UNIVERSITY OF EDUCATION, WINNEBA

VIEWS OF CAREGIVERS ON SATISFACTION DERIVED FROM UTILIZING REHABILITATION SERVICES FOR THEIR CHILDREN WITH CEREBRAL PALSY: THE CASE OF SALVATION ARMY COMMUNITY REHABILITATION AND ORTHOPAEDIC CENTRE AGONA– DUAKWA, CENTRAL REGION, GHANA.

ABU-SADAT RABBI

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A THESIS IN THE DEPARTMENT OF SPECIAL EDUCATION, FACULTY OF EDUCATIONAL STUDIES, SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES, UNIVERSITY OF EDUCATION, WINNEBA IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR AWARD OF THE MASTER OF PHILOSOPHY (SPECIAL EDUCATION) DEGREE.

MAY, 2017.

DECLARATION

STUDENT'S DECLARATION

I, Abu-Sadat Rabbi hereby declare that this research work - views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy: The case of Salvation Army Community Rehabilitation and Orthopaedic Centre Agona– Duakwa, Central Region, Ghana, is the result of my own efforts with the exception of references made to other people's work and in published articles, which have been dully cited and acknowledged. I declare that this work has never existed in part or in a whole elsewhere as a presentation.

Signature……………………………. Date…………………………….

SUPERVISOR'S DECLARATION

I, Dr. Yaw Nyadu Offei hereby declare that, the preparation and presentation of this project work was supervised in accordance with guidelines and supervision of thesis project work laid down by the School of Graduate Studies, University of Education, Winneba.

Signature……………………………… Date…………………………..

DEDICATION

To my dear parents and my family for their understanding, support, patience, encouragement, prayer and commitments during this study. And all individuals who helped me in diverse ways in putting this piece together. I say may Allah bless you all.

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I owe a debt of gratitude first and foremost to Almighty Allah for guiding and helping me complete this work. To all lecturers of the Department of Special Education, University of Education, Winneba, I say a big thank you for their help, support and assistance. My special thanks go to Dr. Yaw Nyadu Offei, my supervisor for his immense dedication, persistence guidance, corrections and exceptional suggestions towards the success of my work. I am also grateful to you, Yaaya for your assistance that made all the difference. I wish to thank my Father once again who came to my aid and spurred me on when all seemed lost.

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ABBREVIATIONS

WHO – World health organization

CP – Cerebral palsy

CBR – Community – based rehabilitation

IPC - Inpatient caregiver

OPC – Outpatient caregiver

PWDs – Persons with Disabilities

FCP - Family – centred Practices

ABSTRACT

The point to which caregivers are satisfied with the care they receive for themselves and their children from the health professionals, has increasingly become an issue for all stakeholders concerned with improving health outcomes. The Salvation Army Community Rehabilitation and Orthopaedic Centre Agona–Duakwa, provides rehabilitation services to children with cerebral palsy and for their caregivers. These caregivers mostly seek these services to address the problems of their children and themselves as caregivers as well. The purpose of this study, was to use a qualitative research approach; case study, to find out the views of caregivers on satisfaction they derive from utilizing the rehabilitation services on offer at the Centre. These views on satisfaction encompasses the prior expectations, the enabling factors to service utilization and identification of barriers that caregivers encounter that might affect their satisfaction with service delivery. Five in-depth interviews were conducted with five caregivers out of the anticipated six caregivers who had attended the centre for ten sessions or more. Data was collected and a thematic analysis was undertaken. The results showed that most of the caregivers generally reported being satisfied with the rehabilitation services. The areas caregivers reported as satisfying included the assurance, responsiveness, empathy and support services that they received from the rehabilitation team. Respondents were also content with the outcome of the service encounter on the basis of the improvement each of them had seen in their children, which they attributed to compliance with home base therapy/programmes. However, majority of the caregivers were dissatisfied with the information provided on the condition of the child, caregiver involvement in decision making and participation in treatment regimes (e.g. therapy/exercise sessions) and timely and appropriate communication of the personnel during the service encounter. Consequently, this may have been attributed to the inability of the personnel to find out the expectations of caregivers, what they perceived to be enabling or barriers in their utilization of service. In conclusion, the study findings were similar to findings of earlier researchers. The study also made some recommendations to the management which included, incorporating caregiver satisfaction into the-quarterly and annual evaluation of the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

The world over, there has been a shift from what healthcare/ rehabilitation service providers consider to be satisfactory to what the service user report as satisfying about a healthcare encounter. This shift in phenomenon of satisfaction may be little for most developing countries and Ghana is no exception, as these countries seemingly evaluate satisfaction from the perspective of the service providers themselves. Increasingly, this has led to the need to find out what satisfaction connotes from the perspective of the care receiver /caregiver providing care to a disabled dependant in various healthcare settings, upon which quality of healthcare can be determined (Palad & Madriaga, 2014). Nevertheless, rehabilitation service as one of the key elements of the health component of the Community Based Rehabilitation matrix is not exempted from the wide range of health services that can be improved on the basis of caregiver views and perceptions on satisfaction (WHO, 1995; Irochu Omare, 2004; WHO – CBR guidelines, 2010).

Although rehabilitation services has become essential to achieving the highest attainable level of primary health care for persons with disabilities, it is estimated that only 2% of 16% of people living with disabilities in Africa have access to even basic health and rehabilitation services (Meikle, 2002; WHO, 2010). It is however, not a surprise but unfortunate that there is no available evidence regarding the percentage of Persons with disabilities (PWDs) including children with cerebral palsy (CP) who have received or continue to receive rehabilitation and other health related service in Ghana (Badu, 2014). In spite of calls for "appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation; in all aspects of life" in Article 26 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD,2006). Again, the account of the disability population at 3% of the entire population does not specify the ratio of the percentage that have access to rehabilitation and other health related service (The Ghana Statistical Service, 2012), even though, providing support services for persons with disabilities and achieving these provisions in UNCRPD and the ACT 715 is dependent on the right and ability of individuals with disability to actively access rehabilitation services and participate in society (Government of Ghana, 2006).

The World Health Organization (1980) estimated that approximately 10% of the world's population at any given time is physically or mentally impaired. This estimate was based on a number of calculations of the disability rates resulting from diseases, trauma, malnutrition and genetic causes available at that time. With majority of disabled people believed to be living in the developing countries. The UN (2002) puts this figure at two thirds of the disabled people, Mitchell (1999a) at 75% while Hutcherson (1991) estimates that one in every seven persons is born with or will acquire a physical, mental or sensory impairment. The WHO in 2010 further estimated that there were about 600 million disabled people worldwide (i.e., about 10% of the world population) with an estimate of about 80% of all disabled people worldwide living in developing countries like Ghana. However, with an increasing rate in the number of people living with disability, globally, the World Health Organization in (2011), estimated that 15.6% representing 650 million population presents with disabilities, with the most prevalent being physical disability (WHO, 2005).The organization again posits that there is an estimated number of children aged 0–14 years experiencing “moderate or severe disability” at 93 million (5.1%), with 13 million (0.7%) children experiencing severe difficulties with rate ranging from 11.8% for those in high income countries to 18.0% for those in low income countries for people age 18 years and above (WHO 2011). On their part, the United Nations Children’s Fund (2005) estimated the number of children with disabilities under age 18 at 150 million. Notwithstanding the general nature of the report by WHO on prevalence, a growing number of countries are using the ICF framework and related question sets in their national surveys and censuses (WHO, 2011), with prevalence rates estimate varying widely across and within countries. Most developing countries such as Ghana report disability prevalence rates below those reported in many developed countries, because they collect data on a narrow set of impairments, which yield lower disability prevalence estimates (WHO, 2011).

An example of the varying nature of prevalence across and within countries is the outcome of the 2010 population census of Ghana, which found the prevalence rate of disability in the country at 3% of the entire population of 24.6 million which represents 737,743. This falls below the estimated rate of 10% to 15% in developing countries captured by the WHO (The Ghana Statistical Service, 2012). Also, estimated prevalence rate of Cerebral palsy as a main cause of childhood physical disabilities have been conducted by a number individual organizations and government bodies around the world. Finnie (1997) and Winter, Auntry, Boyle, and Yeargin-Allsopp (2002) estimate the CP prevalence in Australia was 2.0 - 2.5 per 1000 live births (Flett, 2003). Contrary to this, with an estimation of 85.0% of the world's disabled children of less than 15 years of age living in developing countries like Ghana, very little is known about the prevalence of CP in these countries (Shawky, Abakhail & Soliman, 2002).

Even though, Ghana, as in the rest of the developing countries, has no accurate and reliable data on the prevalence of CP, the country recognizes an estimate of prevalence of disabilities at 15.6% for developing countries as contended by the WHO (2011) of which cerebral palsy was reported as a cause of most childhood physical disabilities. As of May, 2013, CP was one of the most common conditions seen at the Salvation Army Community Rehabilitation and Orthopaedic Centre, with 10% increment each year (Annual Project Report, 2014).

Salvation Army Community Rehabilitation and Orthopaedic Centre as the setting of the study, focuses mainly on persons with physical disabilities of which cerebral palsy is key and in line with the world health organization’s definition of physical disabilities to include, musculoskeletal, neurological and chronic impairments (WHO, 2011). The researcher’s drive to investigate into this area is the outcome of participation in the Salvation Army Community Rehabilitation and Orthopaedic Centre’s, One (1) day stakeholder’s workshop on the theme, “Evaluation of the Salvation Army Community Rehabilitation and Orthopaedic Centre’s activities” for the year 2014 in Swedru. The outcome of the evaluation, happened to have made it very clear that there was the need to prioritize on rehabilitation services offered to children with disabilities, and this effort must be of great concern to each and every stakeholder involved in the rehabilitation process, particularly the caregiver, the rehabilitation personnel and community volunteers.

Caregiver's roles with the home-based therapy they provide in the prevention of secondary impairments were found to be very important. This stimulated the thoughts of the researcher to seeking an answer to the question, "Are caregivers actually satisfied with services provided to their children with cerebral palsy? "And for this reason, views of caregiver on satisfaction in this study has been conceptualized into the reported satisfaction caregivers attain from utilizing rehabilitation services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, the prior expectations caregivers of children with cerebral palsy have with rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, the enabling factors to caregivers utilization of rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre and the inherent barriers to caregiver utilization of services offered at the Salvation Army Community Rehabilitation and Orthopaedic Centre that might predict the reported views of satisfaction caregivers' attained.

Again, a thorough synthesis of literature at the beginning of this program – master of philosophy, special education shows that, there has been a lot more progress made by researchers in their study of patient/customer satisfaction in the healthcare and the marketing sector (Alturki & Khan, 2013; Ofili, 2014; Nkrumah, Yeboah & Adiwokor, 2015; Tweneboah-Koduah, & Farley, 2016; Aduo-Adjei, 2015) with seemingly few that have looked holistically into caregiver satisfaction with rehabilitation services provided for their children/ dependants with disabilities in developing countries like Ghana. However, a lot more studies have been carried out to measure the impact of CBR, experiences of persons with disabilities and community participation in CBR. Nonetheless, Unwin and Sheppard (1995) in their study recommended that parent satisfaction should be investigated as an outcome measure for paediatric physiotherapy services. Similarly, Newacheck and Stein (1996) recommended that the monitoring and evaluation strategies of services for children with chronic illnesses and disabilities should focus on parent outcomes. It is therefore important to investigate views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy at Salvation Army Community Rehabilitation and Orthopaedic Centre. This study sought to provide empirical evidence on the views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre in the Agona - East district in the central region of Ghana, which may not be the same in developed countries.

1.1. Statement of the problem

The provision of rehabilitation services for persons with disabilities at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona –Duakwa has existed for the past 30 years to promote inclusion and empowerment of persons with disabilities. Seemingly, the outcome of the evaluation of the Centre's activities for the year 2014 did not cover views of caregivers on satisfaction they attain from utilizing these services, hence very little is known about the reported caregiver satisfaction with rehabilitation services for children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, in spite of the crucial role caregiver satisfaction plays in improving health services as well as the development of children (Bernheimer, Gallimore & Weisner, 1990). Stimson and Webb (1975) also reported that, satisfaction is connected to how patients perceive the outcome of care and the extent this outcome meets their satisfaction.

Therefore, it is vital to ascertain the reported views of caregivers on satisfaction attain from utilizing rehabilitation services on offer at the centre.

It is also uncertain as to what prior expectation caregivers of children with cerebral palsy have in utilizing rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre. Goldstein, Elliot and Guccione (2000) recognizes that customer expectations prior to services are a vital aspect to ultimate satisfaction and as well the best predictor of patient satisfaction (Hsieh & Doner, 1991), therefore it is crucial to find out the prior expectations of these caregivers and how it influences their reported views on satisfaction with rehabilitation services at the centre.

Again, it is not known what enabling factors account for caregivers' utilization of services at the Centre. Irrespective of the assertion that increased knowledge and health awareness provided for patients/caregivers on their condition or that of their child enables them to make informed decisions concerning their health needs (Buttman & Svarst, 2002), therefore, it is necessary to identify factors caregivers find more enabling to their utilization of services on offer at the Centre .

It cannot further be established as to the nature of inherent barriers that the caregivers encounter when using the rehabilitation services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre. Green (1999) broadly categorized environmental, social, cultural and economic and patient (caregiver) - professional personal characteristics as common barriers patients (caregivers) report in most healthcare encounters. It is therefore, imperative to find out what inherent barriers caregivers of children with CP encounter with utilization of rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona - Duakwa.

1.2. Purpose of the study

The purpose of this study was to find out the views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

1.3. Objectives of the study

The objectives of this study were to:

- Explore the views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.
- Find out the prior expectations caregivers of children with cerebral palsy have in utilizing rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.
- Identify the enabling factors to caregivers utilization of services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.
- Ascertain the inherent barriers caregivers encounter in utilizing rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

1.4. Research questions

The study specifically attempted to answer the following questions:

1. What are the views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. ?
2. What prior expectations do caregivers of children with cerebral palsy have in utilizing rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?
3. What are the enabling factors to caregiver's utilization of services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?
4. What are the inherent barriers caregivers encounter in utilizing rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?

1.4. Significance of the study

The results would reveal the reported views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. . This will urge the management of Salvation Army Community Rehabilitation and Orthopaedic Centre begin to understand the demands placed on them by caregivers to provide services that are more satisfying and value the need for them to appraise their evaluations to include caregiver satisfaction with the services they provide.

The findings from the study would further reveal the prior expectations that caregiver's came with to access rehabilitation services for their children or dependants with cerebral palsy. This will help the Centre put in place measures that will meet the expectations of the caregivers. The findings would again help to identify the enabling factors to caregiver's utilization of services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

The findings from the study would also help in revealing the inherent barriers caregivers encountered as they utilized rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. The results of this study would prove useful to the management and the rehabilitation personnel at Salvation Army Community Rehabilitation and Orthopaedic Centre as it will make them aware of factors that might have a positive or negative effect on the caregivers' expectations with service. It would also help to improve the quality of rehabilitation services and resolve the inherent barriers caregivers encounter at the Centre to increase the use of services and satisfaction.

1.6. Delimitations

Even though, there are quite a number of Community - Based Rehabilitation Centre's that provide rehabilitation services in Ghana, the study focused only on the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa in the Central Region of Ghana, with a particular focus on views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. Again, although the UN convention in (2008) states that comprehensive community – based rehabilitation services, includes Health, Employment, Education and Social services, vocational ability, and full inclusion and participation in all aspects of life, this study considered only an element of the health component namely rehabilitation and the views of satisfaction that comes with utilization by caregivers.

Nonetheless, whereas, many studies on satisfaction seeks to measure the level of satisfaction using the SERVQUAL, the 5Q Model among many standard instrument. This study however focused on finding out the reported views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

1.5. Limitations

The main limitation of this study was that the data was collected from only caregivers of children with cerebral palsy; therefore their responses may not be representative of the responses of caregivers of different types of disability and/or similar sample from other Centre’s in other regions of Ghana. Again, the size of the sample was also small as the criteria for selecting caregivers did not allow for the use of very new cases and this made it impossible to know the views of other caregivers receiving services at the Centre. Hence, the findings did not go beyond what was reported by the participating caregivers.

More so, noting the fact that in- depth investigation of specific phenomenon may not provide entirely all data required, it would have been ideal to triangulate the in-depth interviews with observations to help expand, explain and supplement the information acquired from interview with observations (Creswell, 2012). This is because in-depth interviews have some weaknesses that could be addressed with observations of the process of service encounters.

Also, it would have been appropriate to interview the personnel instead of limiting it to only caregivers. These limited the research findings ability to caption and bring out an understanding of what satisfaction means from both perspectives. Again, as a result of the scant nature of literature in developing countries like Ghana, the bulk of literature reviewed for this study was based on the perspective of developed countries such as the European countries. However, existing literature in the developing context were identified from few Asian, Southern, Western and Eastern African countries which in most case was implied for Ghana as a developing country. Again, one participant could not be interviewed, due to circumstances beyond the control of the researcher.

1.8. Operational definition of terms

- **Caregiver** in this study is defined as anyone who is in position to provide care to a child with cerebral palsy. This includes the biological parent, grandparents, and other relatives or friends because in most instances, biological parents may not necessary be the leading caregiver of a child with CP, or the individual who takes the child for rehabilitation at the Centre.
- **Satisfaction** in this study is the caregiver's perception of quality of the service encounter as they utilize services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.
- **Rehabilitation services** in this study consist of interventions provided by the rehabilitation personnel to caregivers to help them adjust in their caregiving roles.

- **Rehabilitation personnel** refers to team players in the rehabilitation process (e.g. physiotherapist, orthothes, social/medical rehabilitation officers) who provide therapeutic interventions/services for caregivers and their children with CP.
- **Community based rehabilitation** is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all persons with disabilities.
- **Cerebral palsy** a neurological condition that affects movement and body position. It comes from brain damage that happens before the baby is born, during or after the birthing process. The whole brain is not damaged, only parts of it, mainly parts that control movements. Once damaged, the parts of the brain do not recover, nor do they get worse. However, the movements, body positions, and related problems can be improved or made worse depending on how the child is managed and how damaged his or her brain happens to be.
- **Views** are the interpretations caregivers attach to how good or bad they think an aspect of the service they utilize for their children is.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

This chapter reviews literature on views of caregivers on satisfaction they attained from utilizing rehabilitation services. The chapter also covers the theoretical framework and the conceptual framework. The following strands and sub strands were covered;

- **Caregiver Satisfaction from Services**.
    - ➢ The Concept of Satisfaction in the Healthcare/Marketing Sector.
    - ➢ Definition of satisfaction
    - ➢ Theoretical concepts of satisfaction
- **Caregiver Expectations with Services.**
    - ➢ Background concepts to expectations
    - ➢ Definition and Formation of Expectations.
    - ➢ Expectations expressed by parents.
- **Enabling Factors to Utilization of Services.**
    - ➢ Information provided about cerebral palsy (CP)
        - ✓ Parent compliance
    - ➢ Role of the physiotherapist
    - ➢ Family centred – practices
        - ✓ Support for caregivers.
- **Inherent Barriers to Caregiver utilization of services.**
    - ➢ Clinician-Patient(caregiver) Interaction

- ✓ Communication between Caregiver and Clinician
- ✓ Caregiver's attitude towards personnel.

2.2. Theoretical Framework

The theoretical frameworks that guided the study and formed the basis for the analysis and discussion of findings were the Health Belief Model and the Expectancy - Value Model. However, the interconnectivity of these two theories as used in this study is that, they both give the basis for discussing the variables that constitute what satisfaction might mean for these caregivers of children with CP, hence the use of the theories is justified. Below is a detailed discussion of these theories and their implications to the study.

2.2.1. Health Belief Model

The Health Belief Model as propounded by Hochbaum (1958) and Rosenstoch (1974) is a psychological health behaviour model developed to explain and predict health related - behaviour, particularly with regard to the utilization of health service. The health belief model suggests that people's beliefs about health problems, perceived benefits of that action, barriers to the action, and self-efficacy, explain engagement in health-promoting behaviour. A stimulus (motivating factors), or cue to action, must also be present in order to trigger the health-promoting behaviour.

The Health Belief Model as used in a study on "Caregiver adherence to occupational therapy services" was based on the understanding that a person will take a "health-related action if he perceives a given health problem as serious, and therefore more likely to engage in behaviour to prevent the health problem from occurring or reduce its severity. According to this model, the caregiver of a child with cerebral palsy will take action of taking the child for treatment if he/she perceives the condition to be serious"(Biwott, 2014, p.32).

Implications to my study

On the basis of the above model as used in this study, the views of satisfaction caregivers' attain from utilizing rehabilitation is in line with the perceived benefit of their actions. More so, the prior expectations caregivers of children with CP have align with the beliefs about health problems, with the enabling factors they are likely to have in utilizing the rehabilitation services for their children corresponding with the self-efficacy/stimulus (motivating factors); in terms of the information provided to them about the condition of their children, role of the rehabilitation personnel as well as the ability of the caregivers to play their roles effectively in family-centred practices. The inherent barriers they encounter in utilizing the rehabilitation services also are in line with barriers to their action as emphasized by the theory. All the variables in the health belief model explain why it best suits the main purpose of the study of finding out the variables that constitute views of caregivers on satisfaction from rehabilitation services provided for their children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

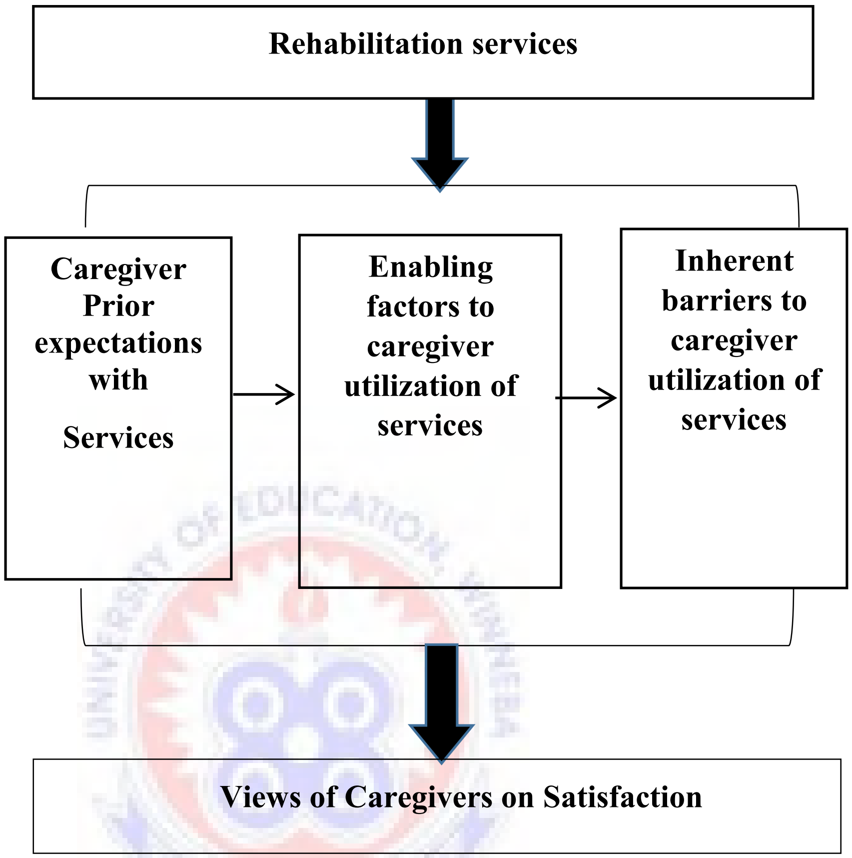
2.2.2. Expectancy-Value Model

As a theory, propounded by Linder- Pelz (1982) on the basis of the definition of satisfaction by Fishbein and Ajzen (1975) and Ware et al (1975), the "Expectancy-Value" theory states that "a person's attitude toward an object is relative to his beliefs that the object possesses certain characteristics and to his assessments of those attributes". Satisfaction, in this theory, is viewed as an attitude which is affected by expectations (beliefs) and the value or importance of the outcomes related to these beliefs (Linder-Pelz, 1982). He further posits that, patients' perceptions, evaluations, and comparisons antecede patient satisfaction. Specifically, patient satisfaction is based on a combination of belief strength about specific attributes of the healthcare experience (access, efficiency, cost, convenience) and evaluation of those experiences.

Implications to my study

Applying this model to views of caregiver on satisfaction, it could be assumed that caregivers' have attitudes towards rehabilitation service (object), which is relative to the beliefs(prior expectations) they bring with them in utilizing the rehabilitation services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa, and this affects their judgment of those experiences.

2.3. Figure 1: Conceptual Framework for Caregiver Satisfaction with rehabilitation services for children with CP.



Source: Author's Construct, 2016.

Figure 1 illustrates the relationship between rehabilitation services and views of caregivers on satisfaction. It explains the constituents of views of caregivers on satisfaction as a dependent variable to rehabilitation services (independent variable) in this study. Caregivers are presumed to look for satisfaction (dependent) from rehabilitation services ((independent). Therefore the gap that exist between the independent and dependent variables are detailed into the prior expectations caregivers of children with cerebral palsy have with rehabilitation services, the enabling factors to utilization of rehabilitation services and the inherent barriers to utilization of services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. All this factors, when favourable, collectively predict how satisfying caregivers find rehabilitation services when utilizing services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

2.4. Caregiver satisfaction from service

2.4.1. The Concept of Satisfaction in the Healthcare/Marketing Sector

In the provision of rehabilitation and other health related services to children, it is essential to find out whether or not caregivers are satisfied with services their children receive. However, the research that exists on satisfaction with services is with respects to the patients/ customers, not caregivers and this are few in developing countries (Badu, 2015; Hussain & Ur Rehman, 2012). Customer satisfaction has inevitably become an area of interest to researchers and organizations such as the healthcare and marketing institutions (Hussain & Ur Rehman, 2012). The marketing industry acknowledged the significance of customer satisfaction in determining the success of their business before the healthcare sector (Peters & Waterman, 1982). Generally, whenever customers want to buy, their aim is to maximize their satisfaction from the product or service. Measuring satisfaction in healthcare has been problematic with increasing growth of the phenomenon into a key area for researchers, practitioners and the consumers of healthcare services (Conway & Willcocks, 1997). This can be attributed to customers' perceptions of satisfaction being closely related to their expectations (Oswald, Turner, Snipes, & Butler, 1998).

However, the rationale for recognizing customer satisfaction was to determine whether customers appreciated the service and would recommend it to others, return for more purchases/services and remain loyal to the industry or hospital (Mittal & Lassar, 1998). This suggests that patient satisfaction regarding health care is a multidimensional construct that has evolved into a very crucial health care outcome (Hussain & Ur Rehman 2012).

In the healthcare, satisfaction is believed to be an attitudinal response to value judgments that patients make about their clinical encounter either implicitly or explicitly as an evaluation based on the fulfilment of expectations (Williams, 1995) and improving service quality dimensions, building trust and getting positive repute in satisfying patient (Hussain & Ur Rehman, 2012). Patient satisfaction ensures the provision of quality results, which is the goal of every health facility (Steiber & Kowinski, 1995). Hence, every healthcare provider and manager is faced up to deliver the definite expected outcomes to satisfy the patient/caregiver by providing superior service and present some of the aftermaths from patient satisfaction such as predicting adherence/compliance with medical advice, re-attendance for further care and improvement in health status (May, 2001). As a result, Goldstein et. al. (2000) in their study observed that patients who were satisfied with the service that they had received were more likely to remain loyal to the provider, which is the therapist.

Similarly, Unwin and Sullivan (2000) explored parent satisfaction with newly developed physiotherapy services for preschools and identified better understanding of the child's condition and prognosis, increased understanding of the child's movements following the physiotherapy visits, and increased ability of the parents to handle the child as some outcome of satisfaction attributes expressed by the parents. King and Cathers (2001) in a study to find out the components related to parent satisfaction and dissatisfaction with paediatric services gathered and arranged the various attributes/domains of satisfaction into structure, process and outcome with the study findings revealing that most of the exceedingly satisfied parents remarked positively about respectful and supportive care, professionals' competence, the provider's attention to the child's needs, an enabling partnership, continuity and coordination of care, the general information provided, and information supplied by the provider as attributes/domains of satisfaction of which most emphasized the 'process'. King and Cathers found that the contrary was factual for parents who were dissatisfied and reported failure of the professional to provide the same attributes. Accessibility of services, service cost, bureaucratic procedures, waiting times at the site, amount, frequency, length or quality of service and the physical facilities, in which the services were provided were summarized by various studies as the reported structural attributes/domains. In contrast, Curry and Sinclair (2002) and Anderson (1995) distinctly studied measurement of service quality of physiotherapy services in Dundee, Scotland and the services at a university health clinic in Houston, Texas respectively. The two studies established that the most important factor in patients' evaluation of satisfaction is the manner in which the service/care is delivered. Expectations of reliability, responsiveness and empathy were rated as equally important when patients evaluated service quality that met their satisfaction in the study findings. In the same way, Adams, Whittington, Saunders and Bell (1994) found empathy/reassurance, encouragement/motivation, rapport, listening and other non-verbal behaviours as most important attributes in their study of affective/socio-emotional behaviours of physiotherapists while treating patients.

Biegel, Song, and Milligan (1995) posited that families of patients appeared to be particularly concerned with emotional resources, aftercare services, responses to requests for information, and greater participation in the patient’s care. For instance, in a study by Tessler, Gamacho, and Fisher (1991) the researchers reported satisfaction of caregivers, with the outcome of contacts with mental health professionals yielding 53 to 73 percent, based on the reason for the contact. Tessler, et al. concluded that caregiver satisfaction varied considerably according to the different types of mental health professionals they had contact with. Respondents were most satisfied with psychologists, followed by nurses, case managers, social workers, and psychiatrists. Biegel et al. reported that two thirds of the caregivers in their sample were satisfied with their relations with professionals with “more communications with professionals” their important need. Caregivers were again found to be more satisfied with outpatient services than with inpatient services, and more satisfied with services provided to the patients than with those provided to them. Caregivers have been reported as rating hospitalization and office-based services more highly than community-based alternatives (Hatfield, Gearon & Coursey, 1996). Stengård, Honkonen, Koivisto, and Salokangas (2000) stated that parents in general were found to be more satisfied than other caregivers who are not the biological parents. Stengård et al. further added that, biological caregiver’s satisfaction with services is strongly influenced by characteristics such as the time of the onset of condition. Meanwhile, Connor and Adams (2003) believed that it was the love most biological caregivers had for their children that influenced the higher levels of satisfaction they reported given the nature of the relationship with the person needing care and determinants of a satisfying experience.

Kramer and Kipnis (1995) added that the characteristics of the caregiver and the care receiver coupled with the context of the caregiving situation potentially play a central role in understanding all other aspects of the caregiver's experience. And this caregiving experience could be rewarding as most biological caregivers reported it brought their families together and help to maintain their family balance (Hooyman & Kiyak, 1999). This resulted in expressions of greater marital satisfaction, a feeling of self-worth and a pride in ability to meet challenges and a meaning in their lives as reported by some caregivers (Kramer, 1997).

Subsequently, interest in patients' satisfaction with treatment has increased in many developed and some developing countries of the world (Juwaheer & Kasean, 2006). This growth in dimension of patient's satisfaction is a demonstration of the move towards a patient-centred care (Beattie, Pinto & Nelson, et al., 2002). Although, there are mixed opinions in the literature regarding whether or not satisfaction level is a reflection of quality of healthcare, the consensus is that patient satisfaction is reflective of patients' view of the quality of healthcare they receive and the quality of the specific institution offering the care (Abdosh, 2006). Ascertaining what the consumer perceives to be quality of care helps to quantify good services (Ramsaran-Fowder, 2008); and likewise, knowing what patients perceive to be quality is important as they are the ultimate consumers of hospital services (Kulkarni, Dasgupta, & Deoke, 2011).

Again, Juwaheer and Kasean, (2006) posited that, like other service industries, the healthcare industry has become highly responsive to the notion that service quality and consumer satisfaction are critically important factors in the success of healthcare organizations, hence monitoring of consumers' view has become a simple but vital strategy for healthcare organizations to appraise their services and improve their performance (Akinpelu, Olaleye, Odole, & Otaiku, 2014; Kulkarni, Dasgupta &. Deoke, 2011).

Akinpelu et al. (2014) conducted a study to investigate the satisfaction of informal stroke caregivers with healthcare services being received by their care recipients in a tertiary hospital in Ibadan. Fifty consenting informal caregivers (12 males and 38 females) of stroke survivors receiving in-patient care on the medical wards of a tertiary healthcare facility participated in this cross sectional survey. The results obtained showed that 48% of the participants were highly satisfied, 48% were satisfied while only 4% reported dissatisfaction. Areas of dissatisfaction included information about the condition of their care recipients. Akinpelu et al. concluded that the extent of satisfaction of informal stroke caregivers' with inpatient care at the University College Hospital was good. The study findings also showed the need to routinely assess the satisfaction of informal carers with services being provided in the hospital for the purpose of quality assurance. The purpose of the research done by Akinpelu et al. (2014) is not very different from the current research since the latter research also sought to find out caregivers' satisfaction with rehabilitation services offered to children with cerebral palsy at the Agona-Duakwa Community Rehabilitation Centre. The review of the Akinpelu et al. study, again, adapted a stroke care questionnaire into three parts while the present study seeks to adapt the Family Caregivers' Satisfaction Survey Questionnaire and the Family Experience and Attitude Questionnaire into a self-developed caregiver satisfaction interview guide to allow for in-depth discussions. However, notwithstanding the findings of the research, it will be interesting to establish, whether findings from that study will be replicated in a case study of reported views of caregiver on satisfaction from rehabilitation service at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

2.4.2. Definition of satisfaction

Several attempts have been made by various researchers to define satisfaction in different sectors, however, the review of related literature so far, shows that there is no exact definition of satisfaction on account of several factors with the main problem being disparity in patients satisfaction - some patients may be satisfied with one factor while the others may not (Hussain & Ur Rehman, 2012). Each and every time a customer is pleased with the product or the service offered, the customer or patient is considered satisfied (Hussain & Ur Rehman, 2012). Goldstein et al. (2000) postulate that the elusive nature of satisfaction as a construct has made it difficult for many authors and researchers to define or describe it, despite its recognition as an extremely important concept. The reason given is that satisfaction, at all times is relative to the patient's expectations, and it changes with the changes of the expectations of what one would ordinarily expect to happen even though the actual health care may remain constant (Goldstein et al., 2000).

The satisfaction of caregivers in health care is the degree to which parents' expectations, needs, and wants are met by the services offered to their children (Palad & Madriaga, 2014). Palad and Madriaga, further maintained that, caregiver satisfaction is not only important for healthcare providers or any individual that is in the position to provide care for a disabled individual, but also has become increasingly important in determining the quality of healthcare delivery from the perspective of the caregiver providing care to a disabled dependent in various healthcare settings.

Caregiver perceptions and satisfaction are crucial in improving health services owing to their significant role in their children's development. They are responsible for acquiring health services needed by their children (Bernheimer, Gallimore, & Weisner, 1990). Their participation in their children's healthcare, especially adherence to health related instructions and remnant of services, is equally important in achieving healthcare goals (Gerkensmeyer & Austin, 2004). They are the most reliable informants about their children, and their preferences and opinions regarding their children's development are most critical (Khadye, Ziviani & Cuskelly, 2011; Wiart, Ray, Darrah, & Magill-Evans, 2010).

Heflinger, Sonnichsen, and Brannan (1996) observed that, with the growth of the phenomenon of caregiver satisfaction into a topic of interest in many studies, some of these studies have focused on child and adolescent mental health services (Palad & Madriaga, 2014), paediatric services in intensive care emergency units, in-patient care and early intervention (Latour, Hazelzet, & van der Heijden, 2005).

However, Linder-Pelz (1982) proposed the definition of patient satisfaction through content analysis of the satisfaction studies in which five (5) psychological variables were proposed to be likely determinant of satisfaction in health care services or a person's feelings of happiness or disappointment as a result of comparing a product/service perceived performance or outcome with its expectation cited in (Kotler & Keller, 2009) as they reflect from their experience over a period of time (Irish Society for Quality and Safety in Health Care, 2003).

- **Occurrence**: The outcomes of a result take place and importance of the individual perceiving what has been ensued.
- **Value**: Judgment of the quality perceived as good or bad or features of health care encounter is considered by the customer as "value".
- **Expectation**: Patient belief that certain attributes might be attached to an object and judging importance of those attributes are the building blocks of satisfaction.
- **Interpersonal comparisons**: Evaluation of the individual experience of current health care encounter with what he/she has experienced previously.
- **Entitlement**: The individual thinking that he has a solid and sound basis for claiming of particular result. By evaluating these attributes the patient satisfaction definition becomes "the individual positive evaluation of distinct dimensions of health care" (Linder - Pelz, 1982).

Furthermore, researchers observed that lack of expertise to estimate clinical aspects on the part of patients' made it extremely difficult for them to evaluate the healthcare quality effectively. For example, Haas (1999) in a qualitative study used interview to collect data from 19 women with diagnosis of gynaecological cancer which were analyzed thematically to examine the presence or absence of expectations prior to the experiences of health care and the relationship between expectations, satisfaction and dissatisfaction in a group of women undergoing surgery in teaching hospitals. The findings were that there is no clear relationship between expectations and satisfaction - as women had different levels of expectations about different types of care and different aspects of care with many of them having felt that their limited experience with/or knowledge about hospitals, medical procedures, and other technical details rendered them less than competent to form expectations about such factors. Also, unfulfilled expectations were found not to have led to less satisfaction because the women were able to express satisfaction either with the care overall or specific aspects of care, as well as being able to distinguish aspects of care with which they were dissatisfied. As a result, patient satisfaction has continued to be conceptualized as a multidimensional construct, because a patient (caregiver in this context) may be highly satisfied with one or more facets of a health care encounter and concurrently displeased with other aspects (Roush & Sonstroem, 1999).

2.4.3. Theoretical concepts of satisfaction

Different organizations with varying background and experiences analyze satisfaction in different ways using various customer satisfaction models (Fakhoury, 1994), usually without a proper theoretical framework, and with a lack of agreement on what satisfaction means, how it is determined, and what dimensions it encompasses. Nevertheless some researches into patient satisfaction has often been conducted (Wilkinson, 1986).

Researchers have over time, continued to develop models to explain experience, expectation and quality of service as factors that influence satisfaction, a multidimensional construct that perceives the customer, as entering a service setting with needs, wants and expectations and the extent to which the provider live up to them defines the degree to which the customer will be satisfied (Conway & Willocks, 1997). They further suggested that, the customer combined all the experiences gained at an encounter with the provider to determine the overall quality of service, which in turn determines the customer satisfaction and the resultant behaviour.

Linder-Pelz (1982) tested hypotheses regarding determinants of patient satisfaction among patients attending the primary care clinics of a university medical centre in Manhattan in the United States, no clear relationship was found between expectations and values on one hand and satisfaction on the other. Instead, Linder-PeIz argued that expectations are the most important experiences to satisfaction. Although the current study does not intend to use a hypothesis, it will be interesting to establish if the outcome of the study will result in a significant correlation between the expectations and satisfaction of caregivers. In addition, Locker and Dunt (1978) suggested that patient satisfaction is influenced by patient's knowledge and prior experiences, and that expectations are not static but likely to change with accumulating experience, time and exposure (Gutek,1978). It was concluded that the expressions of satisfaction are the end product of a comprehensive process of evaluation in which expectations play a very important but not the only role in the perception of the outcome of care (Locker & Dunt, 1978).

The SERQUAL model or the gap model created by Parasuraman, Zeithaml, and Berry (1985) to measure customer satisfaction level concerning the quality of service of an organization had ninety-seven traits put into ten scopes. However, the use of the model by various researchers to measure the service quality scopes revealed and clinched that, there were correlation between these 10 dimensions hence resulting in a decline from 10 to 5 dimensions following specific alterations (Laroche, Kalamas, Cheikhrouhou, & Cezard, 2004).

These expectations/measurement dimensions were outlined as follows:

- **Tangibility**: Physical facilities, equipment, and appearance of personnel.
- **Reliability**: The ability to perform the promised service dependably and accurately.
- **Responsiveness**: The willingness to help customers and provide prompt service
- **Assurance**: The knowledge and courtesy of employees and their ability to inspire trust and confidence.
- **Empathy**: The caring and individualized attention the firm provides to its customers.

These five perspective dimensions forms the basis upon which quality of service can be improved and the customer satisfaction level increased (Laroche, Kalamas, et al., 2004). Conway and Willcocks (1997) proposed a model that was projected to examine the prospect that customer beliefs may be an important influence on the measurement of quality and effectiveness. Consequently, they perceived some correlation between perceived service quality on one side and patient expectations, confirmation/disconfirmation of expectations and patient satisfaction on the other. These authors incorporated in their model the relevant features of service quality - the normative expectations/measurement dimensions of quality as identified in literature by Parasuraman, Berry, and Zeithaml (1988) which spelled out what customers/patients usually consider when evaluating quality of healthcare. These expectations/measurement dimensions were outlined as reliability, responsiveness, assurance, empathy and tangibility (Conway & Willcocks, 1997). Zineldin (2006) however is of the view that patient satisfaction regarding service quality is always dependent on different factors/dimensions and with the passage of time the factors/dimensions have been explored by different researchers.

2.4.3.1. The conceptual model by Zineldin on satisfaction

Zineldin (2006) endeavored to scope the meanings of service quality as underlying factors to patient satisfaction, intensifying the technical-functional and SERVQUAL quality simulations into the context of five quality dimensions (5Q model) were considered into; quality of Object, quality of Process, quality of Infrastructure, quality of Interaction, and quality of Atmosphere which have now become an operative and widespread model on the subject of and for determining patient satisfaction from health care providers perspective. The author further retains that, the technical and functional undertakings of an organizations are not the only influences on the quality of health care service but certain supplementary factors such as interaction, infrastructure and atmosphere that researchers have overlooked are also contributory factors.

Quality of health care service

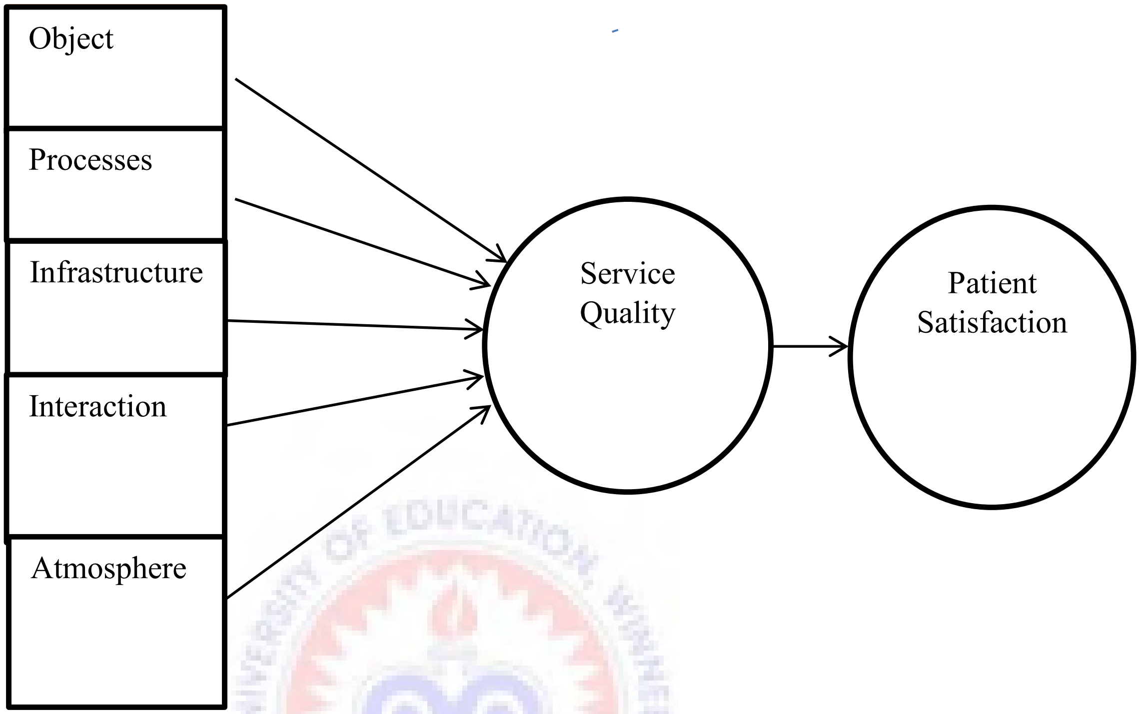


Figure 2: 5Q Model [source: adapted from Zineldin, 2006, p. 70; Hussain & Ur Rehman, 2012].

The construct of the 5Qs model diagrammed in Fig.1 above shows quality of health care service as function Q1-Q5. These 5 scopes of service collectively contribute to quality of health care service which in turn leads the patient to satisfaction (Zineldin, 2006).

- **Q1. Quality of object** – this are technical features that has bearing on the key motivation - basic need and want for which the patient is attending the health care facility.
- **Q2. Quality of processes** – This aspect measures the functional quality indicating exactly how health care institutions offer essential service. It involves patient wait whiles in addition to the promptness with which health personnel carry out health

care activities which aid in pinpointing glitches and recommend explicit resolutions in service delivery.

- **Q3**. **Quality of infrastructure** – This facet of service quality measures the crucial and rudimentary means such as controlling, collaboration and co-ordination as quality traits required for executing health care services and vital to patient satisfaction.
- **Q4. Quality of interaction** – This aspect of service quality measures the quality of factual interchange such as accessibility of information on check- up schedule, degree to which health care professionals appreciate the patient's needs and social altercation. This help to replicate a holistic view of satisfaction patient's attain, despite the unattractive nature of communication/connections amidst people.
- **Q5. Quality of atmosphere** – This element is concerned with the liaison and relations' concerning the two parties on the basis of the quality of the atmosphere as very critical and imperative in an explicit setting where they work together and function for the reason that deficiency in frank and satisfying atmosphere explains low quality of care (Zineldin, 2006).

Hussain and Ur Rehman (2012) investigated how 5Q model of the service quality, trust and reputation could affect patient satisfaction in health care sectors. In that study, the author's focused on using Quantitative research strategy in exploring the perceptions of patients who utilized health services at the Umeå hospital. The findings of the study, based on the 5Q model of effectiveness, suggested that the model of the service quality is not the only factor that could lead to patient satisfaction in health care sectors, but trust and reputation are also factors of great importance. Therefore, it is important for organizations that provide health care services to improve every dimension of service quality create trust and achieve high reputation to gain high level of patient satisfaction. The method used in this reviewed study is quite different from the method to be used in the current study because the current study will not test hypothesis for the collection of data. Another area that the two studies differ is that, the present study will not find out how the 5Q model affects consumers' satisfaction, but rather how the 5Q indicators are embedded in the conceptual framework of the study.

2.5. Caregiver Expectations of Services

2.5.1. Background concepts to expectations

Customer expectations as a concept have been viewed in numerous ways in the service management literature. Not very much can be said about the expectations of caregivers in that respect. However, Zeithaml, Bitner, and Gremler (2006) stated that customer expectations are beliefs about a service delivery that serve as standard against which performance is measured. Zeithaml, Berry, and Parasuraman (1993) however, believes that in practicality, customers have many source of information that lead to expectation about forthcoming service encounters with a particular company. These source include prior exposure to the service, word of mouth, expert opinion, publicity, and communication controlled by the company (e.g., advertising, personal selling, and price), as well as prior exposure to competitive services.

However, in South Africa, Phiri and Mcwabe (2013) in a study that seeks to measure the customers' expectation levels of service quality in the food retail sector against their perceptions levels of the service quality at Pick n Pay using the SERVQUAL survey instrument. This was to determine the gap between customers' expectations and their perceptions of the service quality. The key findings confirmed that customers have higher expectations for service quality in food retail supermarkets than is anticipated. With the role of expectation in satisfaction having been examined in a variety of contexts, its prominent role in client satisfaction with healthcare services cannot be overlooked. This is because there is evidence highlighting increased expectation as related to greater satisfaction (Rosen, Heckman, Carro, & Burchard, 1994).

Garland, Aarons, et al., (2000) in a previously discussed study of multi-ethnic youths' satisfaction with mental health services found more positive expectation about treatment service at admittance was associated with greater satisfaction. It has also been suggested that it is not increased expectations that are associated with high satisfaction, but realistic expectation and the fulfilment of those expectations. Garber, Brenner, Litwin (1986) maintained that clients with less realistic expectations of service provision are less satisfied. McKinley, Stevenson, Adams, & Manku-Scott (2002) in a study that examined client expectation in health care, the effect of expectation on satisfaction with care provided by out-of-hours primary medical services found that patients who received the care they expected were found to be more satisfied than those who did not.

In a study of prognostic expectations and outcome of brief therapy of recipients in community mental health setting, it was found out that expectation may also affect outcome with generally lower expectations correlated with more favourable outcomes (Dew & Bickman, 2005). Disagreeing to these results, other research indicated that expectation of success is an important stimulus on positive therapeutic outcome. Almsalam (2014) in a quantitative study including samples of 250 customers from the 5 Banks in Damascus, Syria to analyze the relationship between two of the most important antecedents of customer satisfaction(namely customer expectation and perceived service quality found that customer expectation and perceived service quality have a positive effect on customer satisfaction. And that improvement in service quality influences customer satisfaction and expectation levels must be considered to increase consumer satisfaction which ultimately retains valued customers. The method used in Almasalam's study is contrary to the method to be used in the current study because the latter intends to use interviews in bringing out the real live experiences of caregivers and the resultant satisfaction they attain. While the former was conducted in a marketing sector, the latter's focus is on primary healthcare Centre. It will seemingly be interesting to establish the outcome of the current study.

Again, a study conducted by Gunawardane (2010) to assess of the dynamic nature of customer expectations in service encounters using the commonly used service quality measurement methods, SERVQUAL indicated that levels of customer expectations on various dimensions of the service vary with repeated use of the service. Notwithstanding the fact that, the SERVQUAL will not be used as an instrument of measurement in the current study, it was important to establish it outcomes. In the same line of investigating service quality in the marketing sector, Nabi (2012) conducted a study on private banks in Dhaka city of Bangladesh to measure the expectations of the customers towards the services rendered by private sector banks. The study findings concluded that among the several dimensions, customers give emphasize on tangibles, responsiveness and assurance while evaluating service quality.

2.5.2. Concepts and Formation of Expectations

2.5.2.1. Defining Expectations

With many different ways of defining and conceptualizing, patient concerns, desires and expectations, literature have been reviewed from the health care and marketing sector. In attempt to simplify understanding and reliability of explanations of satisfaction from expectations, Thompson and Sunol (1995) pointed out that the definitions of expectations are not absolute and products of cognitive processes. However, these authors classified the user expectations into four different types namely, ideal expectations, practical or predicted expectations, normative expectations and unformed expectations. Ideal expectations are those that users would like to happen and can be referred to as aspirations, desires, wishes, wants or the preferred outcomes. Practical or Predicted expectations, on the other hand, expressed what the individual thought would happen during the encounter with the healthcare.

Normative expectations are those that users believe ought to or should happen based on what they believe they deserve and or on what is socially endorsed. Unformed expectations occur when users are unable or unwilling to articulate their expectations due to fear, anxiety, and conformity to social norms, or lack of knowledge or experience to formulate expectations. This may be temporary phenomenon, but quite common in the health care context (Thompson & Sunol, 1995).Parasuraman, Zeithaml, and Berry (1988) however, observed that customer desires or wants sometimes turned out to be what the customers feel a service provider should do rather than what they do. In the health care literature, Potter, Gordon, and Hamer (2003) confirmed this observation in their study by showing that the expectations of the parents differed from those of their physiotherapists.

Kravitz (1996) proposed a framework modelled around patient satisfaction in order to promote improved clinical care and research incorporating these concepts. In this model a patient has initial expectations which are formed prior to an encounter or intervention, but may be modifiable as the encounter proceeds. These primary expectations may be well formed or vague, and factors such as socio - demographic characteristics, prior experiences, or specific bio - psychosocial concerns may be important determinants of these expectations. He further maintained that, content of expectations (Structures, Processes or Outcomes) must be considered while defining patient expectations (Kravitz, 1996).

According to Gabbott and Hogg (1994), ‘cure’ or health is the ultimate expectation in the healthcare sector rather than healthcare service that is challenging to evaluate with the core expectations to the patients centred around the ‘care’ expectations, which are equally as imperative as the ‘cure’ expectations. Conway and Willcocks (1997) on this basis argued that, the means by which the patient evaluates the service throughout the healthcare process and to its completion is influenced by the patient’s expectations of the process of care, their part in the process and the overall outcome of the treatment. For example, customers will make comparisons between the service performance and their prior expectations to determine whether their desires or wants have been met, and they will also apply their expectations to evaluate quality of service received (Anderson, 1995). Hence, Conway and Willcocks affirmed that much of the overall dimension of satisfaction within the health care experience is prejudiced by the patient's previous expectations.

Marple, Kroenke, Lucey, Wilder and Lucas (1997), Sanchez-Menegay, Hudes, and Cummings (1992) autonomously in their studies showed that unmet expectations have been associated with decreased patient satisfaction, no adherence (Linn, Linn, & Stein, 1982), and possibly worse health-related outcomes (Kaplan, Greenfield, &Ware, 1989).

Narayanan (2008) carried out a study to explore the concerns, desires (goals) and expectations of adolescents undergoing surgery for idiopathic scoliosis, and contrasted their priorities with those of their parents and surgeons. Parents were more concerned than their children about the consequences of scoliosis and of surgery. With the exception of improving physical appearance, surgeons' goals of surgery were different from those of either the patients or parents. Parents wanted and expected more from surgery than their children. Parents and patients had greater expectations of surgery than surgeons. Although adolescents had different priorities from their parents, parents were aware of these differences and reliably predicted their children's priorities. These findings have important implications on shared decision-making and informed consent, and might contribute to better understanding and measurement of outcomes that matter to patients (Narayanan, 2008).

2.5.2.2. Formation of Expectations

The formation of expectation is complex and influenced by a variety of factors, both individual and social. There is miniature theory or research available that focuses on the determinants of patient expectations (Kravitz, 2001). A further study on the influences of the growth and manifestation of expectations was carried out, and findings were that perceived exposure to particular health issues (e.g., due to age or family history), past experiences with similar symptoms (either personal or acquired while caring for others) and transmitted knowledge (e.g., from friends, via the media, or through health education) influence expectations by affecting the interpretation of this indicators and instituting an embedded standard of care (Kravitz et.al. 1996, Kravitz, 2001).

Kravitz (2001) posit further, that in a clinical context, the encounter therefore becomes mediation between patient and physician. Rotter (1966) posits that ideal expectations might be most predominant for those without previous experience as patient who have unformed expectations have no idea of what to expect, whereas those with previous experience are more likely to have predicted than unformed expectations based on previous encounters. Robledo (2001) adds that previous experiences are the most influential source of customer expectations with regards to services. He again contends that even with the large role played by previous experiences in the formation of expectations for the future, customers that have not had any prior experiences with the type of service in question, which would be the case for new markets, will still have expectations that need to be reflected (Robledo, 2001). Furthermore, these expectations formed become less refined, more implicit and more unrealistic in instances where the customer have no prior experience hence no point of reference (Higgs, Polonsky, & Hollick, 2005). Concurrently, the expectation then become more refined and clear, explicit and realistic as the service process goes forth and the customer receives more experience resulting into clear changes in expectations (Higgs, et. al., 2005).

Customers are insistently changing their expectations, and the expectations are changed as customers obtain new information, Coye (2004) presents a model which argued that the customers´ expectations constantly change during the service process through a number of decision points where the customers intensely process and interpret information. With a growing body of literature that suggests that patients' expectations are linked with clinical outcomes in many dissimilar treatments, and therefore may be an imperative predictor for treatment outcomes. Iles, Davidson, Taylor, and O'Halloran (2009) who through a systematic review investigated recovery expectations in people with acute non - specific low back pain found a strong predictive role of expectations. Constantino, Arnkoff, Glass, Ametrano and Smith (2011) concluded in their systematic review that there was a small significant effect of outcome expectations on outcomes in psychotherapy.

Haanstra, Berg, Ostelo, Poolman, et al., (2012), systematically reviewed available evidence related to the association between pre-operative patient expectations and different treatment outcomes in patients with total knee or total hip arthroplasty. No significant associations were found between patient expectations and overall improvement, satisfaction and stiffness. These authors concluded that there was no consistency in the association between patients' pre-operative expectations and treatment outcomes for TKA and THA identified in this systematic review.

In an exploratory case study by Andersson and Liedman (2013) to increase the understanding of Findwise´s customers' expectations in order to increase the customer satisfaction, they identified that customer expectations constantly reform along three different dimensions. These dimensions consist of the level of fuzziness, implicitness and unrealism. The expectations are influenced to a large degree on previous experience, and the less Knowledgeable the customer, the more fuzzy, implicit and unrealistic the expectations may be. Therefore it is important for the project supplier to guide the customer through an educational journey and have a continuous identification of the customer´s changing expectations to either influence the expectations or adapt the rehabilitation service and its outcome to match the expectations and achieve customer satisfaction (Andersson & Liedman, 2013).

2.5.3. Expectations Expressed by Caregivers (Parents)

Progressively, researchers recognized that customer expectations prior to service are a vital aspect to ultimate satisfaction (Conway & Willcocks, 1997; Goldstein et al. 2000). Patient's expectations in field of health care are believed to play a significant role to attaining satisfaction (Kravits 1996). However, few studies have actually looked at the expectations expressed by caregivers. With different perceptions of satisfaction held by parents, there were some key attributes/domains interconnected to process and outcome that were found to be common to most of them. It has been augmented by medical professional researchers that their customers evaluate quality according to the process, that is, the personal service they receive and not by the accommodation facilities of the hospital hence the need to focus their studies more on process of service delivery (Carman, 2000).

Gabbot and Hogg (1994) purports 'care' expectations are some of the attributes/domains of satisfaction presented by customers/patients. Unwin and Sheppard (1995) without a doubt reported that parents rated the process of service delivery and the outcome as more important to them. Calnan, Katsouyiannopoulus, Oucharov, Prokhorskar, Ramie & Williams (1994), and King, King, Rosenbaum, & Goffin (1999) separately in their studies on parent satisfaction stressed interpersonal-care giving as most important. The attributes/domains of interpersonal interaction and process as identified by previous studies included respectful and supportive care, the feeling of being listened to and attaining rapport with the provider, the amount and the clarity of general information supplied by the provider, the enabling partnership where the professional involves the patient as a team member in the ultimate decision-making as well as accommodating family needs and wishes and, the competence of the practitioner covering both knowledge and skills (Ireys & Perry, 1999; Unwin & Sullivan, 2000). On the basis of the aforementioned point of views, a number of studies have been conducted on parent utilization of services and their expectations.

In a study on parental experiences of a CP clinic in a poor urban community in South Africa, Anderson and Venter (1997) maintained that parent wanted their children to become like other 'normal' children attending school, attain a good quality of life, and to grow into economically independent and mature adults in addition to being able to walk. Some of these expectations reported by parents were in most cases impractical considering the fact that their children were severely disabled. In a similar study, conducted to identify the key components of an appropriate rehabilitation service which would meet the needs and expectations of children with CP and their caregivers at SA public sector hospitals, the findings showed kind and caring attitudes, exercises or "training" for the child, and practical assistance (handling ideas and suggestions, assistive devices, food supplements, nappies, advice) as components of care expectations most valued (Saloojee, Rosenbaum, & Stewart, 2011).

However, Miles and Frizzell (1990) in a study on multi-Level Skills for handling the children with Cerebral Palsy in Pakistan ensured that any activity to be used at home first demonstrated by the therapist and then tried by the mother. This was reiterated until the mother was comfortable and confident enough to continue at home. The study findings were that most parents, understandably, began with the goal that their child 'should walk and talk', and that through enhanced understanding for the need of exercises in group activity, and parents appreciating the fact that any progress begins with stages and movements well below their expectations and possibly build up an understanding of realistic target in their expectations in the direction of what is doable for each child.

More so, Anderson (1995) in a research to assess the quality of service provided by a public university health clinic used a modified SERVQUAL instrument with the first set of 15 statements measuring patients' expectations of service quality regarding university health clinics in general, while the second set of 15 statements measured patients' perceptions specific to the University of Houston Health Centre's quality of service provided. The findings were that timely provision of services and knowledgeable medical workers who make patients feel safe in their interaction with them, sympathetic, reassuring, and willing to help patients are among other expectations expressed by patients. The researcher concluded that customer evaluations of service quality are based on perceptions of the quality of service received relative to prior expectations which forms the basis of most recent service quality research.

Parkes, Donnelly, Dolk, and Hill (2002) studied the use of physiotherapy services and alternative therapies in the treatment of a population of children with moderate to severe cerebral palsy (CP) in Northern Ireland. The method used was a descriptive cross-sectional survey involving a total of 212 parents of children aged 4–14 years with moderate to severe CP identified from the Northern Ireland Cerebral Palsy Register (NICPR) and a random subsample of their paediatric physiotherapists. The findings were that 74% of parents representing more than half of the parent population in the study wanted more physiotherapy for their child in order to achieve some form of independent walking, making the demand for physiotherapy services to be on the rise (Parkes, et al., 2002).

May (2001), tested the role of the 'expectancy theory' in the health care sector with his findings showing that patients may not always have clear expectations of a complex process of health care, or the expectations may rise with time. In conformity with May’s assertion, Fitzpatrick and Hopkins (1983) in a qualitative study, using content analysis to find out patients’ expectations and satisfaction of patients with chronic headache regarding their neurological referral, and to establish whether those expectations were met, Participants were interviewed before their outpatient appointments, with most patients quite unsure of what to expect. The researchers found that patient expectations were faltering as different concerns were felt by patients about their headaches and were modified by previous experience such as disappointment with their clinic attendance and failures of communication in clinics that led to some patients' concerns not being wholly addressed. The purpose of this study is not very different from the current, as the current study seeks to qualitatively collect data from caregivers of children with cerebral palsy on their reported satisfaction. It will be seemingly interesting to find out if the outcome of the current study will prove same or similar findings.

2.6. Enabling Factors to Caregiver Utilization of Services

2.6.1. Information provided about cerebral palsy (CP)

Caregivers seek out for rehabilitation services as a result of numerous conditions that may be affecting their children and CP is no exception. According to Stanley, Blair and Alberman (2000) and Hagberg, Hagberg, Olow, Von Wendt (1996) CP is a generic term for various types of non-progressive motor dysfunction present at birth, or beginning in early childhood, and is the single biggest cause of childhood disability worldwide. It is a complex condition involving motor impairments, activity limitations, and participation restrictions that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain (Rosenbaum, Paneth, Leviton, et al., 2007). Kibel and Wagstaff (1995) nonetheless, elucidated that although the lesion is non-progressive, these clinical manifestations often change with neurological maturation. This change in turn changes the functional abilities of the individual, their health and social needs (Backheit, Bower, Cosgroves, et al., 2001). This makes CP a lifelong condition with exceptional effects on the individual child and their carers, and as a consequence, also contributes to the increasing numbers of children with disabilities that rehabilitation personnel have to manage. The current estimated incidence of CP is 2.0 to 2.5 per 1000 live births in developed countries (Odding, Roebroeck & Stam, 2006). This estimate is similar to what Finnie (1997) and Winter, Auntry, Boyle, and Yeargin - Allsopp (2002) reported when they estimated the CP prevalence in Australia to be 2.0 - 2.5 per 1000 live births (Flett, 2003) and a prevalence rate of 2.1 per 1000 live births in Norway (Andersen, Irgens, Haagaas, et al., 2008) respectively. However, this prevalence rate may be higher because of increased survival of low-birth weight babies, a group known to be at greater risk of this condition (Darlow, Horwood, Mogridge, & Clemett, 1997). The Ontario Federation for Cerebral Palsy (2011), however contends it is difficult to estimate exactly how many people have CP given the fact that many people with mild CP are never diagnosed, while others may have multiple disabilities which overshadow their CP.

Contrary to this, with an estimation of 85.0% of the world's disabled children of less than 15 years of age living in developing countries like Ghana, very little is known about the prevalence of CP in these countries (Shawky, Abakhail, & Soliman, 2002). Kibel, et. al., believed that by 1995 it was largely attributed to the high incidence of potentially brain damaging illnesses among poorly resourced countries. Ghana, as in most developing countries, has no accurate and reliable data on the prevalence rate of CP but, the country recognizes an estimated prevalence of disabilities at 15.6% for developing countries provided by the WHO (2011). However, as at May, 2013, healthcare officials at the Salvation Army Community Rehabilitation and orthopaedic Centre Agona–Duakwa indicated that CP was the most commonly seen condition at the centre, and in their Annual project report (2014), they reported a 10% annual increase.

Increased knowledge and health awareness provided for patients/caregivers on their condition or that of their child enables them to make informed decisions concerning their health needs (Buttman & Svarst, 2002). The Consumer Protection Act (1986) contends that; each and every parent as a consumer has a right to know the condition of their child and services provided as per provisions made in the Act for them. Caregivers of children with cerebral palsy (CP) need to have information about the condition and its management, given their participation in the process of rehabilitation and care (WHO, 1993).

Review of literature with regards to parental knowledge on cerebral palsy such as the evaluation of the responses of intervention on parental knowledge regarding CP shows that most parents of children with CP lack the rudimentary knowledge regarding the condition - its causation, prognosis, treatment modalities and the result. This can be attributed to provision of very little information from treating physicians, nurses, and therapists, and have many demands about the condition, which have a tendency to remain unanswered (Huang, Kellett, & John, 2010; Karande, Patil, & Kulkarni, 2008; Ribeiro, Barbosa, & Porto, 2011).

Sen and Yurtserver (2007) maintains that this lack of educational and counselling activities to improve parental knowledge, impedes confidence with the process of decision making thereby interfering with the process of rehabilitation, and resulting in poor treatment outcomes. Therefore, there is the need to provide information about the condition for which caregivers are seeking help. A study by Moura, Ribas, Picinini, et al., (2004) to gauge the knowledge of parents about child development in typical children observed that parents who had better knowledge about the stages of their child's development could take better care of their children. And this positively affected the child's development. Their findings could be true for caregivers of children with CP. In another study Miller, Colligan, and Colver (2003) used focused interviews with 13 families selected by purposive sampling to confirm if information held on a register of children with cerebral palsy was not being made available to contributing families. And that if the existence and purpose of the register was not sufficiently understood. They found that many parents would like more information about the data on registers which include their child. They would also like to be more involved in the design of the register and its reports, but there were practical difficulties in making time available for such activity. Miller et al. concluded that registers of children with uncommon conditions can also empower parents by fully involving parents in ways suggested by this study. The purpose of the current study is not very different from the purpose of the study under review, however establishing the outcome of the current study is necessary given the dissimilarity of the context of the two studies.

Arora, Aggarwal, and Mittal (2014) in an uncontrolled interventional trial evaluated the parental knowledge of CP and assessed the impact of an educational programme on it. The study findings indicated that, initially, none of the parents knew the correct name of their child's health condition, but afterwards, 45.3% could name it. Also there appeared to be significant improvement in the knowledge of parents after viewing the film with regard to (a) knowing the cause of CP, (b) knowing that motor involvement was predominant in CP, (c) knowledge regarding management of the condition, and (d) knowledge about special schooling as compared to previous status of parental knowledge. Change in knowledge was found unrelated to socioeconomic or educational status. Majority (94.3%) rather found the film useful and 96.2% learned how they could help in the management of their children. Arora et al. concluded that parental knowledge of CP is inadequate which can be improved by incorporating such educational programmes in special clinics to improve management. With a similar focus of finding out parental knowledge about cerebral palsy in both the current study and the study under review, the current will collect data using purely qualitative method unlike the method under review, hence the need to establish the result of the current study.

2.6.1.1. Caregiver compliance

Few studies on parent compliance were found in the literature, with several studies reported on patient compliance. Poor understanding of the condition of a patient or of the child by caregivers and the required treatment regimes can result in non-compliance to treatment schedules by patients/caregivers (Buttman, et. al., 2002). WHO (2002) however defined compliance as the degree to which a person's conduct match up with established recommendations from a healthcare provider. It also denotes the desire of patients to participate fully with the medication and their positive attitude towards the treatment as well as collaborating with their health care provider within therapeutic services.

According to Walker (1995), patient's beliefs about efficiency of a particular treatment or service may relate to the patient/parent’s understanding of their (or the child's) condition. Walker further maintained that, it is important for the physiotherapist to agree upon the diagnosis and treatment with the patient or parent. Also, the researcher affirmed that patient-therapist relationship is among the most important factors that influence patient compliance. Even though many parents may have slight knowledge of the principles of diagnosis and treatment, the quality of the relationship becomes the main source of information available to the parent about the physiotherapist's skills. For caregivers of children with physical disabilities, their involvement in home base therapy is crucial for successful treatment interventions. Additionally, the active participation of parents during these activities has confirmed positive effects on the children’s outcomes. For example gains in motor skill attainment (Hoare, Imms, Villanueva, Rawicki, Matyas, & Carey, 2013).

Lillo-Navarro, Medina – Mirapeix, et al. (2015) conducted a qualitative study using focus groups and a modified grounded theory approach to find out how parents perception of the characteristics of home exercise programs and physiotherapists’ teaching styles influence compliance. The participants in the study were mainly parents of children with physical disabilities who had been prescribed a home exercise program by physiotherapists. The findings were that home exercise programs in young children with physical disabilities were identified with key themes related to compliance namely, the characteristics of the home exercise program, and the characteristics of the physiotherapist’s teaching style. In the first theme, the participants described their experiences regarding their preference for exercises, the amount of time spent performing the exercises, the effect of the exercises on the family's relationships, and any sense of related burden. In the second theme, participants revealed that they complied better to prescribed exercises when their physiotherapist made an effort to build their confidence in the exercises, helped the parents to incorporate the home exercise program into their daily routine, provided incentives and increased motivation. The authors concluded that the parents perceived that their children's compliance to home-based exercises, which were supervised by the parents, was more successful when the physiotherapist's style and the content of the exercise program were positively experienced. These findings revealed issues which should be considered when prescribing home exercise programs to children with physical disabilities. Notwithstanding the methodological similarities between the Lillo-Navarro et al. study and the current study, instituting the outcome of the current in relation to how provision of information can influence compliance with home based therapy will be noteworthy.

2.6.2. Role of the Rehabilitation Personnel (Physiotherapist) in rehabilitation

The ultimate aim of rehabilitation is for the patient to experience a normal life as early as possible, and rehabilitation does not stop at discharge from the hospital but also continues after the patient has returned to his/her home. Each professional on the rehabilitation team, consisting of physiotherapists, occupational therapists, speech language pathologists and other paraprofessionals, plays an essential role in the rehabilitation process by imparting appropriate handling skills to family and carers to ensure that patients transition into their daily routines (Long, Kneafsey, & Ryan, 2003; Sheeba Kauser, 2014). According to Backheit et al. (2001), in the UK, physiotherapist, psychologist, paediatrician, occupational therapist, speech and language therapist, a nurse and an orthopaedic surgeon form the core team for rehabilitation, and each of the team members has a responsibility to liaise and make each other aware of what they need to know and do for the child. The physiotherapists have an additional role of receiving those referred to them as well as making referrals to the appropriate members of the team, if required. Most developing countries are, however, lacking in personnel with such skills, and Ghana is no exception (Miles & Frizzell, 1990).

Levitt and Goldschmied (1990) state that rehabilitation personnel, such as physiotherapists are anticipated not only to treat people, but also to communicate and advice others in the course of their work. Physiotherapists working with parents must teach parents, relatives and other carers on how to reinforce therapy, making physiotherapy services at the early stages a vital means of supporting the parents/caregivers in their management of children with CP and as the patient/child become older. Backheit et al. (2001) characterized the roles of the physiotherapists in the management of children with CP to include provision of therapy to improve posture and mobility, the use of strategies to try and prevent deformities, the provision of mobility aids, sensory stimulation and support of the carers. The researchers elaborating on the important tasks performed by physiotherapist as a member of the rehabilitation team involved in managing children with CP, further emphasized that the physiotherapist should work as part of the multi-disciplinary team involved in the management of the children with CP. Flett (2003) included definition of the child’s disability, performing a baseline functional and biomechanical assessment, providing mobility aids/ therapy/castings or ortheoses and providing targeted motor training or exercises for the parents or carers to implement.

Moreover, Bhatia and Joseph (2001) in their review of 100 children in rural India recognized the significance of physiotherapists performing a comprehensive assessment of all children with CP prior to the physiotherapy management. The study findings were that 82 percent had one or more associated disabilities with at least one associated disability not being recognized at referral in 43 per cent of the children. Concluding that physiotherapist's assessment therefore, helps in detecting even those accompanying disabilities in order to achieve effective rehabilitation.

Anderson and Venter (1997), and Miles and Frizzell (1990) maintain that, caregivers may be likely to form feasible expectations for each child if appropriate explanations on diagnosis is provided them. For example, Miles and Frizzell discussed with caregivers to describe the select activity, before the caregiver is taken through the learning and handling techniques as they demonstrated the use of goal oriented problem based approach in Pakistan. They commended it as an effective way of managing many patients in a situation where there is a dearth of trained rehabilitation personnel. They further suggested that caregivers be allowed to rehearse the activity repetitively until they are comfortable and confident enough to carry on autonomously at home, again, with an unending direction and reaction from rehabilitation personnel. Caregivers however were found to have reported the use of low cost corrective aids coupled with the handling techniques taught them very useful and helpful in the everyday home care for the child. The use of corner seats and standing frames, emphasizing improvisation but where possible to avoid delay and to change the idea that 'special apparatus' are the key to success was also recommended.

Meanwhile, Chiarello, and Palisano (1998) mentioned encouragement to home-based child-parent interaction by physiotherapists as an important way of contributing to the child's development. These can be promoted by designing interaction programmes to guide parents in understanding and responding to their child's behaviour, interests and needs. Such interaction involves the maternal use of verbal and non-verbal controls to lead her child's behaviour during interactions such as play, feeding and responding to behaviours exhibited by the child. Chiarello and Palisano again observed that, the home environment fosters natural use of skills by providing the natural cues and reinforcement for the parent/caregiver and the child. Accomplishing all these roles effectively is not however, an easy task. To buttress the issues, Miles and Frizzell (1990) emphasized that the effective implementation of the physiotherapist's role requires the therapist to be well - informed, capable in teaching and communication skills, and if possible, have supplementary training in paediatrics. As well as increasing demand on the physiotherapist to have patience and precise interest in children with CP, given the complex and trying nature of CP as condition with slow progress in improvement.

The care and management of children with CP, needs to be based on a goal oriented, problem- solving approach involving a core team as well as the discussing and negotiating with the caregivers and the child the goals of the treatment as emphasized by (Backheit et al. 2001). Aside the emphasis placed on the roles of the physiotherapist as a member of the rehabilitation team, caregiver education and counselling were also found to be cornerstones for effective management and patient (caregiver) care in diverse twigs of contemporary treatment. It has been seen that effective patient (caregiver) education and counselling can improve treatment outcome as well as patient (caregiver) satisfaction in a number of conditions like hypertension, arthritis, asthma, rheumatoid arthritis, etc., hence the need for the provision of rehabilitation counselling (Cabana & Le, 2005; Schroeder, Fahey, & Ebrahim, 2004).

The problem of having very young children receiving the rehabilitation services has been documented in literature. For example, Becker (1985) and Schraa, and Dirks (1982) maintained that rehabilitation counselling is more of a challenge as the patient is sometimes too young to verbalize his or her symptoms and complaints and may not be able to take care of him or herself. In such instances, the duty falls on the caregivers who must innately understand the needs of the child and respond accordingly. The situation is often further complicated in cases where the child has certain special needs or is either abandoned or orphaned and thus may not have an attentive caregiver at all times.

However, despite this challenges, the author's again contended that patient education and counselling have become equally more important in the context of rehabilitation practice because along with the various treatment modalities, the patient (caregiver) often needs to comprehend and comply with particular do's and don'ts which help in quick recovery, prolonged remission as well as avoid exacerbations. They further remarked that, patient (child) and their caregivers can have a tremendous positive impact on the final treatment outcome in spite of the few moments spent in educating and counselling them (Becker,1985).

In a study by Deb, Dhār, and Parikh (2015) to determine the role of patient (caregiver) education and counselling in paediatric dermatology practice, found that effective treatment and management of any dermatoses is dependent not just on simple prescription of medicines to a patient but also, there is the need for the provision of adequate education and counselling which are equally important when it comes to the holistic management of a disease. The findings also showed that, it improves patient compliance as well as satisfaction with any treatment and as well improves the doctor - patient (caregiver) relationship. It is also importance when it comes to paediatric dermatology since patients are young children who can neither verbalize their discomfort nor keep to the treatment prescribed, and are often completely dependent on their caregivers. The outcome of this study reaffirms the importance of parent education and counselling in the rehabilitation process. Attempts were made to establish similar outcomes in my study.

2.6.3. Family-Centred Practices

Evolution of service provision for children with disabilities and their families have shifted to a more family centred approach namely(a) emphasis on partnership between parents and service providers, (b) family role in decision-making about their child, and (c) parents as the specialists on their child's health abilities and needs (Rosenbaum, King, Law, King, & Evans, 1998). Crais, Roy, and Free (2006) believes family-centred practice primarily emphasize on the parents or the caregivers in decision-making and care giving, as they play a major role in early intervention. The role of the rehabilitation personnel in the field of paediatrics has shifted from client (child) centred practice to family centred practice even with careful consideration of the clients' perspective having become part of the clinical decision-making process (Crais et al. 2006). Rosenbaum et al., (1998) explained that the guiding principles of family centred practice (FCP) are: (a) providing opportunities to caregivers in decision-making for their child, (b) entrusting parents with the ultimate responsibility for the care of their children, (c) treating each family member with respect (as individuals), (d) considering the needs of all family members, (e) and encouraging the involvement of all family members.

Law, Hanna, King, et.al. (2003) suggested that knowledge about factors influencing service delivery can be used to improve the satisfaction of a family's experiences with service delivery within the context of children's rehabilitation services. As a consequence, service providers should exhibit particular behaviours that respect and support families and improve their cooperation with families. These behaviours, according to Law and his colleagues, together with other factors such as number of services required, are thought to influence parents' perceptions of care and satisfaction with service. Several studies (e.g. Rosenbaum et al., 1998), have shown that FCP emphasizes working in partnership with families and also, providing FCP is interrelated with improvements in parents' satisfaction with services, decreased parental stress, and positive child outcomes.

The literature also addresses factors that are critical to family satisfaction about services their child receives. Examples of those critical factors were reported by Dunst and Trivette (1996), Hasnat and Graves (2000), and King, Cathers, King and Rosenbaum (2001). For instance, these authors found the process and structure of services as the two characteristics of service delivery that appear to influence a family's perceptions of FCP and their satisfaction. King, Rosenbaum and King (2004) again contended that family - centred practices (FCP) is at the centre of care. It has become an extensively accepted way to place the child's progress and needs within the context of their family and community. FCP consist of values that recognize each family as unique and constant in the child's life**.** Methodological reviews have linked FCP to greater family satisfaction, stronger self-efficacy, greater perceptions of the helpfulness of services (Dunst, Trivette &. Hamby, 2007). As well as better functional abilities in children with disabilities (Baker, Haines, Yost, et al., 2012). The interpersonal aspects of service delivery process in exactness have been shown in many researches, as the most significant to families. King et al. (1996) showed that three factors; namely, information exchange, respectful and supportive care, and partnership/enabling, increase parental satisfaction, with exchange of information having the strongest association with satisfaction. The findings of the King et al. study were substantiated by another study conducted by Baine, Rosenbaum & King (1995). In that study, 80 parents of children with diabetes mellitus and 45 parents of children with cystic fibrosis identified the most significant issues of service delivery process for the children. The parents in that study rated continuity and consistency of service providers over time, parent participation, provision of information, and availability of care as the most important aspects of caregiving.

In another study by Garwick and others (1998), which surveyed the opinions of 63 families caring for a disabled member, the participating parents pointed out that families placed emphasis on individualized care, provision of information, and inclusion of family in care planning and delivery. Specifically, the authors concluded that they considered the parents' responses to be the most significant aspects of the service delivery process for children with disabilities. Van Riper (1999) observed that families' beliefs that service provider relations were more family centred are allied with better satisfaction and greater intent to seek help from health care providers. In his study that involved 89 families of children with Down syndrome, Van Riper confirmed that satisfaction with care is related with less discrepancy between mothers' ultimate family service provider interactions and the real nature of these interactions. Greater parental satisfaction has been linked with information sharing and interpersonal communication between parents and their service provider (rehabilitation worker). With several other researches indicating that the provision of FCP is linked with higher levels of parent satisfaction with service (King et al. 1999; Van Riper 1999), King and his colleagues established that respectful and supportive care was connected with higher parent satisfaction with children's rehabilitation services. Most importantly, providing information about the child's disability and service availability, and interpersonal communication amongst parents and service providers have been found to have a noteworthy effect on parents' satisfaction (Hasnat & Graves, 2000; Knafl, Breitmayer, Gallo & Zoeller, 1992; Stallard & Lenton, 1993).

The organizational structure within the professional service delivery outfit has been cited as a critical factor that affects parental satisfaction. For instance, King et. al., (2001) found that parents who were less satisfied with their children's rehabilitation services felt dissatisfied with the structure and process of service delivery, especially, access to care. This could be attributed to availability of very little information about the effect of the structural characteristics or culture of an organization on parent perceptions of service and satisfaction. In another study that involved 131 paediatric emergency service providers, Hemmelgarn, Glisson and Dukes (2001) examine the importance of the organizational culture and climate in measuring the level of emphasis on the provision of emotional support provided to families of children receiving emergency care. The authors found that emphasis on provision of emotional support of the service providers was directly related to the organizational culture of the emergency room.

Another study conducted by Law et. al., (2003) examined factors that are most important in determining parent perceptions of the family centeredness of care and parent satisfaction with service. A cross-sectional survey was completed by 494 parents, 324 service providers, and 15 CEOs from 16 organizations delivering children's rehabilitation services. The researchers found that the principal determinants of parent satisfaction with services are the family-centred culture at the organization and parent perceptions of FCP. Parent satisfaction with services was also influenced by the number of places where services were received and the number of health and development problems experienced by their child. It was concluded that parent satisfaction with services is strongly influenced by the perception that services are more family centred, fewer places where services were received, and fewer health and development problems for their child. The purpose of this study is not different from the current study as the current study seeks to find out how family centred practice acts as enabling tool to achieving caregiver satisfaction.

In India, Gupta, Mehrotra, and Mehrotra (2012) and Pooni, Singh, Bains, et al. (2013) concluded that, whereas studies have explored perceptions of parents who have a child with disability, the perceptions of paediatric physiotherapists about their practice and the barriers and facilitators to family-centred care have not been examined. Also, Vajravelu1 and Solomon (2013) studied paediatric physiotherapists' perceptions of the barriers and facilitators to family-centred practices in home settings in Salem city in southern India. The researchers conducted semi-structured telephone interviews with a convenience sample of 5 paediatric physiotherapists who offered treatment in the home setting in a phenomenological research design. Open coding analysis revealed themes that were broadly categorized into barriers and facilitators to family-centred paediatric physiotherapy practice in those settings. The researchers found that the physiotherapists identified several barriers, including educational status, frustrated family members, protective family members, cultural beliefs and external influences. Active participation of family members was perceived as a facilitator to family-centred practice. It was concluded that paediatric physiotherapists needed to have better understanding of parental attitudes, and family culture and beliefs, in order to improve the physiotherapist-family relationship and maximize the outcome for children. Although, the target population for the current study was not similar to those in the study under review, it will be important to find out if the perceptions of caregivers about family centred practices will help in identifying barriers to effective service delivery, so that both service providers and caregivers can collaborate on facilitating treatment options for the children.

Saloojee, Rosenbaum and Stewart (2011) in a cross-sectional descriptive study to identify key components of an appropriate rehabilitation service which would meet the needs and expectations of children with CP and their caregivers at SA public sector hospitals. The findings were that caregivers' perceptions of family-centred behaviours; the way the therapists talked to the caregivers, explained what they are doing during therapy made, providing a caring atmosphere, given suggestions and ideas or things to do at home between visits to the hospital made caregivers feel that they were doing a good job and that they gained something from every session. Family-centred behaviours which caregivers perceived in an unfavourable light were insufficient opportunities for the whole family to obtain information, insufficient advice on how to get information or contact other parents; caregivers did not feel that they were given opportunities to make decisions about treatment and that treatment choices were not explained to them.

Even though, this study used a cross-sectional descriptive study using a minimum convenience sample size of 220 of caregivers, this current study will consider a smaller number in a case study. The context of this study and that of the current study is a similarity that cannot be overlooked. Another divergence is that, the current study will try to look at the perception that caregivers have about FCP and not to determine components of an appropriate rehabilitation service which would meet the needs of children with CP and their caregivers at the Agona Duakwa community rehabilitation centre.

Jeglinsky, Autti-Rämö, and Brogren Carlberg (2011) studied the degree to which parents experience the service as being family-centred and to which extent the service providers experience their service provision as family-centred. A translated version of The Measure of Processes of Care 20 (MPOC-20) questionnaire was used to evaluate parents' experience of FCS, and a Measures of Processes of Care for Service Providers (MPOCSP) questionnaire was used to evaluate the FCS provided by professionals. The results revealed that written information about the child's condition, the possibility to choose when to receive information, and contact with other families in the same situation are areas in need of improvement and that providing general information is a challenge for all service providers. It will seemingly be interesting to find out the extent to which parents feel services provided to their children with cerebral palsy at Salvation Army Community Rehabilitation and orthopaedic Centre Agona–Duakwa as being centric to family practice.

2.6.3.1. Support for caregivers

Cerebral palsy, amid the long-lasting conditions that directly impact children, has been found as a singular cause of stress consisting of a stimulating tasks in meeting the needs of children with CP - as a result of the extreme severity of gross motor function limitations. This affects families by changing numerous aspects of their lives, such as time, finance, labour, family and social relationships. The distresses experienced by affected family members becomes detrimental to their physical and psychological health (Benedict, Patz, Maenneret al., 2010; Guyard, Fauconnier, Mermet, & Cans, 2010; Wijesinghe, Fonseka, & Hewage, 2013).

Mancini, Fuiza, Rebelo, et al., (2002), posits that caregivers are primarily in charge for inspiring the child with CP to become independent in activities of daily living. Many parents put leisure activities away and have a more limited number of friend's because of the severe nature of motor impairment requiring the maximum level of support to perform tasks for children with CP. Social support systems are considered to be the organization of relationships between a group of people that are snarled by affective bonds, a point where subjective and objective interactions take place, revolving systems into actual units (Sluzki, 2010).

With further incitements toward these development, caregivers in their pursuit of adapting to the process of the demanding care needs resultant from such diseases, seek services such as medical, rehabilitation, education and community services and these services are confronted with the responsibility of meeting the needs of children with cerebral palsy and supporting their families (Almasri, Palisano, Dunst, Chiarello, O'Neil, & Polansky, 2011). Milbrath, Siqueira, Amestoy, and Trindade (2011) believe with the increasing need for family members to review emerging daily methods, concerning the new and uncommon experiences of raising a child with such conditions. Caregivers must share responsibilities, experienced fears, anxieties and uncertainties. Therefore, there comes the need for social support systems to help in the adaptation process of improving the child's care and wellbeing. This author's further contend that the child's family requires some sort of support further than the practical care processes with the child, explicitly able to cater for the interdependence (Milbrath et.al, 2011). Backheit et al.(2001) further proposed that aiding parents to meet with others who have a child with CP through self-help groups, other parents at the clinic and voluntary organizations could be a another way to help parents come in terms with the diagnosis.

Matsukura, Marturano, and Oishi, (2007) believed that amidst traumatic events, social support is a vital predictor of parental adjustment, as well as a shielding factor to help families through the process of adapting with generated stages of strain connected with the birth of a disabled child. Sipal, Schuengel, Voorman, et al. (2010) found overwrought family relations and social seclusions as a major cause of strain on parent resulting from limited mobility in children with CP. This leads to either diminished or intensified strain depending on the family homeostasis. In this context, the researcher sought to understand what support services caregivers receive from the Salvation Army Community Rehabilitation and orthopaedic Centre Agona–Duakwa and how enabling this is to the utilization of services. What satisfaction it gives them as caregivers which can favour coping with the challenges faced by delivering care to children with CP (Butcher, Wind & Bouma, 2008). Moore, Allegrante, Palma, et al. (2010) believes it is important to explore care and services provided to the family in order to get an understanding of how families deal with the demands of having a disabled child and on what kind of collective support they can hinge on in their day to day living.

Pfeifer, Silva, Lopes, Matsukura, Santos, and Pinto (2013) conducted a study to describe the perception of caregivers of children with cerebral palsy (CP), concerning social support received, and to verify how the characteristics of the children (i.e. type of

CP and severity of motor impairment) and those of their caregivers (i.e. age, level of education, occupation, income and number of children) were significantly related to this perception. A total of 50 children with CP, aged between 3 and 12 years, and their respective caregivers participated in this study. Among the findings of the study were that, caregivers reported receiving support from core and extended family members (i.e. husband, mother, siblings) and friends were the most common providers of support; It was concluded that family members are the caregivers' primary source of social support and caregivers reported being satisfied with the support they received (Pfeifer et al., 2013). In another study by Dezoti, Alexandre, Freire, et al. (2015) using qualitative approach to describe the experience of the families of children with cerebral palsy concerning their social support network, 19 families of children with cerebral palsy were involve in focal group sessions. The study findings pointed out the following thematic categories - experience of the family in caring for the child with cerebral palsy, and frail social support concerning family bonds. It was concluded that the social support network of the families of children with cerebral palsy is basically comprised of family members. And that family undergoes changes in their daily life and experience unfavourable feelings, seeking in the spiritual realm the hope to cope with adversities.

2.7. Inherent Barriers to Caregiver Utilization of Rehabilitation Services

Caregivers may possibly face numerous barriers while using rehabilitation services. Some of the barriers that affect the caregiver utilization of services have been identified in a number of researches. Green (1999) conducted a study on health service utilization in broad-spectrum services and broadly categorized the barriers into environmental, social, cultural and economic and personal features of the patient or carer. Marx, Hirozawa, Soskolne, Liu, and Katz, (2001) found some agency-related obstructions/barriers in their study on explicit required services. These included waiting period before receiving the attention/therapy or appointment, the official waiting time and the attitude of the employer on truancy from work, the lost revenue during time spent at the clinic, the untimely hours/location, the travel time to and from facility and the strain in arranging an urgent and emergency care as well as the mental or expressive barriers such as the reluctance to use the services, and denial or fear of loss of concealment as the identified by other previous researchers. Gwenda, (2000), researched on groups of patients with specific conditions such as low back pain and acknowledged that patients come across both physical and psychological barriers - the access to the services, the patient's own outlook to pain, the patient's apparent attitudes to the health professionals, insufficient information on the patient's condition, limited information on available services to provide assistance coupled with cost of therapeutic proxies and health services.

On a different account, Rastall and Fashanu (2001) believed that patients with chronic conditions, who are seeking rehabilitation progressively discontinue utilizing the services as a result of a prolong stay on the wait list**.** In a study in Ghana, Tolhurst and Nyonator (2006) found distance travelled to health facilities, long waiting times and negative attitude of health care providers as the foremost barriers to the utilization of health care services by caregivers.

2.7.1. Caregiver – personnel Interaction

Many studies that were reviewed are on caregiver-rehabilitation personnel interactions were in relation to patients with few emphasizing on parents. However, a poor clinician-patient interaction is reported to be a barrier to utilization of health care services in Ghana and developing countries alike (Biwot, 2014). The nature of relationship between the patient-physician has transformed over time in response to the changes in healthcare delivery and is substantial to and increases patient satisfaction. Societal influences, public health programs, existing health problems, and levels of technology has been found as four factors that affect how healthcare changes occur (Servellen, 1997). Waitzkin (2000) postulates that even with the recognition that health care has undergone big changes in recent decades, less is still known about its effects on the particulars of the clinician - patient encounter and how it can influence medical outcomes (Frankel, Quill, & McDaniel, 2003).

Neumann, Edelhausa, Kreps, et al. (2010) added that effective client-provider interaction can increase the value of medical treatment and impacts on client satisfaction. Dibbelt, Schaidhammer, Fleischer, et al. (2009) recounted that perceived quality of the physician-patient interaction interrelated with long term treatment results in the rehabilitation of patients with low back pain. This is because, they provided views on their relationship with the physician and not to technical-medical factors of the care they had received. In a study by Zolnierek and DiMatteo, (2009) to meta-analyze published literature between 1949-2008 on the relationship between the physician-patient communication and treatment adherence revealed that physician-patient communication has a significant positive correlation with patient adherence with 19% higher adherence rate in patients whose physicians communicated well as compared to those whose physician communicated poorly.

Stenmar and Nordholm (1994) found that majority of the clinicians believed that the client-provider relationship was more important than the treatment procedures in their exploration of elements that physiotherapists perceived as the most important in successful treatment. Gyllensten, Gard, Salford, & Ekdahl, (1999) reported interaction skills of the expert physiotherapists lead to a positive client outcome in a different study that examined expert physiotherapists' perception of the importance of the factors that influenced the quality of the interaction in physiotherapeutic treatment. Therapeutic nurse - patient relationships have been found to be influenced by the eminence of nurse- patient communication (Edwards, Peterson, & Davies, 2006). In a study that explored patients' perception of the therapeutic effect of interpersonal interactions during hospitalization, the experience of hostile interpersonal interactions obstructed the patients' emotional and physical comfort and was perceived to lessen their prospect for recovery (Williams & Irurita, 2004). Buck, Jacoby, Baker, and Chadwick (1997) in their study on patients with epilepsy in USA found that patients who had a consistent contact with their physician about epilepsy had a superior observance than those who visited the physician haphazardly.

2.7.1.1. Communication between caregiver and personnel

Communication is distinct as "the transmission of messages between provider and patient during frontal encounters, involving messages from providers to patient and vice-versa. In healthcare it has become an enormous and vital constituent of the patient - physician relationship and for the development of the treatment plan (Roter & Hall, 1992). Tyson and Turner (2000) contended communication in rehabilitation and other exonerated settings, is essential for patients' understanding of their follow-up care and management. Good communication seemingly has become the basis of an effective interaction between healthcare professionals and patients. Patients regularly express their want for a physician who they trust, have their paramount interests in mind, and understands and takes their feelings into contemplation (Golin, Thorpe, & Di Matteo, 2007). Golin et. al. explained that prevention of misunderstandings, building trust between physicians and their patients and, above all, bringing better health outcomes have been associated with good communication in doctor-patient interactions. For instance, a variety of outcomes including compliances to treatment, reminiscence and understanding of medical advice, and health improvements have been based on good patient-doctor interactions. Contrariwise, poor communication (both verbal and nonverbal) has yielded lack of trust in the doctor-patient relationship, leading to glitches such as misconceptions or unreliable perception of the doctor's approach.

Undoubtedly, better-quality communications improve patient outcomes and satisfaction because parent satisfaction with quality of care is substantively affected by the interactive skills of the practitioner, mostly in the case of frightened parents (Lashley, Talley, Lands, & Keyserlingk, 2000). Potter, et.al. (2003) ranked communication skill as the two uppermost important qualities of a good physiotherapist in all participants in a study on the qualities of a "good physiotherapist" and the features of both good and bad client experiences in private practice emphasizing that, clients most often attributed positive experiences to effective communication followed by the quality of the service delivered. In contrast, the most common attributes of a negative experience were related to dissatisfaction with the service and poor communication on the part of the physiotherapist. Mira, Fernández-Gilino, Lorenzo (1997) establish that although the caregivers of severely ill patients saw therapists as competent, available, and polite, they found them deficient in skills for adequate communication with the patients and families. Buckman (1992) purported eye contact is gauge of active listening and a "tenet" of communication, and often a times patients perceive that physicians are not paying attention when writing as they talk. Moreover, the use of medical terms confuses and alienates the patients often leading to misunderstanding and misinterpretation. The ability of the clinician's to communicate cooperatively and with care is essential for effective and efficient routine health care; this ability becomes a vibrant support for parents and children challenged with life varying and at times life-ending disorders (Ablon, 2000). Jefferson, Bloor, Birks, Hewitt, and Bland (2013) in a study to determine the effect of physicians' gender on communication and consultation length which may in turn contribute to patient satisfaction and other outcomes systematically reviewed seven electronic databases from inception to September 2010 with no language restrictions (included MEDLINE; PsychINFO; EMBASE; CINAHL; Health Management Information Consortium; Web of Science; and ASSIA). 'Grey' literature was also searched. The findings were that, there were many conflicting outcomes reported for communication variables. Some evidence pointed that female physicians adopt a more partnership building style and spend on average 2.24 min longer with patients per consultation (95% CI 0.62–3.86) than their male colleagues. Jefferson, et. al. (2013) concluded that greater patient engagement by female doctors may reflect a more patient-centred approach, but their longer consultation times will limit the number of consultations they can provide which in turn has implications for planning and managing services. Biwot (2014) in a study to investigate factors that influence caregivers' adherence to occupational therapy service found good patient/doctor relationship as a contributing factor to enhancing compliance, with poor clinician/patient communication resulting in non- compliance.

2.7.1.2. Caregiver attitudes towards personnel

As assumed ideas, attitudes exemplify what an individual views as positive, negative, or neutral - they are encompassed from affective, behavioural, and cognitive reactions and can be changed by inducement and capability justifying attitudes as cognitive, effective, and behavioural in response to a stimulus. Similar to all inner constructs, attitudes are perceived ultimately in human responses but seemingly, research investigations has been centric to the attitudes of healthcare specialists toward disabled adults and infrequently explored attitudes of children with disabilities and their caregivers toward healthcare professionals (Cervasio & Fatata-Hall, 2013).Attitudes caregivers have towards healthcare professionals can affect the process of service utilization in caregivers of children with cerebral palsy. Backheit et al., (2001) however, pointed out that the way parents are initially informed about their child having CP, may affect parents' future rapport with the team caring for their child, and their attitudes toward their child. The authors recommended that parents should be given an explanation of the diagnosis to rule out any uncertainty about it and, and a written record entailing the key concerns discussed with the parent.

Buck et al., (1997) in their study of factors influencing compliance with antiepileptic drug regimens found attitude of caregivers to the health care providers as contributing factor to adherence with antiepileptic drug (AED) treatment. In a study to investigate women's accounts of interactions with health care providers during labour and delivery and to assess the implications for acceptability and utilization of maternity services in Ghana. D'Ambruoso, Abbey, and Hussein (2005) used in-depth interviews and two focus group discussions with women of reproductive age who had delivered in the past five years in the Greater Accra Region. They gathered data on women's perceptions and experiences of care in terms of factors that influenced place of delivery, satisfaction with services, expectations of care and whether they would recommend services. The findings were that attitudes was a factor with significant impact on suitability and use of services, in the sense that it is the foremost imprint the caregiver forms about the clinician either in a negative or positive way, affecting how the patient reacts to treatment.

2.8. Summary of literature review

Generally, despite the indication given by the Ministry of Health (2006) in their five-year strategic plan that the patient's satisfaction is prime to health service delivery and quality care, an extensive search for empirical evidence pivoted around the objectives of the study showed that a number of studies such as Aduo-Adjei's (2015) study to compare patient's satisfaction with quality healthcare in two University hospitals in Ghana (University of Cape Coast hospital and university of Ghana), Owusu-Frimpong, Nwankwo and Dason (2010), study of patients' satisfaction with access to private and public healthcare centres in London, Atinga, Abekah-Nkrumah and Domfeh (2011), examination of the predictors of patients satisfaction with the quality of healthcare in two hospitals located in northern Ghana, and Peprah (2014) study to assess patients satisfaction using the SERVQUAL at Sunyani Regional Hospital in Ghana were studies conducted to evaluate patient satisfaction and quality healthcare delivery in hospitals in Ghana, characterized with challenges of scanty research and a variety of contextual influences that must be well assumed (Aduo-Adjei, 2015; Best & Neuhauser, 2011).

However, no single study has been conducted on caregiver satisfaction with rehabilitation services; in terms of caregiver prior expectations, caregiver enabling factors and the caregiver inherent barriers to utilization of rehabilitation studies that might influence caregiver satisfaction in a national or private rehabilitation Centre in Ghana, irrespective of it role in the provision primary health care services to persons with disabilities. Relative to the outcomes of the above reviewed empirical works in Ghana on patient satisfaction, it is important to establish the outcome of the current study on caregiver satisfaction. The uniqueness of this study however, is that, it is positioned to consider the gap in research of caregiver satisfaction with rehabilitation services in a private rehabilitation Centre (Salvation army Community Rehabilitation and orthopaedic Centre, Agona–Duakwa), which has evolved over the past few decades in the provision of primary healthcare services (rehabilitation) for children with cerebral palsy and disability alike in Ghana.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. Introduction

This chapter presents the methodology for the study. The following sub headings are covered: research method, research design, population, sample size sampling techniques, research setting, procedure for data collection, instrumentation, reliability, validity and data analysis.

3.2. Research Method

Locating one's research in a precise paradigm provides the structural basis for how the inquiry is framed. A research problem starting with ‘what’ or ‘how’, that prerequisite in- depth exploration in order to explain a topic such as the views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy is deemed appropriate for a qualitative research paradigm, and this is in line with Creswell (1998) assertion that the nature of the research problem and the topic that needs to be explored defines what approach might be chosen. Furthermore, Lincoln and Guba (1985) opined that in qualitative research it is the readers’ duty to appraise the context of the findings and decide whether generalization to their case is applicable (Lincoln & Guba 1985, Cohen, Manion & Morrison 2007). Moll (2012) also posits that a paradigm defines a set of assumptions that describe a specific way of viewing reality and informs the kind of approaches that will be appropriate to use for data collection and analysis.

The qualitative paradigm was used as a method of enquiry, because of its merits to the researchers' interest in collecting purely qualitative data, with emphasis on understanding the caregivers' views of satisfaction through examining closely their difference of opinion and schedules to bring out the veracity of their caregiving roles as they experienced them (Maykut & Morehouse, 1994). The researcher also found it convenient to use qualitative method on account of effectiveness with studies of small number of participants (Creswell, 2002). Creswell further added that qualitative research can be a useful tool for collecting in-depth information about a phenomenon from participants in a study and count solely on the opinions of participants (Creswell, 2002). This gives a strong justification for the use of the qualitative paradigm, because in this study, an attempt will be made to explain the phenomenon of views of caregivers on satisfaction only from the viewpoints of the target participants using thematic analysis.

Denzin and Lincoln (1994) again purported that qualitative research method also allows for depiction of challenging instants in the individual's life, hence the qualitative approach was used to describe the prior expectations, the enabling factors to utilization, the inherent barriers to utilization that constitute reported satisfaction attained by caregivers of children with CP in the course of accessing rehabilitation services at Agona – Duakwa Salvation Army Community Rehabilitation and Orthopaedic Centre.

Furthermore, explaining the phenomenon of caregiver satisfaction from the standpoint of the respondents was apparently flexible. This could be attributed to the flexible nature of most qualitative designs. Nonetheless, this does not render the said approach less effective, because it is a valid form of research in comparison to the quantitative methods, as every study or research may be subject to a design or a combination of the two designs (Yin, 2003; English & English, 1958).

3.3. Research design

The research design adopted for this study was a case study. The design of a research study entails the overall approach and explanation of how the research study was carried out, with whom and where (De Vos & Fouche, 1998). This was done with recognition that, the experience of caring for children with cerebral palsy is unique for each and every caregiver caring for a child with the same condition, which was of relevance to the study of views of caregivers on satisfaction. Furthermore, case studies provide a unique example of real people in real situations, enabling readers to understand ideas more clearly than simply presenting them with abstract theories or principles. Without doubt, a case study enables readers to have an understanding of how thoughts and intellectual doctrines fit together as well as infiltrate situations with means that are not always apt to numerical analysis (Acheampong, 2008; Robson, 2002). The strength of case studies is that they observe effects in real contexts, recognizing that context is a powerful determinant of both causes and effects (Acheampong, 2008; Robson, 2002). Therefore, this design was appropriate for finding out the subjective experiences of the individual caregivers in their real context.

Sturman (1999) argued that a distinguishing feature of case studies is that human systems have a wholeness or integrity to them rather than being a loose connection of traits, necessitating in depth investigation. However, case study was also ideal to use in selecting the group of interest or concern (caregivers of children with cerebral palsy), as it allowed for the study of the case in its context (Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa) and collect information using in- depth interviews for development of detailed and interactive knowledge about a small number of related cases on caregivers of children with cerebral palsy (Robson, 2003). Robson further contends that, case study is not a weak experimental design, but a principally different approach in its own rights. On the basis of Robson's argument, the choice to use a case study design for this research is justified, because this study used in-depth interviews as a method for collecting data for a study of this kind which seeks to unravel what prior expectations, enabling factors and inherent barriers caregivers of children with CP come into contact with or experience, that might predict the reported views on satisfaction attain. On the whole, the design was appropriate as it allowed the researcher to determine key themes in the data for analysis, and appropriately within the qualitative paradigm (Yin, 2003).

3.4. Research Setting

Meeting a group of individuals in the context of their own natural situation to be able to comprehend their experiences is key in any research study (Maykut & Morehouse, 1994; Irochu-Omare, 2004). This study was conducted at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa in the central region of Ghana, a natural ecology where caregivers of children with CP are provided rehabilitation services. The community rehabilitation and orthopaedic centre is both an inpatient (a bed capacity of 10 patients) and outpatient facility attached to the Agona –Duakwa district hospital in the central region of Ghana. Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa is among the two rehabilitation centres of the Salvation Army championing for the integration of people with disabilities since 1986.

Currently, the project is under the direction of Major Heather Craig (Director of Medical, Social and Community Services) whiles Mr. Ato Hayford is the local Administrator (Manager) and is responsible for coordinating all the rehabilitation activities at Agona - Duakwa territory. Compared to clinics and community health Centre's in the neighbouring districts, the centre is equitably well equipped.

The services provided are not for free and caregivers have to pay for the assistive devices, which they may need for their children. However, some consideration and arrangements are put in place for the needy and vulnerable as the centre foots half of the bills and give caregivers time to pay the remaining half. For the past three decades, the Centre has not had a full-time physiotherapist but a visiting assistant physiotherapist who visited twice a week, thereby reducing the quantity and time of rehabilitation services being provided at the centre. Most caregivers of children with CP who visit the Centre for rehabilitation services go there through referrals from private sector with some visiting the Centre on self-referral upon discovery of the existence and availability of these rehabilitation services at the Centre, either through friends or families who are accessing services at the centre or through outreach awareness programmes in the community or the media (Annual Project Report, 2014).

3.5. Population

The population for the study comprised of all caregivers of children with cerebral palsy of the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona –

Duakwa. These caregivers continued to receive services at the Centre (a total of 199 caregivers) with 38 reported cases and 161 review cases as at the third quarter of 2016. Creswell (2005) opines that population is a group of individuals with same characteristics, either small or large depending on which group the researcher would like to study within this wide range of population. However, Avoke (2005) refers to population as the group of interest to the researcher, and this population exhibits characteristics that are of interest to the researcher, therefore a justified population for the study.

3.6. Sample size

Six (6) caregivers were purposively selected to participate in the study. The sample consisted of three (3) inpatient caregivers and three (3) outpatient caregivers of children with CP. These were caregivers who had been visiting the centre routinely for some time. Two of them had visited the centre since 2010, two for one year, eleven months and the other two had attended since September 2015. This selection of a sample size from the population is justified as it was not the intention of the researcher to study the entire population. Moll (2012) propose that sample size, should be apprehensive with providing satisfactory data, explore any variances and similarities between accounts, while at the same time not producing an excessive and unmanageable amount of data. Consequently, a small sample size was generally deemed acceptable since characteristics of the population can be drawn from a small sample, if carefully selected. Likewise, caregivers were found to best describe their prior expectations, enabling factors, inherent barriers and satisfaction as they experience it, and not by observers (Oswald et al., 1998), hence a justification for the sample size for the study.

3.7. Sampling technique

The researcher used purposive sampling to select the six (6) caregivers for the study from the larger population. Purposive sampling was considered ideal as it permitted the researcher to intently select the site and individuals for the study and learn or understand the principal phenomenon or their lived experiences (Creswell, 2003). And to also make sure that the sample was composed of participants with usual attributes of the caregiver population (De Vos, 2001).

Furthermore, Cohen and Manion (2003) were of the view that, purposive sampling allow for the researcher to select a small number for a case study or a series of cases as it does not represent any group apart from itself, and it does not seek to generalize about the wider population. These features and typical attributes elaborated on by the aforementioned authors, directed the devising of criteria for choosing the six (6) sampled comprising of three(3) inpatient and three (3) outpatient participating caregivers of children with CP. These were caregivers receiving rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. This was done based on evidence from the register that the child and caregiver had been visiting the Centre and were registered service user. The caregiver and child must have kept to a minimum of ten (10) treatment/review appointments or more in previous years and in the early quarters of 2016. And must have gained ample experience, and is willing and confirmed availability to partake in the study. This was confirmed from the appointment and turnout registers at the centre, which also showed an average registered turnout of not less than 17 records of children with CP and their caregivers each month including both old and new cases.

3.8. Instrumentation

In obtaining data for the study, a self – constructed semi- structured interview guide was used in collecting data for the study because the methodological underpinning used in this study lends itself to this type of instrument. The semi-structured interview guides was chosen because it permitted open-ended exploration of the topics as well as elicit responses that would be quoted in the exact words of the respondents as informed by (Creswell, 2007). Semi structured interviews offered the possibility of modifying a line of enquiry as well as follow up responses. This instrument as expatiated on was carefully chosen bearing in mind the type of research paradigm that best suits it. It was also convenient for me to use this instrument because of the direct face-to-face interactions I intended to have with participants. Also, by using this approach, I was able to make specification of the context of reported views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy at the centre rather than making a generalization (Creswell, 2007).

3.8.1. Semi-structured interview guide

A self-developed semi-structured interview guide on caregivers' satisfaction was used to collect data for the study. Four expansive themes were used (see appendix A). The items in the guide sought to draw out on the holistic nature of caregivers' reported satisfaction from the rehabilitation services provided to their children with CP, in terms of the identified variables. The questions in the interview guide covered the following themes:

- Caregiver's prior expectations.

- Enabling factors to caregivers service utilization.
- Barriers encountered by caregivers.
- Caregivers' satisfaction from services.

Semi structured interview was used in six separate in-depth interviews. The semi - structured nature of the interview allowed for natural expression of views by participants as the items on the guide did not elicit for a yes or no answer (Robson, 2003). Robson points out further that, semi structured interviews allow the interviewer to set questions ahead of the interview, but these question are subject to modifications where the need arises or when the researcher deems appropriate. It was on this note that, an open-ended semi - structured guide was developed based on the objectives of the research topic before the interview interactions. This allowed for collecting a more comprehensive information. Furthermore, probes and prompts also proved useful in exploring and teasing out sensitive information that caregivers would not give out under normal circumstances.

3.9. Reliability and Validity of the study

3.9.1Validity of the instruments

The semi – structured interview guide was constructed to reflect the main issues in the research questions, and submitted to the principal supervisor and allowed time to crosscheck the guide for ambiguity and make other necessary corrections. Some very useful but varying suggestions emerge from the check and this aided the researcher in correcting, reframing/rewording the probes in the guide as well as sought for clarification where necessary before using it for data collection in the pilot study (Creswell, 2012). These check was also to help determine appropriateness, meaningfulness, correctness, and usefulness of any inferences drawn on the basis of data obtained through the use of the interview guide (Fraenkel & Wallen, 2006).

3.9.2. Pilot study/Pre-testing

A small study was conducted at Mephiboshet Child Development and Training Centre prior to the actual research to ascertain if the methodology, sampling, instruments and analysis are standard and appropriate (Bless & Higson-Smith, 2000). More so, Cohen, Manion and Morrison (2003) were of the view that, pilot study aids the researcher in instituting the reliability of responses by allowing for check of clarity in questions, gaining feedback on how usable the test items are, removing vagueness in the questions, ensuring that data collected would answer the research questions and checking and addressing factors that might militate against the coding or system of classification for the analysis of collected data.

A tempora**ry** date for the pilot study was agreed upon after consent had been sought from the Director of the Mephiboshet Child Development and Training Centre to access the Centre for the pilot study. The Centre was considered suitable for the pilot study because parents of children at the Centre exhibited comparable traits to that of the intended participants for the main study. The pilot study was conducted on Friday, 23rd September, 2016 following the granting of consent from the Centre. The date was conveniently agreed on as that was a day parents were likely to be available. Prior to the set date, parent were made aware by the Centre's administration that, some of them were going to be involved in one- on -one interactions alongside the parent teacher association meeting schedule for the same date.

The pilot study involved three (3) caregivers purposively sampled by virtue of the input their responses was going to add to the reliability of the main study which was of interest to the researcher. The researcher set the tape for recording the in- depth interaction with selected caregivers with their consent. The dialogue lasted for a total of 45 minutes in approximation. The interview was conducted in Fantse as the primary language of the participating caregivers. And also because most of them could not respond in English. The researcher straightaway played back the tape recordings to each of the participants immediately after each session to ensure authenticity, at the same time the researcher gave caregivers the opportunity to make recommendations and provide feedback on the guide they responded to. This helped to identify other imperative issues that cropped up and needed to be incorporated in the guide. These issues were collaboratively studied by the researcher and supervisor to ensure that necessary corrections and revisions on interview items, which caregivers had difficulty responding to were effected prior to the actual data collection.

Achieved precision of the interview guide items was an outcome of evaluation of the pilot study that was noticeable to the researcher. As well as equipping the researcher with the necessary interview skills for the main study investigation. Reminding caregivers to communicate loudly enough for good recording, remaining focused through guiding participants from deviation and making them feel their concerns was appreciated were observations that were made and needed to be checked in the main study(Cohen, Manion & Morrison, 2003). In conclusion, there was a general reported satisfaction by the caregivers. However, some caregivers were more satisfied than others, this could be attributed to how long these caregivers had been utilizing rehabilitation services at the centre.

3.9.3. Trustworthiness

The significance of validity in any research cannot be overlooked if the viewpoints of the participants are to be duelly exemplified. However, with qualitative paradigms, validity is centric to ensuring and increasing the authenticity and trustworthiness of the study findings (Creswell, 1998). To warrant this, the researcher right after each session instantly played the tape –recording for the caregiver to have a true reflection of the proceedings, and accept full responsibilities for all the information covered in the dialogue. This is in line with the viewpoint of Robson (2003) who further comments that the tape recorder helps the interviewer and the interviewee reminisce and confirm the data gathered and for easy interpretation and analysis. This was a justified way of ensuring participant validation of recorded dialogue.

3.10. Procedure for data collection

3.10.1 Gaining access/ Ethical consideration

Before data was collected, an introductory letter was taken from the Head of Department and the Supervisor of the researcher to the management of the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. This was to seek permission from the management to allow for the conduct of the study in their facility. Permission was granted on the 5th of October to have the researcher collect data from the 17th October, 2016 - 3rd November, 2016 at exactly 9:00 am each day at the centre, after certifying to the goal, procedures and intent of the study. Creswell (2012) opines that there must be approval from the institution a researcher seeks to carry out his or her study; permission before entering a site, disturbing the site as little as possible during a study, and by viewing oneself as a "guest" at the place of study (Creswell, 2012). In this regard, I embarked on familiarization visits from the 10th - 14th of October, 2016 to create rapport with the institutional ecology. Furthermore, Creswell notes that, the permission of the people to be directly involved in the study cannot be compromised. In this respect, the potential participant permission was orally sought and they were entreated to participate in the study, following a thorough and clear education about the purpose and procedures of the research. This was done without any form of undue pressure to avoid in - prompt withdrawal from the research. Participants however, were also assured of the necessary confidentiality of their responses as well as the autonomy to opt out at any point in time if they felt like doing so (Creswell, 2012). The consent to tape-record the dialogue was sought from these caregivers with assurance of treating information they provided with utmost discretion and anonymity, away from the knowledge of the rehabilitation team working at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. They were also assured that information they provided will be used only for the purpose of the research, with items on the guide devoid of subtle language that might sound ethically wrong to the participants, hence encouraged participants to be open with their responses (Creswell, 2012; Creswell, 2007).

The time, duration and venue for conducting the interview and the mode of recording were mutually agreed upon by the researcher and the participants and confirmed for approval with the head of the facility. Having established the needed rapport and agreeing to the terms of anonymity of participants, the researcher subsequently followed up at the Centre to administer instruments in obtaining data. Interview responses was recorded and documented where appropriate. The interview interactions were held in a calm room of the Counselling Unit at the Centre. The venue was prepared in advance by the researcher and two members of staff of the Counselling Unit of the centre, who assisted with tape recording to enable the researcher focus on the responses of the participant and to facilitate the conversation, without having to continuously make field notes (Creswell, 2012; Creswell, 2007). Caregivers were again reminded about the purpose of the study, the importance of their participation in the study and the trend the dialogue would take prior to every single meeting. The caregivers were reassured of discretion to disregard their fright about giving out their individual responses to the rehabilitation team working on their child. Caregivers were also reminded of the fact that they were being tape - recorded for clarity sake. All the same, two final year Post - diploma rehabilitation students who were on internship and a co -researcher were tasked to assist in taking notes of proceedings from in-depth interactions, but with the consent of the participants.

3.10.2 Period for data collection

Three (3) weeks were used in administering the interview guide and gathering data thus; from the third week in October to the first week of November, 2016. With two (2) interviews per week lasting an hour, that is, thirty (30) minutes per session. The researcher visited the centre on Mondays and Thursdays from 10th of October, 2016 to 3rd November, 2016 (as those were the days the visiting assistant physiotherapist and her team visited the Centre as well as a meeting day for the caregivers support group). Five (5) in-depth interview were arranged with 2 outpatient and 3 inpatient caregivers which begun in October, 2016. These caregivers were coded as OPC (1 -2) and IPC (1 -3) respectively.

Schedules were made for meeting with each of the caregivers who agreed to participate and had given reassurance to avail themselves on the agreed date for the interaction. The rehabilitation team ensured the next appointment dates for the outpatient users to coincide with scheduled dates for each of them. This arrangement prior to the agreed date helped to plan and carry out the interview to which each of them had been allotted, allowing the outpatient caregivers the ample time to adjust their travel schedules and stick to their assurances. Appointment was confirmed 24 hours before the commencement of the interview**.** However, the first and second interviews were carried out on the 17th and 20th of October, 2016, the third and fourth held on 24th and 27th of October, 2016 with the fifth carried out on the 31st October and sixth was scheduled to be conducted on 3rd of November, 2016 respectively, but this could not happen due to circumstances beyond the control of the researcher.

3.11 Data analysis

The analysis of data begun with translation of responses into English using the tape recording, to the transcription of the translated data from tape - recordings that emerged out of each interview interaction. However, the researcher compared the translation in English with field notes taken by the two final year students before transcribing to be sure the data were effectively interpreted during the translation and was a true reflection of the participant’s views. And as well critique the meanings and interpretations of the translated data (Creswell, 1998). At this juncture, the transcripts from each interaction were matched through to identify the dominant themes for the analysis and discussion of the findings drawn from the transcript. These is in line with Maykut and Morehouse (1994) who believe that scrutinizing of the meaning of caregivers' words, actions and inductively developing the research findings from the data for analysis is important.

Furthermore, Miles and Huberman (1994) posit that the analysis of the qualitative data requires for reduction in information into predetermined themes, and for this reason information/data were put into themes by way of looking for similar ideas for grouping and coding them into specific categories for an enriched analysis. Adding to this, Cohen, Manion and Morrison (2003) maintained that, the coding process allowed for organization of large amount of data at the same time to determine patterns and unravel surprise themes that might be difficult to detect simply by reading a transcript or listening to the tape recordings. In this study, transcripts of data were carefully and thoroughly read through and the recordings listened to time and again, to identify the key views expressed by the participants and coded into categories reflecting on the key areas addressed in the research questions, theoretical concepts and key themes discussed in the literature review. This was coupled with attempts at explaining the data, with evidence of statements of participants to back these explanations; bearing in mind the possibility of repetition in the presentation and discussion of data. The two (2) theories – the health belief model and the expectancy value model underpinning the aim of the study were triangulated to help interpret and explain the generated data.

CHAPTER FOUR

RESULTS AND DISCUSSION OF FINDINGS

1.1 Introduction

This chapter presents the results and discussion of findings. The discussion of findings was appropriate to responding to the research questions raised and to drawing conclusion with respect to the reported views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. The researcher coded the transcribed interview data into inpatient caregivers (IPC) and outpatient caregivers (OPC). There was also a careful reading of the coded data to look for and group similar ideas into meaningful categories or themes for better analysis (Cohen, Manion & Morrison, 2003).

The main themes were; Caregiver satisfaction from services, Caregiver prior expectations, enabling factors to caregiver utilization of service and inherent barriers to caregiver utilization of service. Some sub - themes emerged from the main themes and these include caregiver-child relation, access to services, process of care, child normalization, improvement outcome, experience with services, knowledge/information, compliance, emotional support and barriers that sought to answer the problem “what are the views of caregivers on satisfaction derived from utilizing rehabilitation services for their children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa”. The presentation of results was in accord with all four research questions guiding the study and clearly listed, with verbatim expressions quoted in such a way that the language of the responding caregivers was conserved in the discussions. However, the presentation of results for each research question is accompanied by an analysis, and discussion of findings in that order.

Service quality and customer satisfaction have been related to the expectation of the service with what is actually experienced by the customer in various researches. In the same way, this discussion was based on the different but collective views and experiences caregivers gained as they utilize services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa, to bring out their reported satisfaction.

1.2 Results

Research question 1: What are the views of caregivers on satisfaction they derive from utilizing rehabilitation services for their children with CP at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?

In order to answer this research question, the respondents' responses to interview items were used. Caregivers spoke about their relationship with the child with CP and how this relation has affected their outlook to services. IPCs commented as follows;

> *"I am the grandmother, he is the child of my daughter. On the average, I think the services are okay".* (Verbatim expression of IPC 1)
>
> *"He is my nephew, a son of my elder brother. Ahhh… well it is okay".* (Verbatim expression of IPC 2)
>
> *"Am her aunty from her mother's side. Hmmm I will say the services are okay though it has not given the result I expected".* (Verbatim expression of IPC 3)

Similarly, the OPCs also remarked as follows:

> *"Am the biological mother. Very good, very very good, as you can see my child still can't sit but coming here is better than not coming at all, and as I said earlier it's all about love. If the love is there, you won't bother about ups and downs. You will*

> *appreciate everything and anything you come into contact with".* (Verbatim expression of OPC 1)
>
> *"I am his mother, and so far so good, God has been good to us".* (Verbatim expression of OPC 2)

These explanations of the kind of relationship they had with these children showed that, caregivers in most cases do not turn out to be the biological parents of children with cerebral palsy and a determinant of how satisfactory they perceived services, as they utilized services on offer at the centre.

When asked what informed their choice of Salvation Army Community Rehabilitation and Orthopaedic Centre, caregivers said;

> *"A service user who has been receiving services for her child directed me to Duakwa".* (Verbatim expression of IPC 1)
>
> *"One of the staff at the mainstream health services told us to come and that we will get help".* (Verbatim expression of IPC 2)
>
> *"A testimony of the good service by colleague of my sister at work".* (Verbatim expression of IPC 3)
>
> *"A colleague trader, who knew about Duakwa suggested to me. She said he looks very weak and light".* (Verbatim expression of OPC 1)
>
> *"My pastor and the wife, who have received services for their first child and had seen improvement recommended Duakwa".* (Verbatim expression of OPC 2)

These comments from caregivers on what informed their choice to the centre are varying. This could mean that, there are quite a number of different influences that inform choices caregivers make about services they utilize for their children with disabilities.

Caregivers expressed preference for community services to hospital services with comments such as;

> *"It was just a fruitless journey, I got tired of going to the hospital. I like community services".* (Verbatim expression of IPC 1)
>
> *"Hospital was just a waste of our time".* (Verbatim expression of IPC 2)
>
> *"Community services are the best".* (Verbatim expression of IPC 3)
> *"Community rehabilitation services is better with the exercise and everything".* (Verbatim expression of OPC 1)
>
> *"I gave birth to him at korle - bu, but the nurses still wanted me to go and be back in three months. She didn't pay attention to me at all. She told me am not the only one with a sick child so I should go. So I prefer centre service to hospital services and I have actually recommended the centre to a lot of people".*(Verbatim expression of OPC 2)

Apparently, all caregivers seem to agree to have preference for community services as against hospital services. The researcher believes this could be attributed to the negative experiences they must have had with hospital encounters.

Aside expression of preference for community services, caregivers reported a divergent opinion about the type of community services they preferred as they utilize services at Salvation Army community rehabilitation and orthopaedic centre.

> *"It's better you live here as an inpatient, because you are able to comply more with treatment regimes".* (Verbatim expression of IPC 1)
>
> *"Inpatient is the best, because transporting yourself and the child every now and then is not easy".* (Verbatim expression of IPC 2)
>
> *"Here is okay because you wouldn't have to go through the stress of taking a car here always".* (Verbatim expression of IPC 3)

However, OPCs maintained they preferred outpatient services even as they knew inpatient was ideal:

> *"Inpatient is ideal and better. All the same I prefer outpatient services because, I feel free in my own home. I am also able to do my business though it is not moving as I want it, but small small money comes in to support us. If am I here I can do all that".* (Verbatim expression of OPC 1)
>
> *"By God grace, he can sit and so I think the outpatient is okay, because he wasn't placed on admission from the beginning, so that's enough evidence that he can*

> *improve without being put on admission. The only thing left is for him to talk and walk. And I know we will get there".* (Verbatim expression of OPC 2)

These comments suggest that, even with all caregivers vouching for community services, they also had preference between what was ideal community services for them and what community services could actually work for them.

Caregivers found the rehabilitation personnel responsive, assuring and empathetic to them and their children as they utilized services on offer at the centre. Below were some comments by the IPC's:

> *"They are always willing to provide services without allowing any protocols, you are provided the necessary when it's your turn to be attended to. We were well received with a lot of respect, advice and guidance. This made me feel at ease and hope a better outcome…… and I think other caregivers got the same reception because I have not been shouted at nor see other caregivers shouted at".* (Verbatim expression of IPC 1)
>
> *They are always ready to help. They know it is their job, so you do not even have asked, they just do whatever they are to do. But sometimes because they feel we are on admission, they tend look after the outpatient before they attend to us. The personnel that I first met related in a nice way with me and my child. I felt my child was cared for with a lot of kindness and respect due every human. It really got me reflecting about the fact that I have no excuse not to care and be kind to my child if these personnel is able to do that".*(Verbatim expression of IPC 2)
>
> *"They are ready to help you when you come here and they make you feel they know what they are doing. They take their time to do what is appropriate for each child… eerrhm, if it's 15 minute for every child, it is 15 minute, nothing more nothing less".*(Verbatim expression of IPC 3)

The OPCs added that;

> *"They all showed their readiness to fulfill their responsibility to us. They received us well and counselled and encouraged us that things will get better. The necessary and individualized attention was given to each child even when the cue is long. They work with time. But I can say for other caregivers, am okay with the individualized attention given me and my child. I believe it same for all caregivers.* (Verbatim expression of OPC 1)

> *"Errrrh, they are always willing to help but one has to follow the normal procedure. They gave me and my child the appropriate care and attention. One of the personnel I talked to when I first came here encouraged me very well and told me to adhere to the medication and the exercises. She gave me confidence that things are going to change for good. My child is not a liability, he can become an important person in future and this made me to trust them. They made me know they are not the ones to make things to happen, but zeal and compliance will make the difference. There wasn't any harassment, only cordial reception as compared to the frustration I went through at korle - bu and left unattended to".* (Verbatim expression of OPC 2)

Without a doubt, all caregivers gave an impression that they appreciated the characteristics exhibited or the role played by the rehabilitation personnel as they utilize services at the centre.

1.3 Discussion of findings

Research question 1:

Caregiver Satisfaction from services

1.3.1 Caregiver/ Child relation

From the analysis of the interview responses, it was evident that caregiver-child relationship was an important factor for determining satisfaction with service, even though most caregivers were not biological parents. Stengård, Honkonen, Koivisto, and Salokangas (2000) stated that parents in general were found to be more satisfied than other caregivers who are not the biological parents. Supporting the Stengård et al. viewpoint, the OPC caregivers made remarks such as;

> *"Am the biological mother. Very good, very very good, as you can see my child still can't sit but coming here is better than not coming at all, and as I said earlier it all about love. If the love is there, you won't bother about up and downs. You will appreciate everything and anything you come into contact with".* (Verbatim expression of OPC 1)

> *"I am his mother, and so far so good, God has been good to us".* (Verbatim expression of OPC 2)

Analyzing this extract, it is apparent that caregivers who were biological parents reported more satisfaction with the services than other caregivers. Such a view point is in line with Kramer and Kipnis (1995) who opined that the characteristics of the caregiver and the care receiver coupled with the context of the caregiving situation ideally play a central role in understanding all other aspects of the caregiver's experience. And this caregiving experience could be rewarding and satisfying as most biological caregivers reported it brought their families together and help to maintain their family balance (Hooyman & Kiyak, 1999). Meanwhile, Kramer (1997) added that, within the rehabilitation process, it has resulted in expressions of greater marital satisfaction, a feeling of self-worth and a pride in ability to meet obstacles and a purpose in their lives as reported by biological caregivers.

Stengård et al. further added that, biological caregivers' satisfaction with services is strongly influenced by characteristics such as the time of the onset of condition. Consequently, the lesser satisfaction of other caregivers could be associated with the fact that they lack some experiences related to the time of the onset of condition, hence it was difficult that they could report higher satisfaction levels than biological caregivers.

Meanwhile, Connor and Adams (2003) believed that it was the love most biological caregivers had for their children that influenced the higher levels of satisfaction they reported, given the nature of the relationship with the person needing care and determinants of a satisfying experience. In this regard, biological caregiver's reportage of satisfaction is linked with the fact that, they possessed certain traits such as the love for the child that made them see the good in every situation they found themselves in, together with the child. Similarly, the blood ties and love they had was the stimulus that triggered their engagement in a health promoting behaviour as postulated in the health belief model. On the whole, the aforementioned findings prove that the satisfaction reported by caregivers is largely dependent on relationships that exist between them and children with disability. On this basis I speculate that these findings are consistent with the findings of my research because, the caregivers who were biological mothers reported more satisfaction than reported by aunties and grandmother who were providing caregiving roles.

4.3.2. Access to services

From the transcripts of the interview, it was evident from the perspective of the caregivers of the children with CP that, the choice to bring their children to the centre to access services on the basis of perceived quality of care and the innate satisfaction they desire to attain constituted what satisfaction meant to them. The caregivers commented;

> *"A service user who has been receiving services for her child directed me to Duakwa. It was just a fruitless journey, I got tired of going to the hospital, I like community services. It better you live here as an inpatient, because you are able to comply more with treatment regimes".* (Verbatim expression of IPC 1)
>
> *"One of the staff at the mainstream health services told us to come and that we will get help, hospital was just a waste of our time. Inpatient is the best, because transporting yourself and the child every now and then is not easy".* (Verbatim expression of IPC 2)
>
> *"A testimony of the good service by a colleague of my sister at work….community services are the best. Here is okay because you wouldn't have to go through the stress of taking a car here always".* (Verbatim expression of IPC 3)
>
> *"A colleague trader, who knew about Duakwa suggested to me. She said he looks very weak. Community rehabilitation services is better with the exercise and everything. Inpatient is ideal and better. All the same I prefer outpatient services because, I feel free in my own home. I am also able to do my business though it is not moving as I want it, but small small money comes in to support us. If am I here I can do all that".* (Verbatim expression of OPC 1)
>
> *"My pastor and the wife, who have received services for their first child and had seen improvement. I gave birth to him at korle - bu, but the nurses still wanted me to go and be back in three months. She didn't pay attention to me at all. She told*

> *me am not the only one with a sick child so I should go. So I prefer centre service to hospital services and I have actually recommended the centre to a lot of people. By God's grace, he can sit and so I think the outpatient is okay, because he wasn't place on admission from the beginning, so that's enough evidence that he can improve without being put on admission. The only thing left is for him to talk and walk, and I know we will get there".* (Verbatim expression of OPC 2)

As expressed in the caregiver's comment from the interview, access to services on offer at the centre was the intention to bring their children to the centre, and how they perceived the community services as quality greatly added up to what satisfaction meant for them as caregivers of children with CP. Such remarks are in line with that of Abdosh (2006) who commented that patient satisfaction is reflective of patients' view of the quality of healthcare they receive and the quality of the specific institution offering the care. In the same way, Ramsaran-Fowder (2008) also is of the view that ascertaining what the consumer perceives to be quality of care helps to quantify good services. Likewise, Kulkarni, Dasgupta, and Deoke (2011) found that knowing what patients perceive to be quality is important as they are the ultimate consumers of health services. Meanwhile, Akinpelu et al. (2014) found that there is the need to routinely assess the satisfaction of informal carers with services being provided in the hospital for the purpose of quality assurance in a study conducted to investigate the satisfaction of informal stroke caregivers with in-patient healthcare services being received by their care recipients in a tertiary hospital in Ibadan.

Similarly, Bernheimer, Gallimore, and Weisner (1990) said that caregiver perceptions of quality care are crucial in improving health services owing to their significant role in their children's development. They further added that, they are responsible for acquiring health services needed by their children and the most reliable informants about their children, hence their preferences and opinions regarding their children's development are most critical (Khadye, Ziviani & Cuskelly, 2011; Wiart, Ray, Darrah, & Magill-Evans, 2010). In this regard, it was the perceptions of quality that caregivers attached to community services that defined their satisfaction. Contrarily, Hatfield, Gearon and Coursey (1996) reported that caregivers have rated hospitalization and office-based services more highly than community-based alternatives. These notwithstanding, Hatfield et al. (1996) also found that caregivers were more satisfied with outpatient services than with inpatient services, and more satisfied with services provided to the patients than with those provided to them.

On a different account, Goldstein, Elliott and Guccione (2000) and Mittal and Lassar (1998) in their studies observed that patients who appreciated the service they had received were more likely to remain loyal to the provider, who is the therapist, and would recommend therapist/ service provider to others, return for more purchases/services and remain loyal to the industry or hospital. This explains what informed the choices of caregivers in this study to have their children rehabilitated at Agona-Duakwa. In actual fact, it was the appreciations these caregivers had about Duakwa that made them bring their children to the centre. There again, these appreciations could be associated to the health belief model as a stimulus (motivating factor) to engagement in health promoting behaviour. Overall, these findings prove that there is a strong association between quality of care and satisfaction. Therefore, I assume these findings to be consistent with the findings of my research because, the perceptions of quality caregivers had about community services urged them to access services at the centre, influencing their satisfaction as an end result of their ability to access the services.

4.3.3 Process of care

Process of care emerged as a theme from the analysis of the transcript of the interview responses, and influencing the satisfaction of caregivers of children with CP as they utilize services on offer at the centre. According to Conway and Willocks (1997), the customer/patient combines all the experiences gained with the provider during the process of care to determine the overall quality of service, which in turn determines the customer satisfaction and the resultant behaviour. The view of Conway et al. (1997) is supported by the comments of caregivers as follows;

> *"They are always willing to provide services without allowing any protocols, you are provided the necessary when is your turn to be attended to. We were well received with a lot of respect, advice and guidance. This made me feel at ease and hope a better outcome…… and I think other caregivers got the same reception because I have not been shouted at nor see other caregivers shouted at".* (Verbatim expression of IPC 1)
>
> *"They are always ready to help. They know it is their job, so you do not even have asked, they just do whatever they are to do. But sometimes because they feel we are on admission, they turn look after the outpatient before they attend to us. The personnel that I first met related in a nice way with me and my child. I felt my child was cared for with a lot of kindness and respect due every human. It really got me reflecting about the fact that t I have no excuse not to care and be kind to my child if these personnel is able to do that".*(Verbatim expression of IPC 2)
>
> *"They are ready to help you when you come here and they make you feel they know what they are doing. They take their time to do what is appropriate for each child… eerrhm, if it's 15 minute for every child, it 15 minute, nothing more nothing less".*(Verbatim expression of IPC 3)
>
> *"They all showed their readiness to fulfill their responsibility to us. They received us well and counselled and encourage us that things will get better. The necessary and individualized attention was given to each child even when the cue is long. They work with time. But I can say for other caregivers, am okay with the individualized attention given me and my child. I believe it same for all caregivers.* (Verbatim expression of OPC 1)
>
> *"Errrrh, they are always willing to help but one have to follow the normal procedure. They gave me and my child the appropriate care and attention. One of the personnel I talked to when I first came here encouraged me very well and told me to adhere to the medication and the exercises. She gave me confidence that*

> *things are going to change for good. My child is not a liability, he can become an important person in future and this made me to trust them. They made me know they are not the ones to make things to happen, but zeal and compliance will make the difference. There wasn't any harassment, only cordial reception as compared to the frustration I went through at korle - bu and left unattended to".* (Verbatim expression of OPC 2)

From the above comments of the caregivers, even though the caregivers desired to attain satisfaction with rehabilitation services, it was the experiences they gained with the process of care (empathy, assurance and responsiveness) that seem to have satisfied them. In line with this findings are assertions by Dunst and Trivette (1996), Hasnat and Graves (2000), and King et al. (2001) found the process of care as one of the two characteristics of service delivery that appear to influence a family's perceptions of quality and their satisfaction. Caregivers in this study expressed satisfaction with the courteous reception that they received from the rehabilitation personnel. Furthermore, Parasuraman et al, (1988) asserts that courtesy adds to the assurance that caregivers seek in their evaluation of service quality. Such a view point is also in line with King et al. (1999), who established that respectful and supportive care was associated with higher parent satisfaction with children's rehabilitation services. In this regard, caregivers can be said to have perceived the rehabilitation personnel as assuring in meeting their needs and that of their children, hence the satisfaction they attain. There also was a report of satisfaction with the responsiveness of rehabilitation personnel. Responsiveness requires the willingness of the personnel to help the caregivers and the promptness with which the help is delivered. The same findings were reported by Anderson (1995) who found timely provision of services and knowledgeable medical workers who make patients feel safe in their interaction with them, sympathetic, reassuring, and willing to help patients as perceptions of quality expressed by health service users.

Caregivers also expressed appreciation for the empathy and respect that the personnel showed them as they utilize services at the centre. Consistent with these findings are the results of a study on determining the key component of an appropriate rehabilitation services by Saloojee, Rosenbaum and Stewart (2011) who found out that empathetic traits such as kind and caring attitudes, were components of care most valued by caregivers of children with CP. Apart from influencing caregiver satisfaction levels, Law et.al. (2003) suggested that service providers should also exhibit particular behaviours that respect and support families and improve their cooperation with families and to influence parents' perceptions of care and satisfaction with service. The same experience was reported by King and Cathers (2001) who revealed that most of the exceedingly satisfied parents remarked positively about respectful and supportive care, professionals' competence, the provider's attention to the child's needs among attributes/domains of satisfaction emphasizing the 'process of care'. They further added that, the contrary was factual for parents who were dissatisfied and reported failure of the professional to provide the same attributes.

Meanwhile, in a study of measurement of service quality of physiotherapy, Curry and Sinclair (2002) and Anderson (1995) established that the most important factor in patients' evaluation of satisfaction; is the manner in which the service or care is delivered with expectations of reliability, responsiveness and empathy equally important in the evaluation of service quality by patients, that met their satisfaction. Similarly, empathy or reassurance, encouragement or motivation, rapport, listening and other non-verbal behaviours were found as most important attributes in a study of affective or socio - emotional behaviours of physiotherapists while treating patients (Adams et al., 1994). In the same way, the perception of quality caregivers in this study attached to the process of care could be liken to the self-efficacy component of the health belief model that explains engagement in health promoting behaviour, in this instance it was the efficacy of the personnel's in their interactions with the caregivers at the centre that accounted for the perceptions of quality caregivers had about the process of care and the satisfaction they expressed.

Principally, the findings of all these authors points to the fact that perception of the quality of the process of care influenced satisfaction. Therefore, I assume that the satisfaction reported by caregivers in this study is basically dependent on the experiences they gained with the process of care (empathy, assurance and responsiveness) reflecting a perception of quality interactions and that, findings of my research are consistent with the findings of earlier researchers.

4.4 Results

Research question 2: What prior expectations do caregivers of children with cerebral palsy have in utilizing rehabilitation services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?

In order to answer research question 2, the caregivers' responses to interview items showed that caregivers had prior expectations for service and children's improvement through rehabilitation before coming to Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. The IPCs commented as follows:

> *"Honestly, I didn't know much about the services they render here, bringing my child here, I just wanted him to get help and to be normal just like his other siblings. I… 1 seriously expected him to get healed".* (Verbatim expression of IPC 1)
> *"I did not have any idea about the services but the main thing that drove me here is because I wanted my child to be able to do some Activities of Daily Living independently".* (Verbatim expression of IPC 2)
>
> *"I wasn't so sure of services they offered, but coming in here, I came here with some expectations that my child should be able to do some activities even if it just moving from a bed/ chair, walking or just holding a broom to sweep. I strongly expected complete healing for her, I didn't expect her to crawl because she has past that stage. I wanted her to stand, hold on to an object and eventually begin to walk. Those were the kinds of thought I came in with but not really knowing much about the services they offered and to expect".*(Verbatim expression IPC 3) The OPCs added that;
>
> *"I wasn't sure because … I haven't had any detailed information about the kind of services that they had on offer. The woman who recommended Duakwa to me didn't give me any detailed information so I came here not really knowing what kind of services they had. But I had this strong thought that he was going to get complete healing and be fine as soon as possible".*(Verbatim expression OPC 1)
>
> *".....basically I didn't have in mind any set services that if I came, this is the services they are going to offer, I just wanted to get the child here to see what they can do to help. Although deep within me, I hoped and expected that it will stop completely".*(Verbatim expression OPC 2)

The caregivers reported that they expected their children to grow and develop like other children without disabilities in the beginning even though they didn't know much about the services on offer.

Aside of the child's attainment of independence for daily living, the caregivers also expected to be abreast with the causes of their child's condition from the rehabilitation team, how long the condition would take to improve as well as means of handling it, some of them said that;

> *"I wanted to know what happened to my child, how long I am expected to do exercises before the child becomes "normal" like other children".* (Verbatim expression IPC 1)

> *"I expected to get an explanation of what was wrong with her, how long we are to do exercises before the she becomes "normal" like other children and be all right…"*(Verbatim expression IPC 3)

> *"I expected to be shown exercises that would strengthen my child's body … so that he could be able to carry out some activities. I also expected to receive proper treatment from the centre".* (Verbatim expression OPC 1)

The expectations of the caregivers rose with the experiences they got from the services as typified by the following statements made by the caregivers;

> *"With the services given to my child, I know have considerable expectations for my child. Initially, I didn't know what to expect because I didn't know what the services were really about. Now, I expect him to start walking, even if not walk long distance. Because it didn't happen as early as I expected him to. These 14 months of receiving various exercises have guided me to have expectations for my child".* (Verbatim expression IPC 1)

> *"We have been here for the past eight months and I must say there has been some improvement in the condition and every day performance of my child. There are certain exercises given to my child to be able to strengthen his limbs which are very good. And with this improvement I am seeing now, I have hope for more improvement. The staff are doing well I must say, but need to work more on letting us know everything they do".*(Verbatim expression IPC 2)

> *"Sincerely, I am kind of disappointed because, even though there has been an improvement, it is no sign for complete healing as I thought of before coming".*(Verbatim expression IPC 3)

> *"Expectations, asem oooooo!!!!!! For now I will say I don't have any expectations different from the one I came in with because when I had expectations for complete healing, it didn't happen even at that early stages. So why have some again? Hmmm….was so eager to see him start walking oooo but that never happened. So am still continuing with the exercises, if it improves fine and if it doesn't fine because I will still love him".* (Verbatim expression OPC 1)

> *"I still expect him to improve more even though his convulsion do not reoccur, but we still have a long way to go because he still can't talk nor walk".*(Verbatim expression OPC 2)

At this point some caregivers seemed optimistic with the results they were getting while others were uncertain as to what was going to happen next, as they felt the results were not up to their expectations.

The caregivers also spoke about how the experience they got from the early stages of rehabilitation process has helped in transforming their expectations overtime. The IPCs emphasized that;

> *"Yes, a lot, it has changed, yes it has really changed a lot because as I said earlier, when I was coming, even though I really didn't have an idea of the services they were going to take my child through, I expected to have complete healing. But now I have actually come to the realization that, it won't just happen… I mean change will not immediately occur as I was hoping for. It is a step by step thing".* (Verbatim expression IPC 1)
>
> *"It has changed, my thoughts have really changed, they really have because even though we are yet to get the complete change we were looking forward to, he has improved".*(Verbatim expression IPC 2)
>
> *"It has changed a bit, as I am seeing little little improvement, but not to my expectations".* (Verbatim expression IPC 3)

The OPCs also made the following remarks;

> *"I have come to point where I have said to myself that it will only take a miracle to get complete healing. It is actually going to be a miracle! Again, initially I used to think the physiotherapist gives preferential treatment to some of the children because the exercises given was different, but now, I have this idea that not every child with the same disability has to have the same services, as I thought of initially. I was thinking the same laid down procedure should be used for all the children with CP, but now I have come to realize that every child has a specific….. ehhhhm, I mean even though the disabilities are all the same, every child has unique needs that need to be met. So my thoughts have changed in that wise, that not every disabled child is the same".* (Verbatim expression OPC 1)
>
> *"I have actually come to see my child more in the light of being an independent individual, so I have stopped comparing my child to other children with the same condition. You know initially when I came here, I saw other parents with children who have the same condition, I began to think, and they are all the same. So whatever goals this parents expected their child to attain, I unconsciously started*

> *to attach the same goals to him, but now I do not see them to be the same anymore. He can now sit while others can't. So I don't see why I should continue comparing him with others. My only hope for now is that he starts talking and walking".* (Verbatim expression OPC 2)

From these responses of caregivers, there seem to be a change from expecting things to happen immediately to assuming progress of their child through all the developmental stages and finally be able to walk.

4.5 Discussion of findings

Research question 2:

Caregiver Expectation with service

4.5.1. Child Normalization

It is clear from the construct of the findings that caregivers of children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, fell in with the unrealistic expectation that as soon as they started utilizing the services on offer at the centre, their children should become normal. For example, some of them commented that:

> *"…I just wanted him to get help and to be normal just like his other siblings. I… 1 seriously expected him to get healed".* (Verbatim expression of IPC 1)
>
> *"I strongly expected complete healing for her, I didn't expect her to crawl because she has past that stage. I wanted her to stand, hold on to an object and eventually begin to walk".* (Verbatim expression IPC 3)
>
> *"..I had this strong thought that he was going to get complete healing and be fine as soon as possible.* (Verbatim expression OPC 1)
>
> *".....deep within me, I hoped and expected that it will stop completely".* (Verbatim expression OPC 2)

As indicated in the caregiver's responses, it is apparent that expectations for children to grow and develop like other or near children without disabilities was an expectation mainly reported by the caregivers in the study. Dew and Bickman (2005) indicated that expectation of success is an important stimulus on positive therapeutic outcome. It is therefore not unusual that caregivers do have such expectations because it is the expectation of every parent to have his or her child go through all the stages of the developmental milestone and be independent. This view supports the comment by Gabbott and Hogg (1994) that ‘cure’ or health is the ultimate expectation in the healthcare sector. However, given the fact that rehabilitation as a process emphases on improving the functional abilities of the child and to be independent, it in most cases contribute to some extraordinary expectations and impractical hopes amid the caregivers.

This view is also in line with the outcomes of a study conducted on parental experiences of a CP clinic in a poor urban community in South Africa by Anderson and Ventor (1997) in which parents expectations’ geared towards attainment of several levels of independence in different activities including walking in their children and be ‘normal’. However, Parkes, Donnely, Dolk and Hill (2002) who came out with similar findings in Northern Ireland added that, these expectations become unrealistic with severely disabling conditions in children. Garland et al., (2000) in a previously discussed study of multi-ethnic youths’ satisfaction with mental health services found more positive expectation about treatment service at admittance was associated with greater satisfaction. Meanwhile, Garber et al. (1986) maintained that clients with less realistic expectations of service provision are less satisfied. McKinley, Stevenson, Adams, & Manku-Scott (2002) in a study that examined client expectation in health care, the effect of expectation on satisfaction with care provided by out-of-hours primary medical services found that patients who received the care they expected were found to be more satisfied than those who did not.

Similarly, Parasuraman, Zeithaml, and Berry (1988) observed that customer desires or wants sometimes turned out to be what the customers feel a service provider should do rather than what they do. Potter, Gordon, and Hamer (2003) confirmed this observation in their study by showing that the expectations of the parents differed from those of their physiotherapists. Rehabilitation personnel were not asked about their expectations and matched to that of caregivers, perhaps this could form an area for further studies. Thompson and Sunol (1995) were of the view that ideal expectations are those that users would like to happen and can be referred to as aspirations, desires, wishes, wants or the preferred outcomes. At this point, it could again be speculated that the expectation for a normal child before the utilization of services on offer at the centre were desires anticipated by these caregivers.

Drawing from the above extract, caregiver’s expectation for normality in children with CP is associated with increased independence in day to day living as they utilize the rehabilitation services on offer at the centre. One of the caregivers, gave the impression to have accepted the child as "okay" with the CP. Nonetheless, it is likely that the rest of the caregivers may begin to accept the child’s condition, with the realization that slow increase in progress in the child’s physical and functional abilities can improve independence. These expectations that caregivers hold are rooted in the health belief model’s assertion that beliefs held by caregivers about health problems will guide them to engage in behaviours to prevent the health problem from occurring or reduce its severity. Considering that caregivers will want to see their children become normal or near normal, they will engage in health promoting behaviours to achieve independence. Similarly, the value or importance of the outcomes related to these beliefs as elaborated on by the expectancy value theory influences caregiver expectations about the rehabilitation services they utilize for their children with cerebral palsy.

Collectively, the findings of the aforementioned studies show that, expectations for a normal or near normal child at the early stages of rehabilitation could be associated with better health outcome / satisfaction which is similar to the findings drawn from the interview extract. This is because most caregivers seem satisfied with the outcome they were seeing and hoped for better outcome. So it is speculated that it is not increased expectations that are associated with high satisfaction, but realistic expectation and the fulfilment of those expectations (Garland et al., 2000).

4.5.2. Improvement outcome

Caregivers were also found to form and/or improve in their expectations in the process of using rehabilitation services. This is because, as caregivers come to the realization that, their children cannot be normal or near normal soonest, they then tend to focus their energy on what areas could be improved to achieve independence. Rosen, Heckman, Carro, and Burchard (1994) commented that increased expectation is related to greater satisfaction. Rosen et al. view is supported by the following remarks made by caregivers;

> *"With what is given to my child…… now, I expect him to start walking, even if not walk long distance. Because it didn't happen as early as I expected him to. These 14 months of receiving various exercises have guided me to have expectations for my child".* (Verbatim expression IPC 1)
>
> *"… I must say there has been some improvement in the condition and every day performance of my child. There are certain exercises given to my child to be able to strengthen his limbs which are very good. And with this improvement I am seeing*

> *now, I have hope for more improvement…"* (Verbatim expression IPC 2) *"Sincerely, I am kind of disappointed because, even though there has been an improvement, it is no sign for complete healing as I thought of before coming".*(Verbatim expression IPC 3)
>
> *"…still continuing with the exercises, if it improves fine and if it doesn't fine because I will still love him".* (Verbatim expression OPC 1)
>
> *"I still expect him to improve more even though his convulsion do not reoccur, but we still have a long way to go because he still can't talk nor walk".*(Verbatim expression OPC 2)

Analyzing this extract, the implication therefore is that, improvement in expectations could mean forming new expectations or building up existing expectations. It is also evident from the extract of the responses of the caregivers, caregivers are likely to form or improve in their expectations in the course utilizing rehabilitation services. The reason given is that satisfaction, at all times is relative to the patient's expectations, and it changes with the changes of the expectations of what one would ordinarily expect to happen even though the actual health care may remain constant (Goldstein et al., 2000). Such a view point is in line with May (2001) findings that patients may not always have clear expectations of a complex process of health care, or the expectations may rise with time in a study that tested the role of the 'expectancy theory' in the health care sector. This extract again, toes the line of the findings of Miles and Frizzell (1990) in a study on multi-Level Skills for handling the children with Cerebral Palsy in Pakistan which showed that most parents, understandably, began with the goal that their child 'should walk and talk', and that through enhanced understanding for the need of exercises in group activity, and parents appreciating the fact that any progress begins with stages and movements well below their expectations, parents could gradually build up an understanding of realistic target in their expectations in the direction of what is achievable for each child.

Notwithstanding, Dew and Bickman (2005) in a study of prognostic expectations and outcome of brief therapy of recipients in community mental health setting, found out that expectation may also affect outcome with generally lower expectations correlated with more favourable outcomes. This can be said to be consistent with comment made by one of the caregivers;

> *"Sincerely, I am kind of disappointed because, even though there has been an improvement, it is no sign for complete healing as I thought of before coming".*(Verbatim expression IPC 3)

This stance can be attributed to the fact that, the caregiver came in with higher expectations, hence had an unfavourable outcome in that instance. Supporting this point, Haanstra et al. (2012), found no significant associations between patient expectations and overall improvement in his systematic review of available evidence related to the association between pre-operative patient expectations and different treatment outcomes in patients with total knee or total hip arthroplasty at three different follow-up periods. This can be likened to the fact that some caregivers still couldn't relate the improvement they saw as a sign for complete healing.

Meanwhile, Gunawardane (2010) in a study conducted to assess the dynamic nature of customer expectations in service encounters indicated that levels of customer expectations on various dimensions of the service vary with repeated use of the service. This assertion by Gunawardane best explains why the expectations of the caregivers at a point of improving/increasing varied. Such a view point is also influenced by the Expectancy-Value Model's assertion that patient satisfaction is based on a combination of belief strength about specific attributes of the healthcare experience (access, efficiency, cost, convenience) and evaluation of those experiences. Taking the efficiency aspect of the attributes into consideration, it could be said that, some caregivers did not find the improvement they saw as efficient or a good enough evidence for complete healing or normality because of the positive expectation they had at the beginning of the service encounter, thereby resulting in disappointment they felt.

Generally the aforementioned finding attests to the fact that caregivers do change in their expectations depending on what anticipations they had prior the service encounter. Similar to this findings is an outcome of my research because most caregivers reported some improvement/changes in their expectations for their children. Hence it is assumed that their expectations had been fulfilled by the improvement that each of them had seen in their child and depending on how long, caregivers have been utilizing services. Fulfilment of expectations of these caregivers is however, assumed as an indicator to satisfaction with the improvement outcome, with review patients reporting more satisfaction than the reported cases despite some dissatisfaction that some of them might have experienced.

4.3.3 Experience with services received

Before the service encounter, most caregivers did not have a clear idea of what to expect from the services on offer at the centre. Robledo (2001) added that patients without previous experience will still have expectations that need to be reflected. In addition, Fitzpatrick and Hopkins (1983) asserted that patients' expectations were tentative and modified by previous experience in their qualitative study of patients' expectations and satisfaction with health care for headaches. The viewpoint of Fitzpatrick and Hopkins is conflicting to the remarks of the caregivers;

> *"Honestly, I didn't know much about the services they render here".* (Verbatim expression IPC 1)

> *"I did not have any idea about the services but the main thing that drove me here is because I wanted my child to be able to do some Activities of Daily Living independently".* (Verbatim expression of IPC 2)
>
> *"I wasn't so sure of services they offered.....not really knowing much about the services they offered and to expect".* (Verbatim expression IPC 3)
>
> *"I wasn't sure because ... I haven't had any detailed information about the kind of services that they had on offer".* (Verbatim expression OPC 1)
>
> *".....basically I didn't have in mind any set services that if I came, this is the services they are going to offer.* (Verbatim expression OPC 2)

In this regard, caregivers in this study can be speculated to have been rendered incompetent in modifying their expectations with services. This is because they have not had any experience with previous encounters or had any detailed information. Such a point of view is buttressed by Thompson and Sunol, (1995) findings that unformed expectations occur when users are unable or unwilling to articulate their expectations due to fear, anxiety, and conformity to social norms, or lack of knowledge or experience to formulate expectations.

Rotter (1966) asserted that ideal expectations might be most predominant for those without previous experience. In this regard, the expectations of caregivers who have not had experience with other rehabilitation centre's were likely to be what they hope to have which might not always be realistic. Similarly, with regard to caregivers with previous experience, it was easy for them to make a prediction of what was likely to happen or what services they were likely to receive. Therefore, it was not unusual that these caregivers did not form any expectation with services on offer at the centre. Adding to this, McKinley, Stevenson, Adams, and Manku-Scott (2002) reported that patients who received the care they expected were found to be more satisfied than those who did not. The implication of this assertion then is that, as these caregivers did not form expectations for the services they received, it could account for the disappointment a number of the caregivers in this study reported. This emphasizes that customer expectation and perceived service quality have a positive effect on customer satisfaction as commented by (Almsalam, 2014). Again, this could be linked to the self-efficacy aspect of the health belief model that must act as a stimulus to engaging in health-promoting behaviour, as it can be likened to the inability of the caregivers to form expectations for service before utilizing services on offer at the centre. The study objectives nonetheless did not focus on the effect of experiences with previous encounters on the formation of expectations or why lack of detailed information affected expectations, perhaps this could further be investigated into.

However, in a study in South Africa to measure the customers' expectation levels of service quality in the food retail sector against their performance, Phiri and Mcwabe (2013) confirmed that customers have higher expectations for service quality than is anticipated. The findings of these authors is in line with the following comments made by some caregivers;

> *"I wanted to know what happened to my child, how long I am expected to do exercises before the child becomes "normal" like other children".* (Verbatim expression IPC 1)
>
> *"I expected to get an explanation of what was wrong with her, how long we are to do exercises before the she becomes "normal" like other children and be all right…"*(Verbatim expression IPC 3)
>
> *"I expected to be shown exercises that would strengthen my child's body … so that he could be able to carry out some activities. I also expected to receive proper treatment from the centre".* (Verbatim expression OPC 1)

These responses point to the fact that although caregivers did not form clear expectations with services, they expected to be abreast with the causes of their child's condition from the rehabilitation team, how long the condition would take to improve as well as means of handling it, which is beyond expectations with services from them even before the start of the service encounter. Agreeing with this fact is Conway and Willcocks (1997) suggestion that the means by which the patient evaluates the service throughout the healthcare process and to its completion is influenced by the patient's expectations of the process of care, their part in the process and the overall outcome of the treatment. Adding to that, Narayanan (2008) found that caregivers wanted and expected more from the process of care than the actual services in a study carried out to explore the concerns, desires (goals) and expectations of adolescents undergoing surgery for idiopathic scoliosis in contrast to the priorities of their parents and surgeons.

Similarly, Kravitz (1996) in his model of patient satisfaction noted that patient has initial expectations which are formed prior to an encounter or intervention, but may be modifiable as the encounter proceeds. These primary expectations may be well formed or vague, and factors such as socio - demographic characteristics, prior experiences, or specific bio - psychosocial concerns may be important determinants of these expectations. On the whole, the opinions and point of views of these authorities is indicative of the fact that, experiences are vital to the formation of expectations. Clearly, this finding is contrary to the findings from this research as all the caregivers had no previous experiences upon which they could base their expectations.

However, experiences caregivers gathered during the service encounter guided them to begin to change their expectations or reported significant changes in their expectations. Caregivers emphasized that;

> *"Yes, a lot, it has changed, yes it has really changed a lot because as I said earlier…. I expected to have complete healing. But now I have actually come to the realization that, it won't just happen… I mean change will not immediately occur as I was hoping for**.** It is a step by step thing".* (Verbatim expression IPC 1)

> *"It has changed, my thoughts have really changed, they really have because even though we are yet to get the complete change we were looking forward to, he has improved".*(Verbatim expression IPC 2)

> *"It has changed a bit, as I am seeing little little improvement, but not to my expectations".* (Verbatim expression IPC 3)

> *"I have come to point where I have said to myself that it will only take a miracle to get complete healing. It is actually going to be a miracle. ………. but now I have come to realize that every child has a specific….. ehhhhm, I mean even though the disabilities are all the same, every child have unique needs that need to be met. So my thoughts have changed in that wise, that not every disabled child is the same".*(Verbatim expression OPC 1)

> *"I have actually come to see my child more in the light of being an independent individual, so I have stopped comparing my child to other children with the same condition......... He can now sit while others can't. So I don't see why I should continue comparing him with others".* (Verbatim expression OPC 2)

These changes in expectations as reported by the caregivers seemingly is influenced by the acceptance for diversity, and consistent with Coye (2004) findings that customers are insistently changing their expectations, and the expectations are changed as customers obtain new information in his presentation of a model which argued that the customers´ expectations constantly change during the service process through a number of decision points where the customers intensely process and interpret information. Similarly, Higgs, Polonsky, and Hollick, (2005) maintained that as the service process goes forth and the customer receives more experience, the expectation then become more refined and clear, explicit and realistic resulting into clear changes in expectations. Again, Locker and Dunt (1978) suggested that expectations are not static but likely to change with accumulating experience, time and exposure**.** This point of view could be allied to the stimulus (motivating factors), or cue to action which must also be present at some points in time in order to trigger the health-promoting behaviour as elaborated on in the health belief model.

Generally, it is clear from the construct of the findings that most caregivers of children with cerebral palsy at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa did not know clearly what services to expect before coming to the centre, but once they started using the services at the centre, they began to redirect their expectations more towards what the services they received could offer, although it did not always meet their prior expectations. In this regard, expectations of caregiver's in this study can be speculated to have been modified from "not knowing what to expect" of the services to actually realizing "what they could expect" from the services and child's improvement and this is consistent with earlier findings of researchers.

4.6 Results

Research question 3: What are the enabling factors to caregiver's utilization of services provided at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?

In providing an answer to this research question, respondents' views were sought on the interview items and used. Caregivers spoke about the information that the rehabilitation personnel provided them about the condition of their children in the form of explanations about the causes and management practices. Most of the caregivers reported that the explanations about the causes of CP were not very clear as in most cases the personnel didn't know how well to communicate such information to them. However, one of the caregivers reported having received such information from the student CP awareness group from the University of Education, Winneba. As a result, most of these caregivers have been rendered incapable of explaining the condition to others. Thus some of them said:

> *"They didn't explain per say, they only said he is paralyzed in his legs".* (Verbatim expression of IPC 1)

> *"They didn't explain, and I also didn't know the condition. They only said his neck is not well positioned".* (Verbatim expression of IPC 2)

> *"They didn't explain it, they only said she couldn't stand or walk because her neck was not well positioned and we were going to be place on therapeutic treatment. Nonetheless, some student from the university came to explain that it is a condition that affects the brain, and as we continue to exercise and take physiotherapy, small small, she will be normal or improve. The students further added that delayed birth and sometimes, convulsions could also be the cause for the brain damage".* (Verbatim expression of IPC 3)

> *"Oooooooo, the woman explained that delay in giving birth can result in loss of oxygen to the brain and it brings about the convulsion and other mobility problems".* (Verbatim expression of OPC 2)

These responses suggests that caregiver could not out rightly say they didn't have any explanations. As some maintained the explanations were not clear, others seem clear with explanations provided them by the CP student support group. The implication of this therefore is that, there was some form of explanations and it was understood in a different ways by these caregivers.

One of the caregivers however, felt that sometimes the personnel fall short in being honest with them, and kept giving them 'false' hope;

> *"No no no, I didn't know what condition my child had. They told me that eeerh…. In the beginning they didn't want to tell me the truth, because of the love they saw me show my child. For them to confidently tell me, about the condition of my child it was difficult. The kept saying Profs Mother, it won't be long and prof will start to walk and he will be fine. So I should keep hoping for the best, tapping my shoulder as they said it. So my expectations kept rising. But on one occasion, one of the nurses said hhhhhmmm… Profs case is severe, another said oooo nooo do not say that. You see…. So that drew my attention to something but I said to myself, whether severe or not severe, I won't throw him away, I still love him".*(Verbatim expression of OPC 1)

In response to probing on how their understanding of the child's condition has increased based on information received from the students, caregivers remarked as follows:

> *"Initially, we thought it witchcraft but his own started with convulsion, and with what the students said, it has opened my eyes as to the reason why my child is like that".*(Verbatim expression of IPC 1)

> *"In the beginning we didn't know if it was convulsion or not we just didn't know what king of sickness he had. But with what the students have said, I am now thinking it could be a probable course"* (Verbatim expression of IPC 2)

> *"My understanding of the condition has increased because, in the beginning, my sister who is the biological mother tried to find spiritual meanings into the cause of the illness, but with the information provided by the students, I have now come to a realization that, it could be as a result of the prolonged labour my sister had.*
> *And she still couldn't deliver by herself, she had to be operated on to save her life".*(Verbatim expression of IPC 3)

> *"Initially, I didn't know the name of the condition of my child. I didn't know of the condition called cerebral palsy. But when I came here, I got to know. Even though they didn't tell me the type of CP he had. I now know the causes…….ehhh but I also learnt that from a hospital…. It was at korlebu. They said delayed birthing process, intake of hard drugs during pregnancy or medications that may be too strong for the mother's body and sometimes untreated yellow fever in babies can cause CP".*(Verbatim expression of OPC 1)

> "*Errrrh, it didn't change my understanding of the condition. Because if the there was delay, the midwife should have acted fast. I believe it beyond the process of childbirth delay. There is some spiritual reasons to it".* (Verbatim expression of OPC 2)

Some caregivers admitted to have improved in their understanding of their Childs' condition; from superstitious beliefs they attached to the condition to what was the actual reality, whiles others remain adamant in their understanding.

With further probing, all caregivers agreed to the fact that, the education they received from the students from the university was detailed to improve their understanding of the condition, appreciate and be aware of the accompanying consequences. The following were the remarks they made;

> *"This new knowledge has helped me know that even if he is to be healed completely, he can never be like you and me".* (Verbatim expression of IPC 1)
>
> *"It has increased my understanding as we were also educated us about appropriate diet that can help reduce the occurrence of convulsions".* (Verbatim expression of IPC 2)
>
> *"I have now come to a realization that, my sisters quest for finding spiritual meaning to the condition was a complete waste of time, the prolonged labour could have affected the child. She can never be normal, but she can improve".* (Verbatim expression of IPC 3)
>
> *"It has really helped paaa to understand my child's condition, because it took me back to the fact that my child was very yellow when he was born. It has really helped to understand the condition the more and always be careful in caring for him. It has really been helpful, because I have seen that, in his condition, I know he can't do anything for himself, so even if am outside and he is inside, my mind has to be inside as well. So that if something worries him or he needs something…. And am glad to say now he can say ma, I want to do this or I want to that, because of that all the time my attention is divided. If am to go somewhere without my child, I have to hurriedly get to him, because I can't tell when something is happening with him and he can't control. Am always on the run to cater for him".* (Verbatim expression of OPC 1)
>
> *"It has given me a sense of realization that, I have to put extra effort in caring for him, if he has to improve and be okay".* (Verbatim expression of OPC 2)

At this point, acceptance for diversity and how to work their way around the demands of having a child with CP is significant as evidence by the caregiver's responses.

Caregivers expressed differing opinions on the home base therapy provided for them and their children. The IPCs said they did not have such packages with comments like:

> *"For now we don't have any home package, so I can't say how good it is".* (Verbatim expression of IPC 1)
>
> *"None for now, because we are on admission… even though we don't have a home program, I can I say it helpful for the outpatient caregivers. This is because some of them have been reporting improvement when we meet us caregivers".* (Verbatim expression of IPC 2)
>
> *"They will only give us such therapy when we are discharged, it may be helpful to the caregivers who are not on admission".* (Verbatim expression of IPC 3)

As the IPCs said they did not have such a package hence could not say how useful or less useful it was to them, the OPCs expressed otherwise with comments such as;

> *"Yes, we were given repetitive exercise to strengthen his arms and legs. Massage his back to relax the muscles in his back to prevent worsening of existing and development of other deformities….Very helpful, very very helpful better than before. Although he has still not been able to sit by himself. It okay, the exercise has been really helpful. Now he can communicate if something is wrong with him. At first it wasn't like that. Now it's okay. Because now if someone says something and am not around, he is able to communicate to me what happen in my absence. You need a lot of love to be able to do this work".* (Verbatim expression of OPC 1)
>
> *"We have a set of exercise we do at home, and he is on controlled diet. No sugar but honey in his porridge. Added soya beans and smoked fish to his meals. We also have an adapted chair with belt to improve his posture and sitting him by the television to stimulate the mind…It has really been helpful, because he can sit on his own, he has really improved in that aspect".* (Verbatim expression of OPC 2)

The respondents responses show, that caregivers couldn't have expressed same opinions due to the contextual factors under which they utilized the community services.

All the caregivers reported that to have been warmly received by the rehabilitation team at the centre. They described the personnel as social, courteous and kind. They thus said;

> *"They received us very well, spoke to me with a lot of respect, concern. They also encouraged me and gave me hope for recovery without minding how*

> *unkempt/kempt the child might appeared nor my financial status".* (Verbatim expression of 1PC 1)
>
> *"We were well received with a lot of respect, advice and guidance. This made me feel at ease and hope a better outcome…… and I think other caregivers got the same reception because I have not been shouted at nor see other caregivers shouted at".* (Verbatim expression of 1PC 2)
>
> *"I was spoken to in an encouraging way, the social medical rehabilitation officer made me aware, the condition is not a medical condition where by coming here, some medications will be prescribed and within a very short time, my niece will start walking and do things she is unable to do…. It was respecting I must say".* (Verbatim expression of 1PC 3)

The two OPCs however, added care and empathy with which the personnel worked on their children. This responsiveness from the personnel were reflected in the following statements made by these caregivers:

> *"The personnel were very respectful in the way they cared and also took good care of my child …….to me alone I think how you treat your child will either earn you respect or not, it was a nice experience".* (Verbatim expression of OPC 1)
>
> *"The personnel that I first met related in a nice way with me and my child. I felt my child was cared for with a lot of kindness and respect due every human. There wasn't any harassment, only cordial reception as compared to the frustration I went through at korle - bu and left unattended to. It really got me reflecting about the fact that t I have no excuse not to care and be kind to my child if these personnel is able to do that".* (Verbatim expression of OPC 2)

The caregivers also reported have received a lot of compassion and concern from the personnel towards their children. No caregiver reported harassment, discrimination or neglect from the personnel at the centre as they felt equally well attended to regardless of the fact that some children may not be well kept or because they were poor or rich. Most of the caregivers admitted to have received some counselling/education from the rehabilitation team.

> *"Errhm, we are being talked to by the staff and sometimes by pastor who comes to pray with us……….I must say it has really been really been helpful to my emotional wellbeing".*(Verbatim expression of IPC 1)

> *"The staff here always talk to us either individually or as a group about the need for acceptance, because without it, we can't make progress".* (Verbatim expression of IPC 2)

> *"Like I said earlier, some students came here to educate us, and for counselling we receive it every day…..it's usually individual, but we have it has a group when the pastor comes to pray with us which I find more useful because it gives me the confidence to air out my feelings without any fear or doubt".* (Verbatim expression of IPC 3)

> *"I have received counselling from the very day I started visiting, and I still do receive counselling. You know people will always put up an attitude when you have a child like this. My husband neglected us. He wanted us to do away with him even though he was the fifth but surviving pregnancy in my marriage. But with the counselling I have been receiving, I feel I didn't make a mistake by keeping and caring for him…..also the counselling is most times individual as we have different characteristics. The counselling that a single mother will need will be different from that of a mother with or without the support of her husband. Everybody and their situation, so the counselling can never be the same."*(Verbatim expression of OPC 1)
>
> *"Oh yes there was counselling in the beginning and there still is. Sometimes it individual or in group….but the group counselling usually is general for the need to accept the child".* (Verbatim expression of OPC 2)

Caregivers' expressed confidence and competence they felt with the counselling and educative sessions provided them as it catered for their individual needs hence could serve as evidence of satisfaction they are likely to attain.

Meanwhile, to describe the involvement they felt in decision making and therapeutic activities for their child, probably reasons they felt could account for the personnel's failure to involve them, caregivers reported a mixed opinions about it. Below are the comments they made;

> *"No, they do what is good for child, I don't take part in decision making, and probably they think they are the professionals. But they allow us stay in the exercise room and observe, and sometimes they allow us do it".* (Verbatim expression of IPC 1)

> *"They are the professionals, so they do what is best for the child. They may thinking because am uneducated, I can't make any meaningful contribution to matters concerning my child. Am always in the treatment room with my child, I observe and try the exercises out only when am are permitted".* (Verbatim expression of IPC 2)

> *"No they don't involve me in decision making, I act only on their instructions but sometimes I feel they should let me know what ever decisions they take concerning my child. Perhaps too they feel I don't know much about my children conditions to contribute to decisions concerning it. They usually allow us to observe and give the chance to us to try the exercises out so that we can do it for when the physiotherapist is not around".* (Verbatim expression of IPC 3)

> *"They involve me a lot, is not today that I started coming here, at the beginning stages when he was about 9-10 months they use not to involve me but now they do. After the exercising him in every review session, they always reminded me to continue with the exercises done as part of their home programme".* **(**Verbatim expression of OPC 1)

> *"They don't involve me, but I trust their judgment since they are the professionals. And for the exercise, I am not allowed to do it here, I only observe and do same at home".* (Verbatim expression of OPC 2)

It's clear from above statements that, how long these caregivers have been utilizing the services at the centre played a role in the level of involvement or non-involvement they felt or experienced.

Caregivers further commented on ways they felt involvement in therapeutic activities will or has helped them to manage their children in the home environment. They commented as follows;

> *"It will help me continue with the exercise when we are discharged".* (Verbatim expression of IPC 1)

> *"I can continue at home, when we finally leave here".* (Verbatim expression of IPC 2)

> *"You know, from the education gotten from the students from UEW, they said without continues exercise, the muscles will continue to stiffen as the child grows. So the involvement in the exercises will help me continue at home".*(Verbatim expression of IPC 3)

> *"The home programme has helped my child a lot… I can confidently say that I have noticed a great change in my child as a result of what we did at home… even though he still cannot sit he is much better than before and this has drawn his younger sister closer to him and he 'loves' that a lot. Although they keep saying we should continue doing it at home, they never bothered to find out if we actually do it".* (Verbatim expression of OPC 1)

> *"I do the exercises when I have the opportunity. Sometimes even a whole week I may not have the time to exercise him because I have to cater for his younger one and do housework also. If I want to do housework, I place him in the chair and go about the normal housework. Placing him in the adapted chair has also makes feeding easier".* (Verbatim expression of OPC 2)

Most of them appreciated the benefits of the exercises and home programmes as the improvement they saw in their children's abilities was noticeable, although the personnel on several occasions never found out whether or not the home programme was being implemented**.**

All the caregivers reported they met other caregivers with children who have similar conditions to those of their children. Below are the comments they made;

> *"I have very cordial relationship with other caregivers, we always offer helping hand to one another. We meet as a group and discuss our needs and share our experiences every 3rd week in two months. This meetings console us, it gives hope, because when you meet, even if you don't have hope you begin to form hopes for betterment".*(Verbatim expression of IPC 1)

> *"We have good relationship and we meet every two months. This meetings gives you hope because you will see worse conditions. I realize that CP is on the rise anytime we came together and even the cases seem worse than that of my child yet their caregivers had not given up, so I said to myself why should I".* (Verbatim expression of IPC 2)

> *"The way we relate with one another is okay as we meet in every two months. You will just forget all your worries as you share ideas and experiences of caring for your child with other caregivers, some of this experiences actually will make you strong, others too will just……… ".*(Verbatim expression of IPC 3)

> *"Very fine, we come here to share experience and encourage each other in every two months, and sometimes when there is going to be workshop, we are invited to join in. but it is not compulsory that we must come. We think about ourselves and learn from each other's experience. The community health assistant also do give some health talks. And besides ten years down the lane of caring experience, I feel more encouraged to look after my child and encourage other caregivers as well".*(Verbatim expression of OPC 1)

> *"Ooooh we have a very fine relationship we understand one another, when we come we encourage one another because what has happen has happen. We don't depend on any miracle from fetish priests or pastors. We meet on meeting days, usually every 2 months. And this meetings has encourage me, during meetings some of the lectures present worse cases and you also see worse cases than yours and that enough consolation that it will be well".* (Verbatim expression of OPC 2)

Caregivers acknowledged to have benefited a lot from meeting other caregivers at the centre. They shared their problems during such meetings, it encouraged and motivated them from their fears and assured them that all hope was not lost and to keep persevering. They also said sometimes seeing other children with similar or even worse conditions than that of their children made them feel they were not alone and that spurred them on to facing their plight.

4.7. Discussion of findings

Research question 3:

Enabling factors to caregiver utilization of service

4.7.1. Information/ knowledge on CP

Caregivers spoke about their experience of the provision of knowledge and information from the rehabilitation personnel. All caregivers expected the personnel to give them rich details about their child's condition. Huang, Kellett, and John (2010), Karande, Patil, and Kulkarni (2008) and Ribeiro, Barbosa and Porto (2011) were of the view that most caregivers of children with CP lack the rudimentary knowledge regarding the condition - its causation, prognosis, treatment modalities. These they attributed to provision of very little information from treating physicians, nurses, and therapists, and caregivers may have many demands about the condition, which have a tendency to remain unanswered. In line with this view are the following comments made by some caregivers:

> *"They didn't explain per say, they only said he is paralyzed in his legs".* (Verbatim expression of IPC 1)
>
> *"They didn't explain, and I also didn't know the condition. They only said his neck is not well positioned".* (Verbatim expression of IPC 2)
>
> *"They didn't explain it, they only said she couldn't stand or walk because her neck was not well positioned and we were going to be place on therapeutic treatment".* (Verbatim expression of IPC 3)

Analyzing the extract from the findings, it is clear caregivers in the study reported inconsistency in the ability of the personnel to provide them with detailed explanations on the condition of their children. Such viewpoints expressed by caregivers is a contradiction of the assertion by The Consumer Protection Act (1986) that each and every caregiver as a consumer has a right to know the condition of their child and services. Likewise, the WHO (1993) affirms that caregivers of children with cerebral palsy (CP) need to have information about the condition and its management, given their participation in the process of rehabilitation and care. Contrary to the comments of other caregivers, one of the caregivers admitted to have been informed about the causes of her child's condition at the centre, and this is consistent with the viewpoints of the above mentioned bodies. She indicated as follows:

> *"Oooooooo, the woman explain that delay in giving birth can result in loss of oxygen to the brain and it brings about the convulsion and other mobility problems".*(Verbatim expression of OPC 2)

Meanwhile, one of the caregivers remarked to have gotten additional information from other sources, though it was within the confines of the centre, it was not from the personnel themselves thereby putting their abilities to appropriately inform caregivers into question.

> *"Nonetheless, some students from the university came to explain that it is a condition that affects the brain, and as we continue to exercise and take physiotherapy, small small, she will be normal or improve. The students further added that delayed birth and sometimes, convulsions could also be the cause for the brain damage".* (Verbatim expression of IPC 3)

Aside the education given by the student CP awareness group, another caregiver also said she had additional information from Korle - Bu:

> *"…….ehhh but I also learnt that from a hospital…. It was at korle - bu. They said delayed birthing process, intake of hard drugs during pregnancy or medications that may be too strong for the mother's body and sometimes untreated yellow fever in babies can cause CP".*(Verbatim expression of OPC 1)

Supporting this, Arora, Aggarwal, and Mittal (2014) maintain that parental knowledge of CP is inadequate and can be improved by incorporating educational programmes in special clinics and centre's to improve management. Such educational programmes could be allied with the education provided by the CP awareness group. Sen and Yurtserver (2007) also maintain that this lack of educational/informative activities to improve parental knowledge, impedes confidence with the process of decision making thereby interfering with the process of rehabilitation, and resulting in poor treatment outcomes. They further found a need to provide information about the condition (diagnosis and prognosis) for which caregivers are seeking help , because CP have been reported in research works as complex and difficult to understand by most caregivers and it is the same for caregivers in this study.

Another respondent expressed feeling of reluctance on the part of the personnel in being honest with them as to the true state of her child's condition;

> *".... In the beginning they didn't want to tell me the truth, because of the love they saw me show my child. For them to confidently tell me, about the condition of my child it was difficult. They kept saying Profs Mother, it won't be long and prof will start to walk and he will be fine. So I should keep hoping for the best, tapping my shoulder as they said it. So my expectations kept rising. But on one occasion, one of the nurses said hhhhhmmm... Prof's. case is severe, another said oooo nooo do not say that. You see.... So that drew my attention to something but I said to myself, whether severe or not severe, I won't throw him away, I still love him".* (Verbatim expression of OPC 1)

The need for information as expressed in comments of caregivers in this study could be likened to those of reviewed empirical works. For instance, in a study to identify physiotherapist and patient expectations in private practice in Australia, Potter et al. (2003) found 50% of a total of twenty six patients expected to be provided with detailed explanation informing them of the diagnostic and prognostic about the condition of their child. Similarly, Arora et al. (2014) found that caregivers in the early stages did not know the correct name of their child's health condition, but afterwards, 45.3% could name it. Also there appeared to be significant improvement in the knowledge of parents after viewing the film with regard to (a) knowing the cause of CP, (b) knowing that motor involvement was predominant in CP, (c) knowledge regarding management of the condition, and (d) knowledge about special schooling as compared to previous status of parental knowledge in an uncontrolled interventional trial evaluating the parental knowledge of CP and assessing the impact of an educational programme on it.

Meanwhile, King et al. (1996) found exchange of information as having the strongest association with satisfaction among other factors that increased satisfaction. Baine et al. (1995) also found provision of information among the most important aspects of caregiving in a study involving 80 caregivers of children with diabetes mellitus and 45 parents of children with cystic fibrosis. Locker and Dunt (1978) also suggested that provision of knowledge influenced satisfaction. In addition, Hasnant and Graves (2000), Knafl, et al. (1992) and Stallard et al. (1993) found provision of information to have a noteworthy effect on parents' satisfaction.

Collectively, these studies draw us to the point that, provision of information is an important factor related to treatment outcome. However, the same cannot be vouched for findings from this study as caregivers remain indifference in their opinions in that regard. Again, such viewpoints may be associated with the stimulus emphasized by the health belief model because information provided to caregivers can prove useful in triggering compliance/ engagement in health-promoting behaviour on the part of caregivers, therefore attaining satisfaction.

On the basis of these analysis, I assume that the findings of my research to be inconsistent with those of the aforementioned authors. This could be attributed to the inability of the personnel to provide caregivers with rich details on the condition of their children could be an indication of lack of requisite knowledge on CP on the part of the personnel or could perhaps be attributed to unwillingness to give full explanations to avoid loss of hope in caregivers. It is therefore speculated that caregivers felt unsatisfied with the details provided them on the condition of their child by the personnel because they were not well informed, hence could not keep their expectations within what was achievable for their child. However, the education/information they got from the student CP awareness group made them willing to take part in activities that will promote the condition of their children. It is in this light the researcher asserts that providing information as soon as possible is ideal as evident from responses made by the caregivers.

4.7.2. Compliance to management regimes

WHO (2002) equated compliance to the degree to which a person's conduct matched up with established recommendations from a healthcare provider. It also denotes the desire of patients to participate fully with the medication and their positive attitude towards the treatment, as well as collaborating with their health care provider within therapeutic services. Similarly, compliance in this study emerged as a theme influenced by the sufficiency of information, the role of the rehabilitation personnel and how family - centred caregivers felt services were. The understanding was that, as per the definition of the WHO, caregivers comply with the recommendations of the rehabilitation personnel if they are provided with sufficient information, the rehabilitation personnel play their role well and if the caregivers see themselves as partners in the whole rehabilitation process. Hasnant et al. (2000) found provision of sufficient information as a critical factor to satisfaction, they added that, parents who found the amount of information provided them as overwhelming reported more satisfaction than those who found it as sufficient. Such a view point is in line with the following remarks made by the caregivers;

> *"This new knowledge has helped me know that even if he is to be healed completely, he can never be like you and me".*(Verbatim expression of IPC 1)
>
> *"It has increased my understanding as we were also educated about appropriate diet that can help reduce the occurrence of convulsions".* (Verbatim expression of IPC 2)

> *"My understanding of the condition has increased because, in the beginning, my sister who is the biological mother tried to find spiritual meanings into the cause of the illness, but with the information provided by the students, I have now come to a realization that, it could be as a result of the prolonged labour my sister had…".* (Verbatim expression of IPC 3)

> *"Initially, I didn't know the name of the condition of my child. I didn't know of the condition called cerebral palsy. But when I came here with the education from the students, got to know. Even though they didn't tell me the type of CP he had. I now know the causes". "It has really helped paaa to understand my child's condition, because it took me back to the fact that my child was very yellow when he was born. It has really helped to understand the condition the more and always be careful in caring for him….."*(Verbatim expression of OPC 1)

> *"It has given me a sense of realization that, I have to put extra effort in caring for him, if he has to improve and be okay".* (Verbatim expression of OPC 2)

From the analysis of transcripts of the interview, it was evident that caregivers' satisfaction could be matched to the sufficiency of information they had to the improvement of their understanding of the condition, thereby complying with treatment modalities in day to day living. In line with this finding is the outcome of a study by Moura, Ribas, Picinini, et al., (2004) who observed that parents who had better knowledge about the stages of their child's development could take better care of their children, and this positively affected the child's development in a study that gauge the knowledge of parents about child development in typical children. This finding is proven true for caregivers of children with CP, because the knowledge or sufficiency of the information helped them understand the condition, thereby complying with treatment regimes. Meanwhile, Deb, Dhār, and Parikh (2015) found that provision of educative information improves doctor-patient (caregiver) relationship and compliance as well as satisfaction with any treatment in a study to determine the role of patient (caregiver) education and counselling in paediatric dermatology practice.

Similarly, Miller, Colligan, and Colver (2003) found that many parents would like more information about the data on registers which include their child and as well be involved more in the design of the register and its reports in a study to confirm if information held on a register of children with cerebral palsy was not being made available to contributing families and if the existence and purpose of the register was not sufficiently understood. Again, Anderson and Venter (1997), and Miles and Frizzell (1990) maintain that, caregivers may be likely to form feasible expectations for each child if appropriate explanations on diagnosis is provided them. The implication of this assertion by these authors in this study is that, if caregivers are provided with sufficient information and in an appropriate time and manner, they are more likely to comply with treatments.

On the whole, the viewpoint of these authors affirms that the sufficiency of information provided by the rehabilitation personnel to caregivers can predict compliance to treatment regimes, hence an increased satisfaction. It is therefore speculated that these findings are similar to that of the findings from this study because caregivers of children with CP were able to comply on the basis of information provided them by the student CP awareness group in the course of their utilization of services. Such a view point is also in line with the health belief model. Taking the stimulus component of the health belief model into consideration, provision of information can be said to be the stimulus upon which caregivers engage in health promoting behaviour (compliance), hence the satisfaction they derive.

There again, some caregivers expressed the immense contribution made by home programmes to their compliance and improvements in their children in the home environment, and the satisfaction they attained. They thus remarked as follows;

> *"Yes, we were given repetitive exercise to strengthen his arms and legs. Massage his back to relax the muscles in his back to prevent worsening of existing and development of other deformities….Very helpful, very very helpful better than before. Although he has still not been able to sit by himself. It okay, the exercise have been really helpful…."* (Verbatim expression of OPC 1)
>
> *"We have a set of exercise we do at home, and he is on controlled diet. No sugar but honey in his porridge. Added soya beans and smoked fish to his meals. We also have an adapted chair with belt to improve his posture and sitting him by the television to stimulate the mind…It has really been helpful, because he can sit on his own, he has really improved in that aspect".* (Verbatim expression of OPC 2)

These comments suggest that the home based therapy helped caregivers to comply with the treatments even at home thereby contributing to satisfaction. Consistent with these findings is the outcome of a study by Miles and Frizzell (1990) that caregivers in Pakistan found handling techniques and improvised assistive aids as beneficial and supportive in home programmes.

In a similar study, Lillo-Navarro et al. (2015) found that home exercise programs in young children with physical disabilities could be identified with key themes related to compliance namely, the characteristics of the home exercise program and the characteristics of the physiotherapist's teaching style. In the first theme, the participants described their experiences regarding their preference for exercises, the amount of time spent performing the exercises, the effect of the exercises on the family's relationships, and any sense of related burden. In the second theme, participants revealed that they complied better to prescribed exercises when their physiotherapist made an effort to build their confidence in the exercises, helped the parents to incorporate the home exercise program into their daily routine, provided incentives and increased motivation. The authors concluded that the parents perceived that their children's compliance to home-based exercises, which were supervised by the parents, was more successful when the physiotherapist's style and the content of the exercise program were positively experienced in a study to find out how parents perception of the characteristics of home exercise programs and physiotherapists' teaching styles influence compliance. Nonetheless, the teaching style of the personnel and characteristics of the home based programme were not a focus in this study, but could perhaps form an area for further investigations.

Holistically, the findings of these authors are assumed as the same by the researcher, because they all emphasized the importance of home programmes to compliance, when experienced in a favourable light. Again, these findings when associated to the perceived benefit to an action of the health belief model, could be used to describe the satisfaction caregivers attained as a perceived benefit to compliance which is the action.

However, two of the caregivers in this study expressed concern about the fact that caregivers did not bother to find out if caregivers actually did comply with home programmes:

> *"The home programme has helped my child a lot… I can confidently say that I have noticed a great change in my child as a result of what we did at home… even though he still cannot sit he is much better than before and this has drawn his younger sister closer to him and he 'loves' that a lot. Although they keep saying we should continue doing it at home, they never bothered to find out if we actually do it".* (Verbatim expression of OPC 1)
>
> *"I do the exercises when I have the opportunity. Sometimes even a whole week I may not have the time to exercise him because I have to cater for his younger one and do housework also. If I want to do housework, I place him in the chair and go about the normal housework. Placing him in the adapted chair has also makes feeding easier".* (Verbatim expression of OPC 2)

In analyzing this extract of the findings, it can be said that caregivers do not actually implement the home programmes as often as recommended by the personnel, which can be attributed to fact that caregivers will always have other responsibilities to attend to aside that of the child. Such a view point could be associated to barriers to an action as emphasized by the health belief model. I assume so, because other responsibilities aside that of the child is a barrier that prevents the caregivers from carrying out home programmes (action) as much as is required.

Various researchers have studied the importance of involving patients/caregivers in decision-making. However, most caregivers in this study reported that they were not consulted in deciding on the home programmes made available for their children. Nonetheless, they admitted they were allowed to observe the exercise sessions to aid them do same at home. They attributed this failure to involve them in deciding on home programmes to a number of reasons they felt the personnel had with comments like:

> *"No, they do what is good for child, I don't take part in decision making, probably they think they are the professionals. But they allow us stay in the exercise room and observe, and sometimes they allow us do it".* (Verbatim expression of IPC 1)
>
> *"They are the professionals, so they do what is best for the child. They may thinking because am uneducated, I can't make any meaningful contribution to matters concerning my child. Am always in the treatment room with my child, I observe and try the exercises out only when am are permitted".* Verbatim expression of IPC 2)

Contrary the above comments, one of the caregivers had this to say:

> *"They involve me a lot……they always reminded me to continue with the exercises done as part of his home programme".* (Verbatim expression of OPC 1)

On the basis of these interview extracts, caregivers felt allowing them to observe the exercise activities as it was done was not enough involvement. Caregivers did not only want to observe but to be taught with guidance and demonstrations by the personnel, with hands on trial of every exercise activity and to be given feedback on how they fared with the trails in order to improve compliance with home programmes. This viewpoint is again consistent with findings of a study by Miles and Frizzell (1990). These authors found that caregivers reported the use of low cost corrective aids coupled with the handling techniques taught them very useful and helpful in the everyday home care for the child. They also added that discussing with caregivers to describe the select activity, before the caregiver is taken through the learning and handling techniques is vital to compliance and improvement outcomes. They further suggested that caregivers be allowed to rehearse the activity repetitively until they are comfortable and confident enough to carry on autonomously at home, with an unending direction and reaction from rehabilitation personnel as they demonstrated the use of goal oriented problem-based approach in Pakistan.

Meanwhile, Hoare, Imms, Villanueva, Rawicki, Matyas, and Carey (2013) found that, for caregivers of children with physical disabilities, their involvement in decisions about home base therapy is crucial for successful treatment interventions. This according to this authors is because the active participation of parents during these activities has confirmed positive effects on the children's outcomes such as gains in motor skill attainment. More so, Walker et al. (1995) maintain patient's beliefs about efficiency of a particular treatment or service may relate to the patient/caregivers understanding of their (or the child's) condition. Walker further maintained that, it is important for the physiotherapist to agree upon the diagnosis and treatment with the patient or caregiver. Affirming that patient-therapist relationship is among the most important factors that influence patient/caregivers compliance. In this sense, agreeing upon the diagnosis and treatment with the caregiver is the basis for personnel-caregiver relationship, hence the compliance with treatments.

Similarly, Levitt and Goldschmied (1990) suggested that rehabilitation personnel working with caregivers must teach parents, relatives and other carers on how to reinforce therapy, making physiotherapy services at the early stages a vital means of supporting the caregivers in their management of children with CP and as the patient/child become older. The implication of this viewpoint therefore is that, imparting unto caregivers the skills to reinforce therapy will aid them in complying with post-rehabilitation treatment outside the rehabilitation setting, this is because, rehabilitation in healthcare settings is time bound and has to be stopped at some point in time. Nonetheless, caregivers can reinforce such therapies in the post rehabilitation phase for children with chronic lifelong conditions like CP.

Another study by Garwick and others (1998) found inclusion of family in care planning and delivery as an area caregivers attached importance to in an opinion survey of 63 families caring for a disabled member. Likewise, Vajravelu1 and Solomon (2013) found that active participation of family members was perceived as a facilitator to family-centred practice and compliance. Saloojee, Rosenbaum and Stewart (2011) also found that caregivers' perceived services as family centred on the basis of the way the therapists talked to the caregivers and explained what they were doing during therapy which made caregivers feel that they were doing a good job. They also added that the feeling of gaining something from every session or the suggestions of things to do at home between visits to the hospital were areas caregivers saw therapists as doing well. Nevertheless, caregivers feeling that they were not given opportunities to make decisions about treatment and that treatment choices were not explained to them were areas they perceived in an unfavourable light. All findings drawn from the reviewed works on involvement in decision making and participation in therapeutic activities proves that, involvement in decisions helps to predict compliance. This, I assume to be similar to the findings of my research, this is because even though most caregivers reported they were not consulted in deciding on the home programmes, they eventually will be consulted as evident by the remarks of OPC 1 on the same issue.

However, in this study most of the caregivers were dissatisfied with the personnel's failure to involve them in decision making. They felt they should be involved because they were the ones to implement it.

> *"…. I feel they should let me know what ever decisions they take concerning my child. Perhaps too they feel I don't know much about my child's conditions to contribute to decisions concerning it……"* (Verbatim expression of IPC 3)
>
> *"……They may thinking because am uneducated, I can't make any meaningful contribution to matters concerning my child…."* (Verbatim expression of IPC 2)

It is clear from extracts of these findings that, the dissatisfaction caregivers felt could have an effect on the caregivers' ability or willingness to comply with the home exercises, this is because they might not see the need to comply with a regime they know not very well. Such a view point, though on a different note could be allied to the Health Belief Model as used in a study on caregiver adherence to occupational therapy services and based on the understanding that a person will take a "health-related action if he perceives a given health problem as serious, and therefore, more likely to engage in behaviours to prevent the health problem from occurring or reduce its severity. The researcher therefore speculates that caregivers will comply better only if they are made to participate in decisions about home and other therapeutic programmes and be aware of how serious the condition is to dictate compliance and resultant satisfaction.

On a general note, it was obvious from the findings that information provided to caregivers, the role of the rehabilitation personnel and how family centric caregivers felt services were, played a strong predictive role to compliance in this study. It could therefore be speculated that the findings of earlier researchers is consistent with that of these study because the compliance caregivers showed is hinged on how enabling this factors were to their utilization of services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona-Duakwa.

4.7.3. Emotional support

Emotional support emerged as a theme leaning more towards the meetings they held as caregivers and the counselling services provided to them to cater for their emotional needs, as a result and demand of their caregiving roles. It was evident from responses of caregivers that, they appreciated the benefits they derived from meeting other caregivers. This is because they felt it gave them the opportunity to share ideas and face their fears in the utilization of services on offer at the centre. When asked to talk about their experiences of meeting other caregivers at the centre, the caregivers commented as follows;

> *"I have very cordial very cordial relationship with other caregivers, we always offer helping hand to one another. We meet as a group and discuss our needs and share our experiences every 3rd week in two months. This meetings consoles us, it gives hope, because when you meet, even if you don't have hope you begin to form hopes for betterment".* (Verbatim expression of IPC 1)
>
> *"We have good relationship and we meet every two months. This meetings gives you hope because you will see worse conditions. I realize that CP is on the rise anytime we came together and even the cases seem worse than that of my child yet their caregivers had not given up, so I said to myself why should I".* (Verbatim expression of IPC 2)
>
> *"The way we relate with one another is okay as we meet in every two months. You will just forget all your worries as you share ideas and experiences of caring for*

> *your child with other caregivers, some of this experiences actually will make you strong, others too will just……… "*(Verbatim expression of IPC 3)
>
> *"Very fine, we come here to share experience and encourage each other in every two months, and sometimes when there is going to be workshop, we are invited to join in. but it is not compulsory that we must come. We think about ourselves and learn from each other's experience. The community health assistant also do give some health talks. And besides ten years down the lane of caring experience, I feel more encouraged to look after my child and encourage other caregivers as well".*(Verbatim expression of OPC 1)
>
> *"Ooooh we have a very fine relationship we understand one another, when we come we encourage one another because what has happen has happen. We don't depend on any miracle from fetish priests or pastors. We meet on meeting days, usually every 2 months. And this meetings has encourage me, during meetings some of the lectures present worse cases and you also see worse cases than yours and that enough consolation that it will be well".* (Verbatim expression of OPC 2)

The above remarks suggest that, among the caregivers of children with CP, there is a form of relationship knotted by emotional bonds. This makes it much easier for caregivers to face their fears as a group and persevere to achieving better outcomes for their children. Therefore, emotional support provided to caregivers at the centre falls greatly on how useful caregivers perceived such meetings to be. This is in line with findings by Sluzki (2010), who commented that social support systems are organization of relationships between a group of people that are snarled by affective bonds, a point where subjective and objective interactions take place, revolving systems into actual units. Mancini et al. (2002) also noted that caregivers require the maximum level of support to perform tasks for children with CP. They further added that, as caregivers take the primary responsibility for inspiring the child with CP to become independent in activities of daily living, the importance of providing support to them cannot be overlooked as they turn to miss out on the opportunity to socialize. Meanwhile, Pfeifer, Silva, Lopes, Matsukura, Santos, and Pinto (2013) found that caregivers reported being satisfied with the support they received in a study conducted to describe the perception of caregivers of children with cerebral palsy (CP), concerning social support received. In another study by Dezoti et al. (2015), it was found that the social support network of the families of children with cerebral palsy is basically comprised of family members. This might be quite true for caregivers in this study. Backheit et al.(2001) proposed that aiding parents to meet with others who have a child with CP through self-help groups, other parents at the clinic and voluntary organizations could be a another way to help parents come in terms with the diagnosis. Similarly, Moore et al. (2010) believe it is important to explore care and services provided to the family to get an understanding of how families deal with the demands of having a disabled child and on what kind of collective support they can hinge on in their day to day living. Generally, all the findings of these studies prove that, meeting other caregivers through support systems such as self–help groups is beneficial to the emotional wellbeing of caregivers.

Backheit et al. (2001) again found provision of support such as counselling for caregivers as an important role the rehabilitation personnel has to play in the rehabilitation process. Backheit's viewpoint is supported by the following remarks of the caregivers;

> *"Errhm, we are being talked to by the staff and sometimes by pastor who comes to pray with us……….I must say it has really been really been helpful to my emotional wellbeing".*(Verbatim expression of IPC 1)
>
> *"The staff here always talk to us either individually or as a group about the need for acceptance, because without it, we can't make progress".*(Verbatim expression of IPC 2)
>
> *"Like I said earlier, some students came here to educate us, and for counselling we receive it every day…..it's usually individual, but we have it has a group when the pastor comes to pray with us which I find more useful because it gives me the confidence to air out my feelings without any fear or doubt"* . (Verbatim expression of IPC 3)

> *"I have receive counselling from the very day I started visiting, and I still do receive counselling. You know people will always put up an attitude when you have a child like this. My husband neglected us. He wanted us to do away with him even though he was the fifth but surviving pregnancy in my marriage. But with the counselling I have been receiving, I feel I didn't make a mistake by keeping and caring for him…..also the counselling is most times individual as we have different characteristics. The counselling that a single mother will need will be different from that of a mother with or without the support of her husband. Everybody and their situation, so the counselling can never be the same".* (Verbatim expression of OPC 1)
>
> *"Oh yes there was counselling in the beginning and there still is. Sometimes it individual or in group….but the group counselling usually is general for the need to accept the child..."*(Verbatim expression of OPC 2)

From the above comments of the caregivers, even though caregivers admitted to have received some counselling/education from the personnel and students, it was the confidence and competence they felt with the counselling and educative sessions provided them that enhanced their emotional wellbeing, and the resultant satisfaction they attain. Such a view point is line with Cabana and Le (2005) and Schroeder, Fahey and Ebrahim (2004) who found out that effective patient (caregiver) education and counselling can improve treatment outcome as well as patient (caregiver) satisfaction and wellbeing in a number of conditions like hypertension, arthritis, asthma, rheumatoid arthritis and in this study, CP was no exception, hence the need for the provision of rehabilitation counselling. Likewise, Hemmelgarn et al. (2001) found that emphasis on provision of emotional support of the service providers was directly related to the organizational culture of the emergency room in a study that involved 131 paediatric emergency service providers. In this, regard, the emotional support of caregivers in this study can be said to have been influenced by the culture of the Salvation Army Rehabilitation and Orthopaedic Centre.

Similarly, Becker (1985) and Schraa and Dirks (1982) contended that patient education and counselling have become equally more important in the context of rehabilitation practice because along with the various treatment modalities, the patient (caregiver) often needs to comprehend and comply with particular do's and don'ts which helps in quick recovery, prolonged remission as well as avoid exacerbations. It was further remarked that, patient (child) and their caregivers can have a tremendous positive impact on the final treatment outcome in spite of the few moments spent in educating and counselling them (Becker,1985).

In another study, Deb, Dhār, and Parikh (2015) found out that effective treatment and management of any dermatoses is dependent not just on simple prescription of medicines/therapy to a patient but also, there is the need for the provision of adequate education and counselling which are equally important when it comes to the holistic management of a disease/condition. These authors further emphasized that it becomes even more important when it comes to paediatric dermatology since patients are young children who can neither verbalize their discomfort nor keep to the treatment prescribed and are often completely dependent on their caregivers in a study to determine the role of patient (caregiver) education and counselling in paediatric dermatology practice.

Contrariwise, Becker (1985) and Schraa and Dirks (1982) again maintained that rehabilitation counselling is not only important but also more of a challenge as the patient is sometimes too young to verbalize his or her symptoms and complaints and may not be able to take care of him or herself. In such instances, the duty falls on the caregivers who must innately understand the needs of the child and respond accordingly. Analyzing the comments of this caregiver's from this perspective, one may be compelled to speculate that, it is not only the confidence and competence that caregivers felt, that could account for a sound emotional state, but their understanding of the needs of the child and responding accordingly will help to improve child outcomes, hence an improved state of emotional wellbeing will be the dividend.

Collectively, majority of the authors agreed and emphasize the importance of caregiver counselling and education as instrumental to the provision of emotional support. However, there was a contradiction of this assertion by one author. This notwithstanding, the findings from my study was a replication of findings from these authors. This is because, the caregiver counselling/education was more of a motivating factor to the emotional wellbeing of caregivers as they utilize services at the centre and as elaborated by the health belief model.

Although challenges of rehabilitation counselling has been found increasing in paediatric rehabilitation works (Becker, 1985; Schraa & Dirks, 1982). The responses from the caregivers in this study proves otherwise as caregivers felt a satisfaction with the confidence and competence with which they were counselled/educated. This confidence and competence they felt is exemplified with comments made by some caregivers such as:

> *".....it's usually individual, but we have it as a group when the pastor comes to pray with us which I find more useful because it gives me the confidence to air out my feelings without any fear or doubt"* .(Verbatim expression of IPC 3)
>
> *"....but with the counselling I have been receiving, I feel I didn't make a mistake by keeping and caring for him.....also the counselling is most times individual as we have different characteristics. The counselling that a single mother will need will be different from that of a mother with or without the support of her husband. Everybody and their situation, so the counselling can never be the same".*(Verbatim expression of OPC 1)

In analyzing this extract, one can deduce that caregivers felt the personnel were confident and competent by virtue of the fact that, they knew when it was appropriate to provide counselling and what type to provide. This also, is an indication of the fact that, the personnel knew what they were doing and gave out counselling with an understanding of the fact that, caregivers come in with different social, psychological and marital traits in utilizing services on offer, hence the need to provide such services appropriate to their context. Caregivers in this study however, were not asked about the type of counselling offered them, but they were able to make a differentiation of the different types of counselling made available to them at every point in time. This could form an area worth investigating into. On the whole, all the findings of these studies proves that, meeting other caregivers through support systems such as self–help groups and the importance of caregiver counselling and education has proven beneficial to the emotional wellbeing of caregivers. Speculating, this outcome is therefore likened to the findings of my research on the basis of the significant emotional gains caregivers in this study reported. Associating these findings to the health belief model, it is assumed that meeting other caregivers and provision of counselling/education was a stimulus to a perceived benefit in the form of emotional support and satisfaction.

4.8. Results

Research question 4: What are the inherent barriers that the caregivers encounter in utilizing the rehabilitation services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa?

In answering research question 4, responses caregivers' provided to interview items were used. Caregivers were asked about barriers they encountered with the personnel in the course of their utilization of services at the centre. The caregivers were asked questions in areas of interaction, communication and attitudinal barriers they encountered with the rehabilitation personnel. The following were the remarks they made:

> "*Coming here paaaa deii, I can't recall any of the staff showing any negative attitude, their interaction with me and my child is very humane…… but I think they have to improve on how they communicate issues about the condition to us. They most a times try to hide the true state of the child's condition, for example, in the beginning , instead of them to tell me he had CP, they only said he is paralyzed in his leg. It took a while before they told me"* (Verbatim expression of IPC 1)
>
> *"They maintain eye contact when speaking with me and give all necessary attention to my child during consultations".* (Verbatim expression of IPC 2)
>
> *"Even when they are sometimes busy, they make time to listen, and make you feel important".* (Verbatim expression of IPC 3)

From the responses of these caregivers, there apparently was denial or unwillingness to admit to interaction, communication and attitudes as barriers of service utilization they encountered at the centre.

However, some caregivers said they experienced such barriers in the societies, and not from the personnel at the centre;

> *"Not with staff, but we go to church, you and your child become sermon for church members. You are think all you want in your but I just want allow you look down on us".*(Verbatim expression of OPC 1)
>
> *"no challenges from the staff here, but we face that within the society, example we went to a shop a boy wanted to play with my child but his mother openly said to her houseboy to take away her son from my child. Last year, someone told me to forget my child and go give birth to another child"* (Verbatim expression of OPC 2)

When asked to talk about other barriers of services utilization they felt should be talked about, below are the comments they made:

> *"There is neglect from the father and staying at the centre is not easy, it's all about money that is hard to come by these days".* (Verbatim expression of IPC 1)
>
> *"Staying here is not easy, even though am not the one funding our stay here, sometimes we don't get my brother to send money on time".* (Verbatim expression of IPC 2)
>
> *"Finance is a major challenge, and feel you need a break, no family member will be willing to help for a while".* (Verbatim expression of IPC 3)
>
> *"Sometimes I need to take a rest, but no one to help care for him for even few hours. I had to go for weeding but no one to help care for him. Such instances becomes most difficult situation. It has also affected business for me. Transportation is another big challenge because the financial support is not enough. If my husband gives us money and is not enough, is really up to me to know what to do".*(Verbatim expression of OPC 1)
>
> *"Finances becomes a problem because medications are expensive. And this affects compliance to treatment. For two months we had to put his medications on hold because of financial constrain. I get very tired because he doesn't know when to remain calm. It's difficult to transport him here because I have to take 3 vehicles before I reach here. Everybody will be looking at us with some kind of attitudes because he won't sit quietly".* (Verbatim expression of OPC 2)

Most caregivers reported that they had financial problems as they sometimes lacked the funds for transport and that is a major barrier because of the long distance they have to travel to and from the centre. Aside that, caregivers reported that other passengers in the vehicle also did show an attitude of "don't come close to me". Some caregivers expressed concern about the neglect they faced from their spouses and the fact that, they lacked support from family members when they needed some time off their caregiving roles.

4.9. Discussion of findings

Research question 4:

4.9.1. Barriers

Caregivers spoke about the barriers they encountered as a result of their caregiving roles. These barriers have been grouped into those they experience as they utilize the services at the centre, outside the centre and those they felt needed to be talked about. Most of the caregivers reported they did not face any barriers of interaction, communication or attitudinal from the personnel at the centre as they utilized services. Marx, Hirozawa, Soskolne, Liu, and Katz (2001) posit that, healthcare users are likely to deny agency - related obstructions/barriers for fear of loss of concealment as identified by other previous researchers. This could best explain why most caregivers reported not to have experience such barriers.

Meanwhile, Mira, Fernández-Gilino, Lorenzo (1997) establish that although the caregivers of severely ill patients in some instance saw therapists as competent, available and polite, they found them deficient in skills for adequate communication with the patients and families. Fernández-Gilino et al. view is in line with the remark of one of the caregivers:

> "*…… but I think they have to improve on how they communicate issues about the condition to us"*. (Verbatim expression of IPC 1)

The above remark however, is indicative of the fact that, rehabilitation personnel were deficient in their ability to communicate properly about their child's condition with them. It also shows that communication though a good trait associated with child outcome and caregiver satisfaction can be a barrier, if not done properly. Supporting this point are findings of Gwenda (2000) who asserts that insufficient information on the patient's condition is core to a number of physical and psychological barriers patients face in their utilization of health services. In another study, Zolnierek and DiMatteo (2009) found that patient whose physician communicated poorly were 19% less likely to adhere to treatment as compared to those whose physicians communicated well. Likewise, Golin, Thorpe, and Di Matteo (2007) also reported that poor communication (both verbal and nonverbal) has yielded lack of trust in the doctor-patient relationship, leading to glitches such as misconceptions or unreliable perception of the doctor's approach.

Adding to this, Potter et al. (2003) maintained poor communication was the most common attribute of a negative experience with service utilization on the part of both the health professional and the user. Notwithstanding, Backheit et al.(2001) however, pointed out that the way parents are initially informed about their child having CP, may affect parents' future rapport with the team caring for their child, and their attitudes toward their child. Meanwhile, Biwot (2014) found poor clinician-patient interaction as a barrier to utilization of health care services in developing countries like Ghana and alike. Similarly, Buck, Jacoby, Barker, and Chadwick (1997) found attitude of caregivers to the health care providers as a potential barrier to adherence with antiepileptic drug (AED) treatment in their study of factors influencing compliance with antiepileptic drug regimens.
D'Ambruoso, Abbey and Hussein (2005) found attitudes as a factor with significant impact on suitability and use of services, in the sense that it is the foremost imprint the caregiver forms about the clinician either in a negative or positive way, affecting how the patient reacts to treatment.

Collectively, all the findings from these studies prove that interaction, communication and attitudes are possible barriers to service utilization that caregivers encounter and this best explains the barriers to an action(engagement in health promoting behaviour) as elucidated by the health belief model. These findings are in tune or similar to the findings of my research, as communication was found as an aspect that personnel were lacking, hence a barrier to service utilization for caregivers.

Also, a number of caregivers, mentioned societal attitudes as barriers they faced outside the centre which could be discouraging to utilization of rehabilitation services. Such expressions made by caregivers is in line with Servellen (1997), who found societal influences among other factors affecting how healthcare changes occur. Similarly, Green (1999) maintained social factors are barriers to health service utilization in a broad categorization of barriers to utilization. All caregivers recognized finance as a major barrier that they encountered and felt should be talked about. Most caregivers expressed that lack of or inadequate funds was a setback to their upkeep at the centre while on admission or to their ability to transport their children to the centre for review. Such viewpoints is also buttressed by Marx, Hirozawa, Soskolne, Liu, and Katz (2001) who found the travel time and cost, to and from facility as agency-related obstructions/barriers. Meanwhile, in Ghana, Tolhurst and Nyonator (2006) found cost and distance travelled to health facilities, long waiting times and negative attitude of health care providers as the foremost barriers to the utilization of health care services by caregivers. There again, lack of acceptance and moral support from the fathers of these children was also a barrier caregivers reported. Aside these barriers, some caregivers expressed lack of support from other family members at points they felt they required some time off their caregiving roles.

As a group, caregivers admitted to have faced barriers in one way or the other. However, it must be admitted that caregivers could not agree on all the factors that constitute inherent barriers in this study. This notwithstanding, they all agreed to financial constrain as a common barrier they all encountered. This findings therefore, replicate findings from earlier studies on patient satisfaction and is allied with the health belief model assertion that a barrier to an action can influence engagement in health – promoting behaviour, hence a decrease in satisfaction.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1. Introduction

This chapter presents the summary and conclusion of the study. It also presents recommendations and areas for further research.

5.2. Summary

The study presented findings on the reported satisfaction caregivers attained with utilization of rehabilitation services provided to children with cerebral palsy (CP) and caregivers at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona–Duakwa. Five (5) out of the six (6) caregivers who had met the indicated selection criteria took part in the in-depth interactions. Required changes were made to the semi - structured interview guide for use in the main study on the basis of the findings of the pre - test. Consent of the caregivers were sought to preserve their confidentiality, considering the fact that gaining access to a study site did not mean consent and data analyzed thematically.

Findings from research question 1 showed that, caregivers in most cases do not turn out to be the biological parents of children with cerebral palsy, quite a number of different influences informed choices caregivers make about services they utilize for their children with disabilities, caregivers seem to agree to have preference for community services as against hospital services, they also had preference between what was ideal community services for them and what community services could actually work for them. Caregivers revealed that they appreciated the characteristics exhibited by the rehabilitation personnel.

The findings from research question 2 again showed that most caregivers had expectations for normalcy, to being optimistic with results they were getting and assuming progress of their child through all the developmental stages and finally be able to walk. Some caregiver expressed concern for timely and appropriate communication. These expectations were matched with their actual experience as they utilize services on offer at the centre.

Likewise, the findings from research question 3 pointed clearly that caregivers expressed concern about some aspects of the service encounte**r,** such as provision of sufficient information on child's condition, caregiver involvement in decision making and participation in exercise regimes. This was because, caregivers felt rehabilitation personnel were lacking in that aspect, therefore affected their perception of service quality in some ways, and influenced their satisfaction.

Findings from research question 4 indicated that, caregivers apparently could not agree on the variables that constituted inherent barriers in this study. Nonetheless, they reported financial constrain and social factors as major barriers to caregiver utilization of service at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona–Duakwa,, Agona–Duakwa.

These findings from each of the research questions were discussed in themes (e.g. normalization / improvement outcome, provision of information, compliance and barriers), and these findings are not different or far from other findings of earlier researchers on similar subject. Generally, the findings showed that caregivers were satisfied with the services provided to them by the rehabilitation personnel at the Salvation Army

Community Rehabilitation and Orthopaedic Centre, Agona–Duakwa, hence all research questions are considered answered.

5.3. Conclusion

Caregivers of children with CP who utilize services on offer at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona–Duakwa, were satisfied with child improvement outcome, access to service and the process of care (responsiveness, assurance and empathy) of the rehabilitation personnel. They were also satisfied with the support systems made available to them. However, some caregivers expressed concern with some aspects of the service encounter such as provision of sufficient information on child's condition, caregiver involvement in decision making and participation in exercise regimes as well as timely and appropriate communication. This was because, caregivers felt rehabilitation personnel were lacking in that aspect, therefore affected their perception of service quality in some ways and influenced their satisfaction. These findings brought to light financial constrain and social factors as challenges that caregivers have to overcome as they utilize services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa. The study findings also supported assertion of works by earlier researchers that expectations though not an only factor, is a major factor and do influence caregiver satisfaction to a certain degree.

5.4. Recommendations

On the basis of the findings made, the following recommendations were made to reflect the four (4) guiding research questions;

- The Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona - Duakwa has to evaluate caregiver satisfaction with services as part of their internal quarterly and annual evaluations. This will help to capture the views of the numerous caregivers on the reported satisfaction they attain in utilizing services on offer at the centre. This will help them as management; begin to understand the demands placed on them by caregivers to provide services that are more satisfying and for policy purposes.
- It is also recommended that, there should be timely and appropriate communication. The personnel working on the child with CP must communicate the realities of the condition to caregivers' timely and in an appropriate manner. This will help rule out any unrealistic expectations, fears or uncertainties these caregivers might be harbouring as they utilize services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona-Duakwa. Again, personnel who lack the skills for communication have to take on the job training in the use of verbal and non-verbal cues and given appropriate information about the condition among other communication skills.
- Rehabilitation personnel are also to provide sufficient information on the child's condition and involve caregivers in decision making and allow them participation in exercise regimes.

Provision of sufficient information on the child's condition

Providing caregivers with sufficient information about the condition of their children should be done at the beginning of service utilization and also as they progress through the service encounter. This will help prepare their minds about what prospect and setbacks they are likely to encounter as they utilize the services. This would also help them to comply with particular do's and don'ts in the course of their utilization of services at the Salvation Army Community Rehabilitation and Orthopaedic Centre, Agona – Duakwa.

Caregiver involvement in decision making and participation in exercise regimes

The rehabilitation personnel should also involve caregivers in the rehabilitation process. This is because their involvement has been emphasized as a key principle of family-centred approach to rehabilitation; influencing satisfaction with services, most especially in rehabilitation programmes for children. They can also take up refresher courses on effective ways and means for engaging and impacting skills for carrying out home programmes to caregivers utilizing services at the centre.

- Caregivers are also to be confident in expressing agency-related barriers as they utilize services on offer at the centre. By so doing, the management of the centre will be aware of factors that might have a positive or negative effect on the caregivers', hence will put in place measures to resolve any inherent barriers caregivers encounter at the Centre and to increase the use of services and satisfaction.

5.5. Areas for further research/study

- Counselling services for caregivers of children with cerebral palsy in rehabilitation settings.
- Challenges of caregiving in the rehabilitation of children with CP.

- Factors predicting caregiver compliance/non-compliance in the rehabilitation of children with CP.

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APPENDIX A

CAREGIVER SATISFACTION INTERVIEW GUIDE

Duration: 30 minutes

Set the participant at ease: spell out purpose of interview.

A. Background:

- Self-introduction by the Researcher and the two final year students to assist in the interview to the caregivers, establishes rapport by asking how caregiver is feeling, explaining the purpose and importance of caregiver participation in the study.

Agreeing on the mode of data collection/instrumentation and assuring them of anonymity and confidentiality. And reassuring them of the freedom to withdraw from the study if they feel like opting out.

B. Caregivers prior expectations

1. Before coming to Agona - Duakwa Community Rehabilitation Centre, what where your expectations about the services and child's improvement? Any further thoughts (how).
2. What are your expectations now?
3. Overtime, what has changed in your expectations? How

- ***Probe for caregiver expectations in relation to the child's improvement and services available at the Centre.***

C. Enabling factors to service utilization

1. What information (name, type, causes, management and acceptance for unrecovery) did you receive about the problem of your child?
2. In what ways has the information received increased your understanding of the child's condition?
3. How have these understanding helped you to appreciate your child's problem and the accompanying consequences?
4. What home-based therapy package is made available for your child?
5. How helpful is the home-based therapy in day-to-day management of the child at home?

- ***Probe for sufficiency of information about the problem of the child and it relation to compliance.***

6. What would you say about the way the rehabilitation personnel receive or speak to you?

7. How respecting and caring is the experience?

8. What counselling/ education and have you received?

- ***Probe for the role of the rehabilitation personnel - the clarity of the explanations and understanding of information provided.***

9. What do you have to say about your involvement in decision-making about the home programmes?

10. How about involvement in therapeutic activities?

11. In what ways has this involvement help you keep your child at home?

12. What reasons do you think could account for the team's failure to involve you in decision making or allow you participate in therapeutic activities?

- ***Probe to find out the nature and degree of family-centred practices.***

13. What is your relationship with other caregivers like?
14. How often do you meet other caregivers (once a week/ month)?

15. How have these meetings helped you to appreciate and manage your child?

Probe for the effect of meeting other caregivers **D.**

Barriers encountered by caregivers.

1. What are some of the challenges (interaction, communication and attitudinal) you face in service utilization? ***Probe, any further explanations?***

2. What other challenges of service utilization would you like us to discuss?

- ***Probe to find out barriers of interaction, communication, attitudes and other challenges in service utilization.***

E. Satisfaction with services

1. What relations do you have with the child? (Biological/ non biological.)
2. What informed your choice of Agona – Duakwa rehabilitation centre for your child? How, any further explanation!
3. What services do you prefer -community services to hospital services and vice versa?
4. As a caregiver, what aspects/type (outpatient / inpatient) of community services received from Agona- Duakwa community rehabilitation centre are you okay with?