comparing this study to Loghmani, Borhani and Abbaszadeh (2014), it can be seen that, both studies were conducted on communication between formal and informal caregivers. However, in contrast to Loghmani et al's., qualitative research design and purposive sampling method, Brand et al., (2015) used a before and after prospective observational study since the study was an intervention to improve communication between formal and informal caregivers. A questionnaire was administered to 12 physicians and 43 nurses before the TeamSTEPPS Fundamentals course and a year after the course.

The study revealed that nurses' perceptions of communication between physicians and patients and their relatives as well as the communication between physicians and nursing staff concerning changes in treatment plans were improved. The study also found that the TeamSTEPPS Fundamentals course improves how patients rated teamwork between physicians and nurses. The study concluded that the TeamSTEPPS Fundamentals course improved

some aspects of the perceptions of nurses and patients of communication and teamwork between nurses and the physicians of the emergency department.

Toscan et al. (2012) investigated the coordination of care for elderly patients with hip fractures from multiple standpoints, thus formal and informal caregivers and patients. Using multiple sources of data collection allowed the researchers to achieve validity and reliability of results since a qualitative research approach was used. Toscan et al., (2012) sought to determine the main causes of conflicts between formal and informal caregivers for patients who transitioned from one care institution to another in an acute care institutional setting. Interview and observation guides were used for data collection to get explanations and a better understanding of participants' opinions, experiences and behaviour on the coordination of care for the elderly with hip fractures. Participants were selected based on an inclusion criteria which focused on patients diagnosed with hip fracture, patients over 65 years, patients with little or no cognitive impairment and patients with the ability to read and write.

According to Toscan et al. (2012), through relevant, timely, adequate, accurate and comprehensible information, coordination can be achieved between formal and informal caregivers which can play an important role in the care of patients. The study found four causes of conflict between formal and informal caregivers for transitional patients. These causes of conflict include unclear definition of care roles, confusion in the communication between formal and informal caregivers, weak personal stake in patients' care delivery or outcome and strain on formal and informal caregiver roles due to constraints of the system.

Lessons Learnt from the Empirical Review

It is striking that most studies reviewed above are usually centred on the elderly (Armi, Guilley & Lalive D'Epinay, 2008; Litwin & Attias-Donfut, 2009; Toscan, et al., 2012). The studies reviewed on the relationship, interface, coordination, patterns of care, communication and expectations employed mostly a qualitative or mixed-method. The use of the qualitative approach was because studies sought to delve into the interpretive issues of participants and their in-depth understanding, perceptions and views in explaining their real-life situations. The quantitative aspects of the studies reviewed above, however, sought to establish cause and effect. Thus per the nature of the research being conducted and the factors or variables being studied, either a qualitative or quantitative research design was adopted. For instance, in using large sample sizes, some studies used mixed methods to generalise results (Litwin & Attia-Donfut, 2009), or in comparing the changes before and after an intervention on hospital staff using ratios (Paulus, Keijzer, & Raak, 2005). Studies have not yet been seen on the relationship between formal and informal caregivers in Ghana. This study, therefore, adopted a qualitative research approach to explore the relationship between formal and informal caregivers which is an area that is under-researched in Ghana.

Studies reviewed were found to use theories such as the complementation, supplementation, substitution, the task specific, the hierarchical compensatory and the Noelker and Bass theories in investigating coordination and conflict in the relationship between formal and informal caregivers. This study which also studies the coordination and conflicts in the relationship between formal and informal caregivers at the Paediatric Ward of

the Cape Coast Teaching Hospital also adopts the task specific alongside the relational coordination theory.

Conceptual Framework

The conceptual framework is developed from the theories and concepts underlying this study. It tells how the theories and concepts are linked together to explain the focus of this study. The task specific and the relational coordination theories guided this study and the main concepts used include formal and informal caregivers, relationship, caregiving tasks, role expectations, perceptions, coordination, conflicts and communication.

The need for care determines the use of care provided by formal and informal caregivers. Thus, when a person is taken ill, formal care is used due to modernisation, the health conditions of the patient, availability of care, hospital conditions and individualism among other reasons. Informal caregivers are also seen in the hospitals ensuring proper care of in-patients due to social obligations and the perceptions of poor health care quality by Ghanaians. Therefore, both formal and informal caregivers are seen to be performing caregiving activities at the health institutions.

Figure 1 shows the conceptual framework for this study which indicates that the caregiving activities performed by formal and informal caregivers are classified according to Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). A coordinated or conflicted relationship is formed between formal and informal caregivers in performing ADL and IADL. Coordination in relationships between formal and informal caregivers, on one hand, is usually defined as the harmonious working together of both parties to provide care to those in need of it. Conflicts, on the

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

other hand, are usually defined as disagreements between formal and informal caregivers that negatively affect how they work together: thus, the inability of formal and informal caregivers to work together.

The relationship between formal and informal caregivers is influenced by their role expectations and their perceptions of how these roles are performed, how they communicate and how they both perform their caregiving activities or roles. The expectations of formal and informal caregivers is determined by their preconceptions of what caregiving activities each party is to perform. Whether the roles of one group of caregivers are performed to the expectations of the other group of caregivers depends on the level of satisfaction of the expecting group. How they communicate is also determined by the sharing of timely, adequate and accurate information and their understanding (perceived or interpreted for its intended purpose) of information being shared as indicated in Figure 1.

NOBIS

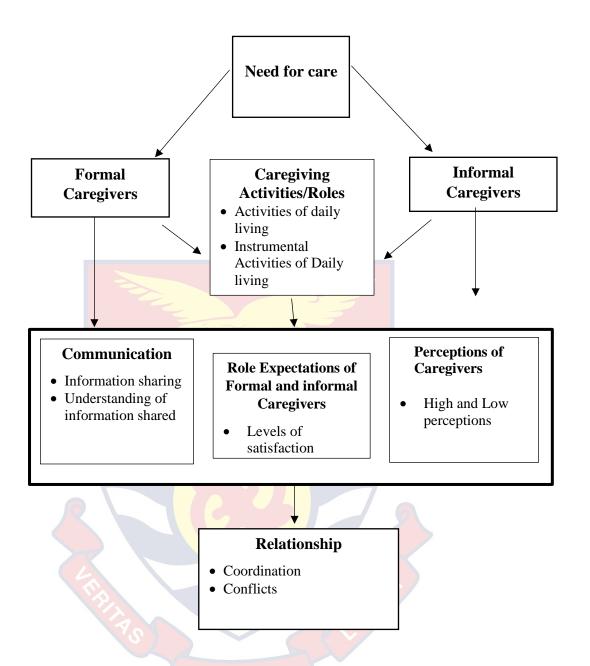


Figure 1: Conceptual Framework showing the Relationship between formal and informal caregivers.

Source: Adapted from Gittell, (2015) and Luong, (2000).

CHAPTER THREE

METHODOLOGY

Introduction

This chapter discusses the research methodology employed which comprises the scientific ways of addressing research objectives (Kumar, 2011) in a logical manner (Kothari, 2004). The chapter focuses on the research design, population, sample and sampling technique, data collection methods, data processing and analysis as well as ethical procedures.

Research Design

The philosophical paragidm of this study is interpretivism. The epistemological principle of interpretivism is that the researcher forms a part of the research as his/her interests are the basis of the research. Interpretivists are concerned with particular contextualised environments and recognise that knowledge and reality are not objective (Whiting, 2020). Instead knowledge and reality are determined by those within that particular environment. Interpretivism was used to explore the relationship between formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. This was deemed necessary as the interpretivist school of thought gives researchers the opportunity to thoroughly analyse a given issue in its context. Interpretivism assumes that social reality is studied best by reconciling peoples subjective interpretations Maxwell, 2012).

Considering the interpretivist philosophical viewpoint, the study adopted a qualitative research design. The basis of qualitative research lies in the interpretative approach to social reality and in the description of the lived experience of human beings. Interpretivism rejects the idea that peoples' behaviours are predictable in the same light as the the natural world and that human behaviour is not as a result of external forces. The qualitative research design was used because it sought to understand the reasons, motivations and opinions underlying the research problem (Schoonenboom & Johnson, 2017). The qualitative research design was also used in this study because it allowed for the in-depth exploration of the perceptions, experiences and opinions of inpatients and formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. A disadvantage of the qualitative research design is that results from the study cannot be generalised for the parent population. However, this study adopted the qualitative research design because results can be applied to contexts that are similar to the parent population which is the Cape Coast Teaching Hospital (Brannen, 2005). The qualitative research design was used to understand the nature of the phenomenon understudy rather than generalising it.

An exploratory study was conducted to better understand the relationship between formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. The exploratory study design is used to investigate a research problem which has not been clearly defined and gain a better understanding of it without providing conclusive results. The exploratory study design was deemed appropriate because it was going to allow the researcher gain an insight into the caregiving tasks performed by formal and informal caregivers, how they communicated, their role expectations of one another and their perceptions of how the expected roles were performed. Pre-existing theories were used to guide the study instead of

generating theories from the data gathered. The exploratory study allowed the researcher to use theories to give a structure to the study by using the concepts from the theories to guide the data collection generation of themes and reporting processes.

This study adopted a theory-driven approach in order for the researcher to gain sensitisation to relevant issues and interpretations that might not have been necessarily identified with the use of an inductive approach. The theory driven approach as againt the deductive approach also allowed the researcher to use concepts that highlight the scope for this qualitative research to assess pre-existing theories (MacFarlane, & O'Reilly-de Brún, 2012).

Knowledge was gained on the nature of information shared and how information shared is understood by formal and informal caregivers. This was achieved by delving into the unique realities of both formal and informal caregivers and in-patients that influenced the relationship between formal and informal caregivers (MacFarlane, & O'Reilly-de Brún, 2012).

Study Area

The study was conducted at the Cape Coast Teaching Hospital, formerly the Central Regional Hospital. It is a referral hospital located in the Central Region of Ghana at the Northern part of Cape Coast and contains 400 beds. The Hospital is located on the North of Abura, on the south of Pedu Estate, on the east of Abura Estate and the west of Nkafua. The Cape Coast Teaching Hospital started operating on the 12th of August 1998 as one of the first advanced regional hospitals set up by the Ministry of Health. It was declared the best regional hospital in 2003 (Quaye, 2015).

The hospital became a teaching hospital at the commencement of the School of Medical Sciences at the University of Cape Coast in January 2008 (Karikari, 2018). It is one of the four teaching hospitals in Ghana. The rest are the Korle Bu Teaching Hospital, the Tamale Teaching Hospital and the Komfo Anokye Teaching Hospital. The hospital provides an all-inclusive range of specialist health care services including orthopaedics, obstetrics and gynaecology, child health medicine and otolaryngology, to the inhabitants of the Central Region, Western Region and parts of Greater Accra and the Eastern Regions (Ghana Health Service, 2015). The Cape Coast Teaching Hospital was selected based on the fact that it has made a formal step towards encouraging the coordination between formal and informal caregivers by including informal caregivers in the care delivery process and also through the provision of a hostel for breastfeeding mothers of in-patients at the Paediatric Ward.

Study Population

The population for this study included in-patients between the ages of 10-15 and their formal and informal caregivers at the selected research site. Formal caregivers included doctors and nurses of the in-patients and informal caregivers included those who stayed with in-patients on admission at the ward. In-patients at the Paediatric Ward of the Cape Coast Teaching Hospital included all admitted children from neonates to 15 years old. However, the study focused on children between the ages of 10-15 for ethical, validity and reliability concerns. The Paediatric Ward was also selected on the basis that children are found to demand and receive more care as compared to adults (Evagelou, Lordanou, Lemonidou, Patiraki, Kyritsi, & Bellou, 2003).

Sampling Procedure

Non-probability sampling was used to select in-patients and their formal and informal caregivers at the Paediatric Ward. Specifically, the convenience and purposeful (maximum variation) sampling techniques were used to select in-patients as well as formal and informal caregivers of in-patients who were easily accessible, willing and available to participate in the study and who could bring out different perspectives on the relationship between formal and informal caregivers. The maximum variation sampling technique was used because it helped to include diverse participants (in-patients and formal and in-formal caregivers) that were relevant for this study.

Sampling was done by selecting participants based on set criteria relevant to this study. The criteria for selecting in-patients included in-patients between the ages of 10-15 years. The selection criteria for in-patients also included those that had been admitted within a period of not less than two days and, those whose medical conditions allowed interaction. The participants' selection procedure ensured that all ailments of in-patients at the ward at the time of data collection except ailments with medical conditions that did not allow the researcher to interact with the patient were represented in the sample. This is because the nature of an in-patient's ailment can affect the interface between formal and informal caregivers (Quinn, Clare, & Woods, 2009). The criteria for selecting formal caregivers (doctors and nurses) and informal caregivers (family) of in-patients at the Paediatric Ward included those who were linked to selected in-patients by virtue of being their primary or main caregivers (informal caregivers who have the greater responsibility of caring for the in-patient on admission).

The population at the Paediatric Ward is fluid and hence, prospective participants go in and out of the hospital often. This is because formal caregivers provide care on a shift basis and because in-patients could be admitted and discharged at any point in time and would go and come along with their informal caregivers. Hence, obtaining the specific sample size of 21 for this study was challenging. Therefore data collection was based on the concept of saturation. Thus, data were collected from participants to the point where no new insights were emerging and no new themes were obtained (Guest et al., 2006). Saturation was reached with a total of 21 participants that were interviewed for the study. The 21 participants included eight in-patients, eight informal caregivers and five formal caregivers comprising three nurses and two doctors.

Data Collection Procedures

Data was collected from the in-patients between the ages of 10-15 years and their main formal and informal caregivers, using in-depth interviews and observation guides (see Appendix A to D). In-depth interviews involved a one-on-one dialogue with the interviewees. They were used to solicit information on the task specifics of formal and informal caregivers which allowed participants to freely express their underlying beliefs, attitudes and values around the area of caregiving tasks and who performs what tasks at the Paediatric Ward.

In-depth interviews were also conducted to investigate the role expectations and perceptions of how these roles were performed by formal and informal caregivers. This enabled an in-depth knowledge about issues around the preconceptions about what caregiving activity each form of caregiver was

to perform and how formal and informal caregivers related to each other. Also, in-depth interviews were used to collect data on the communication between formal and informal caregivers and their role expectations and perceptions in the performance of their caregiving tasks. These interviews were centred on how information was shared and how information shared was understood.

The paediatric ward was visited five days prior to the start of interviews to establish rapport and to do a reconnaisaance survey. Non-participant observation was done during interviews to observe the caregiving tasks of formal and informal caregivers and how they communicated with one another. This helped to gather information and attain insight into the situation at the hospital aside from information provided by participants without being involved in what was observed (Kawulich, 2012).

Actual Field Work

Fieldwork commenced on the 15th of June 2020 and ended on the 29th of June 2020. COVID-19 safety and health protocols were observed in the data collection process. The COVID-19 safety and health protocols that were observed included frequent hand washing, wearing of nose masks and face shields at all times and keeping a distance of six feet from other people including participants. These measures were observed to ensure the safety of both the researcher and participants.

Rapport was initially established with participants to gain their trust and make communication with them easier. Most interviews with the inpatients and informal caregivers were done in Fante while interviews with formal caregivers were mainly in English. This enabled participants to understand the questions being asked and also express their views, feelings

and perceptions thoroughly. Other questions were asked as follow-ups, promptings and probing. Data from interviews were recorded with an audio recorder with the permission of participants and later transcribed.

The activities of in-patients, doctors, nurses and the parents of in-patients at the Paediatric Ward were observed using a non-participant observation guide (see Appendix D). In order not to forget relevant observations made, the observations were documented in a field notebook. This was done for five hours in a day, watching participants go about their daily activities, how they communicated with each other, how caregivers assisted each other to perform caregiving roles and activities and how they shared information amongst themselves. Observation was used to complement and backup the interviews that were carried out. Observations were also made during the conduct of interviews to confirm what was earlier observed using an observation guide (see Appendix D).

Data Processing and Analysis

At the end of each day, responses from interviews were transcribed and observations were edited. Follow-ups were made where necessary to seek further clarity on issues. Naratives in the local dialect were translated into English and transcribed. Data were analysed thematically for each objective using the concepts defined in the conceptual framework based on the theories (task-specific and relational coordination theories) and concepts that underpin this study as the themes for this chapter. These concepts included caregiving activities, Activities of Daily Living and Instrumental Activities of Daily Living, communication, information sharing and understanding of the

information shared, role expectations and perceptions. These concepts guided the analysis of the data gathered. A thematic analysis which involved familiarisation with data gathered from the field was done to gain a general overview of the data. Common trends and patterns (experiences, opinions and sentiments) were then coded (identified and organised) into themes using the concepts defined in the conceptual framework as a guide. These themes were, then, reviewed to ensure that they were a true reflection of the data gathered and presented in the write-up.

Ethical Considerations

The Department of Integrated Development Studies gave an introductory letter which facilitated permission to collect data at the Cape Coast Teaching Hospital. The Institutional Review Board of the University of Cape Coast then gave ethical clearance for the study to proceed. The Cape Coast Teaching hospital was given a copy of the research proposal upon request and also gave its approval for the research to be carried out.

Informed consent from participants was sought. Participants were informed that their voluntary participation is priceless and as such, they could decline to answer any question that they did not wish to respond to. They were also informed that they could withdraw from interviews at any time that they felt uncomfortable without any penalty. Identification codes were used instead of the actual names of participants to ensure their anonymity. De-identified data were stored separately from the coding list to avoid tracing data back to a particular participant. Confidentiality was achieved by ensuring that issues arising from interviews with participants were not discussed with others in a manner that made participants identifiable. What a participant said in an

interview was also not disclosed. Pictures and videos of participants were not taken at the hospital for this study to protect the identity of participants. This was also to ensure confidentiality of information gathered.

Validity and Reliability

Validity and reliability were ensured by the use of triangulation of sources of data and methods of data collection. Validity was ensured through systematically exploring the convergence of different and multiple information sources (in-patients, formal and informal caregivers). The information gathered from multiple sources were categorised into the themes of this study (Creswell and Miller, 2000). Validity and reliability, according to Bryman, (2012) can also be ensured through the trustworthiness of the gathered data. The trustworthiness of data in this study was ensured through triangulation which is the use of various methods in gathering data. The validity of the themes derived from the data gathered which included the caregiving activities of formal and informal caregivers, the communication between formal and informal caregivers and the role expectations and perceptions of formal and informal caregivers were enhanced and made valid because various sources of evidence were employed instead of one source. Validity and reliability were also ensured by interviewing participants to the point of saturation where no new information was gathered.

Reflexivity is the assessment of the researcher's own practices, beliefs and judgments in the research process and the influence these may have on the research. As the researcher I have always received and continue to recieve both formal and informal care when admitted at formal care institutions. As a

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

result I witness other patients receive both formal and informal care. I have also had relatives and friends being in-patients who receive both formal and informal care. This has made me perceive the interactions between formal and informal caregivers as a convention and as a normal and vital part of our lives. However, as I have only played the roles of in-patient and informal caregiver but not a formal caregiver, I realised that I understood and empathised with in-patients and informal caregivers as compare to formal caregivers. This could have made me biased towards in-patients and informal caregivers. In order to avoid bias, a second and third party listened to all audio recordings and read through all transcribed data after interviews with participants. This was to rid the data of bias and also consider a different perspective on information gathered that might have been overlooked.

Chapter Summary

This chapter focused on the methods used in this study to address the study objectives. The methods used were solely qualitative and included an exploratory study design. Non-probability sampling with convenience sampling and maximum variation sampling as the specific sampling techniques used. In-depth interviews and non-participant observation were the data collection methods used after which a thematic analysis was done.

CHAPTER FOUR

RESULTS AND DISCUSSIONS

Introduction

This chapter discusses the results of the issues that address the research objectives. The chapter begins with the background characteristics of participants to describe the participants of the study. Results and discussions are, then, presented under three major themes derived from the research objectives and conceptual framework for the study. The three themes are caregiving activities of formal and informal caregivers, communication between formal and informal caregivers and the role expectations of formal and informal caregivers had of the caregiving activities performed at the Paediatric Ward of the Cape Coast Teaching Hospital.

Background Characteristics of Participants

The background information of participants considered in this study included the age distribution of in-patients, the relationship between informal caregivers and in-patients, the duration of admission of participants, health conditions of in-patients and the professional background of formal caregivers. The ages of in-patients admitted at the Paediatric Ward ranged from neonates to 15 years old.

The next background characteristic considered was the relationship between informal caregivers and in-patients. Out of the eight informal caregivers interviewed, six were mothers and two were fathers. The study also looked at the duration of admission of in-patients and their informal caregivers. This background characteristic was concerned with informal

caregivers and in-patients that had been admitted to the ward for not less than two days. The presence of in-patients and their informal caregivers on the ward ranged from two days to seven days as at the time of interviews which commenced on the 15th of June 2020 and ended on the 29th of June 2020.

The ailments of in-patients included bone fracture, typhoid fever, malaria, esophaeal foreign body disease and nephrotic syndrome. Two patients had bone fracture, two had typhoid fever, two had malaria, one suffered from esophageal foreign body disease while another had nephrotic syndrome. Four in-patients with nephrotic syndrome, malaria, typhoid fever and bone fracture were met in critical conditions as compared to the other four in-patients in less critical conditions.

The professional background of formal caregivers was considered in this study. Formal caregivers interviewed included two junior doctors who were doing their housemanship and three nurses who had been working at the hospital between three and five years. The doctors led the caregiving team for in-patients by drawing treatment plans while the nurses reported to doctors on the health conditions of in-patients and assisted in implementing the treatment plans. Concerning the duration of formal caregivers' presence on the ward, doctors and nurses interviewed were permanent hospital employees who run morning and afternoon shifts. These shifts lasted for a maximum of 8 hours during the day and a maximum of 12 hours during the night.

The length of stay of participants also allowed them to provide information of relevance to the study. Also, the ailments and severity of inpatients' health conditions as well as the professional background of formal caregivers, determined the caregiving activities carried out and how much specialised care they required.

There was a hostel for mothers at the cost of GHC5.00 per night. However, mothers without the financial ability to patronise this facility were allowed to sleep on mattresses besides their children (in-patients) in the ward. As per the hospital policy, one primary informal caregiver (informal caregiver with the greater responsibility of providing care to the in-patient) was allowed to stay in the Paediatric Ward with an in-patient.

Caregiving Activities of Formal and Informal Caregivers

The first objective of the study was to identify the task specifics of formal and informal caregivers. From the conceptual framework (Figure 1), a coordinated or conflicted relationship is formed between formal and informal caregivers in performing caregiving activities (ADL and IADL). Also, according to the tasks specific theory underpinning this study, formal caregivers perform specialised caregiving tasks based on their specialised skills gained from training and education in health care while informal caregivers perform basic caregiving tasks based on knowledge gained from familiarity and socialisation with in-patients. This information guided the analysis of the various roles played by formal and informal caregivers to understand how the performance of one caregiving task could affect the performance of other caregiving tasks. This analysis, therefore, helped to shed light on the interplay of caregiving tasks of formal and informal caregivers and how this determined coordination or conflict between formal and informal caregivers.

The activities performed by doctors at the Paediatric Ward were diagnosis, drawing of treatment plans, drug administration, providing informal caregivers with information on the health of in-patients, prescription of drugs, daily consultations with in-patients, monitoring the health progress or decline of in-patients and discharge of in-patients.

Nurses bathed in-patients, collected the medical history of the patient and administered drugs. Their activities also included laying of hospital beds, daily consultations with in-patients, monitoring the health progress or decline of in-patients and feeding in-patients. In addition to the above, the nurses also provided informal caregivers with information on the health of in-patients, cordinated laboratory investigations and dressed the wounds of in-patients.

The caregiving activities performed by informal caregivers were feeding in-patients, bathing in-patients, assisting in-patients in using the washroom, assisting in-patients to walk around and changing in-patients' clothes. They also included assisting formal caregivers to administer drugs to in-patients by providing emotional and psychological support, monitoring the health progress or decline of in-patients, running errands on behalf of the in-patients (purchasing prescribed drugs) and providing companionship to the in-patients.

Through observation and interviews, it was found that doctors, nurses and informal caregivers formed ad hoc caregiving teams for in-patients. In these caregiving teams, doctors came out with the treatment plans and performed caregiving activities to carry out the treatment plans while nurses performed caregiving activities to implement the plans and informal caregivers assisted doctors and nurses in implementing the treatment plans.

According to two formal caregivers, this order of performance of caregiving activities was based on the skills formal and informal caregivers had and the roles each party played to support the care of in-patients.

The order in which members of the caregiving teams performed their caregiving tasks was perceived by four out of five formal caregivers, all eight informal caregivers and all eight in-patients to be hierarchical. The perceived hierarchical order in this study indicates that participants interpreted the order in which caregiving activities to be based on the importance of one caregiving activity over the other. The perceived hierarchical order of performanance of caregiving activities was also based on their roles as formal and informal caregivers. Thus, participants had the impression that doctors were more important than nurses while nurses were more important than informal caregivers.

Activities of Daily Living, Instrumental Activities of Daily Living and Medical Caregiving Activities

Through interviews and observation it was found that ADL carried out at the Paediatric Ward included toileting (assisting in-patients in using the washroom), dressing (changing of in-patients clothes), mobility (assisting in-patients to walk around the ward) and grooming (hair combing, brushing of teeth and cleaning in-patients with a towel and water). ADL were performed mainly by informal caregivers except for feeding and bathing of in-patients which were performed by both formal and informal caregivers (see Table 1).

Table 1: Activities of Daily Living

List of Activities	Caregivers	Number
Toileting	Informal	8
Dressing	Informal	8
Grooming	Informal	8
Bathing	Informal	7
	Formal	1
Eating	Informal	6
	Formal	2

Source: Field Data, 2020

In-patients were assisted with IADL which included medication management (prescription of drugs) by formal caregivers and movement within the hospital (running errands on behalf of the in-patients: purchasing food and prescribed drugs and bringing clean clothes and other needed items from home) by informal caregivers. Communication management (providing information on the health of in-patients) and an aspect of medication management which was drug administration were performed by both formal and informal caregivers. (See Table 2).

Table 2: Instrumental Activities of Daily Living

List of Activities	Caregivers	Number
Mobility	Informal	8
Communication	Informal	8
	Formal	5
Medication	Formal	5
management		
	Informal	4

Source: Field Data, 2020

Interviews and observation of caregiving activities also revealed other caregiving activities. These caregiving activities are referred to in this study as Medical Caregiving Activities (MCA). These MCAs include history taking,

drawing of treatment plans, laying of hospital beds and daily consultations with in-patients. They also include laboratory investigations, diagnosis and discharge of in-patients. These caregiving activities were found to be performed mainly by formal caregivers, except for monitoring the health progress or decline of in-patients' health, which was performed by both formal and informal caregivers (see Table 3).

Table 3: Medical Caregiving Activities

List of Activities	Caregivers	Number
Daily consultations	Formal	5
Lab investigations	Formal	5
Discharge of in-	Formal	5
patients		
Monitoring health	Formal	5
progress	Informal	3
History taking	Formal	3
Laying hospital beds	Formal	3
Dressing of wounds	Formal	3
Drawing treatment	Formal	2
plans		
Diagnosis	Formal	2

Source: Field Data, 2020

From interviews with in-patients and caregivers, it was found that the first activity performed when patients came to the Paediatric Ward was to provide information on their health conditions. This activity was done with the help of informal caregivers, especially in instances where patients were too

young or too sick to provide the needed information to formal caregivers by themselves. All other caregiving activities performed by informal caregivers were delegated to them by formal caregivers. This was because all caregiving tasks (whether specialised or unspecialised) are supposed to be performed by formal caregivers as part of their duties.

The delegated tasks performed by informal caregivers included feeding in-patients, bathing, cleaning in-patients and mobility (assisting in-patients to walk around). The rest were changing of clothes, assisting formal caregivers to administer drugs to in-patients and providing emotional and psychological support to patients. They also monitored the health progress or decline of in-patients, ran errands on behalf of the in-patients (purchasing prescribed drugs) and provided companionship. These caregiving tasks, except monitoring the health progress or decline of in-patients, were basic and treatment needs that informal caregivers assisted in-patients with.

According to formal caregivers, the caregiving tasks of feeding inpatients, bathing in-patients, medication management (drug administration),
communication management (providing information on the health of inpatients), monitoring the health progress, or decline of in-patients were both
basic and specialised and were performed by both parties. Two doctors and a
nurse indicated that this distinction of basic and specialised tasks was based on
whether the overlapping caregiving tasks required specialised skills gained
from training and education in health care. The distinction was also based on
whether the overlapping caregiving tasks required basic skills gained from
knowledge, familiarity and socialisation with in-patients.

From the observations and interviews with in-patients and caregivers, it was found that six informal caregivers of in-patients were educated by formal caregivers on what to look out for in monitoring the health of inpatients. These in-patients suffered from health conditions which included; nephrotic syndrome (two in-patients); malaria (two in-patients); and typhoid fever (two in-patients). The informal caregivers were educated by informal caregivers on the quantity of food intake as well as the colour, nature and quantity of their excretion. For instance, informal caregivers were taught to monitor details such as the timing of medications before and after meals. The kinds and quantities of food and liquid intake and excretion were also critically monitored due to in-patients' ailments and any changes noticed were reported the to doctors and nurses. This enabled formal caregivers to determine whether the child's health was improving or not since informal caregivers spent more time beside in-patients than formal caregivers did. Details such as the blood pressure, pulse and respiratory rates and temperature of in-patients were, however, monitored solely by the five formal caregivers who included two doctors and three nurses due to the use of special equipment. This was because they alone had the know-how due to their training in health care.

Distinctions were also found in the feeding of in-patients by formal and informal caregivers based on the skills required. From interviews and observations, it was found that two in-patients were fed solely by formal caregivers. One of these two had to be fed through a tube due to the esophageal foreign body disease he was suffering from, which affected his ability to ingest food through his throat. According to the formal caregivers,

feeding a patient through a nasal tube required some skills that informal caregivers lacked and hence could not carry that out. It was observed in the second instance that an in-patient was not supposed to take in food after a surgical operation and her feeding was to be done after some hours. For this reason, the feeding of this in-patient was solely handled by formal caregivers who had to strictly monitor the timing and feeding of the in-patient. The other six in-patients out of the eight were fed solely by informal caregivers because their ailments did not require specialised skills in the feeding regime. The informal caregivers of these six in-patients revealed that they performed caregiving tasks delegated to them by formal caregivers. Formal caregivers delegated caregiving tasks to informal caregivers based on their judgment of the informal caregiver's ability to deliver those services. A nurse explained saying:

Some of the activities are done by the doctors and nurses. However, some are done by the patients' families when we think it's something within their ability because we know they don't have any training in health care. So what the patients' families do are just the basic things and when specialised skills and expertise are needed for a task, we have to step in.

The caregiving task of bathing in-patients was also found to be distinct in its performance by both formal and informal caregivers. It was found that an in-patient admitted with a bone fracture from an accident with injuries was bathed solely by formal caregivers. According to the formal caregivers, the severity of the injury required that nurses bathed her (the in-patient) skillfully to prevent further complications such as infection that could require

amputation. However, with the other seven in-patients, bathing was done by informal caregivers since they did not have health conditions that required special skills to perform that task.

Interviews conducted with formal caregivers and informal caregivers revealed that the caregiving tasks of formal and informal caregivers were interdependent. It was found that the order of performance of caregiving activities for in-patients at the Paediatric Ward differed from one in-patient to the other, based on their different ailments. This was because the different ailments for different in-patients might have required the same caregiving activities, but varied in the order of performance. For instance, the activity of the diagnosis of in-patients by formal caregivers was dependent on the provision of information by informal caregivers. Diagnosis and the provision of information took place before in-patients were fed, or before they were given their medications. The order of drug administration and feeding of inpatients was dependent on the drug to be administration and the ailment of the in-patient. Out of eight in-patients, three needed drug administration before meals, while three needed drug administration after meals. Two other in-patients also needed drug administration before and after meals.

It was observed that formal caregivers had difficulty in administering drugs to some in-patients. When asked to mention the difficulty, one informal caregiver said, "The in-patients feared injections because they were painful and that some of the drugs were bitter to swallow". Indeed, this made inpatients resist medication. In such cases, informal caregivers were made to administer drugs to in-patients under the supervision of formal caregivers. Informal caregivers responded that, in such cases, they administered drugs to

in-patients based on the knowledge they had of in-patients' preference, temperaments and behaviour. They provided the emotional and psychological encouragement the children needed by holding in-patients' hands, convincing them to take injections, luring them with gifts and consoling them. According to four informal caregivers and four in-patients, the trust in-patients had in their informal caregivers and the comfort and assurance in-patients felt in their presence eased the administration of drugs. During an interview with a nurse, she had this to say:

Most often when the children see their parents or guardians around, it helps speed up the recovery process. Sometimes I do all I can to make the child (in-patient) take the medication but they will never take it. However, when you give the drug to the mother, she has a way she does it and the child will take the medication without any hesitation because the children feel more at ease with their mothers around.

The above results from the data gathered around what caregiving tasks were performed by formal and informal caregivers indicate that caregiving tasks performed by formal caregivers required specialised skills, while caregiving tasks performed by informal caregivers required basic skills as espoused by Litwak's (1985) tasks specific theory. The task specific theory states that specialised tasks are performed by formal caregivers whereas informal caregivers performed unspecialised tasks based on their structural features such as skills, expertise and knowledge in health care possessed by formal caregivers and everyday socialisation and familiarity with care recipients. However, there were overlaps in the performance of caregiving

activities. These overlaps in the performance of specialised and unspecialised caregiving tasks were due to the various ailments of in-patients. Therefore, where a minimum level of skill is required, informal caregivers were taught a few skills to enable them to undertake those caregiving tasks. This is akin to Bruhn's (2016) assertion that formal caregivers gave informal caregivers some training on the performance of some caregiving activities.

The caregiving activities of toileting, eating, dressing, bathing of inpatients, mobility and grooming were consistent with Noelker and Browdie's (2013) findings on ADL while medication management, community mobility/movement within the hospital, communication management and history taking were consistent with Noelker and Browdie's IADL. However, some other caregiving activities, including history taking, drawing of treatment plans, laying of hospital beds, daily consultations with in-patients, laboratory investigations, diagnosis and discharge of in-patients that were found to be performed at the Paediatric Ward did not concur with Noelker and Browdie's (2013) findings on ADL and IADL and have been termed as Medical Caregiving Activities for this study.

Communication between Formal and Informal Caregivers

The second objective of this study centred on the communication between formal and informal caregivers in the performance of their caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital. Specifically, the objective centred on issues of information sharing between formal and informal caregivers around the timeliness, adequacy, accuracy and comprehensibility of information and their influence on conflict or coordination. Timely information in this study refers to information that is

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

given when it is needed. Adequacy and accuracy of information in this study refer to the sufficiency and precision of information shared while comprehensible information refers to information that formal and informal caregivers can make meaning of. Conflict is defined in this study as the disagreement between formal and informal caregivers that affects how they work together in providing care to in-patients, while coordination is defined in this study as the ability of caregivers to work together for the common goal of providing care to in-patients.

Quality of Information Shared by Formal and Informal Caregivers

Informal caregivers shared timely, accurate and adequate information on the quantities of food and liquid intake and the quantities of excretion with formal caregivers. Informal caregivers gained this information from monitoring the colour and nature as well as the amount of intake of food, water and excretion, a skill informal caregivers acquired through education by formal caregivers as indicated earlier in this chapter. This information shared by informal caregivers enabled formal caregivers to make diagnosis of inpatients' ailments and determine which treatment plans and caregiving activities in-patients required (see Table 4).

NOBIS

Table 4: Quality and Channel of Information Shared between Formal and Informal Caregivers

Type of Information	Channel of	Quality of
Shared	Information Sharing	Information
		Shared
Policies and	Nurses to informal	Timely, accurate,
regulations	caregivers	and adequate
governing stay in		
the ward		
Informal caregiving	Nurses to informal	Timely, accurate,
activities	caregivers	and adequate
Information on the	Doctors and nurses to	Timely but
health condition of	informal caregivers	inaccurate, and
in-patients	Informal caregivers to	inadequate
	nurses and doctors	
Interpreting	Doctors and nurses to	Timely, accurate,
symptoms	informal caregivers	and adequate
		•
Discharge dates	Doctors through nurses	Accurate but
	to informal caregivers	untimely and Inadequate
		•
Preventing similar	Doctors and nurses to	Timely, accurate,
future ailments	informal caregivers	and adequate
Drug administration	Nurses and doctors to	Timely, accurate,
	informal caregivers	and adequate
Symptoms	Informal caregivers to	Timely but
experienced by in-	nurses and doctors	accurate, and
patients		inadequate
Health history	Informal caregivers	Timely but
	through nurses to	inaccurate, and
	doctors	inadequate
Quantities of food	Informal caregivers	Timely, accurate,
and liquid intake	through nurses to	and adequate
and excretion	doctors	

Source: Field Data, 2020

Formal caregivers also shared timely (information was given when it was needed), accurate and adequate information with informal caregivers on

the policies and regulations governing the ward and the caregiving activities informal caregivers were expected to perform. Formal caregivers also shared with informal caregivers timely, accurate and adequate information on how to interpret the in-patients' symptoms, how to prevent such ailments in the future and the drug dosage for in-patients (see Table 4). This was to prepare informal caregivers emotionally, psychologically and financially for any future occurrences in and out of the ward. Informal caregivers were informed that only one person could visit an in-patient and their primary informal caregiver at a time. They were also informed about the roles they were expected to perform towards the caregiving of in-patients. Most participants indicated that the sharing of timely, accurate and adequate information in these areas allowed them to coordinate their caregiving activities with one another at the Paediatric Ward.

During an interview with a nurse, she had this to say regarding information they give to informal caregivers:

When you come on admission, I always tell the mother, or the one who will often stay with the child, "Madam now your child is on admission and so until he/she is recovered we will all be here together, but the rules here are that, especially in this time of Corona infections we will allow only one person to visit you and the child..."

Another nurse also had this to say about information she shared with informal caregivers on the rules on bathing and feeding of in-patients:

When a patient is admitted, we make them know the rules over here, for example, you have to bath the child before the bathroom is locked at 6:00 am and there should be no eating on the hospital beds because it attracts ants that bite the inpatients...

An in-patient said this in affirmation:

The day we got to the ward the nurse told us that we had to make sure our surroundings were clean always to avoid ants.

She told us to bathe early since the bathroom would be locked by 6:00 am. The nurse also informed my mother that I have typhoid fever.

Two formal caregivers claimed that informal caregivers did not provide accurate and adequate information that they required about in-patients regarding their health history with diseases such as HIV and AIDS. According to the formal caregivers, the failure to disclose such information mostly occurred in instances where informal caregivers were ashamed of the diseases in-patients had and the fear of stigmatisation attached to some ailments. This usually misled the treatment process, which implied that there was the need for a whole new process of history taking and restructuring of treatment plans and drug prescription to suit the actual health conditions of in-patients. Formal caregivers found this frustrating which led to conflicts between formal and informal caregivers in the form of exchange of unprintable words. A nurse indicated:

The mother did not tell us that the child was HIV positive. And we chose to add the HIV test to the investigations and it ended up that the child is positive. I think because of stigmatisation

she didn't tell us the truth that the child is already on HIV drugs.

Inaccurate and inadequate provision of information was found in the case of the in-patient with esophageal foreign body disease. This was due to the fear of being blamed by formal caregivers for not taking proper care of the child at home. During an interview with a doctor, he narrated:

The reason why some informal caregivers choose to hide information about their wards may be that they don't know what my reaction would be. I'm sure he thought I would blame him for the child's condition so he rather hid it than, to tell the truth. Everything boils down to fear...my investigation revealed that there is more to it than what he was saying...they think we are judgmental. They will say "oh it started yesterday, meanwhile, it started over a month ago and they were trying to treat it by themselves but they will not tell you the truth.

During an interview with a doctor on the information shared between him and the informal caregiver of the in-patient with bone fracture, it also emerged that the informal caregiver hid information about the actual cause of the in-patient's fractures and injuries. According to most formal caregivers, the concealment of the cause of fractures and injuries was out of fear of being judged as bad parents and guardians by hospital staff and society. A doctor had this to say:

So starting with the first encounter, some informal caregivers will give us wrong information, especially when it's a case of abuse, they will lie to you. But we know the kind of injuries a

child at a certain age should experience and its probable cause and so we probe further by asking the children and this creates tensions between us and the informal caregivers because issues hidden would be revealed.

A nurse also shared her experience:

We need the right information to also make diagnosis and give appropriate drugs, but if the information they provide to us is not accurate, then how can the finding we make out of that be right?

The quality of information shared was also found to be inaccurate from interviews with two doctors. It emerged that, in a few cases, in-patients and informal caregivers did not accurately describe the symptoms of patients' illnesses. In such cases, the doctors could end up misunderstanding the symptoms of the actual ailment and thus, could wrongly diagnose the patient. The doctors added that wrong diagnosis was, however, avoided in these few cases because laboratory investigations and scans on the in-patients were usually conducted.

Inaccurate information sharing by informal caregivers with formal caregivers was found regarding the symptoms of in-patients' ailments. Informal caregivers also shared inaccurate and inadequate information concerning the health history of in-patients. Inaccurate and inadequate information sharing in these areas was due to the stigmatisation attached to certain ailments, fear of being judged as irresponsible parents, informal caregivers being ashamed of in-patients ailments and the inability of in-

patients and their informal caregivers to correctly describe the symptoms of in-patients' ailments.

With the quality of information shared by formal caregivers, three informal caregivers indicated that formal caregivers gave them inaccurate and inadequate information on in-patients' health conditions. These were in instances where formal caregivers did not yet have all the results on laboratory investigations on the in-patients' health at their disposal but wanted to ease the anxiety and curiosity of informal caregivers. In such instances, formal caregivers mostly gave informal caregivers information that ended up being inaccurate and inadequate when laboratory results were finally obtained. Informal caregivers upon noticing inconsistencies in information regarded formal caregivers as unreliable and withholding information that they felt entitled to. A doctor shared his experience during the interview:

It is possible that a doctor or nurse will give informal caregivers information that is not enough or incorrect in a case where speculations had already been made on the in-patients' conditions based on the symptoms the in-patients and their informal caregivers describe. But the right information will definitely be given to them when the laboratory results are out.

Channelling of Information Shared

It was found that all information shared by informal caregivers with formal caregivers except the symptoms of in-patients ailments were found to be channelled from informal caregivers through nurses to doctors. Doctors received the information on the health history and the quantities and nature of food intake and excretion of in-patients to make diagnoses. The three nurses interviewed indicated that doctors and nurses were informed about the symptoms of in-patients' ailments by informal caregivers and in-patients during consultations with in-patients on ward rounds and also during the day if changes occurred (see Table 4).

Policies and regulations governing the ward and information on the caregiving activities expected of informal caregivers were found to be channelled from nurses to informal caregivers directly (see Table 4). According to participants, the channelling of this information to informal caregivers was usually done by nurses as part of their hospital duties at the ward. Information on the health of in-patients, how to prevent ailments of in-patients in the future and how to interpret symptoms were found to be channelled from both doctors and nurses to informal caregivers. From interviews with formal and informal caregivers, it was found that these channels of information sharing outlined above were done verbally and regularly. This practice was accepted between formal and informal caregivers. The health history, background of in-patients and treatment plans of in-patients were further indicated in in-patients' folders and the computer system at the Paediatric Ward. The use of hospital folders and the computer system was a channel of information sharing used by formal caregivers.

According to formal caregivers, the right channelling of information around the discharge dates of in-patients was from doctors to nurses and then from nurses to informal caregivers. On ward rounds, doctors indicated to nurses the discharge dates of in-patients which were further indicated on the in-patients' hospital folders. This information was for the nurses to prepare the in-patients for discharge. Formal caregivers shared this information on in-

patients' discharge dates verbally, through patients' hospital folders and the computer system formal caregivers shared among themselves. Usually, informal caregivers were later informed about the discharge dates of inpatients verbally by nurses. This channelling of information was also necessary due to the shift system run by formal caregivers at the hospital.

In a few instances, a break in the channel of communication was found between doctors and nurses. This was when the channel of information sharing on the discharge dates of in-patients did not include verbal communication. A break in communication also occurred when formal caregivers failed to obtain adequate information on in-patients' discharge dates from the in-patient's folder. In these instances of communication break, in-patients were not discharged by nurses as expected by informal caregivers due to the information they already received from doctors during ward rounds.

In another instance, there was a communication break between doctors and nurses because the discharge dates of the in-patient were not yet reflecting on the computer system that contained information of all in-patients on the ward. As such, the nurse was oblivious of when the in-patient was to be discharged and so did not prepare the in-patient for discharge as expected by informal caregivers. One nurse, in explaining the cause of the argument between the succeeding nurse and the mother said:

The doctor didn't tell me that the patient is due to be discharged and the discharge date. The discharge date didn't also show on the computer. But, I am told that the doctor had already informed the mother about their discharge today. Because of this, she is expecting me to prepare them for

discharge. That's what sometimes happens and they (informal caregivers) would be saying things like, "it's time for us to go and you are not discharging us".

In most cases, the break in communication between formal caregivers, according to four formal caregivers, negatively affected the quality of information shared on discharge dates, by affecting its timeliness (when the information was needed) and adequacy. This caused delays in the discharge of in-patients, leading to conflict between formal and informal caregivers.

Informing informal caregivers at the Paediatric Ward on policies and regulations of the ward by formal caregivers as stated (see Table 4), is consistent with a communication strategy suggested by the Agency for Health care Research and Quality (AHRQ). It states that patients and their families should be kept informed about the background of the hospital environment. The sharing of information on the health conditions of in-patients shared by formal caregivers, the caregiving activities expected of informal caregivers by formal caregivers at the ward, how to interpret symptoms as well as drug dosage as indicated above are consistent with the third communication strategy suggested by the AHRQ. The third communication strategy of the AHRQ indicates that patients and patients' families should be made aware of the acceptable activities that can be demonstrated as part of the caregiving team. These communication strategies by the AHRQ are towards the improvement of institutional communication and coordination related to the safety of patients for health institutions.

Meaning Made of Information Shared between Formal and Informal Caregivers

Understanding information shared between formal and informal caregivers enabled them to coordinate their caregiving activities on the ward. However, for formal and informal caregivers to coordinate their caregiving activities, there is the need to understand the information on the health of the in-patient. Understanding of information implies that the information given was interpreted according to its intended meaning.

Meaning Made of Information Shared by Formal and Informal Caregivers

It was revealed by all five formal caregivers interviewed that they mostly made meaning of information given to them on the health history and daily symptoms of in-patients by their informal caregivers. The formal caregivers interviewed also responded that they understood information shared by informal caregivers about the details they monitored on the quantities of food and liquid intake and the quantities of excretion by in-patients.

Formal caregivers further indicated that, as a result of this meaning they made out of the information shared by informal caregivers, they were able to monitor the health progress and decline of in-patients. They were also able to structure their treatment plans that included other activities formal and informal caregivers performed such as medication management and feeding of in-patients. This ability of formal caregivers to make meaning out of the information given to them by informal caregivers, according to formal caregivers, was facilitated by their health educational background.

It emerged from the interviews with informal caregivers of the two inpatients with malaria, two in-patients with typhoid fever and one in-patient with nephrotic syndrome that, they found information shared by formal caregivers easy and clear to understand. This understanding, according to the informal caregivers, was because the information was shared in a local dialect (Fante) which all participants were most fluent in. An informal caregiver had this to say:

For me if you speak English I won't understand so it's good we all speak Fante to one another. That way they understand me and I understand them.

An in-patient also had this to say:

The doctors and nurses speak to us in Fante which we understand better. They try to explain to us whatever we need to know about my health very well so that we can understand.

Six informal caregivers revealed that both formal and informal caregivers often explained to one another the details concerning the health of in-patients to give each other understanding of the in-patients' health conditions. Formal caregivers also explained to informal caregivers all medical terminologies that were used concerning the health of in-patients in an understandable language.

The rest of the two informal caregivers also indicated that they had difficulty making meaning out of laboratory results expressed in medical terminologies that they were not familiar with. However, all five formal caregivers interviewed revealed that the case of the use of medical terms was recurrent at the Paediatric Ward. However, they mostly took time to explain

all terms to informal caregivers to enable them to make meaning of the information given to them about in-patients. This was especially in cases where informal caregivers sought more clarity on medical terms on the health of in-patients. An informal caregiver shared his sentiments:

I do not understand the medical terms the doctors and nurses use when they are talking about the child's diseases, so later I have to ask the nurse to explain what they are saying and some of the medical terms they have been using.

It was revealed from the interviews that communication between formal and informal caregivers in the area of the health history and daily symptoms of in-patients, details of the quantities of food and liquid intake as well as the quantities of excretion by in-patients, mostly consisted of the sharing of information that both formal and informal caregivers could make meaning out of. This aided in coordination between both parties. However, from discussions on the quality of information shared by formal and informal caregivers, it can be concluded that information sharing on in-patients' health history, symptoms of in-patients health conditions, were sometimes inadequate and inaccurate. The inadequacies and inaccuracies were also due to the inability of in-patients and informal caregivers to provide formal caregivers with the right information on the symptoms of in-patients' ailments. All of these impacted negatively on the treatment process. The untimeliness and inadequacy of in-patients' discharge dates were also due to a break in communication between doctors and nurses.

The untimeliness, inaccuracy and inadequacy in the quality of information shared served as a hindrance to coordination between formal and

informal caregivers thereby causing conflicts between formal and informal caregivers. The finding is supported by the assertion made by Toscan et al. (2012) that when communication between formal and informal caregivers consists of the dissemination of timely, adequate, accurate and understandable information, coordination can be achieved between them. This implies that communication between formal and informal caregivers influenced their relationship both negatively and positively, depending on the quality of the information being shared and how formal and informal caregivers understood what they shared. This is consistent with Gittell's (2015) relational coordination theory that posited that the relationship between formal and informal caregivers could be coordinated based on the communication of shared information and understanding of shared information. Based on the findings on information sharing, it can be concluded that information needed more timeliness, accuracy and adequacy to reduce conflict especially around the discharge dates of in-patients, prevent misleading treatment processes and what is more, improve the coordination between formal and informal caregivers.

Role Expectations and Perceptions of Formal and Informal Caregivers

The third objective of this study was to investigate the expectations and perceptions of formal and informal caregivers in the performance of their caregiving tasks. According to the conceptual framework, the relationship between formal and informal caregivers is influenced by their role expectations (preconceptions of what each party is to perform) and perceptions (cognition) of the performance of the caregiving activities they carry out. Issues discussed concerning this objective included the tasks formal and

informal caregivers expected of each other and how those activities were performed to their expectations. Issues discussed also included how caregiving activities performed were perceived by formal and informal caregivers as well as how role expectations and perceptions determined coordination or conflict between formal and informal caregivers.

Table 5: Role Expectations Formal Caregivers have of Informal Caregivers

Role Expectations	Level of satisfaction
Feeding	Satisfied
Drug administration	Satisfied
Monitoring health progress of in-	Satisfied
patients	
Mobility	Satisfied
Purchasing prescriptions	Less satisfied
Compliance with housekeeping rules	Less satisfied
Provision of information	Less satisfied

Source: Field Data, 2020

Formal caregivers revealed that they were satisfied with the NOBIS

performance of feeding, drug administration, mobility and monitoring the health progress of in-patients by informal caregivers (see Table 5). Upon questioning informal caregivers, it was found that these activities were performed with ease since they did not require much effort or more money. Informal caregivers claimed that they were also able to monitor in-patients' health progress and administer drugs up to the expectations of formal caregivers because they were taught a few skills by formal caregivers in these

areas. According to formal caregivers, the performance of these caregiving activities enabled them to coordinate their caregiving activities in providing care for in-patients.

Formal caregivers also revealed that they were less satisfied with the purchase of prescriptions for in-patients by informal caregivers (see Table 5). This was because some informal caregivers could not purchase medication and pay for services such as laboratory investigations and consultations that were needed for in-patients' treatment as expected due to financial constraints. Some informal caregivers could not pay for prescribed drugs because the financial assistance for medical care for some patients came from the inpatients' fathers who were not usually present on the ward due to their job demands and their non-availability at the ward. This did not facilitate the effective delivery of health care, especially when in-patients were covered by the National Health Insurance Policy. A doctor had this to say:

Sometimes, we will be communicating with the father who lives in a certain village somewhere or does some business somewhere. It becomes very difficult when we need some money to do something for the child. That's the problem. Because the money has to come from the man, but he will not be around, they can't reach the man or something like that...those financial issues are there.

According to formal caregivers, they were less satisfied with the provision of information by informal caregivers and their compliance with housekeeping rules. Considering the provision of information, four out of five formal caregivers also indicated that to diagnose in-patients and draw their

treatment plans, they expected adequate and accurate information on inpatients health conditions. Informal caregivers could not provide adequate and accurate information to formal caregivers because of the fear of stigmatisation attached to the ailment and also the fear of being held accountable for the improper care of the children as discussed earlier in this chapter.

Three formal caregivers responded that a few informal caregivers did not comply with housekeeping rules, such as keeping their surroundings clean as expected and bathing in-patients on time. The housekeeping rules also included sleeping on mattresses provided by the hospital on the Paediatric Ward at the apportioned time (informal caregivers could only use hospital mattresses which they laid on the floor after 11:00 pm). Three mothers revealed that their inability to bathe in-patients before 6:00 am was because it was too early in the morning for them and the in-patients. Two fathers (informal caregivers) responded that they could not get to the ward to bathe in-patients before 6:00 am because they did not sleep at the ward. A mother who got into an argument with a nurse due to non-compliance with this housekeeping rule reported this reaction from the nurse:

The other night, I went for a mattress to sleep, but it was too early for the collection of the mattresses. The nurse got angry and hit me at my back. I felt so bad that when it was time to go for it I declined and sat and slept in a chair till the next morning.

Even though this instance of conflict between formal and informal caregivers indicated above did not occur often, the three nurses interviewed reported that it was problematic when informal caregivers did not perform the

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

caregiving tasks they were expected to perform and did not also comply with housekeeping rules. This was because their superiors held them responsible for all caregiving activities at the ward and the failure by informal caregivers to perform their caregiving tasks made nurses seem incompetent before their superiors.

Table 6 shows the caregiving activities that informal caregivers expected of formal caregivers. From the data gathered, it was found that informal caregivers were satisfied with the performance of caregiving activities which included drug administration, monitoring the health progress of in-patients, laboratory investigations and diagnosis by formal caregivers. Informal caregivers were less satisfied with the discharge of in-patients and the provision of information and the dressing of wounds. The informal caregivers claimed that this enabled them to coordinate their caregiving activities by working together to provide care to in-patients.

NOBIS

Table 6: Role Expectations Informal Caregivers have of Formal Caregivers

Role Expectations	Level of
	satisfaction
Laboratory investigations	Satisfied
Diagnosis	Satisfied
Monitoring the health progress of in-	Satisfied
patients	
Drug administration	Satisfied
Discharge	Less Satisfied
Provision of information	Less Satisfied
Dressing wounds	Less satisfied

Source: Field Data, 2020

Informal caregivers were less satisfied with the timing of in-patients' discharge because even though they were informed that they were to be discharged, they were not prepared for discharge when expected (see Table 6). An informal caregiver's dissatisfaction with the dressing of wounds by formal caregivers was also because the wounds of the in-patient were not dressed regularly and this led to an infection. A father and daughter narrated their experience:

My hand has been bandaged since the day I came here (Five days back) and it was too tight it is beginning to pain me. The nurse didn't attend to me and my dad had to come and relax the bandage a bit to relieve me of the pain. (Daughter)

Sometimes, they don't do what you expect them to do and the child will be in pain. Since we came they have dressed her wound from the accident only once. Eventually, the plaster came off by itself and exposed the wound. That was when the nurse came and dressed the sore. I will say the care provided can be improved, it's not the best. (Father)

Three informal caregivers were less satisfied with the provision of information on the health of in-patients by formal caregivers. According to these informal caregivers, they expected formal caregivers to provide them with timely, adequate and accurate information on the health condition of in-patients (see Table 6). As discussed earlier under information sharing by formal and informal caregivers, however, formal caregivers did not always provide informal caregivers with adequate and accurate information on in-patients' health. This was because formal caregivers did not have laboratory results and because they did not get the right description and health history of in-patients' ailments.

Formal and Informal Caregivers' Perceptions of Caregiving Tasks

All formal caregivers reported that they had high perceptions about the performance of expected caregiving tasks which included mobility, drug administration, feeding and the monitoring of in-patients' health. Formal caregivers' high perceptions were because these expected caregiving activities were performed by informal caregivers to their satisfaction. Formal caregivers, however, had low perceptions about the provision of information, purchasing prescriptions and the compliance of housekeeping rules by nearly half of the

informal caregivers. This was because they were less satisfied with the performance of the above-mentioned caregiving activities.

All eight informal caregivers had high perceptions of the performance of expected caregiving activities by informal caregivers which included drug administration, laboratory investigations, diagnosis and monitoring of the health of in-patients. This resulted from the satisfaction they had with the performance of these expected caregiving activities. However, some informal caregivers had low perceptions of the performance of expected caregiving activities which included the provision of information, discharge and compliance with housekeeping rules. The low perceptions of informal caregivers were because these expected caregiving activities were not performed to their satisfaction.

Both formal and informal caregivers explained that emotions such as anger, frustration and disappointments are triggered when their perceptions of the performance of expected caregiving activities are low. Formal caregivers explained that they feel frustrated because the actions or inactions of informal caregivers impede the recovery of the in-patients. They, therefore, lose their patience and express anger at informal caregivers when they fail to carry out their expected caregiving tasks or fail to adhere to hospital regulations governing the ward stay. A nurse shared her experience:

They make us furious on several occasions. I will tell you the truth, especially when they refuse to tidy up their small spaces around the bedside of in-patients. Some of the informal caregivers, especially mothers, don't obey simple instructions. You tell them, "don't put this here", you will go and come back

and it is there; she will finish eating, wash her hands in the bowl and leave it there. Just the small area she has to keep clean is so dirty. They will put used diapers, sachets, polythene bags among others anywhere at all. At a point, you just lose your patience because it's very annoying.

Participants revealed that on one hand, the high perceptions of formal and informal caregivers resulting from their satisfaction with the performance of expected caregiving tasks allowed them to work in coordination as they performed their caregiving tasks. On the other hand, low perceptions of formal and informal caregivers resulting from their low satisfaction with the performance of caregiving tasks determined conflict between them.

The conceptual framework of this study asserts that the role expectations and perceptions of formal and informal caregivers ultimately determine coordination or conflict in the relationship between them. This depends on whether or not the caregiving activities are performed to their expectations. With this information as a guide, the findings of this study showed that when caregiving activities were not performed to the expectations of formal and informal caregivers, they had low perceptions of the performance of these caregiving activities. This triggered emotions of anger, frustration and disappointment. The result of these triggered emotions were conflicts between formal and informal caregivers. This finding is consistent with Siassi's (2007) finding that when caregiving activities are not performed to expectations, feelings of anger, frustration, disappointment, powerlessness, shame, self-blame or despair emerge. These emotions felt by informal caregivers are understandable because they provided care to those close to

them and, therefore, had emotional attachments to them. They are also explainable for formal caregivers because they have the aim of providing the best quality of care to care recipients (Janzen et al., 2006).

Chapter Summary

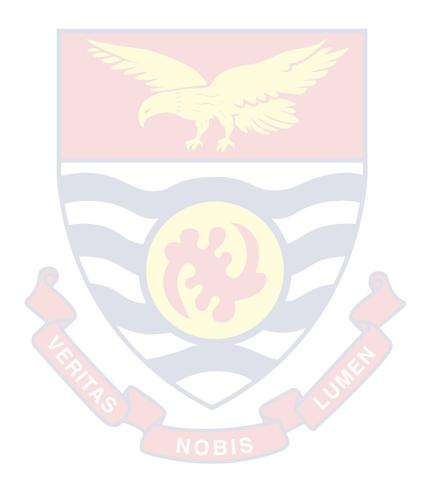
This chapter examined the caregiving activities performed by formal and informal caregivers and described how they communicated in the performance of their caregiving tasks. The chapter also investigated the role expectations of formal and informal caregivers as well as their perceptions of the care provided to in-patients. The caregiving activities performed by formal caregivers at the Cape Coast Teaching Hospital included diagnosis, drawing of treatment plans, drug administration and providing informal caregivers with information on the health of in-patients. The caregiving activities of formal caregivers also included the prescription of drugs, daily consultations with inpatients, monitoring the health progress or decline of in-patients, conducting the medical history of patients and discharge. The rest were laying of hospital beds, feeding in-patients, laboratory investigations and dressing of wounds.

Formal and informal caregivers could make meaning out of the information they shared. However, information shared between formal and informal caregivers was sometimes inaccurate and inadequate due to the stigmatisation attached to some ailments and the fear of being judged as irresponsible parents. The inaccuracies and inadequacies were also a result of the inability of in-patients and informal caregivers to provide formal caregivers with the right information on the symptoms of in-patients' ailments. Communication was also characterised by the sharing of information that was

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

provided later than it was required. The late sharing of information was attributed to a break in communication between doctors and nurses.

Formal and informal caregivers had high perceptions of the performance of caregiving tasks. The high and low perceptions of formal and informal caregivers resulted from their high and low satisfaction with the performance of expected caregiving activities.



CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Overview

This chapter concludes this study by summarising the research process and the key findings of each objective. It concludes the key findings and makes recommendations that could be considered by the health sector to enhance health care provision. The chapter ends with suggestions for further studies.

Summary

This study aimed to explore the relationship between formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. To achieve this purpose, the study specifically examined the task specifics and the actors of various tasks. The study described the communication between formal and informal caregivers in the performance of their caregiving tasks. The study also investigated the role expectations and perceptions that formal and informal caregivers have of the caregiving activities performed. A qualitative research approach was used to conduct the study with the aid of interview and observation guides to elicit data to address the research objectives. Convenience sampling and maximum variation sampling techniques were used to select a total of 21 participants for the study. Data were, then, analysed thematically.

Key Findings

The first objective of the study sought to examine the task specifics of formal and informal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. The following were the findings:

The caregiving activities performed by formal caregivers included diagnosis, drawing of treatment plans, drug administration, providing information on the health of in-patients and prescription of drugs. The rest were daily consultations with in-patients during ward rounds, monitoring the health progress or decline of in-patients, discharge of in-patients, history taking, bathing of in-patients and laying of hospital beds. They also checked vital signs such as temperature, blood pressure, respiratory rate and pulse rate, dressed wounds, fed in-patients.

Caregiving tasks performed by informal caregivers included feeding in-patients, monitoring the health progress or decline of in-patients, bathing, cleaning in-patients with water and a towel. Informal caregivers also assisted in-patients in using the washroom, assisted in-patients to walk around and changed their clothes. They were also involved in assisting formal caregivers to administer drugs to in-patients by providing emotional and psychological support. They ran errands on behalf of the in-patients (buying prescribed drugs) and provided companionship.

The study found that specialised tasks were performed by formal caregivers while informal caregivers performed unspecialised tasks delegated to them by formal caregivers. However, due to the ailments of some inpatients, some caregiving tasks that otherwise required unspecialised skills needed to be performed with specialised skills. Where a minimum level of skill is required, informal caregivers were taught a few skills to enable them to undertake those tasks. Formal caregivers performed unspecialised caregiving tasks as part of their roles as formal caregivers at the Paediatric Ward of the Cape Coast Teaching Hospital. This answers the first research question of the

study on what tasks formal and informal caregivers perform at the Paediatric Ward of the Cape Coast Teaching Hospital. This also fills in the gap in the task specific theory about the reasons for the overlaps in the performance of specialised and unspecialised caregiving tasks by formal and informal caregivers.

The second objective of this study was to describe the communication between formal and informal caregivers in the performance of their caregiving tasks at the Paediatric Ward of the Cape Coast Teaching Hospital. The communication between formal and informal caregivers as they performed their caregiving tasks was found to bring about both coordination and conflict in the relationship between formal and informal caregivers. In boosting coordination, the information shared between formal and informal caregivers was found to be shared using understandable language. Communication brought about conflict between formal and informal caregivers when it was inaccurate, inadequate and untimely.

The third objective of this study was concerned with investigating the expectations and perceptions of formal and informal caregivers of the caregiving activities performed at the Paediatric Ward of the Cape Coast Teaching Hospital. The caregiving activities that were performed to the expectations of formal caregivers included monitoring the health progress of in-patients, feeding, drug administration and mobility. The caregiving activities that were not performed to the expectations of formal caregivers included purchasing prescribed drugs, compliance with housekeeping rules and the provision of information by informal caregivers. The caregiving activities that were performed to the expectations of informal caregivers

included drug administration, monitoring the health progress of in-patients, laboratory investigations and diagnosis. The caregiving activities that were not performed to the expectations of informal caregivers also include the provision of information, diagnosis and dressing of wounds. On one hand, the satisfaction of formal and informal caregivers due to the performance of expected caregiving tasks was found to boost coordination between them as a result of the sense of progression towards the main goal of provision of quality care to in-patients. On the other hand, the low satisfaction of formal and informal caregivers due to the performance of expected caregiving tasks by formal and informal caregivers determined conflicts between them. This was because caregivers felt that this would negatively impact the recovery of inpatients at the Paediatric Ward of the Cape Coast Teaching Hospital.

Conclusions

The caregiving activities performed by formal and informal caregivers, how they communicate and their role expectations and perceptions of caregiving activities did not solely support coordination neither did they solely cause conflicts between them. These factors determined both coordination and conflict between formal and informal caregivers even though there was more coordination and less conflict between formal and informal caregivers.

Based on the key findings of the study, the following conclusions have been drawn:

Though literature assigns specialised tasks to formal caregivers and unspecialised tasks to informal caregivers, this study found that there were no clear cuts in this distinction. This is because there were instances where formal caregivers performed unspecialised tasks while informal caregivers preformed

specialised tasks. These tasks have been labled as overlapping tasks in this study. Specialised, unspecialised and overlapping caregiving tasks are essential for the recovery of in-patients at the Paediatric Ward of the Cape Coast Teaching Hospital. If formal and informal caregivers fail to communicate amongst themselves and fail to perform their various caregiving activities as expected, they will not be able to offer their best to ensure the recovery of in-patients.

When information shared between formal and informal caregivers was considered by either party as meaningful, timely, adequate and accurate, there was coordination between them. Conflict occurred when either party or both formal and informal caregivers considered the information received to lack clarity, adequacy or accuracy or not delivered at the right time. Communication between formal and informal caregivers must be improved to enhance the coordination between the two. If communication between them is not improved, it will affect the quality of health care delivery for in-patients.

The role expectations of formal caregivers included feeding, drug administration, monitoring health progress of in-patients, mobility, purchasing prescriptions, compliance with housekeeping rules and the provision of information. The role expectations of informal caregivers included laboratory investigations, diagnosis, monitoring the health progress of in-patients, drug administration, discharge, the provision of information and dressing of wounds. Formal and informal caregivers had high and low perceptions of the performance of their caregiving tasks. High perceptions were as a result of their satisfaction with the performance of caregiving tasks while low perceptions were as a result of their dissatisfaction with the performance of

their caregiving tasks. High perceptions boosted coordination while low perceptions led to conflicts. The role expectations of formal and informal caregivers should therefore be geared towards giving them high perceptions to improve their relationship and enhance health care delivery to in-patients.

Recommendations

Based on the findings and conclusions of this study, the following recommendations are made for consideration by the Cape Coast Teaching Hospital, formal and informal caregivers and the general public. These recommendations are geared towards reducing conflicts and fostering coordination between formal and informal caregivers thereby improving their relationship to enhance in-patient health care delivery.

Formal and informal caregivers should be educated and counselled at the hospital by the hospital administration and health workers, on the need to maintain and ensure the sharing of understandable information. They should also be educated and counselled on the need to reduce the problem of inadequate, inaccurate and untimely information, to enhance coordination between formal and informal caregivers at the hospital.

To reduce conflicts as a result of dissatisfaction with the performance of expected caregiving tasks, caregivers should be educated and counselled on the need to perform all tasks required of them at the ward. This will improve upon the perceptions formal and informal caregivers have of the care given to in-patients. This will go a long way to improve the relationships between formal and informal caregivers through coordination.

The Cape Coast Teaching Hospital should ensure that all technology employed in the dissemination of information between formal and informal

© University of Cape Coast https://ir.ucc.edu.gh/xmlui

caregivers are properly functioning to reduce the delay of information shared. This will increase the timeliness of information shared and improve upon the relationship between formal and informal caregivers by enhancing their coordination of caregiving activities.

Suggestions for Further Research

The following suggestions have been made for further studies:

This research was to explore the relationship between formal and informal caregivers, but further research could be done on coordination and conflicts in the relationship between caregivers (formal and informal) and inpatients. This will bring to light issues on the interactions between patients and caregivers in a hospital setting.

Further studies could be carried out quantitatively to access the impact of the relationship between formal and informal caregivers on the health of inpatients. Thus, more research can be done to know the health outcomes of the relationship between formal and informal. Further studies could also be carried to determine how the age of an in-patient influences the relationship between formal and informal caregivers.

NOBIS

REFERENCES

- Abekah-Nkrumah, G., Manu, A., & Atinga, R. A. (2010). Assessing the implementation of Ghana's Patient Charter. *Health Education*.
- Abor, P. A; Abekah-Nkrumah, G; Abor, J (2008). An Examination of Hospital

 Governance in Ghana. In: Leadership in Health Services Vol. 21 Issue

 1, 2008, 47-60 (published on essa.org.za)

 http://www.essa.org.za/download/2007conference/Abor;Abekah-Nkrumah&Abor.pdf
- Abuosi, A. A., Domfeh, K. A., Abor, J. Y., & Nketiah-Amponsah, E. (2016).

 Health insurance and quality of care: Comparing perceptions of quality between insured and uninsured patients in Ghana's hospitals. *International journal for equity in health*, 15(1), 1-11.
- Agbelie, J. A. D. (2017). Caregivers' Perception Of Quality Of Care At The

 Out-Patient Department Of Princess Marie Louise Hospital,

 Accra (Doctoral dissertation, University of Ghana).
- Agbenyefia, G. (2017). The Interface between the Health Professionals and

 Lay Caregivers at the Koforidua Central Hospital in the Eastern

 Region of Ghana (Doctoral dissertation, University of Ghana).
- Alsan, M., Bloom, D. E., & Canning, D. (2006). The effect of population health on foreign direct investment inflows to low-and middle-income countries. *World development*, *34*(4), 613-630.
- Armi, F., Guilley, E., & Lalive D'Epinay, C. (2008). The Interface Between Formal and Informal Support in Advanced Old Age: A Ten-Year Study. *International Journal of Ageing and Later Life*.

- Åstedt-Kurki, P., Paavilainen, E., Tammentie, T., & Paunonen-Ilmonen, M. (2001). Interaction between Family Members and Health Care Providers in an Acute Care Setting in Finland. *Journal of Family Nursing*, 7(4), 371-390.
- Badr, H., Smith, C. B., Goldstein, N. E., Gomez, J. E., & Redd, W. H. (2015).

 Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer*, 121(1), 150-158.
- Barimah, K. B., & Mensah, J. (2013). Ghana's National Health Insurance Scheme: insights from members, administrators and health care providers. *Journal of health care for the poor and underserved*, 24(3), 1378-1390.
- Baskin, A., Dalal, N., Das, V., Goyal, P., Harkins, S., Nanda, C., Nanda, G., Silberstein, S., Singh, C., Singh, M., Singh R., & Svenson, J., (2016).

 INFORMAL PROVIDERS: Understanding Motivations and Behaviours. Stanford India Health Policy Initiative Institute of Socio-Economic Research on Development and Democracy (ISERDD)
- Berman-Kishony, T. (2011). "Interpersonal Tensions in Hospitals: Their Fingerprints, Consequences and Resolution". *Graduate Doctoral Dissertations*. https://scholarworks.umb.edu/doctoral_dissertations/48
- Bellou, P., & Gerogianni, k. (2007). The Contribution of Family in the Care of Patient in the Hospital. *Health Science Journal*, 1-6.
- Bostan, S., Acuner, T., & Yilmaz, G. (2007). Patient (customer) expectations in hospitals. *Health policy*, 82(1), 62-70.

- Brand, S. I., Slee, K. M., Chang, Y. H., Cheng, M. R., Lipinski, C. A., Arnold,
 R. R., & Traub, S. J.(2015). Team Strategies And Tools To Enhance
 Performance And Patient Safety Training: The Effect Of Training On
 Both Nursing Staff Perceptions Regarding Physician Behaviours And
 Patient Satisfaction Scores In The ED. *Journal of Hospital*Administration, 4(2), 48-53.
- Brannen, J. (2005). Mixing Methods: The entry of qualitative and quantitative approaches into the research process. *International Journal of Social Research Methodology*, 8(3), 173-184.
- Bruhn, J. G. (2016). Who are Caregivers? In J. G. Bruhn, *After Diagnosis:*Family Caregiving with Hospice Patients (pp. 1-6). Switzerland:

 Springer International Publishing AG.
- Bryman, A. (2012). Social research methods. (4th Ed.). New York: Oxford University Press.
- Büscher, A., Astedt-Kurki, P., Paavilainen, E., & Schnepp, W. (2011).

 Negotiations about helpfulness—the relationship between formal and informal care in home care arrangements. *Scandinavian journal of caring sciences*, 25(4), 706-715.
- Byrne, D., Goeree, M. S., Hiedemann, B., & Stern, S. (2009). Formal Home Health Care, Informal Care, and Family Decision Making. *International Economic Review*, 50(4), 1205-1242.
- Cantor, M. H. (1975). Life space and the social support system of the inner city elderly of New York. *The Gerontologist*.
- Care, I. P. (2014). Care Coordination Measures Atlas.

- Carpentier, N., Ducharme, F., Kergoat, M.-J., & Bergman, H. (2008). Social Representations of Barriers to Care Early in the Careers of Caregivers of Persons with Alzheimer's disease. Research on Aging, 30, 334-357.
- Carpentier, N., Pomey, M. P., Contreras, R., & Olazabal, I. (2008). Social care interface in early-stage dementia: practitioners' perspectives on the links between formal and informal networks. *Journal of Aging and Health*, 20(6), 710-738
- Coiera, E. (2006). Communication Systems in Health care. The Clinical Biochemist Reviews. US National Library of Medicine.
- Covinsky, K. E., Palmer, R. M., Fortinsky, R. H., Counsell, S. R., Stewart, A. L., Coyne, I., Murphy, M., Costello, T., O'Neill, C., & Donnellan, C. (2013). A survey of nurses' practices and perceptions of family-centered care in Ireland. *Journal of family nursing*, 19(4), 469-488.
- Creswell, J.W. (2009), Research Design: Qualitative, Quantitative, and Mixed Methods Approaches, 3rd edn, Sage Publications, Thousand Oaks, California.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. Theory into Practice, 39(3), 124-131.
- Cropanzano, R., & Mitchell, M. S. (2005). Social exchange theory: An interdisciplinary review. *Journal of management*, 31(6), 874-900.
- de Boer, A., & de Klerk, M. (2013). Informele zorg in Nederland.de Klerk, M., de Boer, A., Plaisier, I., Schyns, P., & Kooiker, S. (2015). Informele hulp: wie doet er wat? Kerncijfers.
- Edelman, P. (1986). The impact of community care to the home-bound elderly on provision of informal care [Special Issue]. Gerontologist 26, 263.

- Edwards, H. E., & Chapman, H. M. (2004). Caregiver-carereceiver communication Part 2: Overcoming the influence of stereotypical role expectations. *Quality in Ageing*, *5*(3), 3-12.
- Egan, K. A., & Labyak, M. (2006). Hospice palliative care: A theory for qualityEnd-of-life Care. In *Textbook of palliative nursing* (pp. 13-46). Oxford University Press, Inc, New York.
- Evagelou, E., Lordanou, P., Lemonidou, C., Patiraki, E., Kyritsi, E., & Bellou, P. (2003). Parental Participation in Their Hospitalized Child's Physical and Psychological Care: Nurses' Perceptions. *ICUs and Nursing*, 13:1-13
- Ghana Health Service. (2015). The Health Sector In Ghana Facts and Figures.

 Accra: MOH.
- Girmay, A., Marye, T., Haftu, M., Brhanu, T., & Gerensea, H. (2018).

 Patient's expectation strongly associated with patients perception to nursing care: hospital based cross sectional study. *BMC research notes*, 11(1), 310.
- Gittell, J. H. (2015). How interdependent parties build relational coordination to achieve their desired outcomes. *Negot. J.*, *31*, 387.
- Greene, V. (1983) Substitution between formally and informally provided care for the impaired elderly in the community. Med. Care 21, 609±619.
- Greenlee, J., & Scharlach, A. (2001). Caregivers' Characteristics and Needs
- Griffin, R. and Moorhead, G. (2007) Organizational Behavior: Managing People and Organizations. 18th Edition, Houghton Mifflin Company, Boston.

- Guest, G., Bunce, A., Johnson, L. (2006). How many interviews are enough?

 An experiment with data saturation and variability. Field Methods

 18:59–82
- Hagerling, L. (2015). Nurse Attitudes Toward Caring For Older Patients With Delirium. Colorado
- Heitmueller, A., & Inglis, K. (2007). The earnings of informal carers: Wage differentials and opportunity costs. *Journal of health economics*, 26(4), 821-841.
- Hengelaar, A. H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., & Satink, T. (2018). Exploring the collaboration between formal and informal care from the professional perspective—

 A thematic synthesis. *Health & Social Care in the Community*, 26(4), 474-485.
- Hermanns, M., & Mastel-Smith, B. (2012). Caregiving: A Qualitative Concept

 Analysis. *Qualitative Report*, 17, 75.
- Hudson, L. P., Aranda, S., & Kristjanson, L. J. (2004). Meeting the Supportive Needs of Informal caregivers in Palliative Care: Challenges for Formal caregivers. *Journal of Palliative Medicine*. 7(1), 19-25.
- IFA. (2014). Connecting The Dots: Formal caregivers and informal Care.

 Toronto: SOM.
- Jacobs, M. T., van Groenou Broese, M. I., & Deeg, D. J. (2014). Discussion between informal and formal caregivers of community-dwelling older adults. *Tijdschrift voor gerontologie en geriatrie*, 45(2), 69-81.
- Jansen, L., Forbes, D. A., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., & Leipert, B. (2009). Formal care providers' perceptions

- of home-and community-based services: informing dementia care quality. *Home Health Care Services Quarterly*, 28(1), 1-23.
- Janzen, J. A., Silvius, J., Jacobs, S., Slaughter, S., Dalziel, W., & Drummond, N. (2006). What is a health expectation? Developing a pragmatic conceptual model from psychological theory. *Health Expectations*, 9(1), 37-48.
- Karikari, N. A. (2018). Exploring the socio-cultural interpretations of breast cancer and the coping strategies of patients at the Cape Coast Teaching Hospital, Ghana (Doctoral dissertation, University of Cape Coast).
- Kawulich, B. (2012). Collecting data through observation. *Doing social* research: A global context, pp 150-160.
- Kelly, K. P., Wells, D. K., Chen, L., Reeves, E., Mass, E., Camitta, B., & Hinds, P. S. (2014). Caregiving demands and well-being in parents of children treated with outpatient or inpatient methotrexate infusion: a report from the Children's Oncology Group. *Journal of pediatric hematology/oncology*, 36(6), 495.
- Kothari, C. R. (2004). Research methodology: Methods and techniques (2nd ed.). New Delhi, India: New Age International Publishers.
- Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. Journal of advanced nursing, 34(5), 593-602.
- Kumar, A. (2011). Research and Writing Skills. New York, NY: Lulu Press.
- Kumpers, S., Mur, I., Maarse, H., & van Raak, A. (2005). A comparative study of dementia care in England and the Netherlands using neo-

- institutionalist perspectives. Qualitative Health Research, 15, 1199-1230.
- Lai, C. K. (2003). Formal Caregivers, Informal caregivers, and Carers.

 Retrieved From Reflections on Nursing Leadership:

 :https://www.reflectionsonnursingleadership.org/features/more

 features/Vol39_3_formal-caregivers-informal-caregivers
- Litwak, E. (1985) Helping the Elderly: The Complementary Roles of Informal Networks and Formal Systems. Guilford Press, New York.
- Litwin, H., & Attias-Donfut, C. (2009). The Inter-Relationship Between Formal health care and informal Care: A Study in France and Israel.

 *Ageing and Society, 71.
- Loghmani, L., Borhani, F., & Abbaszadeh, A. (2014). Factors affecting the nurse-patients' family communication in intensive care unit of kerman: a qualitative study. *Journal of caring sciences*, *3*(1), 67.
- Loghmani, L., Borhani, F., & Abbaszadeh, A. (2014). Determination Of The

 Content Of Communication Between The Care Team And Family

 Members Of Patients In The Intensive Care Unit: The Experience Of

 Nurses And Patients' families.
- Lum, J. E. (2011). Informal Caregiving. *In Focus*, 1-2. American Health Care

 Association. (2017, August 15). *Types of Care*. Retrieved from

 CareConversations.org: https://careconversations.org/types-care
- Lunenburg, F. C. (2010). Communication: The process, barriers, and improving effectiveness. *Schooling*, *I*(1), 1-10.
- Luong, V. (2000). Theoretical Explanations of Differences in Community-Based Long-Term Care Use between Black And White Elders.

- Lustig, N. (2007). Investing in health for economic development: The case of Mexico. In *Advancing Development* (pp. 168-182). Palgrave Macmillan, London.
- MacFarlane, A., & O'Reilly-de Brún, M. (2012). Using a theory-driven conceptual framework in qualitative health research. *Qualitative Health Research*, 22(5), 607-618.
- Marco, L., Bermejillo, I., Garayalde, N., Sarrate, I., Margall, M., & Asiain, M.
 C. (2006). Intensive Care Nurses' Beliefs and Attitudes Towards the
 Effect of Open Visiting on Patients, Family and Nurses. *Nursing in Critical Care*.
- Maxwell, J. A. (2012). *Qualitative research design: An interactive approach*.

 London: Sage Publication Inc.
- McDonald, S. M. (2011). Perception: A concept analysis. *International Journal of Nursing Terminologies and Classifications*
- Mlinac, M. E., & Feng, M. C. (2016). Assessment of activities of daily living, self-care, and independence. *Archives of Clinical Neuropsychology*, 31(6), 506-516.
- Moyer, C. A., Adongo, P. B., Aborigo, R. A., Hodgson, A., & Engmann, C.
 M. (2014). 'They Treat You Like You Are Not a Human Being':
 Maltreatment During Labour and Delivery in Rural Northern Ghana.
 Midwifery, 30(2), 262-268.
- Noelker, S. L., & Browdie, R. (2013). Sidney Katz, MD: A New Paradigm for Chronic Illness and Long-Term Care. *The Gerontologist* 54(1), 13-20.
- No, M. S. Report on the study of the relationship between formal and informal caregivers in caring for older people.

- Orpin, P., Stirling, C., Hetherington, S., & Robinson, A. (2014). Rural dementia carers: formal and informal sources of support. *Ageing & Society*, 34(2), 185-208.
- Paulus, A. T., Raak, A., & Keijzer, F. (2005). Informal and formal caregivers' involvement in nursing home care activities: Impact of integrated care. *Journal of Advanced Nursing*, 49(4), 354-366.
- Penning, M. J., & Keating, N. C. (2000). Self-, informal and formal care:

 Partnerships in community-based and residential long-term care settings. Canadian Journal on Aging/La Revue canadienne du vieillissement, 19(S1), 75-100.
- Quaye, G. (2015). Factors motivating doctors and nurses at the Cape Coast Teaching Hospital (Doctoral dissertation, University of Cape Coast).
- Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental health*, *13*(2), 143-154.
- Reis, H. T., & Collins, W. A. (2004). Relationships, human behaviour, and psychological science. *Current Directions in Psychological Science*, 13(6), 233-237.
- Salin, S., Kaunonen, M., & Åstedt-Kurki, P. (2013). Nurses' perceptions of their relationships with informal carers in institutional respite care for older people. *Nursing Research and Practice*.
- Salisu, A., & Prinz, V. (2009). Health care in Ghana. Wien: ACCORD:

 Austrian Centre for Country of Origin & Asylum Research and

 Documentation.

- Savolainen, R. (2017). Information sharing and knowledge sharing as communicative activities. *Information Research: an international electronic journal*, 22(3).
- Schoonenboom, J., & Johnson, R. B. (2017). How to construct a mixed methods research design. KZfSS Kölner Zeitschrift für Soziologie und Sozialpsychologie, 69(2), 107-131.
- Shih, H. P., Lai, K. H., & Cheng, T. E. (2015). Examining structural, perceptual, and attitudinal influences on the quality of information sharing in collaborative technology use. *Information Systems Frontiers*, 17(2), 455-470.
- Siassi, S. (2007). Forgiveness, acceptance and the matter of expectation. *The International Journal of Psychoanalysis*, 88(6), 1423-1440.
- Sicotte, C., D'Amour, D., & Moreault, M.-P. (2002). Interdisciplinary coordination within Quebec community health care centres. Social Science & Medicine, 55, 991-1003.
- Smith, L. N., Lawrence, M., Kerr, S. M., Langhorne, P., & Lees, K. R. (2004).

 Informal carers' experience of caring for stroke survivors. *Journal of advanced nursing*, 46(3), 235-244.
- Sudhinaraset, M., Ingram, M., Lofthouse, H. K., & Montagu, D. (2013). What Is The Role of Informal Care Providers in Developing Countries? A Systematic Review. *Plos One*, 8(2).
- Toscan, J., Mairs, K., Hinton, S., Stolee, P., & InfoRehab Research Team. (2012). Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. *International journal of integrated care*.

- US Department of Health and Human Services. (2006). Agency for Healthcare Research and Quality. TeamSTEPPS: Instructor Guide.
- Victor, C. R., Healy, J., Thomas, A., & Sergeant, J. (2000). Older patients and Delayed discharge from hospital. Health and Social Care in the Community, 8, 443-452.
- Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: partners in care?. *Advances in Nursing Science*, 22(3), 89-103.
- Wanjau, K. N., Muiruri, B. W., & Ayodo, E. (2012). Factors affecting provision of service quality in the public health sector: A case of Kenyatta national hospital.
- Whiting, D. (2020). Epistemic worth. Ergo, 7(3).
- Wittenberg, Y., Kwekkeboom, M. H., & de Boer, A. (2012). Bijzondere mantelzorg.
- World Health Organisation. (2018). Health Workforce.
- Yaussy, S. L. (2019). The intersections of health and wealth: Socioeconomic status, frailty, and mortality in industrial England.
- Zhang, L. (2020). Primary Caregivers and Chinese Elders' Demand on Community Services. *Journal of Social Service Research*, 46(2), 283-297.

APPENDIX A

Interview Guide for Informal Caregivers

Date of interview
Time of interview

Background Information on Participants

- 1. Relation with the in-patient
- 2. Duration of admission

Caregiving Tasks Performed by Formal and Informal Caregivers

- 3. What caregiving roles do you perform in the ward?
- 4. In your opinion why do you perform those caregiving roles?
- 5. How relevant are your roles in the hospital?
- 6. How do you relate to formal caregivers when performing caregiving roles?
- 7. How do the roles of formal caregivers affect your roles as an informal caregiver?
- 8. How do formal caregivers assist with caregiving roles?

Perceptions of Informal Caregivers

- 9. How important are the caregiving activities of formal caregivers?
- 10. How do you view the performance of caregiving activities of formal caregivers in the care of in-patients?
- 11. How do the caregiving activities of formal caregivers meet your expectations?
- 12. How do your perceptions of formal caregiver roles affect how you relate with them?

Role Expectations of Informal Caregivers

- 13. In your opinion what caregiving activities do formal caregivers expect you to perform for in-patients?
- 14. What aspects of caregiving would you like to be more or less involved in?
- 15. What caregiving activities do you expect formal caregivers to perform when you came into the hospital?
- 16. What caregiving activities do they perform?
- 17. In your opinion why do formal caregivers perform those roles?
- 18. What is your level of satisfaction with the performance of caregiving activities by formal caregivers
- 19. How does your level of satisfaction with the performance of formal caregiving activities affect how you relate with them?

Communication between Formal and Informal Caregivers

- 20. What sort of information do you share with formal caregivers?
- 21. How does the information being shared between formal and informal caregivers help in providing care to in-patients?
- 22. How adequate is the information being shared between formal and informal caregivers in the areas that are enquired about?
- 23. How timely is information being shared?
- 24. How accurate is information being shared?
- 25. How comprehensible is the information being shared between formal and informal caregivers?
- 26. What causes misunderstanding of information between formal and informal caregivers?

27. How can communication between formal and informal caregivers be improved to enhance understanding between both parties?

Recommendations

28. In your opinion, how can the relations between formal and informal caregivers be improved?



APPENDIX B

Interview Guide for Formal Caregivers

Date of interview	
Time of interview	

Background Information of Participants

- 1. Age
- 2. Professional background of the participant
- 3. Occupation

Caregiving Tasks Performed by Formal and Informal Caregivers

- 4. What caregiving tasks do you perform in the ward?
- 5. In your opinion why do you perform those caregiving tasks?
- 6. How relevant are your roles in the hospital?
- 7. How do you relate to informal caregivers when performing caregiving tasks?
- 8. How do the activities of informal caregivers affect your roles as a formal caregiver?
- 9. How do informal caregivers assist with caregiving activities?

Perceptions of Formal Caregivers

- 10. How important are the caregiving activities of informal caregivers?
- 11. How do you view the performance of caregiving activities of informal caregivers in the care of in-patients?
- 12. How do the caregiving activities of informal caregivers meet your expectations?

13. How do your perceptions of informal caregiver roles affect how you relate with them?

Role Expectations of Formal Caregivers

- 14. In your opinion what caregiving activities do informal caregivers expect you to perform for in-patients?
- 15. What aspects of caregiving should informal caregivers be more or less involved in?
- 16. What caregiving tasks do you expect informal caregivers to perform when a patient is admitted?
- 17. What caregiving tasks do they perform?
- 18. In your opinion why do informal caregivers perform those tasks?
- 19. What is your level of satisfaction with the performance of caregiving activities by informal caregivers
- 20. How does your level of satisfaction with the performance of informal caregiving activities affect how you relate with them?

Communication between Formal and Informal Caregivers

- 21. What sort of information do you share with informal caregivers?
- 22. How does the information being shared between formal and informal caregivers help in providing care to in-patients?
- 23. How adequate is the information being shared between formal and informal
 - caregivers in the areas that are enquired about?
- 24. How timely is information being shared?
- 25. How accurate is information being shared?

- 26. How comprehensible is the information being shared between formal and informal caregivers?
- 27. What causes misunderstanding of information between formal and informal caregivers?
- 28. How can the communication between formal and informal caregivers be improved to enhance understanding between both parties?

Recommendations

29. In your opinion, how can the relationship between formal and informal caregivers be improved?



APPENDIX C

Interview Guide for In-Patients

Date of interview	 	٠.	 •	 	•	٠.	•		
Time of interview									

Background Information of Participants

- 1. Age
- 2. Health condition
- 3. Duration of admission

Caregiving Tasks Performed by Formal and Informal Caregivers

- 4. What caregiving tasks do formal caregivers perform in the ward?
- 5. What caregiving tasks do informal caregivers perform in the ward?
- 6. In your opinion why do they perform those caregiving tasks?
- 7. How do the activities of formal and informal caregivers affect each other's roles?
- 8. How do formal and informal caregivers assist each other with caregiving activities?

Role Expectations and Perceptions of Formal and Informal Caregivers

- 9. How do the expectations of formal and informal caregivers affect how they relate with each other?
- 10. How do the perceptions of formal and informal caregivers affect how they relate with each other?

Communication between Formal and Informal Caregivers

11. What sort of information do formal and informal caregivers share?

- 12. In your opinion, how is the communication of information between formal and informal caregivers?
- 13. What causes misunderstanding between formal and informal caregivers?
- 14. How can communication between formal and informal caregivers be improved to enhance understanding between both parties?

Recommendations

15. In your opinion, how can the relations between formal and informal caregivers be improved?

APPENDIX D

Observation Guide

CAREGIVING TASKS PERFORMED BY FORMAL AND INFORMAL

CAREGIVERS

- 1. What tasks formal caregivers perform.
- 2. What tasks informal caregivers perform.
- 3. How tasks are performed.

