# DETERMINANTS OF PSYCHO-SOCIAL WELL-BEING OF INFORMAL CAREGIVERS OF PHYSICALLY CHALLENGED CHILDREN IN SOUTH-WESTERN NIGERIA

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# DECLARATION

I hereby declare that the thesis submitted for the degree of D. Social Science: Social Work at the University of Fort Hare is my own original work, that it has not been submitted to any other institution and that all the sources consulted or quoted are indicated and acknowledged by means of comprehensive references as presented in the references.

A.I. Oyeleke

# DEDICATION

This study is dedicated to the glory of God the Father, Son and the Holy Spirit whose grace and mercy and inspiration empowered me to accomplish this task. Secondly to the memory of my late father Pa Jacob Ajala Oyeleke. May he continue to rest in the bosom of Almighty God.

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# ABSTRACT

Informal caregiving denotes care that is provided by a family member or friend rather than by a professional who is reimbursed for services. Assuming a caregiving role can be stressful and burdensome. The effects of caregiving on the caregiver's health are moderated by individual differences in resources and vulnerabilities, such as socioeconomic status, prior health status, and level of social support.

This work describes the determinant of psycho-social well-being of informal caregivers of physically challenged children in southwest of Nigeria. This study is guided theoretically by Ryff"s psychosocial well-being theory, The study adopted expo facto research design. Multistage samplings involving the use of random and purposive techniques were used to select 812 respondents who are informal caregivers. Social support questionnaire, Social support satisfaction level, Ryff's psychological well-being scale were used.

Findings indicated that social support predicted psycho-social well-being of informal caregivers of physically challenged children. Social support and satisfaction level combine together have impact on psycho-social well-being of informal caregivers of physically challenged children. More also, socio-economic factors such as occupation, educational level and income also predict psycho-social well-being of informal caregivers. Finally, marital status and gender also contribute to well-being of caregivers.

It was therefore, recommended that social inclusion should be pursued with de-institutionalization of children with disability. Parents of children with disability should be encouraged to form support group and as well as encouraging fathers of children with disability to take an active part in ensuring their children with disability well-being. More also, there is need to empower informal caregivers through training and education. More importantly governments at the three levels ( Federal, State and local) should assist caregivers at ensuring their own and that of their children with disability well-being through improvement on various existing social welfare services in the country.

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# CHAPTER ONE

# INTRODUCTION

## Background to the Study

It is recognized that childhood disability is more prevalent in developing than industrialized countries with an estimated eighty-five percent (85%) of children with disabilities living in the developing world (Mont, 2007); disproportionately distributed among younger populations. It is based on this report that this study investigates the role of social support and socio-economic status of caregivers in psychosocial well-being of physically challenged children in the southwest of Nigeria. In most countries of the world, caregivers (both formal and informal) often provide assistance to other people who, because of physical disability, chronic illness, or cognitive impairment are unable to perform certain activities on their own. Formal caregivers are volunteers or paid care providers from several professions that provide care usually within a service system or palliative care institutions, but are not restricted to these settings (Collings, 2006).

Service systems might include for-profit or non-profit nursing homes, intermediate care facilities, assisted living, home care agencies, community services, hospices, church or charity service groups, adult day cares, senior centres, association services, state aging services and so on (Dan-Fisher, 2009). Informal care can be offered by family members, religious association members, social club members, neighbours, friends, paid or volunteer professional cares often in a home setting, the community or from institutions such as nursing facilities or government institutions (Family Caregiver Alliance, 2009).

The word caregiver in this study denotes the people who look after the well-being of physically challenged infants and young children. However, there is considerable controversy about the most accurate and appropriate term by which to denote the wide variety of people involved in regular care for the children. Some advocates used the term parent or parenting to denote long-term family care. Parenting embodies past and future perspectives and deep emotional involvement in the rearing and socialization of a young child. In these ways, it is distinguishable from the motives and activities of people involved in short term or professional care of children. Call et al., (1999) concluded that the term caregiver, used instead of mother, loses something essential to the core activities of what mothering care involves and which is precisely what young children need. The word caregiver does not capture the continuity and emotional commitment to a child that is part of parenting, and thus potentially obscures what might be latent features of childcare that are critical to healthy development.

Nevertheless, the term caregiver is preferred because many young children are not looked after by their biological mothers. Furthermore, with the exception of the earliest days of life, the care of young children is not limited to one person. Infants and young children frequently have several key caregivers, as occurs in many African societies, as well as in situations in which fathers, other relatives, siblings and friends participate actively in the care of young children. There is no evidence that biological mothers are more capable of caring for young children, apart from their role in breastfeeding, than fathers or other people who have a stable presence and are emotionally committed to the well-being of the child (Yee, & Schultz, 2000). There are other ways in which the term caregiver, as a single individual responsible for the care of one or more young children, may distort the understanding of the effects of care giving on the psychosocial well-being of physically challenged children. Physically challenged children are infants and adolescents who are suffering from motor, cognitive, communication and behavioural problems, resulting from trauma, brain and spinal cord injuries, congenital or progressive muscle, nerve and bone diseases, severe burns, orthopaedic or neurosurgical procedures, respiratory insufficiency, various feeding disorders (Hendriks, 2002).Physically challenged children can also be described as those certified by a specialist in any field of therapy as having one or more of the following disabilities: blindness, partial blindness, emotional disorder, deafness, partial hearing, physical handicap, speech defects, learning disability, social maladjustment, exceptionally gifted and mental retardation (Hendriks, 2002).

In view of the above, the importance of psychosocial well-being of physically challenged children has stimulated the attention of various experts, researchers and scholars of various fields in the areas of child development and rehabilitation. Rehabilitation is a process that leads to the restoration of a person to his or her fullest physical, social, vocational and economic usefulness of which he or she is capable.

In developing countries like Nigeria where there is absence of community or long term care, informal caregivers provide almost all care to people living with disabilities (Ducharme et al., 2005). In fact it is estimated that caregivers assume 70%-80% of all care and support given to people with disabilities (Bontout, Colin & Kerjosse, 2002; Wimo, Von Strauss & Nordberg, 2002; Lavoie, Guberman, Montejo, Lauzon & Pépin, 2003; Thompson, 2004). Informal caregiver's role to children with disability includes all activities that meet their physical, psychological and social needs. Although caregiving has been seen by many as a traditional domestic work role of women (Bowers, 1987; Lavoie, 2000; Levine & Hart, 2004), caregiving to physically challenged children carries more responsibilities that include providing emotional support and identity work, behaviour management, supervision of rehabilitation exercises, and other treatments, mobilisation and advocacy for services and other resources, mediation with various professionals, control of the quality of the care, decision - making for the person and the development of strategies for role conflict management (Guberman, & Maheu, 1999; Lavoie, 2000; Levine & Hart, 2004). Meaningful and effective rehabilitation of physically challenged children must end up with making them self-sustained and ensure psychosocial well-being.

Variability exist in the level of psychosocial well-being of physically challenged children in Nigeria as a function of family factors and as well as characteristics of the social environment. Perhaps the most pervasive factors influencing psychosocial well-being of physically challenged children are social support and socioeconomic status of caregivers expressed in the level of nutrition, healthcare, rehabilitation programme and facilities e.t.c (Underwood, 1998). Psycho-social well-being of physically challenged children simply explains the physical, social and behavioural comportments of infants and adolescents who are being diagnosed of one or more of motor, cognitive, communication and behavioural problems such as speech disorder, movement disorder, sight impairment, mental retardation, and Down's syndrome also called trisomy (Mutlu et al., 2011). Their rehabilitation could be achieved through the provision of effective rehabilitation services, which largely depend on social support and socio-economic status of caregivers. Available evidence however suggests that, social support and socio-economic status of caregivers may significantly play positive roles in the management of psycho-social well-being of physically challenged children (Cummins, 2001). Physically challenged children are children who have one form of disability or the other and as a result they lack ability to perform normal activities. Social support and socio-economic status may play an important role in mediating the outcome of care giving. Studies suggest that the greater the social support and socio-economic status the less stress the caregiver may have and the more effective the care giving to the psychological well-being of physically challenged children (Baillie, Norbeck, & Barnes 1988; Thompson, Futterman, Gallagher-Thompson, Rose & Lovett, 1993; Chen & Greenberg, 2004;). Caregiver decisions about the feeding of physically challenged children, their level of satisfaction with life, and willingness to seek advice during child illnesses, as well as the number of individuals available to assist with domestic tasks, are caregiving characteristics associated with social support and socio-economic status (Cummins, 2001). Informal caregiving to children with disability goes without pay despite its contribution to the psycho-social well-being of the recipient (Talley & Crews, 2007).

Family members are usually the caregivers for their disabled member (Freedman & Boyer, 2000; MacDonald & Callery, 2007). However due to the changes that have occured in the family structure there is need for family to be assisted in the care of disabled members. Fewer old adults and children exist to give support in contemporary family (Cummins, 2001). Peculiar characteristics of children with disability demand for various support mechanisms for informal caregivers (Freedman & Boyer, 2000; Damaini, Rosenbaum, Swinton & Russell, 2004). Support programme has the ability to equip the family with necessary tools for caregiving and also ensure caregivers' well-being (Heller et al., 1999). Studies have revealed impact of social support on the health outcomes of caregivers (Fowler & Christakis, 2008). Individual roles as parent, child, co-worker, church goers in society connect them to social support networks that improve their well-being. Social support results in less stress for family caregivers (Heller et al.,1999). In reducing the burden of care among caregivers different supportive mechanisms have been found to be effective in promoting the psycho-social well-being of caregivers. One such programme is the respite care. Shaw et al., (2009) found positive health outcomes on caregiver's depression and anger towards the care recipient as a result of respite care use. It also decreases caregiver's burden (Mason, Weatherly, Spilsbury, Arksey & Golder, 2007). Psycho-social support that includes education, skill-building, counselling, information and emotional support impacts on the caregivers' coping ability (Cassie & Sanders, 2008). Technology based support programmes such as telephone and computer services were found to reduce caregivers' depression, burden, and anxiety and promote optimal coping (Magnusson, Hanson & Borg, 2004).

Caregivers' characteristics such as socio-economic status may influence the children's nutritional status even when socio-economic status is controlled. Zeitlin, Ghassemi & Mansour (1990) similarly concluded that the social support and socio-economic status of caregivers are important variables influencing child growth, especially in low income families living in deprived conditions. Socioeconomic status (SES) is often measured as a combination of education, income, and occupation. It is commonly conceptualized as the social standing or class of an individual or group. SES affects overall human functioning, including physical and mental health. Low SES and its correlates, such as lower education, poverty, and poor health, ultimately affect society as a whole. Some data suggest causal relationships between low SES and the development of disability in late adulthood (Cooper et al., 2008). These barriers contribute to discrepancies in wealth and socioeconomic opportunities for persons with a disability and their families. Interest in the processes by which children cope with various forms of disability or illness is one of the emerging areas of study in recent years (Andersson & Hägnebo, 2003; Fugl-Meyer & Oberg, 2008).

People often think of those who provide care as trained doctors, nurses and other health care personnel. But, when a person has a chronic illness or physical disability in which the basis of his or her medical care is assistance with eating, bathing, dressing, shopping, transportation etc., a family member or friend is often qualified to assist in these daily activities and often takes on the informal role of the primary caregiver (Guberman et al., 2009).

In Nigeria, there are no available statistics of the number of informal caregivers but it is estimated that there are millions of informal caregivers in Nigeria who care for their children with severe disabilities well into caregivers or children. The roles that informal caregivers play are not only important to the people for whom they provide care, but also the overall economy of the nation (National Alliance for Caregiving & AARP, 2008). Informal caregiving comes with many personal rewards and satisfaction, but also with emotional, physical, and financial challenges (Cummins, 2001). Informal caregivers often go unnoticed and with less than adequate support at the local, state and national levels. It is vital that the leaders from all realms of society from public officials and policy makers, to clergy and educators, to the community-at-large, work together to provide recognition and assistance to the informal caregivers that play such an important role in society. In some cases, while one person takes on the role as the primary caregiver, others who are close to the caregiver or the one who is providing care can work out a schedule to offer supplemental assistance to the caregiver. The caregiver can take this time to attend to his or her own needs and obligations (designated respite time), and the person receiving care can look forward to weekly visits from others that expand their social circles (Carretero, Garcés & Rodenas, 2007). In addition to having others come into help with the daily care of a physically challenged child, weekly in-house gatherings with others can help alleviate feelings of depression and boredom for both caregivers and care recipients. Often both the caregiver and the person for whom they provide care can feel trapped in their home and/or immediate community, but there are options. Informal caregivers often derive satisfaction and fulfilment from their physically challenged children. However, care giving can be a physically and emotionally exhausting job, and people who provide care to their disabled children often do not receive the training, guidance or support necessary to carry out their responsibilities effectively (Guberman et al., 2005). The fact that caring for relatives children who are physically challenged is not considered an " official job", informal caregivers often do not know who to contact for information and support for both themselves and for those for whom they provide care. In addition, because their role as a caregiver is considered voluntary, the federal, state and local resources to assist them have traditionally been quite limited.

The caregivers' social support and socio-economic status influence on psycho-social well-being of physically challenged children are under-observed and therefore called for more intensive scientific investigations. The term psycho-social well-being is used nowadays in the literature to refer to a wide range of issues including, but not limited to, mental, emotional, social, physical, economic, cultural, and spiritual health and, consequently, it has been defined in numerous ways. According to Valeria (2010) psychosocial well-being has four dimensions which are subjective well-being related to every day's events, subjective well-being related to faculty events, psychological well-being and social well-being. Researches on psycho-social well-being have been divided into two perspectives which are the *hedonic* approach and the *eudemonic* approach. The first approach defines psychosocial well-being as when one is happy, having pleasure and absence of pains (Bradburn, 1969; Diener, 1984; Diener, Emmons, Larson, & Griffin, 1985). The second approach equates psychosocial well-being with human potential which when fully achieved leads to effective human functioning in life (Diener, 1985; Ryan & Deci, 2001). Different studies agreed that well-being is multidimensional and includes three dimensions which are subjective, psychological and social and they are in themselves also dimensional (Valeria, 2010). Subjective well-being according to Diener, Lucas and Osihi (2005) refers to a person's cognitive and affective evaluations of his or her life. Subjective well-being composes of two main components which are a cognitive (satisfaction) and an affective (pleasant affect and low levels of unpleasant affect) (Bradburn, 1969; Andrews & Withey, 1976; Diener, 1984; Diener et al., 1985).

There are other definitions of subjective well-being which includes that of Seligman (2002) who, defines well-being by distinguishing between feelings of meaning, pleasure (including happy, emotions), and engagement (interest and "flow") and view subjective well-being in terms of happiness with a substructure consisting of:

1. Pleasure (or positive emotion);
2. Engagement;
3. Meaning.

Subjective well- being is also defined as getting involved in interesting activities that ensure equilibrium between challenge and skills (Csikszentmihalyi, 1990). The eudemonic proponents have also argued that well-being goes beyond experiencing more pleasure than pain but rather a striving for perfection and achieving full potential in life. Ryff (1989); Ryff and Singer (2005) affirmed that subjective well-being is a valid indicator of well-being which was not created to define psychological well-being. Ryff (1989) therefore proposed a concept of psychological well-being *that is* multidimensional and consists of six distinct facets:

(a) Positive attitude toward oneself (self-acceptance);

(b) Satisfying relationships with others (positive relationships with others);

(c) Independence and self-determination (autonomy);

(d) Sense of mastery and competence (environmental mastery);

(e) Sense of goal directedness in life (purpose in life);

(f) Feeling of personal continued development (personal growth).

Keyes (1998) defines social well- being as people evaluation of their situations and human functioning in the society. The model is multidimensional and consists of five dimensions which measure the extent of individual social functioning. They are:

(a) Social integration (individuals' appraisal of the quality of their own relation with society and community);

(b) Social contribution (the feeling of being a vital member of the society, with something important to offer to the world);

(c) Social acceptance (trusting others, and having favorable opinions about human nature);

(d)Social dimensions of students' psychosocial well-being and their measurement actualization (the evaluation of a society's potential to improve);

(e) Social coherence (the perception of that the social word is well-organized). Although the term psychosocial well-being has been defined in so many ways, there is a general consensus that a good definition must relate together all the various dimensions of overall well-being (Linley et al., 2009).

The materials, biological and psychosocial aspects of well-being are integrally related and depend on many factors. The overlapping circles suggest that individual and collective well-being depends on what happens in a variety of areas, and meeting at least some minimal level of need in each of these areas is necessary, and that these areas are to some extent interrelated. Thus, the psychosocial well-being of informal caregivers thus refers to the physical, social and behavioural comportments of parents and family members of a disabled child.

More also, well-being is postulated to combine 'life satisfaction' or how people think their lives turned out to be, and 'affect' or what they feel about their lives. Well-being is related to personal satisfaction, engagement, hope, gratitude, mood stability, meaning, self-esteem, resilience, contentment and optimism. It involves recognising individuals' strengths and developing their interests and talents. This leads to being creative, playful, and involved in what they are doing.

## 1.2 Statement of Problem

A number of studies have been conducted to identify antecedents of psychological well-being among formal and informal caregivers. However, the impact of perceived social support and socio-economic status on psychosocial well-being of informal caregivers caring for physically challenged children has not been given adequate attention, especially in Nigeria, and therefore called for more intensive scientific investigations (Department for International Development (DFID), 2008). In Nigeria, though there is availability of formal care giving system, the balance seems tilted more towards informal care giving because of the low number of formal care giving centres, the number of staff, quality of services rendered, and their proximity to their intended users. Yet, the World Health Organisation (WHO) has estimated that there are approximately 19 million physically challenged people living in Nigeria (DFID, 2008; Okoye, 2010). In the absence of functional formal care giving system, this number may have to depend largely on a small percentage of the population of Nigerians over the age of 18 who provide unpaid social support to children with disabilities or special health needs of children who live in the community and who have limited ability to carry out daily activities (e.g., bathing, managing their medication or preparing meals). Not surprisingly, anecdotal evidences and literature have shown that majority of the physically challenged children and adults in Nigeria have poor psycho-social wellbeing and social outcome mainly due to psychological, physiological, and socio-economic circumstances of the caregivers (DFID, 2008; Okoye, 2010). The implication is that the process of rehabilitating people who because of physical disability, chronic illness, or cognitive impairment are unable to perform certain activities on their own becomes a challenging one for the informal caregivers. This is because meaningful and effective rehabilitation of physically challenged, children goes hand in hand with psychological state of the helpers (Liu et al., 2011). Most carers experience some degree of deterioration in their general health or well-being after taking on a care giving role (Okhakhume, 2007). Indeed, care giving has been associated with chronic fatigue, sleeplessness, stomach problems, back pain, elevated blood pressure, poor immunity system functions, viral illnesses, and increased health care use (Wilfred, 2005).

Perhaps the most pervasive factors influencing psycho-social well-being of physically challenged children are social support and socio-economic status of caregivers expressed in the level of nutrition, healthcare, rehabilitation programme and facilities etc (Underwood, 1998). Underestimating the role of social support and socio-economic status in ensuring psycho-social well-being of informal caregivers may create barriers to the development of interventions and rehabilitation of physically challenged children. Based on this assumption, this study investigates the role of social support and socio-economic status in psychosocial well-being of informal caregivers caring for the physically challenged children in south-western Nigeria. In this study, socio-economic factors are used to describe social classification that predisposes an individual to a particular class in the society. It is commonly indicated by someone's occupation, income and educational level.

## 1.3 Aim of the Study and Specific Objectives

The general objective of this study is to investigate the role of social support and socio-economic status as determinant of psycho-social well-being of informal caregivers of physically challenged children in special schools.

The specific objectives of this study are as follows:

- To investigate the impact of social support on psycho-social well-being of informal caregivers of physically challenged children in special schools.
- To examine the role of income on psycho-social well-being of informal caregivers.
- To assess the impact of occupational status on psycho-social well-being of informal caregivers.
- To investigate the impact of educational level on psycho-social well-being of informal caregivers.
- To examine the role of marital status on psycho-social well-being of informal caregivers.
- To assess the impact of gender on psycho-social well-being of informal caregivers

## 1.4 The Research Questions

To better explore the impact of social support and social-economic status, and the associated factors that influence the ability of caregivers to provide care services, previous studies have advocated that research trends on well-being should lay more emphasis on the quality and quantity of social support services available to caregivers as well the socio-economic status of caregivers. Perhaps these variables may be the major determinants of the psycho-social well-being of the physically challenged children.

In view of the above, the present study seeks to provide answers to the following research questions:

- What is the impact of social support on the psycho-social well-being of informal caregivers and how satisfy are they with the support?
- To what extent does occupational status contribute to psycho-social well-being of informal caregivers?
- How does family income contribute to psycho-social well-being of informal caregivers?
- In what way does the level of education contribute to psycho-social well-being of informal caregivers?
- How does marital status contribute to psycho-social well-being of informal caregivers?
- What is the significance of gender in psycho-social well-being of informal caregivers?

## 1.5 Relevance of Study

Physically challenged children need affection and attention to be able to have a sound mental and psycho-social well-being and a successful life. Through combined efforts, they could be trained to build their self-esteem and to achieve a sound state of psycho-social well-being. Research evidence abounds from many fields of study that the care and support received by physically challenged children in terms of good health, nutrition and psycho-social care and protection are crucial in the formation and development of intelligence, personality and social behaviour.

In view of this, findings in this study will enhance the understanding of the importance of caregivers' socio-economic status and support to the psycho-social well-being of the physically challenged children. Findings from this study will also extend the knowledge frontiers through enhancing the relationship between caregivers' social support, socio-economic status and physically challenged children's psycho-social well-being.

This study will also facilitate improved government and non-government organisations' support for the physically challenged children in Nigeria and help the nation in maximizing the utilization of her human resource. This study would be of great significance for both future practice and future research. In terms of practice, several constituencies like governmental and non-governmental organizations, professionals such as social workers, psychologists and mental health practitioners might benefit from the results.

## 1.6 Scope of the study

Three South-western states of Nigeria were chosen as the setting for the study. These states are predominantly inhabited by the Yoruba speaking group of Nigeria. Historically the Yoruba people have been the dominant group on the west bank of the River Niger. Their nearest linguistic relatives are the Igala who live on the opposite side of the Niger's divergence from the Benue, and from whom they are believed to have split about 2, 000 years ago (Iloje, 1989). The Yoruba were organized in mostly patrilinear groups that occupied village communities and subsisted on agriculture. From approximately the 8th century A.D., adjacent village compounds called *He* coalesced into numerous territorial city-states in which clan loyalties became subordinate to dynastic chieftains. Urbanization was accompanied by high levels of artistic achievement, particularly in terracotta and ivory sculpture and in the sophisticated metal casting produced at Ife.

The Yoruba believe in a Supreme Deity, called *Olorun,* and 400 lesser deities who perform various tasks. *Oduduwa* is regarded as both the creator of the earth and the ancestor of the Yoruba kings. According to one of the various myths about him, he founded Ife and dispatched his sons and daughters to establish similar kingdoms in other parts In Nigeria alone, Yoruba land included about 40 million estimated populations (Iloje, 1989).

The former western state of Nigeria was formed in1967 when the western region was subdivided into the states of Lagos and western states. Its capital was Ibadan, which was the capital of the old region. In 1976 the state was subdivided into three new states, Ogun, Ondo and Oyo. Educationally south west is the most developed and this is where most of the special schools were located. Lagos which was the former capital of Nigeria and Ibadan the former capital of the old western region are located in the south west Nigeria and boast of many special schools than any other states in Nigeria (Iloje, 1989). As a result of this, parents of physically challenged children from other parts of Nigeria send their disabled children to all the various special schools both in Lagos, Oyo and Ondo states. The participants in the research study included selected informal caregivers of children with physical disability in various special schools in south western states of Nigeria that include Lagos, Oyo and Ondo states.

## 1.7 Structure of the thesis and chapter outline

The study is grouped into seven chapters, each with a short introduction to give the reader a preview of what to expect in the study and how the chapters relate to one another.

### Chapter 1: General overview of the study

This chapter covers background to the study, statement of problem, aims and objectives, research questions and significance of the study, scope and structure of the thesis and chapter outline.

### Chapter 2: Conceptualization and theoretical framework

This chapter is referred to as conceptualization and theoretical framework which considers the definitions of various concepts used and the theoretical framework upon which the study is built.

### Chapter 3: Social support and informal caregiving

Social support and informal caregiving is the title of chapter three. It covers review of relevant studies in the area of social support and informal caregiving by various authors that have been found to be very useful to this study.

### Chapter 4: Methodology

This chapter deals with method utilized in conducting the research which includes research design, study area, study population, research instrument, validity and reliability, research procedure, method of data analysis, ethical consideration and relevance of the study.

### Chapter 5: Findings of study

It covers the result of findings on the field in form of tables and brief explanation thereof. This chapter covers social support, education, occupation, income, marital status and gender of informal caregivers. These variables were examined to determine the role they play in the psycho-social well-being of informal caregivers.

### Chapter 6: Discussion of findings

The chapter covers the discussion on the findings of the impact of social support and socio-economic factors on the psycho-social well-being of informal caregivers of physically challenged children.

### Chapter 7: Summary of findings, conclusions, implications for the study, recommendations and limitations of study.

This chapter deals with summary of findings, conclusions, suggested framework for dealing with informal caregivers and recommendations. The summary of the findings was presented according to the research questions from where the conclusions of the study will be drawn. The author suggested a framework that will cater for the psycho-social well-being of informal caregivers and specific recommendations made to policy makers, caregivers and other practitioners in the area of physically challenged children. Some suggestions for further studies were also presented.

# CHAPTER TWO

# CONCEPTUALIZATION AND THEORETICAL FRAMEWORK

## 2.1 Introduction

In this chapter some basic concepts that were used in the study were reviewed such as social support, socio-economic status, informal caregiver, and physically challenged children and psycho-social well-being together with theories used in the study. In explaining how a caregiver's psycho-social well-being is affected, the following theories are found to be suitable: subjective wellbeing, psychological wellbeing, social support theory, social well-being, capability theory and models of disability theories (social, economic and individual).

## 2.2 Conceptualization

Under this sub-heading, concepts such as social support, socio-economic status, informal caregiver, physically challenged children and psycho-social well-being were reviewed because they were the variables under discussion in this study. More also, for the purpose of giving definitions to these concepts so as to give their meaning as they were used in the study.

### 2.2.1 Social Support

Social support refers to the "verbal and non-verbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioural effects on the recipients (Gottlieb, 1983).This conceptual definition was further broken down to make distinctions between different categories of social support (Antonucci & Jackson, 1990; Heller, Price, & Hogg, 1990). The types of social support include instrumental, emotional, informational, tangible aid, positive social interaction, affection, and esteem (Yu, Lee & Woo, 2004).Social support has been identified to play a significant role in individual's well-being (Mikulincer & Florian, 1998; Kahn, Hessling & Russell, 2003;), such as mental health (Sayal et al., 2002) and the progress of a variety of chronic disease conditions (Heckman, 2003; Bisschop , 2004 & Garssen, 2004).Hogan, Linden and Najarian, (2002) and Rhodes, (2004) suggest that individuals with more supportive families or friends have a better health status and they recover faster from health problems, compared to persons who are less socially integrated.

Parental social support is viewed as a mediator and coping resource with both main effects and buffering effects. The impact of the main effect is limited to family well-being, with the assumption that social integration and a sense of belonging contribute to a family's sense of wellness. Emotional and esteem support, concrete aid, and problem solving have both direct and indirect buffering effects on family well-being and quality of life. These dimensions include the structural characteristics of the informal social networks from which social support emanates, the types of supportive activities or behaviours exchanged by network members, and the informal social network members' subjective evaluations of the supportive behaviours and relations that occur between network members (Lakey & Cohen, 2000 &Krause, 2001;).

It is important to note a distinction between formally and informally provided social supports. Formal social support is defined here as assistance provided by paid helpers or volunteers who are affiliated with social or health service agencies. Informal support, is defined as assistance provided by family members or friends based upon feelings of affection or personal obligation toward the recipient(s) of the assistance. Informal social support activities may take many forms such as concrete assistance with personal or household tasks, the provision of monetary assistance or other resources, advice or guidance, companionship, and the provision of emotional encouragement. Throughout this thesis, the term social support refers to the types of social support exchanged by members of informal social networks.

Social support has been found to influence a variety of complex human behaviours and the way people perform their social roles. It is one of the most important factors in predicting the physical health and well-being of everyone, ranging from childhood through older adults. The absence of social support shows some disadvantage among the impacted individuals. In most cases, it can predict the deterioration of physical and mental health among the victims. The initial social support given is also a determining factor in successfully overcoming life stress. The presence of social support significantly predicts the individual's ability to cope with stress (Corey, 2005). Knowing that they are valued by others is an important psychological factor in helping them to forget the negative aspects of their lives, and thinking more positively about their environment. Social support not only helps improve a person's well-being, it affects the immune system as well. Thus, it is also a major factor in preventing negative symptoms such as depression and anxiety from developing. Mothers with children who have permanent and chronic diseases usually become overwhelmed with all of the demands. They often feel burdened because it takes too much responsibility to take care of disabled children and meet such social demands as work at the same time (Corey, 2005). The availability of social support from others, especially family members, helps the affected mothers to adjust to environmental demands (Horton & Wallander, 2001). Therefore, according to this study, social support is used to describe assistance giving by friends, neighbour, co-workers, family members and people around an individual. It ranges from financial, psychological, physical, and spiritual and information etc. Social support could be formal or informal.

### 2.2.2 Informal Caregivers

Informal caregivers refer to an unpaid family member, friend, or neighbour who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Charlton, 1992). For centuries, family members have provided care and support to each other during times of illness.

Recent surveys estimate there are 44 million caregivers over the age of 18 years (approximately one in every five adults) (AARP, 2004). The economic value of their unpaid work has been estimated at $257 billion in US dollars (Arno, 2002). Although both men and women are involved in care giving, women predominate in both the numbers involved and the nature of their contributions. The Majority of caregivers are women who handle time-consuming and difficult tasks like personal care (DHHS & DOL, 2003). Caregivers spend a substantial amount of time interacting with their care recipients, while providing care in a wide range of activities. This is a day-in, day-out responsibility. More than half of family caregivers provide 8 hours of care or more every week, and one in five provides more than 40 hours per week (AARP, 2004).

Most researchers in the caregiving field conceptualize the care that family members give as assistance with activities of daily living and instrumental activities of daily living. But those concepts do not adequately capture the complexity and stressfulness of care giving (Reinhard, 2004). Caregivers are sometimes pressured into the role because they are perceived by others in the family as being available or having more time. Family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from the formal health care providers. (Stewart & Archbold, 2000; Bucher, Loscalzo & Zabora, 2001; Scherbring, 2002).

Nurses and family caregivers rarely agree about specific needs or problems during hospital admission or discharge, (Rose, Bowman & Kresevic, 2000) in part because nurses are often unaware of the strengths and weaknesses of both the patient and caregiver. Due to inadequate knowledge and skill, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed. Family caregivers may not know when they need community resources, and then may not know how to access and best utilize available resources. (Given, Given & Stommel, 1994). As a result, caregivers often neglect their own health care needs in order to assist their family member, causing deterioration in the caregiver's health and well-being. (Given, et al. 1994; Jepson, McCorkle, Adler & Ostrove, 1999; Schulz & Beach, 1999). Therefore, caregivers are parents or family members rather than a professional who care for children who cannot manage everyday living without help or support.

### 2.2.3 Psycho-social well-being

The term psychosocial underscores the close connection between psychological aspects of human experience (e.g., thoughts, emotions, and behaviour) and wider social experience (e.g., relationships, traditions and culture). Mental disorders, which often benefit from clinical treatment, tend to involve severe psychosocial difficulties in managing thoughts and feelings, maintaining relationships, and functioning in expected social roles. However, many psychosocial problems do not require clinical treatment but are rooted in stigmatization, lost hope, chronic poverty, uprooting, inability to meet basic needs, and inability to fill normal social roles such as that of disability. Well-being is a condition of holistic health in all its dimensions: physical, cognitive, emotional, social, and spiritual. Also a process, well-being consists of the full range of what is good for a person: participating in a meaningful social role; feeling happy and hopeful; living according to good values, as locally defined; having positive social relations and a supportive environment; coping with challenges through the use of appropriate life skills; and having security, protection, and access to quality services (Diener, Lucas & Osihi, 2005).

### 2.2.4 Physically challenged children

Physically challenged children are referred to as children who have many restrictions or lack ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being (Altman, 2001). People with disabilities have been treated in many different ways, most of it is not positive though with physical and behavioural problems have been exposed to a variety of treatment ranging from their beloved mascot, looked upon as freaks, ridiculed to being marked for extermination (WHO, 2012).

Research has shown that although all societies are similar in basic ways, they do not treat people with disabilities the same, it can range from outcasts, to high social status, however this depends on the amount of economic surplus (Funnell, Rita, Gabby & Karen, 2008). Westat Corporation (1993), reported that even within religion, in certain sections of the Old Testament disability was seen to be something unclean and polluting contrary to the New Testament that taught about charity towards people with disabilities. As far back as the medieval period, people with disabilities were seen as being related to Satan and countless mothers that gave birth to children with disabilities were burnt as witches (Baladerian & Nora, 1998).

### 2.2.5 Socio-economic status

The socioeconomic status is the measurement of the level of income each person has to determine their level of economic status in society. Individuals with low socioeconomic status also tend to have less self-control. Consequently, they become more sensitive to stressors in their environment and less able to control their reactions (Corey, 2005).Financial adequacy is important to all family caregivers. Policymakers should consider potential strategies to provide better financial support to family caregivers (Lai & Leonenko, 2007).

Gender is a strong predictor of becoming an unpaid caregiver. Women are far more likely than men to assume the role of unpaid caregiver in families and communities. According to projections from the Bureau of Labour Statistics (2012), women will make up nearly half of the workforce forty-seven percent (47%) by 2014, and they will make up fifty-one percent (51%) of the new additions to the labour force, between 2004 and 2014. With this projected increase in female workforce participation, and given that females make up the majority of all caregivers, care giving will pose financial challenges for many female workers as a consequence of lost wages from reduced work hours, timeout of workforce, family leave, or early retirement (Family Caregiver Alliance, 2008). Although men also provide assistance, female caregivers may spend as much as fifty percent (50%) more time providing care than male caregivers (Family Caregiver Alliance, 2008).

## 2.3 Theoretical framework

According to Larxer (2008), theory is a set of assumptions, propositions, or accepted facts that attempts to provide a plausible or rational explanation of cause-and-effect (causal) relationships among a group of observed phenomena. The word's origin (from the Greek *thorns,* a spectator), stresses the fact that all theories are mental models of the perceived reality. In this section relevant theories are reviewed to give a better understanding of the phenomenon under discussion in this study

### 2.3.1 Social support theory

Barnes (1954) was the first to describe patterns of social relationships that were not explained by families or work groups. Cassel (1976) found a relationship with health. Social support served as a "protective" factor to people's vulnerability on the effects of stress on health. Social networks are closely related to social support. Nevertheless, these terms are not theories per se. Social support and social networks are concepts that describe the structure, processes and functions of social relationships. Social networks can be seen as the web of social relationships that surround individuals.

Social Support is associated with how networking helps people cope with stressful events. Besides it can enhance psychological well-being. Social support distinguishes between four types of support (House, 1981). The first type of support is emotional support associated with sharing life experiences. It involves the provision of empathy, love, trust and caring. Secondly, instrumental support involves the provision of tangible aid and services that directly assist a person in need. It is provided by close friends, colleagues and neighbours. Informational support is a third type of support which involves the provision of advice, suggestions, and information that a person can use to address problems. Finally, appraisal support involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison. Social relationships have a great impact on health education and health behavior.

Shumaker and Bronwell (1984) define social support as an exchange between two people with the perception from either party that the exchange is aimed at the positive outcome for the receiver. This definition is different from that of Cassel (1976) in that in it is embedded the concepts of exchange, perceptions and outcome. This definition suggests that the word perception and outcome of the exchange may be positive, negative or neutral and it does not see support coming only from a network of relationships. According to the authors, support exchange involves costs and benefits for the participants and reference is made to Cobb (1976) that component of social support network is mutual obligations and Gottlieb (1983) on the inequity in supportive relationships. Further reference is also made to the concepts of reciprocity by Gouldner (1960), and indebtedness by Greenberg (1980) which are very important in social support. Reciprocity means the return of earlier received benefits and can be influenced by the recipient's perception of the cost, intention and the extent to which the benefit is of assistance to the recipient (Gouldner, 1960; Shumaker & Jackson, 1979).A recipient at times could reject benefit or reciprocate it directly Castro (1974) because of feeling of indebtedness; however, it is uncommon to reject benefit due to societal pressure even when the recipient cannot reciprocate (Greenberg, 1980). Rejection of benefit can also be in the form of deriding the provider (Castro, 1974; Gross & Latoni, 1974; Shumaker & Jackson, 1979), giving help to different person when they cannot reciprocate Kahn & Tice (1973) and decreasing their perception of indebtedness by re-evaluating the benefit (Shumaker & Jackson, 1979).

The implication of reciprocity model is that firstly, people are less likely to seek assistance or accept it when they know that they cannot reciprocate. Secondly, lack of reciprocity may lead to diminishing relationship between a provider and recipient and thereby cause weakening of social ties (Shumaker & Bronwell, 1984). However this negativity can be minimized through making a provider have a sense of equal contribution to the need of the recipient, recipient can assist a neutral person and replacing informal helper with formal helper such as social worker, psychologist, clergy and therapists (Dunkel-Schetter, 1984). This replacement is of importance because, formal professional do not expect reciprocity like the informal helper. Apart from this, they do not become threatened by the needs of the recipient and are in a better position to provide necessary and adequate information to the recipient (Shumaker, 1983).

Chesler and Barbarin (1984) express limitation as to how exchange concept could be used in explaining social support. The fluidness of giving and receiving help do not allow for viewing social support from economic point of cost / benefit and more also value cannot be fixed for assistance provided to a loved one. An individual decides to help when he/she sees the need to do so, sees an emergency situation and has the capacity to offer the necessary assistance (Latane & Darley, 1970; Latane & Nida, 1981).
The implication of this, according to the authors, is that there is need for recipient to seek for help and also the helper ability and willingness to see the helpless situation of the recipient which is determined by provider's social skills, mood and value (Raven & Rubin, 1983). The definition also implies that there are two people in relationship; the influence of the relationship for support and two different views of what is social support. Social support does not only occur among a network of friends and relatives as it is usually believed, but could also involve strangers such as the smile or friendly greeting from a passing stranger or acquaintance, which is interpreted as a form of mutual nurturance. Strangers in this context are anyone that is outside the network of social relationship and provide support. A non network member could be a fellow passenger on an airplane, another patient in a doctor's waiting room, the patron at a bar. Support from this set of people can be rewarding *because* of the anonymity of the participants (Rubin, 1973; Spinner, 1978). This theory provides alternative source of support to informal caregivers in a situation where they find it difficult to reciprocate support from close relatives. Caregivers can turn to professionals such as social workers, psychologists, nurses and physiotherapists for support in caring for their children with disability.

Social support is a communication process that takes place between the provider and the recipient. It has different forms such as financial, psychological and physiological help that promote coping strategy which lead to well-being of an individual (Junker & Shutterstock, 2011).The concept of social support is also defined as the function of social relationships. Social Support theories established the linkage between social support provided and health outcomes. There are two main theories in social support theories: Direct effect theories and stress-related theories. Direct effect theories stress the rewards of receiving social support based on social identity, social control, or loneliness models (Uchino, 2004). According to the social identity model, social support has a beneficial value on psycho-social wellbeing when recipients are part of social network that gives individuals meaningful roles that give self-esteem and increase the meaning of life, which in turn affects the well-being of support recipients (Thoits, 1983). Secondly, social support also has positive value on well-being when an individual is involved in a social networking capable of placing pressure on people to embark on healthier behaviours by giving individuals tangible roles that enhance an obligation to life (Lewis & Rook, 1999). Thirdly, loneliness model states that loneliness is related to negative health outcomes for the reason that loneliness affects self-esteem, meaning of life, and obligation to life. This may lead to negative health behaviours such as smoking and the intake of alcohol (Stroebe & Stroebe, 1996).Buffering model of social support revealed that social support is healthy because it lessens the negative impact of stress on health (Cohen & Herbert, 1996). Stressors such as bereavement and daily hassles have serious psychological implication for health and can be reduced through social support. So during an extreme stressful situation like death of a spouse, social support acts as buffers and promotes coping strategies. It can further play a preventive role (Uchino, 2004).

Social support theory is a theory that gives the researcher a basic idea of the importance of social relationships as it lessens the effect of stress on human health. Social support is very essential to individuals passing through a difficult situation to cope with such situations and also could serve as a preventive method to stressful situations. The social support theory therefore, formed part of the framework for this study to explain social support as predictor of psycho-social well-being of informal caregivers in south west of Nigeria. There is no theory adequately explaining the link between social relationships and health. Closely related to health components of social relationships are social integration, social network and social support (Berkman et al., 2000). Social integration has been used to refer to the existence of social ties. Social network refers to the web of social relationships around individuals. Social support is one of the important functions of social relationships. Social networks are linkages between people that may provide social support and that may serve functions other than providing support (Glanz, Rimer & Lewis, 2002). There is also no theory adequately explaining the link between social support and psychological well-being. This shortcoming informs the inclusion of other theories to be employed in this study; Ryff's Psychological Well-Being theory, social well-being, subjective well-being, capability theory, economic, social and medical model theories of disability.

### 2.3.2 Subjective well-being theory

Subjective well-being (SWB) theories refer to wellbeing as the individual's current evaluation of his/her happiness. Such an evaluation is often expressed in affective terms; "I feel good" (Schwartz & Strack, 1999). Cheng and Lam (2010) have identified that subjective well-being has three main components: life satisfaction, positive effect and negative effect. Subjective authors identified correlates and determinants of Subjective well-being, classifying them in six broad groups:

(i) personality factors;

(ii) contextual and situational factors;

(iii) demographic factors;

(iv) institutional factors;

(v) environmental factors; and

(vi) economic factors.

Well-being may be evaluated by examining its cognitive and affective dimensions. If one frequently experiences a high level of life satisfaction and positive effect, and seldom experiences negative effects, then it could be said that one has a high level of subjective well-being. In contrast if one is seldom satisfied with one's life and frequently experiences negative effects, one can be said to have a low level of subjective well-being (Diener & Diener, 1997). Thus, the existing body of evidence suggests that subjective happiness within disability is a mix of internal characteristics and that of external factors that mitigates it. For example, most people define themselves as being happy, regardless of their material wealth (Diener et al., 1996) while extremely minor incidents, influence estimate of subjective well-being (Schwartz & Strack, 1999). Most people assume that the external circumstances of others are powerful determinants of subjective well-being, in spite of the fact that such circumstances may have little effect on their own subjective well-being (Schkade and Kahneman,1999). Though disability can have lasting and quite large effects on subjective well-being the presence or absence of good care giving experiences will definitely moderate the people living with disability and their caregivers' perceptions and experiences of wellbeing.

### 2.2.3 Ryff's psychological well-being theory

Ryff’s (1989) positive criteria of mental health, which offer extensive descriptions of what it means to be in good psychological health were generated to replace definitions of well-being as the absence of illness. Ryff (1989) regardswell-being as ideal mental health (indicates efficient in self-perceptions, realistic self-esteem and acceptance, voluntary control behavior, true perception of the world, sustaining relationship and giving affection, self-direction and productivity). Ryff and Keyes (1995) point out that there is more to being well than feeling happy, content and satisfied with life. Ryff (1989) identifies multiple frameworks for positive psychological functioning and came up with the core dimensions of an alternative formulation of psychological well-being. She suggested a six psychological dimensions that includes positive evaluations of oneself and one's past life (Self-Acceptance), a sense of continued growth and development as a person (Personal growth), the belief that one's life is purposeful and meaningful (Purpose in Life).

The possession of quality relations with others (Positive Relations With Others), the capacity to manage effectively one's life and surrounding world (Environmental Mastery), and a sense of self-determination (Autonomy) (Ryff & Keyes, 1995). Psychological well-being, therefore, involves perception of engagement with existential challenges of life and examines perceived thriving with regard to those challenges, such as: establishing trusting relationships with others, having a positive attitude towards the self, having a sense of directedness in life, growing and developing as a person (Ryff & Keyes, 1995) etc. A good psychological wellbeing for disabled persons suggests the existence of a positive attitude towards themselves and a good relationship between them and their caregivers. Good social support and adequate care giving activities may determine to a large extent of the level People Living With Disability (PLWD) wellbeing.

There is no theory adequately explaining the link between social support and psychological well-being. This shortcoming informs the inclusion of the other theories employed in this study.

Reviewed literature showed that Ryff (1989) defined each aspect according to how that concept should be achieved. First, self-acceptance is a positive attitude toward the self. It is the acknowledgment and acceptance of multiple aspects of self, including good and bad qualities. It is the positive feeling about past life. Second, positive relations with others refer to warm, satisfying, trusting relationships with others. It is about the individual's concern about the welfare of others. It is the capability of strong empathy, affection, and intimacy. It is the understanding of the 'give and take' of human relationships. Third, autonomy refers to individuals' self-determining and independence. It is the ability to resist social pressures to think and act in certain ways. It is the regulation of behaviour from within. It is the evaluation of self by personal standards. Fourth, environmental mastery is the sense of mastery and competence in managing the environment. It is the controlling of a complex array of external activities. It is how individuals make effective use of surrounding opportunities. It is the ability to choose or create contexts suitable to personal needs and values. Fifth, purpose in life refers to a person's goals in life and a sense of directedness. It is the feeling that there is meaning to present and past life. It signifies that a person holds beliefs that give life purpose. It refers to the occurrence of aims and objectives for living by a person. Sixth, personal growth is the feeling of continued development. A person must see self as growing and expanding. It is openness to new experiences. It is the sense of realizing one's potential. A person sees improvement in self and behaviour over time. It is the changes in ways that reflect more self-knowledge and effectiveness.

Ryff's (1989) assessment of theoretically-derived constructs of psychological well-being has been mired in fundamental challenges. However, hypothetical perspectives of well-being had little, if any, empirical impact because they lacked credible measures. Additionally, Ryff's criteria regarding what constituted well-being were diverse, extensive, and value-laden. Because credible theoretically-derived assessments of psychological well-being were non-existent, non-theoretical conceptions were frequently used, though they were limited in their definition of constructs. This theory will help us define and determine the psychological well-being of the single parent formal caregivers. The psychological well-being of a person refers to the wellness and stability of a person's self. Thus, this theory will enable us to assess the well-being of formal carers. Ryff's theory of psychological well-being has profound implications for assessing the well-being of individuals, because of the knowledge of how individuals view themselves, their significant others and their society.

However, this theory did not lay emphasis on the supports that one can receive from family members and relatives. Little importance was placed on social support and one's economical status rather self appraiser was given much consideration as one's positive evaluation is central to having psychological well-being ignoring that social support and economic status that play significant role in developing psychological well-being. There is no theory adequately explaining the link between social support and psychological well-being.

### 2.3.4 Social well-being theory Keyes, (1998)

According to Keyes' (1998) social well-being theory, to understand maximum human functioning there is need to know about the social well-being of people because it is through social life and its challenges that people can assess their well-being. Social well-being is the ability to evaluate one's situation and functioning in life. He proposed five dimensions of social well-being which are:

1. Social Integration
2. Social Contribution
3. Social Coherence
4. Social Actualization and
5. Social Acceptance.

**Social integration** connotes the degree to which individuals see themselves as part of the society or community. He drew largely from the work of Durkheim on social cohesion, Seeman's work on cultural estrangement and the work of Marx on class consciousness.

**Social acceptance** is the meaning people give to life through behaviours of others in the society. Individuals who have social acceptance have positive feelings about other members of the society and social acceptance leads to personal acceptance. Therefore well- being is achieved when people feel good about their personality and accept both positive and negative aspects of life.

**Social contribution** is one's value in the society which is determined by the belief that one is vital and has something of value to contribute to the society. Keyes likened this to the concept of self efficacy. Social contribution is the extent to which people feel that their contribution to the society is valued.

**Societal actualization** as one of the dimensions means people's belief about the potential of the society for growth and development. People with strong belief in the societal social structure are healthy people because they are hopeful and have the belief that they can realize their own potentials through societal institutions.

Furthermore, social coherence connotes the full understanding of the dynamics of the social world. It is the understanding of the imperfectness of this world and ability to cope with it.

**Social coherence** is therefore the ability to maintain calmness even in the face of traumatic life events. Keyes (1998) regards social structure as the determinant of social well-being. Social stratification determines people social well-being as it is the major determinant of people's accesse to life chances such as education, occupation, income, housing, health and environment. Individuals with low socioeconomic status are more likely to have poor social well-being because of their inability to have access to good things of life while people with high socioeconomic status are likely to have good social well-being because of their access to good things of life. Age is also a determinant of social well-being in that ageing comes with loss of some personal aspects of life such as personal control (Mirowsky & Ross, 1989) and could also come with increased psychological well-being leading to more satisfactory life. However this suggests that ageing is one the factors determining social well-being.

### 2.3.5 **Capability theory:** Easterlin (2001)

A person's financial capability affects their psychological health through two processes. Firstly, financial capability is likely to be correlated with other observable characteristics that affect psychological health, such as income and material wellbeing. The financially capable will manage their incomes more efficiently and, all else equal, have higher levels of disposable income (or lower levels of debt) than the less financially capable with otherwise similar characteristics. Access to greater economic resources infers higher living standards and wellbeing as people with higher incomes are more able to meet their material aspirations and will feel better off (Easterlin, 2001). However there is no empirical consensus about whether income itself enhances wellbeing, as theory would predict. Most studies report a small positive impact (Frey & Stutzer, 2000; Clarke, 2001; Frijters, Haisken-DeNew & Shields, 2004), while others argue that it is relative rather than absolute income that matters (Blanchflower & Oswald, 2004). In this case, what affects people's psychological health is the difference between their own economic resources and those of others in their reference group (Wagstaff & Doorslaer, 2000). If the impacts of financial capability on psychological health operate only indirectly through this relationship with economic resources, then we should find no statistically significant relationship emerging in multivariate models that control for a household's income and current financial situation.

However financial capability may have a direct impact on psychological wellbeing independent of its effect through current income and economic wellbeing. Low financial capability implies a lack of control over the current financial situation, and an inability to plan ahead or to act on acquired knowledge. In contrast high financial capability infers the ability to control economic resources efficiently and hence to control future incomes and material and economic wellbeing, and to exploit knowledge of financial information. A great deal of research testifies to the importance of feelings of control in maintaining well-being. For instance, individuals who have control over their work tend to have fewer health problems than workers who lack such control (Kivimäki et al., 2002). This is analogous to the literature on locus of control which differentiates between an internal locus of control, in which people feel control over outcomes, and an external locus of control, in which people feel their outcomes rest with others or are the result of luck. It has been consistently demonstrated that individuals with a more internal locus of control tend to enjoy higher levels of psychological well-being than individuals with a more external locus of control (DeNeve & Cooper, 1999; Peacock & Wong 1996;

Peterson, 1999). In addition, capability theory suggests that high financial capability, as well as providing a stock of knowledge and skills, also allows people wider access to institutions and their external environment. This aids the development of other abilities that allow them to adopt their desired life-style and take advantage of the opportunities that they have (Sen, 1993; Nussbaum, 2002; Robeyns, 2005; Johnson & Sherraden, 2007).

This theory suggests that people with high financial capability have more control over their financial situation and their external environment and are more able to manage their economic resources and adopt desired lifestyles. Therefore, the lack of financial control implied by low financial capability will result in stress and psychological ill-health, particularly when dealing with negative outcomes such as shocks and that this will persist in multivariate analyses that also control for household income and financial situations. This approach is to assess the impact of financial capability on psychological wellbeing of informal caregivers over and above its effect through income and material wellbeing, when holding a range of other observable characteristics (such as occupational status, educational level, and marital status) constant.

### 2.3.6 The economic model of disability

The Economic Model refers to a disabled person, someone who is unable to participate in work. It also assesses the degree to which impairment affects an individual's productivity and the economic consequences for the individual, employer and the state. Such consequences include loss of earnings for and payment for assistance by the individual lower profit margins for the employer, and state welfare payment.

Again, this model proposes that people can be disabled by lack of resources to meet their potential because they can still contribute and add value to the economics of the society if given equal opportunity and equal right instead of seeing them as a burden on public funds. This model is relevant to this study because it enables us to know that though the disabled people are unable to participate fully in the workforce like their able counterparts, they have potentials in them through which they can contribute and add value to the society e.g. areas like Sports, Arts and creativity.

**Economic Model of Disability**

**Not 'worth' investing in disabled children**

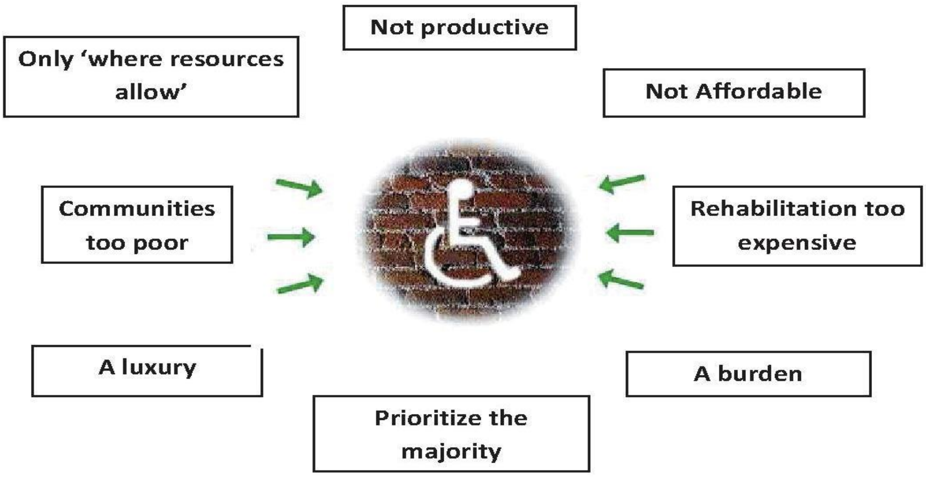

**Figure 1: Economic Model of Disability**

**Source:** Children Development Centre (2007: 24-25).

Fig 1 shows economic view of disability. People with disability are groups of people who cannot take part in the economic activities because of their disabilities and are unproductive elements with so many needs and source of burden to the society at large. This model illustrates disability in term of an individual's ability to take part in job activities, and their negative economic consequence is the economic model of disability. These consequences affect the individual, employer and the government in terms of loss of earnings and payment for assistance by the individual, and reduce profit margins for the employer; and government welfare payments. The Economic Model is used by policy makers to evaluate distribution of social welfare package to those who cannot take part fully in work. The main disadvantage of Economic Model of disability is the ability to produce in an economic term a policy to justify a socially desirable policy that increases the participation of disabled people in work. Since disabled people can only contribute less than what their able-bodied counterparts will contribute, their contribution reduces labour value, thereby leading to losses in production and reduced profits for employer.

The fact that businesses are created for profit purposes, employers may not be able to substitute economic gains for altruistic purposes. Employers are left to take from the options of paying disabled employees less or have their losses taken care of through subsidy. However these options lead to problem of stigma for the disabled people in that they now see themselves as second fiddles to their able-bodied colleagues at work. Furthermore, there arises the problem of attaining the correct level of subsidy to be paid to employers of disabled people.

The dilemma for the economist model theorist is how the society arrives at a very equitable and correct welfare package for the unemployable disabled individuals who depend solely on the public welfare without being labelled as public burden rather than partners in the creation of general prosperity. This leaves one outstanding difficulty for the socially minded economist. As long as social security benefits do not remove poverty from disabled people it is the responsibility of the policy maker to arrive at an effective equilibrium between the right of the individual to self-fulfilment and social participation through work.

### 2.3.7 Medical /individual model of disability

Individual Model of disability holds that disability is some terrible chance event which occurs at random to unfortunate individuals. It locates the "problem" of disability as within the individual and they often feel a loss for all the things they would like to do but cannot, a loss of goals and dreams that seem unobtainable.

Furthermore, this model reveals that the disabled people often feel they are a burden on family and friends and a problem to doctors, who cannot cure them, but see the causes of this problem as stemming from the functional limitations or Psychological losses which are assumed to arise from disability. The Model states that if the barriers to disabled people were removed systematically; they could play a full part in community life working and paying taxes like everyone else. In the long run it argues that it is cheaper and more economical to support disabled people to be independent by providing services which foster and maintain anon dependency throughout their lives.

This theory or model is relevant to this study because it explains disability as an occurrence which locates within the individual and also assumes that the individual with a disability is a victim who must be cared for or made normal. It establishes that if the society is encouraged to invest resources in health care and related services in an attempt to cure disabilities, medically the disabled people will be able to live a more normal life. In addition, it established the fact that it is cheaper and economical to support people being independent that providing services which foster and maintain a dependency throughout their lives.

The medical model focuses on what a physically challenged person cannot do:

**Figure 2: Medical/individual model of disability.**

Source: Children development centre. (2007: 23-24).

| Impairment | Disability |
|---|---|
| A wheelchair user | Cannot climb the stair or walk |
| A partially sighted person | Cannot read information clearly |
| A person with brain injury | Cannot speak quickly as other |

The medical model which is also known as 'individual' model or Biological-Inferiority or Functional-Limitation Model of disability centres on the individual's medical state and sees disability within the individual. The Model holds that disability comes from an individual person's physical or mental limitations, and has nothing to do with social environment in which the person lives. According to the World Health Organization (WHO, 2006), disability is defined with contributions from medical doctors as thus:

- Impairment: any loss or abnormality of psychological or anatomical structure or function.
- Disability: any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being.
- Handicap: any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual."

This definition carry with it stigmatization as it focus on the individual for solution. Another form of medical model is the one that brings the economic factor into it. It recognizes the unemployable nature of disabled persons in a bad economy and thereby recommends solution to the impairment so that disabled people can take part in work. The solution provided by this model could not solve the problem as disabled people are not sick people who need to be brought back to normal state of health, but rather should be helped on how to live with their disabilities through various programmes that include rehabilitation, vocational training for employment, income maintenance programs and the provision of aids and equipment.

Despite medical model domination of disability policy for years, it is not a realistic solution to problem of disability as it justifies institutionalization and segregation of disabled people. This in turn has negative implications for disabled people who find it difficult to realise their potentials. Thus medical personnel concentrate on the inability of the disabled person e g. their inability to walk or talk. In order to restore people with disability back to normal medical personnel try to find a cure and in the event of getting a cure, all energy is geared towards it and on the contrary the individual with disability will need to be cared for instead. Care is to be provided by professionals such as social workers, counsellors, therapists and psychologists. The criticism against this model is that it views disabled people as somehow "lacking", unable to contribute to society. Thus it has implications for research and policy with disabled people's needs being marginalized (Shakespeare, 2006). Cure is prolonged, painful and time wasting while giving false hope of restoration to the family of disabled patients (Shakespeare, 2006). Rehabilitation model is a brand of medical model, which sees disability as a lack that must be removed by rehabilitation professionals. It is similar to the medical model in that it focuses on the person with a disability as person needing help from rehabilitation professionals who can provide therapeutic services such as training, therapy, counselling or other services to replace the deficiency. This model informs the current Vocational Rehabilitation system. Persons with disabilities have shown disgust for this model in that while it is possible to fix some disability through medical treatment, it is inappropriate to think medical measures can solve the problem of disability. There are people with disability who can function well in the society despite their impairment.

Another medical model that has given people with disability a negative image is the Tragedy/Charity Model. This model portrays people with disability as people that must be pitied and classified along with victims" of famine, poverty, and child abuse. Traditionally this model has been used to raise funds for people with disability. Just like the medical model it is discriminatory, isolatry and leading to institutionalization of people with disability.

### 2.3.8 Social model of disability

The social model of disability enables physically challenged people to look at themselves in a more positive way, which increases their self-esteem and independence. This model sees the problem of disability as society's barriers rather that the person's condition. It allows the disabled people to lift the blame from their shoulders and place it squarely unto society. The Social Model of disability empowers disabled or physically challenged people to challenge society to remove those things which erects barriers.

Furthermore, the social model ignores how "bad" a person's impairment is, instead it establishes that everyone is equal and demonstrates that it is the society which erects barriers that prevent disabled people from participating and restricts their opportunities. According to the table below, the disabled experience a kind of discriminatory behaviour from the society. They suffer isolation and lack of policy of inclusion which could enable the disabled or physically challenged people accessibility in the environment where they have been denied. Moreover, they are faced with unfair distribution of resources, poverty and global injustice, segregation and institutionalization.

The social model views disability as a consequence of environmental, social and attitudinal barriers that prevent people with impairment from maximum participation in the society. The strength of this model lies in its placing the onus upon society and not the individual. At the same time it focuses on the needs of the individuals. Social model of disability is relevant to this study because it enables us to know that the society did not deny the problem of disability but locates it squarely with the society. It also made us to know that it is not individual limitations of whatever kind which are the cause of the problem but society's failure to provide appropriate services and adequately ensure that needs of disabled people are fully taken into account in its social organization. In addition, it revealed the need to develop lots of schemes or programmes which will empower people with disabilities and give them full and equal rights alongside their fellow citizens.

**Figure 3: Social model of disability**

Source: Children Development Centre (2007:25-26).

The diagram above shows social model of disability focusing on ridding society of barriers, rather than relying on 'curing' people who have impairments:

**Differences between medical and social model of disability**

| Medical | Social |
|---|---|
| Disability is a 'personal tragedy' | Disability is the experience of social oppression |
| Disability is a personal problem | Disability is a social problem |
| Medicalisation is the 'cure' | Self-help groups and systems benefit disabled people enormously |
| Professional dominance | Individual and collective responsibility |
| Expertise is held by the (qualified) Professionals | Expertise is the experience of disabled people |
| The disabled person must adjust | The disabled person should receive affirmation |
| The Disabled' have an individual Identity | Disabled people have a collective identity |
| Disabled people need care | Disabled people need rights |
| Professionals are in control | Disabled people should make their own choices |
| Disability is a policy issue | Disability is a political issue |
| Individual adaptations | Social change |

The Social Model of disability sees disability as socially created through artificial barriers that prevent people with disability from participating in the normal life like other members of the society. In other words social model focuses on the inability of the society to meet the needs and aspirations of people living with disability. It places the burden of disability on the society rather than the individual and the society must remove all attitudinal, physical and institutional barriers that prevent people with disability from participating in the society like other members of the society. Social model was developed in response to medical model with the notion that if barriers placed in education, information and communication systems, working environments, health and social support services, transport, housing, public buildings, negative images in the media and amenities by the society are removed, people living with disability will have the same opportunity as everyone else to determine their own life styles. The model has provided a framework through which people living with disability come together to fight for equal rights in the society.

However, as good as this model is, it fails to acknowledge the personal experience of individuals with disability but unilaterally placed the problem of disability on the society. The social model has hitherto not fully considered the nature and extent of 'sanism' or psychiatric oppression (Shakespeare, 2006). This may lead to the problem of continuity because as the number of people with disability rises within the population, the society may find it hard to adjust. The ability of the model to shift problem of disability on the society on one hand, and at the same time focus on the need of the individual has become its strength. Apart from giving the researcher the definitions of disability, these models also provides a framework within which disability issues can be understood and the implications of disability to the informal caregivers, government and the society at large.

# CHAPTER THREE

## SOCIAL SUPPORT AND PSYCHO-SOCIAL WELL-BEING OF INFORMAL CAREGIVERS OF PHYSICALLY CHALLENGED CHILDREN

### 3.1 Introduction

In research literature review is very important and it entails relevant scientific approach and making of the review needs to be documented in a manner that allows for the duplication of the search process (Metsamuuronen, 2003). The major goal of a literature review is to seek for information and answer the set study questions. Past relevant studies and information are employed when conducting a literature review (Kaariainen & Lahtinen 2006). According to Kylma et al., (2008), in literature review, the researcher needs to analyse the contents of the researches and combine the results in order to create a synthesis. This chapter consists of studies carried out by scholars in the field of psycho-social well-being of informal caregivers of people with physical disability. The literature considered relevant to this study includes:

Social supports and psychosocial well-being of caregivers of physically challenged children

- Socio-economic status and well-being of caregivers
- Income on psycho-social well-being of informal caregiver
- Marital status and gender on psycho-social well-being of caregivers
- Occupational status and psychological well-being of informal caregivers
- Educational level of informal caregivers and psycho-social well-being of children with disability
- Psycho-social well-being of informal caregivers
- Impact of disability on caregiver's family

- The impacts of care giving on psycho-social well-being of informal caregivers
- Impact of caregiving on physical health of informal caregivers:
- Impact of caregiving on mental health of informal caregivers
- Impact of caregiving on the financial resources of informal caregivers
- Home care in Europe
- Respite care in America
- Women and caregiving in America
- Caregiving in Nigeria
- Caregiving in South Africa
- Caregiving in Finnland
- Caregiving in India
- Coping strategy among caregivers
- Caregivers' assessment
- Psycho-social intervention
- The rights of children with disabilities
- Social work services to people living with disability
- Social work services to informal caregivers

## 3.2 Social supports and psycho-social well-Being of caregivers of physically challenged children

Families are a critical source of support for children with disabilities. Family members absorb the added demands on time, emotional resources, and financial resources (Baker, Brookman & Stahmer, 2005) that are associated with having a child with a disability. Yet, rewards from having a family member with a disability, such as personal and spiritual growth, have also been noted (Scorgie & Sobsey, 2000). Özlem, Dilek and

Demirtepe (2011) conducted a study on perceived social support as a moderator of the relationship between caregiver well-being indicators and psychological symptoms. The data were obtained from 100 caregivers of children with leukemia. The study revealed that the caregivers who were more able to satisfy their basic needs, and perform their daily activities, reported lower levels of psychological symptoms if they perceived higher levels of social support. However, perceived social support did not alleviate the level of psychological symptoms of the caregivers who reported lower levels of satisfaction of basic needs and performance on daily activities.

In the study conducted by Singhi and Rosen (1998) on psychosocial problems in the families of disabled children. They observed significant correlation between social burden scores and marital adjustment (r= 0.32) in the families having a disabled child. Marital dissatisfaction may stem from the tension of having an abnormal child or sexual dissatisfaction. Hostility of husband was significantly higher in families with disabled children, according to Gath (1998). Wallender and Varni (1998) observed that the marital adjustment scores were influenced more by the social environment characteristics like family support, marital satisfaction and social support network. Whitney et al., (2007) highlighted the fact that mothers of disabled children were more likely to be separated or divorced. The burden of care-giving a disabled child if not shared equally by both parents, may mount to marital disharmony and hence indicating the need to establish counselling sessions for both parents and a day care centre, to reduce the burden on parents. Most of the parents, seventy-one percent (71%) perceived moderate burden on their own physical health (Baker et al., 2005). Although the physical illnesses cannot be directly attributed to the disability itself but they could arise out of self neglect. Sixty percent (60%) parents of mentally handicapped children, reported being severely burdened as they felt that rearing a disabled child leads to neglect of their own health (Gathwala, & Gupta, 2004). Singhi et al., (1998) also revealed that more than half of the mothers, fifty-eight percent (58%) had physical illness such as back pain and loss of weight. They found a significant correlation between the social burden scores and maternal health (r= 0.58). Dupont (1998) observed that 80% of the parents had sleep disturbances and fifty-six percent (56%) of the mothers showed significantly higher scores on scales of anxiety, phobia and depression than fathers. A qualitative research among such caregivers described the negative mental health consequences of long-term, informal caregiving. There is a dearth of such studies in India. Monique and Gigniac (2004) reported that only 8% of the respondents consulted a psychologist or psychiatrist owing to economic constraints and found it difficult to stick to frequent clinic attendance.

Using a structured questionnaire Daniel, Caroline and Thomson (2009) conducted a study on the impact of perceived adequacy of social support on care giving burden of family caregivers. Data were obtained from a random sample of 340 family caregivers of adults aged 65 and older in Calgary, Canada through telephone interviews. The findings revealed that perceived adequacy of social support is important to family caregivers and is predictive of caregiving burden. Although the specific types of social support were not measured in this study, perceived adequacy of social support was found to be important for reducing family caregiving burden, for both male and female caregivers. Although emotional support had a more marginal effect on caregiving burden, support for daily care giving activities and financial and material support were found to be important for both male and female caregivers. The authors argued that support for family caregivers of older adults should first concentrate on strengthening tangible services and resources, such as home care services and community support resources, as well as financial assistance and support for material needs.

Jennifer (2011) conducted a study on impact of social support and family resilience on parental stress in families with a child diagnosed with an autism spectrum disorder in a sample of 50 primary caregivers of children between the ages of 6 and 12 diagnosed with Autism Spectrum Disorder (ASD), results indicate that most families experienced clinically high levels of stress. Greater family resilience was associated with lower levels of stress. Unexpectedly, higher levels of perceived social support were associated with increased parental stress. This may suggest that families who are experiencing clinically significant levels of stress seek out community supports at higher rates than other families. It also suggests that some social connections may potentially elevate stress in parents of children with ASD. This and other possibilities were explored with implications for social work intervention. The findings of this study shed new light on the role of social support and family resilience on parental stress in families with a child diagnosed with ASD. Since the results of this study show that more resilient families report less parental stress clinicians need to focus on programming for families that enhance key processes of family resilience and reduce stress (Jennifer, 2011).

Shu-Mei and Hsiu-Hung (2008) studied the relationship between caregiver's strain and social support among mothers with intellectually disabled children. Data were collected among one hundred and twenty-seven (127) mothers of children with intellectual disabled. Results showed that mothers with intellectually disabled children had a rather high level of strain and received inadequate social support. Social support and strain had a significant and negative correlation. Stepwise regression analysis revealed that mothers' health status, social support and amount of time spent as a caregiver, as well as the intellectually challenged children's dependent degree of daily living activity, were major predictors of caregiver's strain, which accounted for 38-4% of the total variance. The results provide a guide for healthcare professionals in designing effective interventions and preventive care to reduce the level of strain in mothers with intellectually disabled children. This, in turn, could improve the quality of life of the mother and her family.

Caregiver's depression and quality of life as a result of caregiving activities was measured by Touseef and Rukhsana (2009). The study sampled 25 caregivers of people affected by stroke. The study comprised 17 male caregivers and 8 female caregivers. The caregivers' age range was from 21 to 45 years and only younger adults were included because older adults may not have been able to provide care to the affected persons and old age itself might pose health problems. Results showed that almost half the caregivers were depressed forty-eight percent (48%) and a quarter scored at the borderline twenty-four percent (24%) i.e. they were at risk of developing depression. Caregivers' score on the QOL scale showed that carers scored lower on social QOL and psychological QOL indicating that caregiving responsibility had adversely affected social and psychological health of carers. Results also indicated that there is a negative relationship between quality of life and depression. The results revealed that caregivers' age had negative relationship with social quality of life indicating that social quality of life of younger carers was adversely affected. The affected person's age had a negative relationship with the carer's depression. Carers of younger patients experienced more depression. Moreover, the carer's income had significant negative relationship with depression. Also in a study conducted by Ainsworth (1990) on attachment relationships between children with physical disabilities and their caregivers, caregiver's experience of raising a child with disability was linked with high level of parental stress, depression, social isolation, psychological maladjustment, and child maltreatment. The researcher thus concluded that the cumulative influence of these factors may significantly affect the child-caregiver attachment relationship and likewise, exposure to medical intervention, repeated hospitalizations, onerous caregiving responsibilities, and extensive financial outlays may constitute a source of stress for the caregivers of a child with a physical disability. A consequence of this stress is that attachment relations may, in some instances, be adversely affected (Ainsworth, 1990).

In another study conducted on caregiver's depression by Margaret, Mary, and David (2011) it was established that there is a prevalence of depression among family of caregivers of children with intellectual disability in a rural setting in Kenya. Caregivers of children with intellectual disability have a great responsibility that may be stressful. The psychological well-being of the care giver may affect the quality of care given to children with intellectual disability. The objective of this study was to determine the risk of depression in caregivers of children with intellectual disability. The study was conducted among 114 caregivers registered at the Gachie Parish program in Kenya for the intellectually disabled children. Results indicated that seventy-nine percent (79%) of the caregivers were at risk of clinical depression. In their conclusion, the majority of the caregivers of children with intellectual disability were at risk of developing clinical depression (Margaret, Mary & David, 2011).

According to Cramm and Nieboer (2011), in their study on psychological well-being of caregivers of children with intellectual disabilities, the study set out to investigate those providing care and support to children with learning disabilities when they are about to seek outside support and care. The researchers wanted to understand under what conditions psychological well-being and parental stress are affected and they used parental stress as a mediating factor in the study. They found that parental stress and the child's depressive feelings strongly affected psychological well-being as well as an indirect relationship to restricted caregiver social activities. The researchers recommended that support services to parents and caregivers should address depressive feelings among children and facilitate the social activity of caregivers to protect their psychological well-being.

The psychological well-being of mothers raising a child with a developmental disability varies with the nature of the disability. This was revealed in a study by Abbeduto et al., (2004) on psychological well-being and coping in mothers of youths with autism, Down syndrome, or Fragile X Syndrome. The sample was comprised of mothers of children with fragile X syndrome, Down syndrome, or autism. Mothers of individuals with fragile X syndrome displayed lower levels of well-being than those of individuals with Down syndrome, but higher levels than mothers of individuals with autism, although group differences varied somewhat across different dimensions of well-being. Their findings support the notion of differential experiences for family members depending upon the specific diagnosis of their child with a developmental disability. However, these differences reflect the unique challenges posed by the young people with the diagnoses of interest. Thus, treating these behavioural challenges directly may alleviate some negative outcomes for mothers. It may also be helpful, given the intractable nature of some of these behavioural challenges, to provide parents with respite and other forms of social support that may buffer some of the inevitable stress associated with these behaviours. Their results, however, are also consistent with the notion that some parents have a genetic vulnerability for less than optimal outcomes and that this vulnerability is magnified by the challenges of raising a son or daughter with special needs.

Dyson (1997) found in his study on fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. Thirty pairs of fathers and mothers who had school-age children with mental retardation and other disabilities were compared with each other and with thirty-two (32) father and mother pairs of parents of children without disabilities. Results show that fathers and mothers of children with developmental disabilities did not differ from each other or from fathers and mothers of children without disabilities in parental stress, family social support, or family functioning. However, parents of children with disabilities experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities.

Dyson (1997) concluded that both parents' stress was associated with aspects of family functioning as perceived by themselves and their spouses.

In a study comparing the physical and mental health status of women providing care to adult relatives with developmental disabilities, and that of the general female population in the United States by Susan and Jennifer (2007), the result showed no differences on physical health across four age groups. However, the mental health of midlife caregivers (45-54 years of age) and older caregivers (older than 65 years) was worse than national norms. Susan and Jennifer (2007) concluded that this result may be associated with two key periods: transitions to adulthood of individuals with disabilities and transitions when aging caregivers are no longer able to provide care. Greater unmet needs for services contributed to poorer mental health. Poorer access to health care also contributed to poorer mental and physical health. Unmet needs for services and out-of-pocket disability-related expenses appeared to pose difficulties for working age caregivers in affording the financial costs of health care for themselves (Susan & Jennifer, 2007).

### 3.3 Socio-economic status and psycho-social well-being of caregivers of physically challenged children

Becoming physically challenged may mean that a person requires health and social care help. Depending on the extent of the disability this can include in-house care, grants to adapt a house to meet new requirements or a place in an assisted living community or hospital. Friends and family often become the primary carers for a physically challenged person in the home. They may be incurring financial assistance in supporting the child if they take on this role.

However in a study conducted by Sheri, Alfred and Gottschalck (2009) on the characteristics of employed female caregivers and the history of their work experience, their analysis was focused on the characteristics of employed women aged 25 to 62.Their findings indicated that employed female caregivers on average were older, predominantly white non-Hispanic and less likely to be black, less likely to have a Bachelor's degree or higher level of educational attainment, more likely to be married, and more likely to be in sales or office type of occupation. Fifty-seven percent (57%) of caregivers had one interruption that lasted at least six months to take care of someone compared to twenty-two percent (22%) that had two and twenty one percent (21%) that had three or more interruption in their lifetime. They were more likely to have taken care of a child than an elderly or a disabled family member (ninety-five percent (95%), four percent (4%), and one percent (1%) respectively).

Those employed female caregivers with one interruption earned more per month than those caregivers who experienced multiple interruptions ($2, 406 and $2, 153, respectively). Also, employed female caregivers differ from their non-caregiver counterparts in several key economic and demographic characteristics. Caregiver and non-caregiver females on average had similar employment status; seventy-two percent (72%) and seventy-one percent (71%) respectively, were employed. There were small differences in work experience between the two groups. This may be due to caregivers being older on average and/or working longer to catch up as a result of lost time in the workforce. Although the majority of employed female caregivers worked full-time over their work careers, those who had interruptions to take care of someone were more likely to work part-time compared to the ones who never had such interruptions (forty-one percent (41%) and thirty-one percent (31%) respectively). Caregivers were less likely to have a bachelor's degree or higher level of education compared to non-caregivers (twenty-seven percent (27%) and thirty-four percent (34%) respectively). Mean monthly earnings were lower on average for caregivers than non-caregivers ($2, 298 and $2, 817, respectively). Thirty-seven percent (37%) of caregivers were in sales and office occupations compared to thirty-two percent (32%) of non-caregivers. Thirty-nine percent (39%) of caregivers were in management, professional, and related occupations compared to forty-two percent (42%) of non-caregivers.

In a study on psychosocial effect and economic burden on parents of children with locomotors disability, Ananya et al., (2010) observed that the parents of the disabled children were severely burdened in terms of financial burden and mental health. More importantly, the study also revealed that the parents have to bear huge financial liabilities, over and above that of rearing of a normal child. The study points towards an urgent need for support activities for the physically disabled children at national level, in order to curb the huge economic and social burden of care-giving. According to these authors, sincere efforts should also be made to strengthen the existing schemes for the disabled, with special focus on the parents working in the unorganized sector. They also proposed the introduction of health insurance schemes and day-care centres for disabled children should be given serious thought. All these initiatives will go a long way in bringing down the social burden associated with physical disability.

Gathwala, Singh and Singh (2004) also assessed the burden of parents of mentally disabled children, using the same scale and reported that 40% of the families had disruption of family routine and leisure. The difference in the magnitude of disruption could be due to the difference in the type of disabilities. However, the above findings are at variance with observations of some authors in developed countries as Langergren, Boyeson and Kohley, (2000) did not observe any significant disruption in the family routine. This may perhaps due to differences in socio-economic conditions, cultural practices and attitudes of the parents as well as the society.

A longitudinal study by Jane, CrammAnna and Nieboer (2011) on parents' impact on quality of life of children and young adults with intellectual disabilities measured quality of life (QoL) and its component domains by administering questionnaires to 147 parents of children with intellectual disabilities. Data were collected as part of a longitudinal study on preferences on decision information and support in the Netherlands. The QoL of children with intellectual disabilities was evaluated by asking parents perspectives on QoL (children), material wellbeing (parents), development and activity (children), physical well-being (children), social well-being (children and parents) and emotional well-being (children and parents). The study found no significant determinants of QoL of children with intellectual disabilities in the material well-being or development and activity domains. However, because the study did not measure changes within them, according to Jane et al., (2011) it is possible that changes in parents' income or children's development and activity do significantly affect QoL outcomes, and suggested that future research should investigate these potential relationships.

Moreover, because parents of children with disabilities generally experience decreased financial resources, relative income levels of all households in the study might be lower than those with non-disabled children. They also discovered that parents with lower incomes were more likely to drop out before pointing to increased vulnerability. In their conclusion, the study found predictors of QoL among children with intellectual disabilities in the following domains: physical well-being (children), social well-being (parents and children) and emotional well-being (parents and children). Jane et al. (2011) therefore confirmed that emotional, social and situational variables can change QoL among children with intellectual disabilities. The study provides preliminary indications for interventions that aim to improve certain QoL domains among parents of children with intellectual disabilities. Such interventions may consist of social support, stress management and emotional education for parents and should complement and augment such support for the children. Social support for children with intellectual disabilities can be enhanced through interventions in the direction of improving children's resilience to parental distress or poor social well-being levels.

In another study titled giving parents a voice: a qualitative study of the challenges experienced by parents of children with disabilities was conducted by Resch et al., (2010). The study sought to examine the specific sources of challenges as identified by parents of children with disabilities. Focus groups were conducted with forty parent (40%) caregivers. Four themes emerged as the most prominent barriers to positive parent wellbeing: (a) Access to information and services,

(b) Financial barriers,
(c) School, and community inclusion, and
(d) Family support.

According to Reschet et al., (2010)these four themes are indicative of problems associated with a lack of match between caregiver needs and services, resources, or support available in the community to meet those needs. They concluded that caring for a child with a disability can be challenging, but many of these challenges are likely due to a lack of necessary environmental supports. They urged that policy makers, scientists and providers should give particular attention to the environmental support needs of parents in order to create policies and interventions that are more family-cantered.

Seubsman et al., (2010) in a study: predictors of burden among lower socioeconomic status caregivers of persons with chronic mental illness; in the study they used a stress-coping-support framework to examine the predictors of caregiver burden with a sample of 103 lower social class family caregivers of persons with chronic mental illness. Results of their finding show that the greater the frequency of client behavioural symptoms the lower the amount of perceived support from family members, the higher the level of overall caregiver burden. Examination of the predictors of specific types of burden-family disruption, stigma, strain, and dependency reveal that different constellations of variables predict different types of burden. Seubsman et al. (2010) conclude that there is need for mental health agencies to address caregiver and client concerns.

The study on the relationship between the level of stress, depression and anxiety experienced by informal caregivers by Ersin and Duru (2010), was conducted employing a cross-sectional study among parents whose children attend a Special

Education and Rehabilitation Centre. The total number of 127 parents voluntarily participated in the study. The results show that among the stressful experiences, the parents gave the highest points to attitudes of society towards disabled people, having limited free time and financial problems. The relations between financial problems and being an individual who has close relations with disabled person other than his/her parents were defined employing the STAI-state as effective variables were statistically significant. Ersin and Duru (2010) conclude that financial problems are the most important factors that affect the psychology of the parents of disabled people, and recommended that social programmes that will support the parents in respect of both financial matters and home-care facilities should be set up.

Another comparative study on the adherence to attendance on a Simple Massage Training and Support Programme by Williams, Cullen and Barlow (2005) were conducted based on a twelve month comparison study of adherers and non-adherers on the psychological well-being and self-efficacy of careers of children with disabilities following attendance on a Simple Massage Training and Support Programme. The results show that adherers had significantly higher levels of self-efficacy for managing their child's psychosocial well-being, self-efficacy for carrying out the massage, and significantly better psychological well-being at follow-up compared to non-adherers. And also there were no significant differences over time on self-efficacy for managing their child's psychosocial well-being, self-efficacy for giving massage and levels of anxiety and depression at 12-month follow-up for adherers, suggesting that their improvements noted immediately post-programme were maintained at follow-up. Significant decreases on self-efficacy and depression were noted for non-adherers and there was a trend towards deterioration in anxious mood. In their conclusion, the study suggests that the positive benefits the training and support programme has for careers of children with disabilities can be maintained if carers continue to practice the massage at home with their child.

## 3.4 Socio-demographic variables and psycho-social wellbeing of informal caregivers

Socio-demographic variables are varying characteristics that are vital in social statistics of an individual, sample group or population. It includes such information as income level, gender, educational level, location, ethnicity, race, occupational status, sex, marital status and family size. In this study socio-demographic variables of informal caregivers are reviewed as they affect their psycho-social well-being.

### 3.4.1 Gender

The literature has paid relatively little attention to how caregiving affects men (Pinquart & Sörensen, 2003; Winqvist, 2010). It is both timely and relevant to pay more attention to the experiences of male caregivers, as men have gradually become more involved in caregiving over the last decades (Carmichael & Charles, 2003). In addition, men may become even more involved in the future, because of a greater need for informal care and greater gender equality in work and domestic roles, a development that is perhaps nowhere more evident than in the Nordic countries (Mencarini & Sironi, 2012). Nonetheless, it is expected that possible associations between caregiving and psychological well-being are more negative for women, who tend to carry a larger load of caregiving responsibility (OECD, 2011). Age greater longevity implicates that elder care will increasingly be provided by children who are themselves elderly.

On the one hand, caregiving may be less demanding in older age, because of fewer responsibilities and role conflicts (e.g., between work and family). On the other hand, caregiving in older age may be more physically challenging, and more stressful because of fewer potentially stress-buffering roles and activities. The gender differences are consistent with the fact that women more often tend to be a primary caregiver and more emotionally involved in the care recipient's situation, and that caregiving may be more physically challenging and entail less social recognition for women than for men (Pinquart & Sörensen, 2003b; Winqvist, 2010). The partnership status differences may reflect that single caregivers have less access to social support, which is a critical buffering factor against caregiver distress (Borg & Hallberg, 2006). In the future, because of increasing need for informal care and growing female employment, more adult children are expected to combine family caregiving with paid work.

Men and women may experience burden differently. Schneider, Steele, Cadell and Hemsworth (2010) conducted a study in Canada to determine gender difference in 273 parents caring for children with life-timing illness. Results showed that there was a significant difference in gender in terms of their burden. Women had higher score in caregiving, depression and burden compared with men. It can be explained by social gender role and hormonal factors. Related to social role, women were predominant in caregiving, in other word women spent more time in caregiving than men. Some caution is warranted, however, as employment may have a stronger impact on caregiver distress at higher levels of working hours than examined (15 hours or more per week), or in countries with less flexible work arrangements than in Norway.

### 3.4.2 Educational level

The educational differences suggest that higher-educated caregivers cope better with the demands and stresses of caregiving, perhaps by being more adept at obtaining help from the public services and by relying on greater financial resources. That caregiving has fewer consequences for women with higher education are interesting in the light of marked cohort changes in educational level, especially among women. Because of higher education, the negative consequences of caregiving may be (even) weaker in future cohorts of caregivers. Juvang, Lambert and Lambert (2007) investigated relationship between demographic characteristic of caregiver and family caregiver's burden when providing care for a member with schizophrenia in China. They also predicted the best predictor of caregiver's burden. Findings showed that the education level has negative correlation with caregiver's burden. It was assumed that the higher the level of education, the higher the salary would be. High salary would decrease financial problem related to providing care for ill family member.

The level of education of the caregiver also tends to have more knowledge to deal with the stressful event.

Therefore caregiver's education level influences burden of the caregiver. Increasing education in the population, especially among women, implies a higher educational level in future cohorts of caregivers. More educated caregivers may have better coping skills, partly by being more adept at accessing services and using financial and social resources to alleviate the caregiver burden. However, more educated caregivers may be more vulnerable to role strain and have more difficulty accepting or handling the demands of caregiving. The relationship between education and caregiver's psychological well-being is inconclusive. Ory et al., (1999) found that higher education of dementia caregivers is a predictor of higher emotional strain in the caregiving process. In Covinsky, Newcomer and Fox (2003) research, less educated caregivers showed higher depression. Some studies (Dura, Stukenberg & Kiecolt-Glaser, 1991; Rapp & Chao, 2000; Hooker et al., 2002) report that education of caregivers is not significantly related to his/her mental health.

### 3.4.3 Income status

Income may have influence on the burden of the caregiver. Andren and Elmstahl (2006) conducted a study in Sweden to examine relationship between income, subjective health and caregiver's burden in people with dementia. Findings showed that low income was associated with a higher degree of burden on the caregivers. Lower income was a stressor that influenced stress feeling during providing care for ill family member. Besides caregivers providing care for ill member, they also had to solve financial problem and find out source of money.

The literature indicates that lower income and financial inadequacy is related to caregiver's mental health. Convinsky et al. (2003) found that caregiver who had lower household income reported more depression. Schulz, O'Brien, Bookwala and Fleissner (1995) also proved the negative relationship between income and psychiatric morbidity. Income is also positively correlated with caregiver's life satisfaction. Lee, Brennan and Daly (2001) found caregivers with higher income appraised the caregiving situation as more satisfactory and beneficial. Caregivers with higher income also reported less depression. In Russo, Vitaliano and Brewer (1995) study, however, income was not related to a caregiver's mental health.

### 3.4.4 Marital status

Many research studies show that single caregivers experience more negative aspects of caregiving than spousal caregivers (Coen et al., 1996 & Cahill, 1997). In Lawton et al., (1991) study, for example, the psychological well-being of adult children caregivers, unlike spousal caregivers, was very sensitive to the amount of care they provided and the extent to which there was an appraisal of the burden. The authors argued that the different results for the two groups could be explained by their different perceptions of caregiving. For spousal caregivers, a caring husband/wife is part of an experience of marital commitment and human development. Therefore, the objective caregiving workload does not impact the spousal caregiver's appraisal of burden and psychological well-being. For children caregivers, however, caring for a parent is an extra activity in addition to current roles. Therefore, they are more burdened, and their psychological well-being is challenged by the amount of caregiving workload (Lawton et al., 1991). Some researchers, however, argue that spousal caregivers are more vulnerable to psychological and physical morbidity in some aspects.

In Pinquart and Sorensen (2003) review, spousal caregivers showed higher levels of burden and depression, and lower subjective well-being than other caregiving groups. Hooker et al. (1998) mentioned that spousal caregivers are already fragile populations due to their own health issues and lack of social support. Therefore, this population is an ideal caregiving sample to examine chronic stress; the immune system, and cardiovascular response (Hooker et al., 1998).Interestingly, co-residency brings divided results in caregiving research. One would expect that co-residency will bring higher burden and depression.

Zanetti et al., (1997) showed that caregivers who co-reside with their care receivers had higher depression and burden than the caregivers who live apart from the care receivers. In fact, some studies prove that co-residency is not significantly related to caregiver's mental health (Russo et al., 1995; Song, Biegel, & Milligan, 1997). These inconsistent results infer that institutionalization of the care receiver is not the end of caregiving but a continuum of caregiving (Clyburn et al., 2000). The Canadian study of health and aging working group (2002) documented that the depression of dementia caregiver group did not disappear even after the care receivers' institutionalization.

Many studies have identified the importance of marital status, pointing to the heightened risk of widowhood (Cohen et al., 1997) or more generally not being married (Shapiro & Tate, 1988 &Hughes et al., 2005;). Living alone, which is associated with marital status, was identified as a risk factor in additional studies (Branch & Jette, 1982). Studies which evaluate the impact of home care and case management services on the use of nursing homes have relevance. Hughes et al., (2005) reported that participation in a home care service program was associated with lower risk of nursing home admission. The National Long Term Care Demonstration reported no significant reduction in admission (Wooldridge & Schore, 1998). It should be noted that assessment of social supports has not received the same care as that of functional limitations, and that conclusions concerning the importance of social support have been based on single item measures of socio-demographic characteristics, rather than detailed assessment of support networks.

### 3.4.5 Age

The roles of care receiver age's and gender on caregiver's mental health have been investigated along with caregiver's demographic factors. Care receiver's age and gender do not have a distinguishing relationship with caregiver's mental health. In Covinsky et al. (2003) study, care receiver's age was a significant predictor along with dementia severity where younger dementia caregiver showed higher depression. Care receiver's gender, however, did not have a significant relationship with caregiver's depression in the same study. Noonnan and Tennstedt (1997) also found that the care receiver's age and gender were not significant predictors of caregiver's depression and self-esteem.

### 3.4.6 Occupational status and psycho-social well-being of informal caregivers of physically challenged children

The economic well-being and maternal employment of parents whose children did or did not have developmental disabilities was compared by Parish et al., (2004). The study was a secondary analysis of data from the Wisconsin Longitudinal Study, collected when respondents were aged 18, 36, and 53, on average. The result of income and savings differed markedly by age 53 despite that the two groups were similar at age 18, but statistically significant differences were not found on other measures. They conclude that mothers of children with disabilities were less likely to have job spells lasting more than 5 years and had lower earnings when they were 36 years old. Also, there was a trend for them to be less likely to have full-time jobs as their children grew older.

The influence of employment on parenting stress among mothers of 5-year-old children with developmental disabilities and the influence of parenting demands and family support on their work quality and absenteeism from work was examined by Warfield (2001). The results show no significant associations between employment status and parenting demands, family support, or stress for the sample as a whole. Among employed mothers, those who rated their jobs as interesting reported significantly less parenting stress when they experienced low or mean levels of parenting demands. Mothers' interest in work did not moderate the negative influence of high levels of parenting demands on stress. Finally, he concluded that parenting demands increased absenteeism but had no effect on work quality.

In a study conducted to understand the relationship between several measures of child health status and the employment of parents by Kuhlthau, Perrin and Ettner (2001), the results indicated that having a child with poor health status, as measured by general reported health, hospitalizations, activity limitations, and chronic condition or disability status, is associated with reduced employment of mothers and fathers. In their conclusion, having a child with poor health status is associated with reduced maternal and paternal employment. Moreover a qualitative study with 18 mothers of children with disabilities aged between 5 and 15 years found employment difficult and encountered unusual time demands, and a lack of adequate and affordable child care (Shearn & Todd 2000). Furthermore, the authors felt that their employment opportunities were restricted by attitudes prevalent in society concerning appropriate roles for women, especially mothers of children with disabilities. The lack of opportunities to engage in employment led, in varying degrees, to feelings of isolation, a lack of fulfillment and low self-esteem. The mothers felt that they were on the periphery of society with little release from the pressures of caring. Mothers who had part-time jobs often did poorly paid work of low status, thereby encountering few opportunities to use their skills and abilities to the full. Those who attempted a full-time job experience stress from the dual demands of home and work, and from a fear that they were failing as mothers (Shearn & Todd, 2000).

Family strategies for care giving and income generation are examined in a qualitative study of employed parents of disabled children in the United Kingdom by Kuhlthau et al., (2005) on financial burden for families of children with special health care needs. Four family patterns for working and caring emerged: modified single earner, one-and-a-half earners, dual earners, and flexible dual earners. A number of social, economic, and ideological factors contributed to decision making for these families. Gender expectations and related ideology of caring were usually the most salient, coloring the meanings ascribed to other influencing factors. Gender assumptions in the wider context underpin the difficulties many families experience in obtaining formal supports. The authors argue that flexible community-based support and employer supports are crucial to help parents with disabled children to work and care. Beyond this, however, strategies that challenge gender expectations can extend the range of options available to parents, whereas more traditional approaches perpetuate inequalities and family hardship.

Olsson and Hwang (2006), found that a positive relation between level of participation in paid work and well-being was found for both mothers and fathers in their comparative study on differences in well-being as a result of involvement in paid work and child-care among fathers and mothers of children with intellectual disability (ID). No difference in the division of child-care tasks was found between families of children with ID and control families. Differences in involvement in paid work and child-care in families of children with ID only explained 5% of the variance in the difference between mothers' and fathers' well-being. In conclusion, families of children with ID differ from control families in that the parents are less involved in paid work and have lower levels of well-being. A positive relation between involvement in paid work and well-being was found.

### 3.4.7 Income on psycho-social well-being of informal caregiver of physically challenged children

According to Carpenter et al., (2000); Horsburgh (2002); Horsburgh and Trenholme (2002), disability has direct financial burden on informal caregivers. The informal caregivers bear huge financial liabilities over and above that of rearing of a normal child. These burdens can be loss of daily wages for those who are either daily wage earners or small traders. They also experience frequent job change and loss of job unlike government employees who could still avail of casual or medical leaves. Informal caregivers spend most of their income on non- recurring cost of treatment and rehabilitation. Huge amounts of their income are also spent on transport, food, accommodation and making the house barrier free.

However, this financial burden has a resulting effect of making the informal caregivers more impoverished and indebted. Financial pressure adds to stress, places constraints on the manner in which they can care for their child and severely limits participation in normal activities for other children in the family. There are additional expenses arising from medical appointments, transportation and parking and home modifications (Carpentered et al*.,* 2000; Horsburgh, 2002; Horsburgh & Trenholme, 2002).

In addition, low income is a major source of stress for all caregivers. The more dependent the disabled child, the more support needed by a caregiver and level of income affects ability to purchase additional support. The Researchers concluded that care giving can cause levels of poverty which potentially prevent the whole family from achieving acceptable standards of living (Lungley, Parkin & Gray, 1995; Nikora et al., 2004).

### 3.4.8 Marital status and gender on psycho-social well-being of caregivers of physically challenged children

Marital status and gender are two variables that have been found to influence psycho-social well-being of informal caregivers. Ha, Hong, Seltzer and Greenberg (2008) conducted a study on age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: report of a national study. Using data from the Study of Midlife in the United States (MIDUS), Ha et, al. (2008) examined the effect of having children with developmental or mental health problems on parents' mental and physical health, the extent to which this effect varies by parental age and gender, and the effects of disability-related factors on the well-being of parents of children with disabilities. Compared, the result indicated that parents of non-disabled children, parents of disabled children experienced significantly higher levels of negative effect, marginally poorer psychological well-being, and significantly more somatic symptoms, controlling for socio-demographic variables. Mothers did not differ from fathers in their well-being. Older parents were significantly less likely to experience the negative effect of having a disabled child than younger parents, suggesting an age-related attenuation of the stress of non-normative parenting.

Gender differences in psychiatric morbidity among family caregivers were examined by Jennifer and Richard (2000). Although the major goal of this article was to review and synthesize the empirical research on caregiver gender in almost all studies reviewed in this study, women caregivers reported more psychiatric symptoms than men caregivers. Results of comparisons with non-care giving community samples suggest that female caregivers experience excess psychiatric morbidity attributable to care giving. In their conclusion, with the use of a stress process model as an organizing framework, the study demonstrated that at all stages of the stress process; women are at greater risk for psychiatric morbidity than men. Identity structures and psychological well-being were compared based on their gender and marital status by Thoits (1992). Seven hundred (700) married and divorced urban adults were interviewed in the study. Identities refer to self-conceptions in terms of individuals' roles in this study. The salience or importance of various identities should differ systematically by gender and marital status; highly salient identities should have greater impacts on psychological symptoms than less salient identities; and identities that are more salient to particular gender-by-marital status subgroups should benefit those subgroups more than other subgroups.

Contrary to expectations, the result reveals that identity hierarchies of married and divorced men and women were remarkably similar. In most comparisons, identities valued more highly by one group than another did not benefit the group that valued it more highly. In general, the salience of an identity did not reduce psychological symptoms. Instead, more voluntary identities (e.g., friend, churchgoer) reduced symptoms, and difficult-to-exit identities (e.g., parent, son/daughter-in-law) reduced symptoms only when stress experienced in the role domain was low. Furthermore, the psychological impacts of identities depend on their combinations, and differently so by gender. Thoits (1992), conclude that psychological well-being does not depend on the number or salience of particular identities that individuals hold.

Apart from the above study, Al-Kuwari (2007), also conducted a study to compare the prevalence of psychiatric morbidity among mothers of mentally disabled children and mothers of non-disabled children, and to identify the determinants associated with psychiatric morbidity. The data were collected from 195 mothers of mentally disabled children selected as a study group, and 139 mothers with non-disabled children as a comparison group. Results of the study indicated that the prevalence of psychiatric morbidity was higher among mothers caring for mentally disabled children than mothers of non-disabled children in the comparison group. The study found the following predictors for developing psychiatric morbidity: having more than one disabled child, mentally disabled child less than 5 years of age, disabled child is first in order of birth, presence of chronic illness in addition to the mental disability, and presence of other type of disability besides the mental one. Furthermore, it was also found that educating mothers in caring for a disabled child has a protective effect on developing psychiatric morbidity. In conclusion, mothers of mentally disabled children have poorer psychological health than mothers of non-disabled children. Mohamed (2007) recommended shifting the rehabilitation services from child-centred to family-centred services through providing supportive services.

Furthermore, Xiaoqin and Alfred (1996) reported in their study conducted to investigate on whether differences in the stress-producing circumstances of the lives of men and women, and the married and unmarried might explain the differences in their levels of depression. Using data from the National Survey of Families and Households, they found that gender differences in depression were accounted for by chronic strains. Family-based strains and economic hardship are significant predictors of higher distress in women. Chronic strains also explain why variations in depression are more pronounced among the married than among the unmarried.

In addition to this, race and gender differences in perceived informal caregiver availability for participants aged 45 and older in a large national epidemiological study was examined by David, et.al (2007). About 32, 999 participants were interviewed through structured telephone interviews. The results show that more than eighty percent (80%) of the participants reported having an available caregiver. Variables associated with lower perceived caregiver availability from a multivariable logistic regression analysis included being female, White, or unmarried; living alone; being older than 85; and having worse self-rated health. Spouses were the most likely caregivers for all racial and gender groups except for African American women, who identified daughters as the most likely caregivers. African American women also showed the smallest differential in perceived caregiver availability between married and unmarried (82.8% vs 75.7%), whereas White men showed the largest differential (90.9% vs 60.4%). David, et.al (2007) concluded that most individuals believe they have an informal caregiver available to them, but certain factors increase the risk of reporting no available caregiver.

In another study of 67 to examined the contribution of the marital relationship to the well-being of both mothers and fathers of children with developmental disabilities, Kersh et al., (2006) affirmed that for both mothers and fathers, greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socio-economic status, child characteristics and social support. In relation to parenting efficacy, marital quality added significant unique variance for mothers but not for fathers. For fathers, greater social support predicted increased parenting efficacy. Child behavior was also a powerful predictor of parental well-being for both mothers and fathers. In conclusion, the findings support the importance of the marital relationship to parental well-being and illustrate the value of including fathers in studies of children with developmental disabilities (Kersh et al., 2006).

The findings in the study "specifying caregiver outcomes: gender and relationship aspects of care giving strain", revealed consistent patterns of strain. Women, non-spousal caregivers, and daughters, in particular, experienced the most severe after effects (Rosalie & Eva, 1989). These findings support a care giving outcomes model proposing that the patient-caregiver relationship is an essential component of caregivers strain. Research conducted by Anne and Scott (1999), showed that widowed and never married people have helping networks that are larger than those of married people. Diversity across marital statuses in sources of assistance was revealed in analyses of two measures of care giving network composition:

(a) Having more kin than non-kin helpers and
(b) Presence of specific helpers (adult children, siblings, friends, and formal helpers).

Moreover, gender interacts with marital status to influence the composition of care giving networks. Susan, Frances and Desiree (1999) conducted a study on gender roles, marital intimacy, and nomination of spouse as primary caregiver. They observed that wives are only one third as likely as husbands to select their spouses as caregivers, and spouses who name their mates as confidants are three times more likely than those who do not to also name them as caregivers. The authors concluded that although gender role norms are keys to caregiver's selection, the intimacy inherent in the care giving role renders an emotionally close marriage an important criterion to the selection of spouse as caregiver.

The study on the differential experiences by gender in informal care giving revealed that compared with men caregivers, women caregivers were significantly more likely to be sixty-five (65) years of age or older, black, married, better educated, unemployed, and primary caregivers; provide more intensive and complex care; have difficulty with care provision and balancing care giving with other family and employment responsibilities; suffer from poorer emotional health secondary to care giving; and cope with care giving responsibilities by forgoing respite participation and engaging in increased religious activities (Navaie-Waliser et al., 2002). They concluded that, informal caregivers, particularly women, are under considerable stress to provide a large volume of care with little support from formal caregivers. They suggested that program planners, policy makers, and formal care providers must act together to provide accessible, affordable, and innovative support services and programs that reduce family care giving strain.

### 3.4.9 Educational level and psycho-social well-being of caregivers

Educational level is another socio-economic factor that affects psycho-social well-being of informal caregivers. Andrea and René (2011) conducted a study on effect of educational and supportive strategies on the ability of caregivers of people with dementia to maintain participation in that role. A systematic review of evidence of the effectiveness of educational and supportive strategies for enabling caregivers of people with Alzheimer's disease (AD) or related dementias to maintain participation in that role was conducted as part of the American Occupational Therapy Association's Evidence-Based Literature Review Project. Forty-three (43) articles met inclusion criteria. The results of the study suggest that interventions that jointly engage people with AD and their caregivers in education and training in the home setting are more successful than strategies that focus solely on people with AD. Greater carryover is noted when education and training are implemented at the time that the caregiver identifies concerns. Interventions should provide caregivers with problem solving, technical skills, support, simple home modification strategies, and referral to community resources (Andrea & René, 2011). Interventions mediated by technology have a positive effect on the caregiver and are especially important for those who live in rural areas.

A study carried out by Shirley and Timothy (2007), investigated the effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. The study examined the association between several variables and the use of specialist physician services, developmental therapies, and prescription medications among 38, 866 children with special health care needs. A bivariate probity model was used to estimate whether a given child needed specialized services and whether that child accessed those services. Shirley and Timothy (2007), controlled for activity limitations and severity of special needs. Variables included family income, mothers (or other caregivers) educational level, health insurance coverage, and perceived need for specialized services.

Data from the 2001 National Survey of Children with Special Health Care Needs was used. The results of the study indicated that lower-income and less-educated parents were less likely than higher-income and more-educated parents to say their special needs children needed specialized health services. The probability of accessing specialized health services -when needed- increased with both higher family income and insurance coverage. The results of this study clearly point to the importance of targeted outreach to low-income and less-educated parents who have children with special health care needs. Shirley and Timothy (2007) found these children were less likely to access health services because their parents did not recognize the need for those services or did not know what services were available.

In her own contribution Elizabeth, (1990) conducted a study on perceptions of head start staff concerning child development associate competencies and process. This study examined relationships between behaviours towards children and a variety of caregiver characteristics which include formal education, child-oriented attitudes, satisfaction with child care employment, and commitment to the child care field as a career. Detailed narrative descriptions of the behaviour of 37 centre-based caregivers responsible for groups of three to five-year-olds were collected. Caregivers also answered attitude and job satisfaction questionnaires and provided information about their educational background and child-related preparation. Overall findings indicated that, for the most part, caregiver actions stressed caretaking as opposed to educational functions. However, variations in behaviour were related to caregiver characteristics. In contrast to previous research, higher education, as well as child-related preparation was associated with several qualities of caregiver behaviours which include decreases in restriction and increases in encouragement, development of children's verbal skills, and the use of indirect forms of guidance. Education was positively associated with caregiver commitment to child care as a career. Also, career commitment, child-oriented attitudes, job satisfaction, and stimulating but nondirective behaviours towards children were positively correlated with one another (Elizabeth, 1990).

Also Laura and Pedro (2010), conducted a study on the prevalence of informal caregiving to elderly parents by their mature daughters in Europe and the effect of intense (daily) caregiving and parental health on the employment status of the daughters. Laura et, al. (2010) grouped the data from the first two waves of share into three country pools (North, Central and South) which strongly differ in the availability of public formal care services and female labour market attachment. They use a time allocation model to provide a link to an empirical IV- treatment effects framework and to interpret parameters of interest and differences in results across country pools and subgroups of daughters. They focus on the impact of parental disability on the rates of employment and daily caregiving of daughters and on the ratio of these impacts which is a Local Average Treatment effect of daily care on labour supply under exclusion restrictions. Laura et. al. (2010) found that there is a clear and robust North-South gradient in the (positive) effect of parental ill-health on the probability of daily caregiving. The aggregate loss of employment that can be attributed to daily informal caregiving induced by parental disability seems negligible in northern and central European countries but not in southern countries. Large and significant impacts are found for particular combinations of daughter characteristics and parental disability conditions. The effects linked to longitudinal variation in the health of parents are stronger than those linked to cross-sectional variation.

Socioeconomic status (SES) is one of the most widely studied constructs in the social sciences. Several ways of measuring SES have been proposed, but most include some quantification of family income, parental education, and occupational status. Research shows that SES is associated with a wide array of health, cognitive, and socio-emotional outcomes in children, with effects beginning prior to birth and continuing into adulthood (Robert, 1998). A variety of mechanisms linking SES to child well-being have been proposed, with most involving differences in access to material and social resources or reactions to stress-inducing conditions by both the children themselves and their parents. For children, SES impacts well-being at multiple levels, including both family and neighbourhood. Its effects are moderated by children's own characteristics, family characteristics, and external support systems.

## 3.5 Psycho-social well-being of informal caregivers

The study carried out by Schofield et al., (1998) revealed that caregivers of people with physical impairment and who are intellectually intact express a greater sense of well-being than do caregivers of people who are affected intellectually. In a study by Hoare et al., (1998), greater distress in caregivers of severely intellectually disabled children was associated with increased disability in the child. Similarly, the presence of behavioural problems in the care recipient with dementia was associated with increased depression in the caregiver (Schultz et al., 1995). However, a comparison of mothers of adults with mental health problems with mothers of adults with intellectual disability found that the latter group experienced greater gratification and a better relationship with the care recipient than did mothers of an adult with mental health problems (Greenberg, Seltzer & Greenly, 1993). In the latter study, mothers of adults with mental health problems reported more behaviour problems in care recipient (Greenberg et al., 1993). In the latter study, mothers of adults with mental health problem reported more behavour problems in care recipient (Greenberg et al., 1993). Some aspects of the impact of care giving on the caregiver's mental health differ depending on the nature of the care recipient's disability (Bigby & Ozanne, 1993). For example, caring for a person with mental illness may involve a degree of uncertainty for the caregiver, a lack of control for the caregiver and manipulation by the care recipient. For caregivers whose care recipient has dementia, there is the loss of the person who once was, and witnessing the gradual decline of that person. Caregivers who are parents of children with disabilities may need to deal with the knowledge that their child will not develop as other children do, and the milestones celebrated by other parents may be times of grief for them. As caregivers who are parents of adults with disabilities age themselves, they face the additional concern of who will care for their child when they are no longer able to (Bigby & Ozanne, 1999).

In their own contribution to psycho-social well-being of informal caregivers, Lach et al., (2009), exhibited a greater number of health and psycho-social problems. Lach, et al., (2009) therefore suggested that while addressing children's problems, health care professionals should also consider caregiver's physical and psycho-social health, as this may also have an impact on children's well-being.

Guat (2008) in a study characteristic of family caregivers and care recipients and their care giving experiences found that care recipients were mostly parents and majority lived with their caregivers. Caregiving activities were frequently "light", such as accompanying care recipients on hospital/clinic visit, providing emotional support, etc, as compared to "heavier" duties, such as feeding, bathing, toileting and dressing. Pruchno, Patrick, and Burant, (1996) in contributing to factors that affect African American women caregiver's mental well-being, using a broad literature base, suggested that there are multiple contributing factors that may challenge or adversely affect African American women caregivers' mental well-being. Pruchno et al., (1996) in summary stated that those factors include social demographic and environmental factors, social support, social roles, appraisal and coping factors. The author further suggested that more researches should be carried out to investigate how these factors impact on the mental well-being of African American women caregivers within their own racial and gender group. African American women share the common experience of race and gender but they may differ across class and location of residence in terms of their caregiving experiences.

The type of disability of the care recipients and where the caregiver is in the caregiving process will affect the impact caring has on the caregiver's mental health. The important role of moderators of the impact of caring, such as the caregiver's financial situation and coping strategies used, should also be considered by service providers when planning how to assist caregivers (Sally and Susan, 2003). Greater consideration of some of these factors may assist in more efficient use of the resources available to support caregivers. Attention should be paid to the individual situation of each caregiver. Careful assessment of caregivers' need should consider the factors associated with a negative impact of caregiving and of the various mediators of this impact (Sally & Susan, 2003). It is also important to acknowledge the positive aspects of the caring role to ensure that these are not obstructed by interventions to assist caregivers. Global responses to the needs of all caregivers will not provide the most benefits to individuals. While the importance of practical assistance, such as financial or respite services should not be overlooked, other avenues for supporting caregivers should be examined, Sally & Susan (2003) suggested. Empowering individuals by helping them make available sources of social support, providing assistance with coping strategies and enhancing feeling of mastery or self efficacy may be particularly worthwhile for some caregivers, but are not currently part of mainstream services (Logsdon, McCurry & Teri, 2007).

Cuijpers (2005) in his study of understanding quality in kith and kin child care, found that family, friends and neighbours providers who have lower depressive symptoms and positive affect will be more likely to have higher awareness of children's emotional state and show greater warmth and appropriate social behaviour directed to the children. Being able to respond appropriately and positively to children is important because of the process aspects of the child care relationship. The processes include quality of interaction between the provider and the child, degree of warmth, and communication, and are related to high quality child care in both licensed and family, friends and neighbour settings. Cuijpers, (2005) conclude that providers who have more positive well-being will be more able, and more inclined psychologically to enact such positive behaviours, as reading to children, will be more cognizant of preventing negative behaviour, such as accidents. The providers are also likely to have more psychological energy to communicate with parents, engage in quality care giving behaviour, and to develop better quality relationship with mothers. Henly, Sandra, Dazinger and Shira (2005) found that after controlling for job quality, over time welfare mothers who perceived positive support from their informal social network were more likely to move out of poverty.

According to Bradly (2002), usually friends, family members, co-workers, neighbours, and people at a house of worship make up a circle of support for family. The people in this circle of support are not paid to help, but do so out of care and concern for the individual or the family. Also the need to care for the elderly has the same basis as caregiving for mentally-challenged individuals. Boyd (2002) found that the female caregivers of mentally challenged individuals experienced less involvement in social activities, including recreational, cultural, and other stress reducing activities than mothers of typical children.

Marks, Lambert and Choi (2003) found out that mothers who are caregivers of mentally challenged individuals show much greater levels of stress, loneliness, and isolation than mothers of non-mentally challenged individuals. Yee and Schulz (2000) found that mothers of mentally-challenged individuals acting as primary caregivers who report more help from their spouses do experience higher marital satisfaction and less distress. Wallsten (2000) found that caregiver's health symptoms are negatively affected by both the chronic and on-going nature of caregiving, and the disabled individual's ability to perform daily living activities. He also found out that a new caregiver of a child with disability either man or woman report a significant greater increase in depressive symptoms.

## 3.6 Impact of disability on caregiver's family

Different studies have shown the effects of disability on the family of children with disability. Mothers most especially develop anticipation regarding their infants (Ones et al., 2005). Most of the problems associated with caregiving include anxiety, stress, marital adjustment and family low levels of confidence and in general, depression. Substantial evidence has shown that over a long period of time that disability or chronic illness in children causes an increase in emotional disorders for informal caregivers of children with disability (Okhakhume, 2007).

The consequences of nurturing a child with a developmental disability can be highly challenging. Caregivers and the family as a whole experience some exceptional pressure starting from the moment the child is diagnosis of disabilities. The birth of a child with disabilities is a stressful event that mostly leads the informal caregivers to inadequate coping styles and reduced social contact as a result of the limited time they have due to caregiving activities (McConkey, 2008). Many of the caregivers of physically challenged children suffer some emotional disequilibrium as a result of their unending patronage of both traditional and orthodox healing homes which results in serious emotional distress (Giallo & Gavidia-Payne, 2006).

According to Mittelman, Roth & Coon (2004), there are three sources of support that are very central to affecting a favourably informal caregiver's ability to cope and reduce feelings of hardship, stress and contribute to successful care of children with disability. These supports include:

I. Cooperation, discussion and consultation of parents with family, friends and professionals contribute to strengthening parental functioning,
II. A positive bond between a parent which support and strengthens them,
III. Utilizing the various services available for diagnosis, treatment, counselling and
IV. Training, whether assistance is directed to the child or the family.

### 3.7 The Impacts of care giving on psycho-social well-being of informal caregivers.

Caregiving has many impacts on psycho-social well-being of informal caregivers of physically challenged children. Carpenter, Nagell and Tomassello (1998) during an interviewing session with 54 New Zealand caregivers of children with disability, found that parents were exhausted as a result of providing care for their children. The parents also revealed that they exercise extreme vigilance to ensure the safety and comfort of these children and others in the vicinity. These parents suffer lack of enough sleep due to night time care giving tasks as a result of the sleeping disorder habits of the child. These informal caregivers had to combine the demands of their other children, with coping with the normal tasks of keeping the household financially sound and tried to maintain their own well-being.

### 3.8 Impact of caregiving on physical health of informal caregivers

Researchers conducted with New Zealand parental caregivers of children with physical disability shows that informal caregivers had general conditions of ill health as a result of persistent stress, worry, lack of sleep which lead to mental and physical exhaustion and also developed back or other injuries caused by the child's behaviour (Carpenter et al. 2000).

Raina, Donnell and Rosenbaum (2005) concluded that physical stress related to caregiver's duties may be a risk factor for Lower Back Pain (L.B.P.) in parents of physically challenged children. These informal caregivers of physically disabled children between the ages of 5 and 12 years reported the range of important physical issues that they dealt with regularly. The research further suggests that L.B.P. is a considerable problem within this group and has a negative impact on informal caregiver's ability to care for their physically challenged children who may depend solely on parental help to perform daily routine. Moreover, taking care of children involves considerable resources, but the demands for these resources becomes more challenging when caring for a child with disability is involve. However this challenge has implications on the psycho-social well-being and physical health of the informal caregivers (Lach et al., 2009).

## 3.9 Impact of caregiving on mental health of informal caregivers.

Many of the informal caregivers of children who are physically challenged reported that they suffered mental health problem due to persistent stress, lack of relaxation and exposure to aggression and violence by their disabled children. Many also reported suicidal feelings on different occasions (Carpenter, et al., 2000).In a study conducted by Hui (2010) with 18 Whanau caregivers, they revealed the depth of emotional turmoil and stress experienced by Whanau caregivers as a result of the needs of disabled Maori children. Whanau Caregivers expressed caregiving as hard and stressful work, and more challenging if the recipient of care had a complex condition. Whanau caregivers shared the excruciating pains, grief and frustration of seeing the person with disability struggle and wishing they could render more assistance (Nikora, et al., 2004).

## 3.10 Impact of caregiving on the financial resources of informal caregivers

Available literature on caregivers of physically challenged children reported a huge impact of disability on the financial resources of informal caregivers of children with disability. These are financial implications coming from the consequences of financial decisions taken as a result of caregiving and the financial status of the informal caregiver (Lungley et al., 1995; Nikora et al., 2004).

Informal caregivers of children with physical disability are usually under financial pressure especially the single parents and those with low incomes. Financial pressure and the stress they encounter, severely hinder their participation in normal activities for other children in the family. Besides, there are other expenses coming from medical appointments, transportation and home modifications (Carpenter et al., 2000; Horsburgh, 2002; Horsburgh & Trenholme, 2002).

Furthermore, low financial incomes constitute major sources of stress for all caregivers. The more profound the disability of a child, the more support the child requires from the caregivers and the level of income affects ability to purchase additional support(Lungley et al., 1995; Nikora et al., 2004).The authors therefore submitted that care giving is a source of poverty which potentially hindered the whole family from attaining a positive psycho-social well-being.

### 3.11 Informal caregivers of children with physical disability

The nature of the impact of caregiving varies depending on the age of the recipient and their relationship to the caregiver. Caregiving to a child with a disability can be highly challenging and stressful to the whole family system. Informal caregivers of children with disability struggle with balancing the needs of these children with the needs of their siblings. The challenging coming from this to informal caregivers is their difficulties in maintaining consistent parenting while operating with different expectations between the disabled and non-disabled children (Sally & Susan, 2003). Other children in the family may become a point of concern for informal caregiver who cannot spend sufficient time with them, or a target of transferred aggression (Carpenter et al., 2000).

Another challenging issue to informal caregivers is their marital relationships. Many informal caregivers have their marital relationships suffer due to stress and not having quality time to spend together with their spouses. Many informal caregivers of physically challenged children are either separated or divorced from their partners (Wakabayashi &

Donato, 2005). However the disabled child may not necessarily be the cause of separation, but can be a contributing factor (Carpenter, et al., 2000). Research suggests that informal caregiver's participation in workforce is very low when comparing to others in the general population, this is because Care giving is harder if it conflicts with employment. (Roth et al., 2009).

Another study on relationship between informal care giving and employment based on caregivers' different occupations revealed that there was an inverse relationship between the hours spent on care giving and participation in paid employment (i.e. caregivers spent more hours on paid work (Arksey, Jackson & Croucher, 2005). The authors therefore, submitted that most caregivers who are in paid employment before taking on the care giving role relinquish paid jobs reluctantly. They also suggest that people try to combine paid work and care giving by using lunch time for care giving activities, taking time off paid jobs, finding less demanding paid jobs, moving closer to the place of work. Besides, they also avoid applying for better jobs, becoming self-employed, working fewer hours, using holiday entitlements for caregiving purposes, and taking sick leave to attend to care recipient.

## 3.12 Caregiving around the world

Caregiving is a global phenomenon. Both formal and informal caregiving activities are embarked upon by people in every society but with differences in the way it is been carried out. This section looks at the activities of caregivers across the world.

### 3.12.1 Europe

In Europe many people prefer home care to institutionalization. There are many reasons for this preference and the main reason is that home care has a lot of advantages over institutionalization (Thornicroft & Tansella, 2003). The increase in the number of care-dependent of older people, children with disability, people with mental disorder and the rise in the number of people living with non-communicable diseases home care services becomes more widely used (Ehrenfeld, 1998; Stone, 2001; Lamura & Polverini, 2005). Despite this preference, the trend in caregiving tilts towards institutionalization as a result of socio-demographic changes and mobility. Urbanization has led to the breakup of traditional family settings, with family becoming smaller, occupying small place and the movement of the younger ones away from their family as a result of work commitment. This trend only portrays a situation where family caregiving will no longer be available (Stone, 2001). Researches revealed that care recipients and informal caregivers prefer home care where the environment is friendly (Eurostat, 2008).

In Europe generally the demand and supply of home care has increased due to general trend in demographic, social, technological, epidemiological and political pressures (Lamura & Polverini, 2005). (1) Social attitudinal change in values and behaviour, increasing number of women joining labour force and tighter regulation of labour markets has led to shortage of informal caregivers. Although there is no uniformity in the history of home care services policy and provision across Europe, different European nations have different approaches and strategies for funding, organizing and delivering home care services (Thome, Dykes, & Hallberg, 2003). Differences also exist in tax-based provision, municipal, regional and national levels of responsibility, health and social service boundaries and greater or lesser policy support for informal care (Hutten & Kerkstra, *1996).* However, traditionally provision of home care across Europe relied on informal care and voluntary or church. It was during the 19th century that growing influence of institutionalization support for vulnerable people began to take dominant form (Twigg, 1993). As from 1950, deinstitutionalization, community care, continuous care, integrated care and home-based care policies have been in place to cut short number of long-stay beds for older people and children in hospitals, improvement of nursing and residential homes for older people, children, people living with disability and the closure of long-stay mental institutions across Europe(Nies & Berman, 2004). Although, Institutionalization and deinstitutionalization policies in Europe occurred at various times and places, for instance, in southern and eastern Europe the two policies are a recent development while in some other countries in eastern Europe institutional care still remains the dominant form of care (Risse, 1999). All European nations recognize the importance of social care but there are varying meaning and policies attributed to it due to differences in histories and context.

Many countries in southern Europe have not developed their formal home carefully, whereas some Nordic countries have comparatively underdeveloped voluntary sectors (Hutten & Kerkstra, 1996; Ehrenfeld, 1998). Many professionals and non-professionals have been employed to deliver home care services and they include nurses, therapists (physical, occupational and speech), home care assistants, social workers, physicians, dieticians, homemakers, companions, volunteers and others. Out of these groups nurses have the

largest percentage that plays different roles in the care management of care recipients. Informal caregivers have been and still remain the bulk of home care provider in southern Europe and without them home care will be unsustainable (Mestheneos & Triantafillou, 2005). However in northern Europe such as Denmark and Scotland informal care are less common due to the fact that municipalities provide extensive personal care and domestic services. Informal caregiver activities vary within and between European countries (Penning, 2002). The most common home care in Europe include rehabilitation, supportive, health-promoting or disease-preventive, occupational therapy, physiotherapy and technical nursing care for both chronic and acute conditions (Shepperd & Iliffe, 2005). Countries such as Belgium, France, Italy, Portugal, Spain and the United Kingdom have similar home care health structure in which home care is part of the health care system and the social component is part of the social system (Hutten & Kerkstra, 1996; Ehrenfeld, 1998).

Whereas, in Denmark, Finland and Sweden the municipalities are the dominant structure. Care in the home has been found to provide emotional and physical association between the caregiver and the care recipient. It has also been found to give comfort and memories as many have discovered that it keeps family together and promotes healing. Part of home care advantages also, include allowing more freedom to individuals and it always tailored towards the specific need of the individual. Lastly home care prevents or delay early institutionalization and is always deliver at home where many people prefer to stay when they are sick. (Hutten & Kerkstra, 1996 Ehrenfeld, 1998)

### 3.12.2 America

Caregiving to a loved one could be highly challenging, in fact it could go beyond the informal caregiver's physical and mental capability. As a result it can lead to psychological and physical health problems to caregivers thereby reducing the quality of care given and may eventually lead to early institutionalisation of the care recipient (Carretero, Garcés & Rodenas, 2007; Garcés et al., 2009).In America there is respite care and it has proven to be a good means of relieving informal caregivers of stress, bring back their energy, and promote their psycho-social well-being. The main goal of respite care is to allow caregivers to have time to attend to their own personal issues, such as running errands, meeting a friend for coffee, or even a time to recharge and at the same time give care.

Besides, it gives women caregivers more employment opportunities, and could act as a source of revenue to government. It also acts as a preventive measure for in-home abuse or neglect due to caregiver burnout. Respite care also has the advantage of keeping older people in their homes for longer time, thereby reducing early institutionalisation. Respite services have different forms but mainly act as a break to the caregivers which are very important to caregiver's well- being. It is usually a short break that can last for few days and at same time could also last for weeks or month. Respite services can be a temporary substitute supports or a living arrangement for the care recipient, which could be offered in an inpatient setting or in the home. This could be done by formal or informal providers occasionally or regularly.

#### 3.12.2.1 Women and caregiving in America

In America, majority of elders that need long-term care are usually cared for by informal caregivers. In fact only seven percent (7%) of those that have family caregivers are in institutional homes (U.S. Administration on Aging, 2000). Women have been found to be essential in caregiving roles as they provide majority of care needed by spouses, parents, parents-in-law, friends and neighbours and it is estimated that the value of care provided by women in America is up to between $148 billion to $188 billion annually (Navaie-Waliser et al., 2002). Although there are male informal caregivers but more female spend more of their time in caregiving than male (Family Caregiver Alliance, 2001).

Majority of women are younger and tend to outlive their husband. This places them in a position of long-term care provider and at same time care recipients (U.S. Census Bureau, 2000). As more women join the workforce, the expensive nature of caregiving and the time out of work for caregiving, many women caregivers face financial challenges that incapacitate them from meeting family needs. In fact it is estimated that 33% of working women decreased work hours, twenty-nine per cent (29%) passed up a job promotion, training or assignment, 22% took a leave of absence, twenty per cent(20%) switched from full-time to part-time employment and 16% quit their jobs (MetLife Mature Market Institute, National Alliance for Caregiving & The National Centre on Women and Aging, 1999).

Another study revealed that female caregivers retire five times more than non-caregiving women and female caregivers with many care recipients have 50% chances of retiring earlier than non-caregiving women (Older Women's League, Women and long-term Care, 2003). They are also less likely to receive pension and likely to spend up to 12years out of workforce for family caregiving (Social Security Administration, 2002).

Dettinger and Clarkberg (2002) found out that female caregivers did not increase work hours even when they have stopped caregiving and those who went back to full-time employment are most likely to earn lower wages, have a "benefit-poor" job and receive reduced retirement benefits. Apart from financial challenges, women caregivers experience a high level of stress from depression, anxiety and other mental challenges. Vlasblom and Schippers (2004) revealed in their study that women caregivers are likely to suffer depressive or anxious symptoms six times more than non-caregiving women. The amount of caregiving provided by a female caregiver per week determines the impact of caregiving on health. Furthermore the number of time spend on caregiving may likely determine the escalation of mental health consequences (Vlasblom & Schippers, 2002). Women caregiver are also likely to experience other symptoms such as a higher level of hostility and decline in happiness, increases in symptoms of depression, less personal mastery, less self-acceptance and high caregiving-related stress (Gallant & Connell, 1998; Marks, Lambert & Choi, 2002;).

More importantly is that many women caregivers have poor health as a result of lack of support they receive from family members for their own poor health (Langa et al., 2001). Majority of women caregivers do not make use of preventive health services because they lack information and high cost of service (U.S. Administrations on Aging, 2000). Those that spend more time on caregiving are likely to develop coronary heart disease (CHD), elevated blood pressure and increased risk of developing hypertension; lower perceived health status; poorer immune function; slower wound healing; and an increased risk of mortality (Lee et al., 2003). Women caregivers with low income face additional challenge as they could not afford paid caregiving and thereby spending more than 20 hours per week on giving care to their loved ones (The Commonwealth Fund, 1999). However as much as caregiving is associated with negative impact, some women caregivers have expressed positive aspect of caregiving which includes more purpose, autonomy, personal growth, and self-acceptance in life than their non-caregiving women peers when caring for friends (Marks, Lambert & Choi, 2002).

### 3.12.3 Caregiving in Nigeria

In Nigeria, with a high prevalence of sickle cell disease (SCD), families bear most of the burden of care for patients with this chronically disabling illness, because there are no national social welfare provisions. Global rating of burden was significantly predicted by disruption of family routines and higher age of caregivers (Jude & Wuraola, 2002). The psychosocial burden of SCD can be significantly reduced by controlling the frequency and duration of crises, as well as providing adequate information and socioeconomic support to families. Haematology staff should be sensitive to the psychosocial dimensions of SCD (Jude et al., 2002).

Igberase et al., (2012) in their studies reported that Schizophrenia is a devastating mental disorder which places immense burden on family members. Level of burden showed significant associations with caregivers' educational level, age of patient, employment status of patients and global rating of difficulty in coping with caregiving. Public health education as well as targeted interventions in the area of employment, financial and other support for persons with mental disorders would help to ameliorate this burden (Igberase et al., 2012).

In a study conducted by Abdulraheem and Parakoyi (2010) to determine the opinions of caregivers towards caring for the elderly in Ilorin and the caring patterns and relationships that exist between the elderly and caregivers' attitudes. The difference between respondents with and without formal education concerning where to care for the elderly was not statistically significant.

Nigeria with a population of over 140 million has so many religious groupings. Despite evidence that people frequently turn to religion for support in the face of adversity, there are no studies examining the prevalence of religious coping in the carers of the mentally ill in Nigeria (Ukpong, 2009). The association between religious coping and burden levels in these caregivers has also not been assessed. The study investigated the prevalence of religious coping in caregivers of patients with mental illness, and the association between burden and religious coping. The burden of mental illness and religious coping was studied using standard instruments Caregivers play important roles in the collaborative efforts that characterize successful stroke rehabilitation, and their quality of life (QoL) may have implications for outcome of care(Grace, Aisha & Talhatu, 2012). Although QoL of stroke caregivers was fair across domains, the physical domain recorded the lowest mean scores. Older age, lack of formal education, unemployment and caring for stroke patients within the second year post-stroke were associated with lower QoL scores. Information from this study may aid in identifying those caregivers who require support programmes and care the most.

Burden of care is a multi-factorial construct which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger and feeling of guilt and self-blame. It is customary to describe burden as objective or subjective. Objective burden refers to changes in household routine, family or social relations, work, leisure and physical health; while subjective burden consists of subjective distress among relatives, including impact on mental health (Grace et al., 2012). Family caregivers have been described as forgotten patients and it was suggested that caregiver's symptoms such as mood swing, fatigue, headaches, joint and muscle pains, marital and family conflicts, and financial problems may be a reflection of caregiver stress in looking after a sick relative (Folorunsho et al., 2010).

Folorunsho, Abdulkareem, Akinsola, Joseph, Obafemi, Zainab andOlaniyi (2010) in their studies have shown that caregivers of patients with epilepsy have high levels of strains, fears that the illness may cause injury or death as well as concern about what will happen to patients in future when the caregiver will not be available to cater for patients. In addition, it has been shown that relatives who care for patients with epilepsy have higher burden of care than control groups and that depression and patient's functioning separate from seizure control and low income are predictors of burden in caregivers (Folorunsho et al., 2010). In Nigeria, it has been reported that caregivers of patients with schizophrenia and dementia are strained while caring for their relatives and that high burden was associated with living in rural areas, large family size, and severity of patient's illness and caregiver's low level of education (Folorunsho et al., 2010). However there is paucity of literature on the burden experienced by caregivers looking after patients with epilepsy especially in the northern part of Nigeria and it is against this background that the authors studied caregivers of epileptic patients in their centre to assess their level of burden in caring for their patients.

In a study by Izibeloko, Leana and Lyn (2013), to explored the family caregiving experiences of persons with serious mental health problems in terms of the mental health-care policy and health systems environment stigma, poor knowledge in managing symptoms of ill relatives, financial implications, lack of support network, and absence of community outreach clinics were found to affect family caregiving experiences. Policies need to be developed and implemented that provide mental health care through primary health-care services to ameliorate families' financial burden, enable early diagnosis and treatment, reduce the need to travel, and improve the quality of life of family caregivers. Abdulkareem and Folorunsho(2011) suggested that caregivers play an important role in the management of chronic mental illness in the community. Caring for patients with chronic mental illness like schizophrenia can cause emotional distress in the caregivers. However, the magnitude of the problem remains largely unknown in Sub-Saharan Africa and other developing countries. Emotional distress is common among caregivers of patients with schizophrenia and the risk factors were similar in most communities.

Christopher et al., (2011) investigated that caring for stroke survivors in Nigeria seems to have adverse effects on the QOL of closer relatives who are either women or older. There is a need for clinicians to help those caregivers at risk find ways of improving and optimizing their QOL.

Uwakwe and Modebe (2007) describe the pattern of disability and care for older community residents in a selected Nigerian location. Many co-morbid physical diseases were reported. Most of the older subjects' children had left the community and females were the main care providers. Help with self-care was the greatest problem reported by the carers and care giving was regarded as very heavy burden associated with high emotional distress, Disability is high in community elderly subjects. Care giving is proving a great challenge in the face of children disserting their parents, and increasing harsh economy. There is need for a systematic, realistic plan to implement qualitative care policy for older Nigerians (Uwakwe et al., 2007).

Ukpong and Turk (2012) determine the relationship between symptoms of schizophrenia and caregiver burden/distress among caregivers of people with schizophrenia in south-western Nigeria. These results underscore the need for continued intervention for family members of Schizophrenic patients. Part of the care plan for the caregiver should include education on the negative symptoms of the illness.

Margaret, Talhatu and Olusegun (2013) in a comparative study on quality of life (QoL) of Nigeria caregivers of children with cerebral palsy (CP), found out that motor function of the children with CP correlated with the QoL of their caregivers. Also people caring for children with CP had a lower quality of life than their counterparts caring for normally developing children.

Abdulkareem et al., (2011) examined the nature and magnitude of the problems facing caregivers of patients with cancer in an urban African setting, the result revealed that caregivers remain largely unknown in developing countries of the world. The study addresses these issues in a group of caregivers of patients with cancer in Zaria, Nigeria. The study demonstrated a high level of caregiver burden, psychological morbidity and financial strain in family caregivers coming to the clinic with a relative who has cancer in an urban Nigerian setting.

Prasanth, Sasidhar and Padam (2012) revealed that Caregivers of individuals suffering from psychiatric illness are at risk of being subjected to mental health consequences such as depression, anxiety and burnout. Community-based studies proved that 18-47% of caregivers land in depression. The caregiver burden can be quantified into objective, subjective and demand burdens. There is paucity of data comparing the caregiver burden of psychiatric patients and that of chronic medical illness patients. The caregiver burden was found to increase with the duration of illness as well as with the age of caregiver. The caregiver burden in the sample population was less as the objective and demand burden did not cross the reference higher value in the given scale, whereas the emotional impact given by the subjective burden was on higher side.

Samuel and Emmanuel (2012) in a study on psycho-social burden on families in Nigeria reported that Sickle Cell Disease (SCD), the most common genetic disorder amongst black people, poses a significant psychosocial burden on the sufferers, the caregivers and their families. Caregivers are faced with enormous financial, interpersonal and psychological problems. Social support should be available to alleviate caregivers' and/or family members' burdens, Samuel and Emmanuel (2012) recommended.

Additionally, Abikoye (2006) in his study on subjective quality of life among caregivers of mentally ill persons in South Western Nigeria reported that the introduction of Community-focused psychiatric care has placed increasing responsibility on families for the care of people with psychiatric disabilities, resulting in significant burden, distress and reduced quality of life in family members who are saddled with the responsibility of caring for these individuals. Furthermore, male caregivers and relatively younger ones reported significantly lower subjective quality of life compared to females and older ones.

### 3.12.4 Caregiving in South Africa

In South Africa, caregivers are the primary persons for the provision of care and support to individuals with learning disabilities. This became more prominent following the establishment of the primary health care approach (PHC), a function of the introduction of the White Paper in 1997, Transformation of the Health Service in South Africa (Mavundla, Toth & Mphelane, 2009). The principal aim of the PHC is to ensure the provision of comprehensive and holistic care to individuals in the community, including people with disabilities. In Limpopo, caregivers and care recipient have access to community-based PHC clinics for supportive counselling and prescribed medication. During these visits, they mainly engage with nurses and nurses do play a crucial role in the PHC service. In rural areas, they are often described as 'mini doctors' with the remit of offering education and training as well as diagnosing and treating common illnesses (Mavundla et al. 2009). In South Africa, nurses are hardly trained in the provision of psychosocial care, and so the care they provide remains largely biomedical in nature (Van Niekerk & Sanders, 1997).

Although it is explicitly stated in these accounts that people with learning disabilities may experience difficulties living independently, the social model adopted in the Western world and South Africa suggests that people with these difficulties are expected to live a normal life in their communities (Al-Krenawi, Graham & Al Gharaibeh, 2011). This expectation can be achieved if they are supported by their families (Clark & Griffiths, 2008). The deinstitutionalization of mental and learning disability care, which was a critical part of the transformation of the South African healthcare service, supports this view. Deinstitutionalization was the replacement of institutional or inpatient settings with community-based alternatives for the care of people with learning disabilities and/or mental health problems (Bachrach, 1996; Mavundla et al., 2009). The adoption of this strategy made families to become the main providers of care, with healthcare professionals assuming a secondary role. Caring for individuals who are intellectually disabled can generate enormous amount of stress in caregivers, particularly if 'caring' takes place over a protracted period of time (Mavundla et al., 2009; Merrifield, 2011).

It is known that stresses of caregivers can arise from the behaviours presented by children in their care. However, there is no literature on parents' experiences in South Africa and presently evidences on such issues rely heavily on studies carried out in the West. For example, children with learning disability can display a range of challenging behaviours, which may include aggression and self-harm (Merrifield, 2011). Exposure to these behaviours can be overwhelming and threatening to observers (Shaw, Keenan, Madaus & Banerjee, 2010). Caregivers may react to these experiences by distancing themselves or withdrawing their attention from the care recipient (Royal College of Nursing, 2006). These experiences may also have a negative impact on the quality of care caregivers offer to children. Such reactions can be attributed to lack of or limited knowledge and skills on how to respond to behaviour that challenges, a view also acknowledged by Sen and Yurtsever (2007). Taking this into account, it is essential that caregivers' needs are frequently assessed and provided with regular support in order to develop understanding of learning disabilities as well as offer timely and effective care to children in their care.

Despite this urgent request, caregivers in Western studies are infrequently supported by healthcare professionals experienced in care provision for children with learning disabilities (Pasacreta & McConkey, 2008). It is therefore not surprising for caregivers to frequently present with symptoms of anxiety, depression and burnout (Merrifield, 2011). Frequent experiences of these symptoms may not only lead to the development of negative attitudes, but it may affect the quality of care provision of caregivers (Sandy & Shaw, 2012). Despite these findings, there is currently no study in South Africa that has explored the support needs of caregivers for people with learning disabilities. Hence, study, which seeks to explore the support needs of caregivers, as identifying these would lead to the development of a training programme. If implemented, such a programme could result in the provision of tailor-made assistance for addressing the stresses and anxieties that caregivers may experience.

On many occasions, the caregivers from low-income families described their financial needs as part of a double-trouble. This description was related to being financially poor and having the responsibility to care for children who are physically, mentally and socially demanding (Al-Krenawi, Graham & Gharaibeh, 2011). Although the South African government offers grant to children with learning disabilities, some caregivers clearly stated that the money they were offered was not sufficient to meet the daily economic needs of this group of children. According to some caregivers, being unemployed and/or unable to work because of the need to offer 24-hours of care contributed to their financial difficulties (Sandy, Kgole & Mavundla, 201*3).* Clothes were not the only items associated with financial constraints reported by caregivers. Food shortage and deprivation of educational needs were also discussed during interviews. Added to this, most caregivers expressed experiences of affiliate stigma and social exclusion because of their close association with children who are learning disabled (Mak & Cheung, 2008).

Children with learning disabilities and their caregivers are often stigmatized, and as a result, exposed to discriminatory acts, labelling and prejudice that are usually embedded with negative attitudes from both healthcare workers and members of the public (Al-Krenawi, Graham & Gharaibeh, 2011). Discriminatory acts, labelling and prejudice were also claimed to take place in family homes. Disabled persons more often than not suffer from discrimination because of prejudice and ignorance (Statistics South Africa, 2005). Only very few people and community organizations are willing to embrace them in their activities. Generally, they experience social exclusion. This is a burden for caregivers as they are restricted to a small number of places they can visit or attend with their children.

Sandy, Kgole and Mavundla (2013) reported that caregivers carry great responsibility for ensuring the needs of children in their care are met. Such responsibility can generate great amounts of stress that may negatively impact caregivers' day-to-day functioning. Yet, research concerning how to support caregivers in meeting the needs of this group of children in Limpopo has never before been carried out. Caring for children with learning disabilities was perceived as difficult and frustrating, yet rewarding. This difficulty was noted to be compounded by caregivers' lack of skills and knowledge of caring for these children. They also had experiences of stigma, which sometimes involves overt acts of discrimination and social exclusion that further added to their frustration. Sandy et al., (2013) findings have implications for practice and policy. Regular training and support should be offered to caregivers in order to broaden their understanding of learning disabilities and enhance their caring ability. Nurses are the main source of training and support and offer these during clinic-based engagement and home visits.

### 3.12.5 Caregiving in Finland

Finland is one of the European countries where there are about 300 000 unofficial caregivers caring for their next of kin (Järnsted et al., 2009). A caregiver in Finland is defined as a person who made an agreement with municipality in order to be warranted to the caregiver benefit (Reetta, 2012). Municipalities in Finland provide different social support services to caregivers in order for them to give quality care to their loved ones. According to Reetta (2012), there is financial benefit for caregivers granted by the municipalities to ensure effective home care. The benefit includes services embedded in the care and service plan made for individual caregiver. In this plan a caregiver has right to three days off each month if he/she is a full-time worker and must compulsorily provide the care (Reetta, 2012). The municipality also provides such services that include renovation at homes, medical equipments and aids that enhance effective home care delivery. Prior to the provision of these services a home evaluation would have been conducted by the municipality and social services worker and the plan drafted together with the care recipient and the caregiver. The service plan does not guarantee service delivery but rather decisions are made for each service in the plan.

The agreement contains the amount of fee granted by the municipality as financial aids, the days off and the organization of the days off (Wang, Chien & Lee, 2012). The usage of services are planned irrespective of the financial status of individual and the fee varies depending on the service provided while guidance, promotion of services, performance maintenance and social services are free (Lappalainen & Turpeinen, 1999).

Reetta (2012) further stated that included in the care- and service plan are the quantity and the quality of care provided by the caregiver and the required services by the care recipient such as meal service, bathing service and transportation services. More also, the possibility need for both short and long term interval care, required aids and the description of the support need for caregiver's work. On the part of the municipality, it is required that they provide guidance and education to caregiver by attaching a contact person to him/her. The possibilities of attending lessons class and caregiver group meeting and organization of the treatment plan for the care recipient in case of short term care are also in the care plan (Järnsted et al., 2009). Recommendations are also made in the care plan as regard the information on the safety of the nursing environment, functioning ability of the care recipient and possible recourses of the caregiver and more importantly the state of health of the caregiver. Embedded also in the care plan are the aims and goals of the treatment plan, the need for annual review of the service plan and when there is improvement at home. The services provided must also reflect the service demand of the caregiver and the care recipient (Järnsted et al., 2009).

Volunteering is one of the assisted services in Finland for a person who is receiving home care. The volunteer work makes it possible for caregiver to have a break so as to have time to take care of personal needs. The work of a volunteer can include taking the care recipient out for walks and assistance in hobbies. Information regarding where to get service and home nursing are provide by the organization providing the service (Lappalainen et al., 1999)

Diaconal work is another respite service provides by parishes in Finland and their services include provision of people living in the parish with guidance, support and discussion help. They also pay home visit if requested by caregiver and support group where caregivers meets and receive peer support are also organized by the parishes. Camp meetings and other activities are also arranged by parishes (Lappalainenet al., 1999). Information that are very vital to caregivers are also supplied at the parish level on what to know about caregiving in order for them to give effective home care and to promote coping ability among the caregivers (Telaranta, 2001).

The municipality provides home- and support services that help to nurture and care with short or long- term services. Support services that can also be provided by the private sector can include, cleaning, meal, bathing, and emergency phone services which are mostly targeted at recipient who live alone and need help in day to day living (Lappalainen et al., 1999). Coping ability among caregivers are supported through this services and home nursing is provided by individual health care centre regularly or occasionally. Required home nursing visit are provided in the night, weekends and evenings while transportation services are offered in case of recipient with mobility problem (Lappalainenet al., 1999)

### 3.12.6 Caregiving in India

India has the third largest number of HIV positive individuals and the demand for resources for care is increasing and impacting the health system. Contextual factors such as stigma, discrimination, fear and neglect at the workplace, healthcare settings and in the community and depletion of financial resources have intensified the situation. Care interventions for the HIV epidemic cannot operate in isolation but must be embedded into the spheres of health facility, the community, the workplace environment and also the household. To mitigate the impact of the HIV epidemic there is a need for an integrated and expandable care agenda linked up with the family.

Research has shown that HIV epidemic impinges upon community resources and weighs down caregivers. The review of literature on care provision and HIV by Ogden and Nyblade (2006) shows that family caregivers provide the majority of care to PLHIV. There are many challenges for the 'family caregivers' ranging from burnout and financial strain to injury, increased vulnerability to illness and emotional despair. There may be changes in the family structure and sentiments due to urbanization, but the family continues to be a source of strength and support for most people, especially during illness and death. In India, families represent the largest group of caregivers for all chronic illnesses, including HIV. Kakar and Kakar (2001) reported that the family or the household provides an ideal setting for any intervention because of the existing strong emotional bond that binds members together symbiotically. The caregivers for a PLHIV may belong to a nuclear or an extended family and the family as a whole also takes some responsibility of taking care of PLHIV when he/she is not well and requires care and support.

While assessing any kind of work, economic indicators do not cover the activities of family caregivers, as they do not fall under a monetized economy (Kakar et al., 2001). This results in disparities between family caregivers and various voluntary groups acting as caregivers. The latter have advantages like recognition, sharing of feelings with other members, getting time-off and having access to support from formal sectors. Moreover, it is a form of duty or job with limited or no emotional attachments. Despite the efforts made globally to improve the care agenda, there are gaps between the formal and informal caregivers that need to be addressed in terms of fulfilling needs of family caregivers. In India, the family members are expected to provide care to any person who is ill in the family and hence, the patient does get care. However, in the context of care for PLHIV family caregivers are still not recognized (Ogden & Nyblade, 2006).

## 3.13 Coping strategy among caregivers

As much as caregiving could be rewarding to caregivers, challenges resulting from the activities such as daily tasks of living, anxiety and varying demands of care could affect their coping ability. Fatigue can set in especially when there are no enough resources to cope with (Järnsted et al., 2009). Different reasons have been attributed to decision to become a caregiver, such reasons include sense of responsibility for one's next of kin, the sense of emotional closeness, the lack of other choices and the expectations of the parent (Lipponen, 2007). Sources of strength to caregivers to cope with the demand of cargiving have also been identified. These sources are feelings related to closeness, affection and love, Joined achievements and memories, knowledge and information relating to the illness, information about support and social services available to them (Järnsted et al., 2009). More importantly caregivers draw strength from appreciation of their efforts by family members and healthcare professionals (Järnsted et al., 2009). Other sources of coping mechanisms to caregiver is the ability of the caregiver to pay attention to his/her own well-being as this is very crucial to long time home care management for the care recipient. Identification of available resources and limitations, identification of tasks that require assistance and ability to ask for help when necessary are also very important to coping with challenges of caregiving. Caregiving responsibilities can be shared with adult members of the family when one of the spouses is a caregiver (Lappalainen & Turpeinen, 1999).

However, as good as these sources are, they could be threatened by some factors that include strange relationship between the caregiver and care recipient (Lipponen, 2007). Such poor relationship affects both care recipient and caregiver negatively. Poor relationship occurs when caregiver have feelings of suspicions, and guilt blaming and care recipient taking out his/her own feelings of fear and anxiety related to the illness on the caregiver (Lappalainen et al., 1999). Coping can also be affected if enough financial and mental resources are not available to caregiver. Decision making among family members on whether to use home care or inpatients often act as a source of problem to coping capability of caregivers whereas caregiving at its best can be an affair of the entire family members (Lipponen, 2007). Feeling of loneliness on the party of caregiver especially when the care recipient condition deteriorate to the point of not been able to communicate with the caregiver may lead to depression. Also, changes in the personality of the care recipient may affect the coping ability of the caregiver if the care recipient had become aggressive, depressed or the patient become difficult to handle (Lappalainen et al., 1999).

The relationship between caregivers' coping abilities and their emotional experiences is complex. Several factors affect formal caregivers' ability to cope. These factors, which may have persistent effects on the caregivers' experience of caregiving, are often dependent on external circumstances, the individual patient, as well as the caregiving strategies employed (Chadda, Singh & Ganguly, 2007).

Coping strategies are often viewed as either emotion-focused or problem-focused (Parks & Novielli, 2000). Emotion-focused coping is concerned with the emotional strain surrounding a situation, while problem-focused coping considers a structured approach towards strain, as if seeking a solution to the presenting problems (Scherck, 1999). The literature also distinguishes between internal and external coping strategies, thus providing a multifaceted understanding of potential coping structures (Pratt et al.,1985). Although an individual's coping style is considered a stable variable, the strategies employed differ among people and over time (Scherck, 1999). The coping strategies adopted by caregivers regulate their emotional experiences, and are therefore inherently related to maintaining their wellbeing as caregivers (Tugade, Fredrickson & Barrett, 2004). Coping strategies are not simply reactions; rather they are actively employed strategies that create a resource that influences caregiver wellbeing (Tugade et al., 2004). Coping strategies are vital in assisting caregivers to manage burdens as they form a preventive measure against affective disorders commonly associated with caregiving (Parks & Novielli, 2000).

Caregiving experiences are multifaceted, presenting a combination of positive and negative elements (Pierce et al., 2007). Emotional management among caregivers in palliative care institutions is often one of the most vital aspects necessary to maintain work requirements and satisfaction (Karabanow, 1999). The nature of emotional experiences and the quality of the caregiving relationship are often intertwined (Cousineau et al., 2003).Positive and negative emotions and the relationship between them play an important role within caregivers' emotional experiences and their coping ability. Ineffective coping strategies may increase the negative emotional impact on the individual, while effective coping can be emotionally protective. Coping strategies are protective when they sustain positive emotions, thus serving as a resource against negative influences; they can in turn replenish coping mechanisms (Steiner et al., 2008).

Understanding the subjective importance caregivers attribute to both positive and negative experiences provides insight into caregiving and the influences on caregivers' experiences from a phenomenological perspective. An understanding of caregivers' positive experiences can foster these experiences and strengthen interventions that assist and prevent negative experiences, thus increasing the caregiver's coping ability. The present study sought to identify both the emotional components that foster growth and those that deplete the individual caregiver, with the goal of promoting the patient's wellbeing and the wellbeing of the caregivers (Sussman & Regehr, 2009).

This significant finding supports existing evidence that a high workload often places the individual in a vulnerable position as they experience the additive effect of increased stress (Kim et al., 2006). This additive effect may have significant negative effects on an individual caregiver's health (Steiner et al, 2008). A high workload that incites high stress (Hawkins, Howard & Oyebode, 2007) is often associated with perceptions of inadequacy related to the difficulties in trying to manage during these periods (Keidel, 2002).These situations highlight the caregivers' burden of simultaneously occupying both the role of a patient and that of a caregiver, a situation that necessitates a considerable degree of self-care on the part of the caregiver (Steiner et al., 2008).In other studies, religious or spiritual means of coping have also been associated with positive outcomes (Stepfanek, McDonald & Hess, 2005). Often religion or spirituality has been shown to provide a sense of meaning, hope, and reassurance to the caregiver (Bussing et al., 2008).

This spiritual coping can also operate in a negative manner (Mytko & Knight, 1999). The emotional and spiritual strength that participants gained from their relationship with God confirmed the findings of other studies that found religion to operate as a support system (Blinderman & Cherny, 2005). For these participants, this relationship led to a significant amount of trust. One participant stated, "I trust nobody except for him." Trusting in the higher guidance provided by religious or spiritual beliefs and practices is known as 'intrinsic religiosity' (Bussing et al., 2008). Such beliefs, which were illustrated by participants in the study, illustrated that religion also operates as a source of motivation and hope, as seen in the comment, "the only hope I have is from Jesus." This type of spirituality facilitates a sense of control as meaning is made from these experiences (Fillion et al., 2009).

Adaptation theory suggests that people are able to adapt to stressors through being exposed over time (Miller & McFall, 1991). This exposure decreases their sensitivity to stressors through familiarity. Although caregivers' familiarity with the situation may also emphasise their helplessness and inability to control aspects within, and reactions to, the caregiving process, being able to accept the consequences of stressors provides caregivers with a sense of control over the process. This ultimately may help them to control the outcome of caregiving. The multiple factors contributing negatively to caregiver coping in this study are significant in that they are able to influence one another, having a cumulative effect on the caregivers' wellbeing. The stress proliferation theory considers that these daily stressors continue to accrue, resulting in the caregiver being overwhelmed, not by one particular incident but by the cumulative effect of continuous exposure to stressors (Pavalko & Woodbury, 2000). These stressors impinge on the caregivers' emotional management, increasing their vulnerability as additional stressors arise, until the caregiver is at risk for potential failures in emotional management. The implications of such are that the caregiver is not able to continue, or take on any additional stressors, without being severely affected both personally and professionally. This highlights the importance of the long-term effect of coping strategies, as well as the need for interventions to assist caregivers to manage stressors consistently, rather than allowing them to become overwhelmed by the accumulating stressors (Pavalko & Woodbury, 2000).

Kuo et al., (2012) investigated that caregivers of orphaned and non-orphaned children reported similar levels of social support. In terms of sources of support, all caregivers were more likely to draw support from family and significant others rather than friends. These findings indicated a need to develop interventions that can increase levels of social support for caregivers of AIDS-orphaned children, particularly networks that include friends and significant others.

### 3.14 Caregiver assessment

Quality care is very paramount to the overall well-being of people living with disability and achieving this role of family caregivers in providing care cannot be overemphasized. The significant role they play and their own care-related strain and compromised health calls for recognition, respect and addressing their needs (Family Caregiver Alliance, 2006). In all countries of the world, informal caregivers provide care for people with chronic, acute and provide long term care at home. Caregiver assessment is one of the ways of recognizing and strengthening caregiver in care settings (Family Caregiver Alliance, 2006). Different studies (Gallant & Connell, 1998; Marks, Lambert & Choi, 2002;) have shown that informal caregivers themselves are at the risk of emotional, physical and financial problems arising as a result of burden of caregiving. These problems have the ability to obstruct the ability of caregivers in giving quality care and impact negatively on their quality of life and that of the recipient. Caregiver assessment simply means information gathering that leads to description of a caregiving situation with the aim of knowing specific problems, need, resources and the strength of the family caregiver. It also includes viewing caregiving from caregiver's perspective and culture, caregiver's desired assistance, expected support outcome by family members and maintenance of caregiver's overall well-being (Family Caregiver Alliance, 2006). Informal caregiving has become an issue of public health due to some reasons that include:

a) High cost of hospitalization that has shifted the care of most people with chronic disability to families. Family members are now responsible for the health management, of their loved ones without prior training or support which traditionally were carried out by health care providers (Donelan et al., 2002).

b) Increase in the population of the aged people, shortage of care workers has placed so many responsibilities on the caregiver necessitated for the consensus on the caregiver assessment.

c) The recent upsurge of more women in the work place and the associated movement has a great impact on the care recipient and the caregiver. Many of the caregivers who are women are faced with role conflict that makes them juggle work, caregiving and other family chores (Putnam, 2000).

d) Preference of home care to institutionalization among people in order to have their family members take care of them in a more proper manner has also contributed to the emergence of caregiver assessment (LaPlante, Harrington & Kang, 2002)

However, caregiver assessment policy is guided by some principles (Family Caregiver Alliance, 2006) which are:

1) The need to recognize respect, assesses and addresses the needs of caregivers who are a major stakeholder in long-term care.
2) Assessment that should be family focused and takes care of the need of both recipient and caregiver.
3) Assessment is expected to lead to care plan that is jointly prepared with the caregiver and with a set goal and evaluation
4) Multidimensional nature and subject to interval review.
5) Assessors who are knowledgeable and skillful in the area of caregiving process, its impacts, benefits and what makes a good caregiver assessment.
6) Payment for caregiver assessment that is oversees by government as part of care for people with disability.

Apart from these principles, according to Family Caregiver Alliance (2006, p. 13) general considerations are given to the following:

a) Care recipient and caregiver as unit of care.
b) Caregiver as member of care team and service plan
c) Services are family focused
d) Improvement of outcome and continuity of care for recipient.
e) Assessment processes must be caregiving context, service setting and programme oriented.
f) Caregiver assessment has no set rules and approach multidimensional.
g) Consideration to be given to ethical issues, technological resources and capabilities based on settings and existing service programme.
h) Clarity of purpose of assessment to both caregiver and assessor.

i) Identification of caregiver and other informal caregiver in order for them to know their role and what it takes to be a caregiver.

j) Determination of care recipient eligibility of service and provision of help to caregiver.

k) Assessment must help caregiver in making informed decision and link caregiver with community services.

Assessment is conducted on an individual who identify himself/herself as caregiver and come in contact with health and social service systems. Screening can also be done on families in form of group interview and at this level conflict resolution may be necessary (Guberman et al., 2003). According to Zarit, Reever and Bach-Peterson (1980), embedded in caregiver assessment is a sensible approach that addresses the main concern of caregiver and every other person involve in caregiving. The right time for assessment to occur is when a person with disability health and well-being depends on an informal caregiver who can give a detailed description of what is needed. The venue and time of assessment should also depend on caregiver situations and convenience e.g., at home, work place, on phone or online. The assessment is very clear, self-explanatory, transparent and tagged "interview" and not assessment so as not to suggest a test of competence (Burke, Feder & Van de Water, 2005).

Gaugler, Kane and Langlois (2007) stated that caregiver assessment are best conducted by professionals such as physicians, nurses, social workers and care managers that have been trained in caregiver assessment and possess the required skills, knowledge and ability. Their expertise is needed in areas such as

1) Purpose of the assessment.
2) Self-determination versus safety issues.

3) Mental health, aging, life-span development issues.
4) Family systems perspective and conflict resolution.
5) Resources and brokering.
6) Building a community care support network.
7) Consumer-driven model.
8) The importance of caregiver participation and the strengths-based perspective.
9) Buy-in to purpose of assessment, listen and reflect.
10) Deal with emotional content.
11) Be sensitive to differences in framing questions around culture, religion, age, etc.
12) Empathize with the caregiver.
13) Understand what you know, what you do not and when to hand off.
14) Have comfort with an educational and self-management approach.
15) Be aware of personal biases and strong opinions and keep these in check.
16) Communicating purpose of assessment to caregiver.
17) Interviewing engagement, particularly with people who are not asking for help.
18) Disseminating information clearly, appropriately and as needed to connect to the Care plan.

One of the features of caregiver assessment is the reconciliation of care recipient needs with that of the caregiver. According to Bass (2002), the right care plan is the type that connects the needs and preferences of the care recipient with those of the family caregiver. However, for their needs not to be conflicting, certain strategies and practices are to be given consideration in caregiver assessment. This includes sadding care recipient's needs and preferences into the caregiver assessment and employing family-cantered approach to merge caregiver in planning and assessment for the care recipient. Additionally, assessor flexibility in conducting assessment, application of technology for accessibility of assessment information and application of "care navigator" or "point person" to integrate assessments and respond to care recipient and family needs across settings are also very important in avoiding conflict of needs.

Caregiver assessment is an important policy because it is a core part of care for people with chronic disability and also the fact that most people with disability depends solely on their own families and friends for assistance and well-being (Larizgoiti, 2009). It also allows for formal recognition of informal caregivers as well as providing better understanding of family in need to practitioners in health care settings. Accessing support becomes easier for caregiver and maximum outcomes for care recipient while information distribution among policy makers and programme administrators for effective service delivery is also ensured (Family caregiver Alliance, 2006).

### 3.15 Psycho-social intervention

Psycho-social intervention has been defined as any form of support that has positive outcomes and last for a relatively long period of time (Reetta, 2012). The best intervention at improving coping skills of caregivers is the individual assessment of caregivers' situation (Hyvärinen et al., 2003). According to Sussman and Regehr (2009), psycho-social intervention to caregivers is aimed at alleviating the demand of care through respite services and training and it can also be designed to improve the well-being and coping skills through support groups. Psychotherapy and psycho-educational interventions aimed at improving caregiver's knowledge and abilities to cope with the demands of caregiving has a significant effect on caregiver's psycho-social well-being (Sussman & Regehr, 2009).

Studies also revealed (Ostwald et al., 1999; Hepburn, Tornatore, Center & Ostwald, 2001) that training programme for caregivers of people with dementia has a direct effect of improving caregiving skills, confidence building and improved communication skills among family caregivers. Andren and Elmståhl (2008) concluded in a study that when caregivers were provided with information and access to a conversation group as a psycho-social intervention, they experienced fewer feelings of strain and disappointment and increased satisfaction level for 12 months. Additionally, Eronen (2010) concluded that information provided by doctors and other healthcare practitioners enables care recipient and caregiver access public health services. Adequate informational support increases the usage of human services among caregivers (McCallion, Tosenland, & Banks 2006). Furthermore, the study on the influence of psycho-social intervention to caregiver by Andre, Márquez-González, Peñacoba, and Romero-Moreno (2008) revealed that information provision and group meetings increased satisfaction level and decreased feeling of disappointment among caregivers. In line with the above studies, combination of support group with informational guide to ceragivers results in positive health outcomes among caregivers (Hyvärinen et al., 2003).

Roelands, Van-Oost and Depoorter (2008) also concluded that increase in the awareness of services available to care recipients and caregivers; combine together with other sources of help received by caregivers lessened the burden of behavioural problems on the caregivers. Andre et al. (2008) also revealed that the earlier the psycho-social intervention the more effective it is to avoid institutional care and produce positive outcome for both care recipients and the caregivers.

In a study conducted by Wang, Chien & Lee (2012) in China, a support group programme was put in place for caregivers of persons with dementia caused by

Alzheimer. The support group meeting had educational, mental healthcare factors, informational guide, discussion and psychological support. The caregivers also had the opportunity of developing social support network with other caregivers. A comparative analysis between the impact of the programme and previous social support given to the caregivers was conducted. The result shows that there was improvement in the quality of life as a result of decrease in stress level, embarrassment, guilt and discomfort of caregivers. The researchers concluded that the intervention programme could possibly promote psycho-social well-being of caregivers.

In a psycho-social intervention programme in Taiwan by Huang, Sousa, Perng, Hwang, Tsai, Huang and Yao (2009), during which a comparative analysis was made between the support received by caregiver of stroke patients and caregivers of person with Alzheimer. Caregivers of stroke patients received much more of support in terms of information, emotional and tangible support and help. Despite their low income the caregivers of stroke patients experienced less depressive symptoms than the caregivers of person with Alzheimer, Berit et al., (2012) carried out a study on the psychosocial well-being in persons with Aphasia participating in a nursing intervention after Stroke incident. The study was to explore the well-being of seven aphasia victim participating in psycho-social well-being intervention programme. The intervention was organized as an individual, dialogue-based collaboration process based upon ideas from "Guided self-determination." Psycho-social issues such as mood, social relationships, meaningful activities, identity, and body changes were addressed during the intervention program. Data were collected during and after the intervention at different intervals of 2 weeks, 6 months, and 12 months. The result shows that the participant experienced psychological support and motivation to move on with their lives as a result of the intervention and also benefit from the knowledge and information shared during the programme.

### 3.16 The rights of children with disabilities

According to United Nations Children Fund (UNICEF) (2007), in 2001 an ad hoc committee was set up by the General assembly of the United Nations to come up with a proposal for the convention on the rights of person living with disabilities. The goal of the convention is to establish the rights of person with disabilities. The ad hoc committee submitted the draft of the proposed convention and was adopted by the UN General Assembly on 13 December 2006. Member's state appended their signature which signified intention to take steps towards the endorsement of the draft at international level. By August 2007, 101 countries had signed the convention and four countries had already ratified it. The convention identified different categories of persons with disabilities and established that all persons with disabilities must enjoy all human rights and fundamental freedom. The convention further clarified and described all categories of rights of person with disabilities and areas where adaptation was needed for effective utilization of their rights. The convention is a turning point in the psycho-social well-being of persons with disabilities in that for the first time, an effort was made to change attitude towards treating person with disabilities as objects of charity and medical treatment to viewing persons with disabilities as subjects with rights to decision making and being active members of the society.

The general principles of the convention (article3) states as follows:

(a) Respect for the inherent dignity of individual autonomy including the freedom to make one's own choices, and independence of persons.
(b) Non-discrimination
(c) Full and effective participation and inclusion in society
(d) Respect for difference of persons with disabilities as part of human diversity and humanity.

(e) Equality of opportunity

(f) Equality between men and women

(g) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

There are various other rights stipulated by the convention for people with disabilities. These rights include the right to health, rehabilitation and welfare services. About 200 million children with disabilities are living in developing countries without access to health, rehabilitation and other support services. This alone had resulted in high mortality rate of about 80 per cent in income poor countries like Nigeria (Committee on the Rights of the Child, 1997). Under this condition children with severe disabilities may not be able to survive childhood as a result of a lack of basic primary health care facilities (Groce, 1999). This right under article 24 of the CRC states that every child has the right to enjoy the highest attainable standard of health and must have access to facilities for rehabilitation and the treatment of illness once a child is confirmed as having impairment. The right protects children living with disabilities from every form of discriminations about their health and equal right to health facilities like their non-disabled children.

The right to education is also enshrined in human right treaties that include articles 28 and 29 of the CRC. This right made primary education to be compulsory and available for everybody. It further stated that secondary education is to be available and accessible to every child, with the provision of financial assistance when needed. The convention builds upon this principle and recommended access to lifelong learning opportunities for children with disabilities. This right also protects children with disabilities from barriers to access regular education. It gives them right to all inclusive education where they can study together with their non-disabled counterpart in the same classroom and environment. Other rights include right to protection from violence, exploitation and abuse which is enshrined in article 39 of the CRC that calls for recovery and reintegration support for children who have suffered abuse. This right becomes important for children with disabilities as there are reports of several abuses of these children from caretakers, attendants, family members, peers or anyone who enjoys a position of trust and power. Over the years children with disabilities have been victims of physical, sexual and psychological abuse than their peers without disabilities. Various factors such as powerlessness, social isolation and stigma have contributed to their vulnerability to violence and exploitation (Baladerian, 1991). With this right, children with disabilities are entitled to protection from violence, exploitation, abuse, economic and sexual exploitation and any similar practices against child's welfare.

As part of this right is also the removal of barriers to supporting children with disabilities in emergency and conflict situations. Many times children with disabilities are the most vulnerable during conflict and wars as they are often the ones to be abandoned by families and usually the last to receive emergency relief and support. In the article39 of the CRC provisions are made for the needs of children with disabilities in emergency planning and training and in the design of systems for evacuation, shelter and emergency communications during disasters. Their involvement as stakeholders in emergency response and relief efforts becomes essential with this right. Children with disability's right to participation and access to opportunities are also given consideration in the convention. Their right to express their views freely in all matter concerning them in accordance with the age and maturity of the child is given due consideration. Recognition is given to their competence to contribute effectively to decision making processes and as well as timely availability of information and knowledge for both the children with disabilities and their family caregivers.

This particular right is enshrined in the Article 17 of the CRC which asserts a child's right to information and material aimed at the promotion of the child's social, spiritual and moral well-being and physical and mental health. The Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities was a land mark in recognizing the rights of children with disabilities through social inclusion processes. The convention also represents the rights and freedom of a marginalized group to actualize their full potential and bring them from obscurity to limelight.

### 3.16.1 Social work Services to people living with disabilities

According to Weaver et al., (2006) social workers are saddled with the responsibility of helping marginalized people in the society and this distinguished them from other helping professionals. It is part of social work roles to reach out to marginalized members of society, that include the poor, homeless, children, the elderly and people with disabilities. DuBois and Miley (2005) also stated that in line with its goals as a human and helping profession, social workers' interventions generally seeks to enhance human functioning and to promote the effectiveness of societal structures that provide resources and opportunities for clients and beneficiaries of services, including people with disabilities.

Chitereka (2009) listed the roles of Social workers to people living with disabilities and these roles include the following:

a) Preventive, curative and rehabilitative services for disabled persons. Disability care services to disabled people includes improving capacity for caregivers and parents to care for their disabled children and facilitating inclusive education and social integration for disabled people

b) Generally vocational rehabilitation centers provide support to adults and youth with any form of disability by providing vocational guidance and training, literacy and numeracy training skills, technical skills in metal work, leather work, carpentry, sewing, knitting, agriculture, general repair skills and basic training in business management so as to reduce poverty among disabled individuals

c) With the scourge of HIV/AIDS and its consequences, social workers have also been saddled with the responsibilities of providing information about the pandemic to people with disabilities. People living with disability have been educated on the important of knowing their status and to seek treatment from hospitals for those who are already infected with the virus.

d) Social workers work within the Department of Social Welfare where public assistance are provided to the poor and vulnerable people.

e) Social workers working in psychiatric hospitals as psychiatric social workers, and in these settings, they provide services to mentally challenged patients and their families by providing counseling services. They also provide home services to these people to encourage them not to abandon their medications.

f) Social workers also render discharge services in the hospital setting. This is supported by Zastrow and Kirst (2010) who rightly notes that, discharge planning is of great importance in some rehabilitation settings, such as hospitals. In a situation where an individual with disability cannot return home, placement in some other setting must be arranged, such as in a nursing home or a group home.

g) Additionally, Social workers also provide counseling service to people with various forms of disabilities to help them cope with their disability. Such counseling in most instances involves different areas of disability problems such as personal, interpersonal, family, financial, vocational adjustment and educational adjustment. The counseling service is also extended to the family members of people with disability in a case where the disabled person is a child. According to Zastrow and Kirst, (2010) working with the family is initiated to help them understand the nature of a disability and the prognosis, to make the essential adjustments to help the PWD and to deal with personal and interpersonal concerns associated with the disability.

h) Social workers are also found in correctional institutions and are known as rehabilitation officers. They work with prisoners with disabilities and their families. They serve as a link between the family and the correctional services authorities. This is also in line with (Zastrow and Kirst, 2012) who states that in a rehabilitation setting, social workers can serve as a liaison between the agency staff and the family to discuss disability conditions of people with disabilities, factors affecting rehabilitation and required future plans and services. Besides, social workers make plans for the release of inmates especial those with disabilities. They help in providing various therapeutic measures to inmates while in prison in order to ensure their proper integration into the society after their release.

i) Furthermore, another major role of the social worker is advocacy. This includes raising awareness about disability in the society. Social workers are to enlighten the public about issues surrounding disability so as to remove the negativity that is usually associated with disability.

j) There are other community resources which are of great use to the people with disability. It is part of social worker responsibility to link people with disabilities with such resources. There are NGOs that can provide financial assistance, wheelchairs, and prosthetic services as well as transportation. These non- profit organizations provide services that help reduce poverty among people with disability. It is important that social workers possesses knowledge of all these agencies and their services.

k) There are also social worker educators who teach people with disability who are social work students. These educators also conduct researches in area of disability as it affect people living with disability which can inform governmental policies.

### 3.17 Social work services to informal caregivers

In 2010 National Association of Social Worker *(NASW)* made a release on the *Standards* for Social Work Practice with Family Caregivers of Older Adults which signified a turning point in social workers attending to the needs of informal caregivers. *The goal of the* standard is to create awareness to the contributions of social work practice *to* strengths, needs, and goals of informal caregivers and the recognition of informal caregivers as individual with needs and not only as care providers. Social workers work directly with care recipients and their caregivers in different settings. Social services in the form of service linkage and support are provided to caregivers so as to enable them give adequate care to their loved ones. Social workers in collaboration with other professionals provide services that assist caregivers to cope with the demands of care, manage responsibilities of care to recipient, and to themselves. Care to physically challenged children may be very stressfully and leading to some health challenges to their caregivers (Mavundla et al. 2009; Merrifield, 2011).

Professionals such as social workers need to be alert to the potential harmful effects of caregiving to informal caregivers. Adoption of family friendly policies is one of the ways through which social workers help informal caregivers. This involves careful assessment of family structure such as understanding of cultural diversity within the family and the role of family members in decision making. This process has the capacity to strengthen the resources for the caregivers and a way of knowing the impact of caregiving on the caregiver. The inability of caregivers to plan and prepare for caregiving as suggested by different studies (Horowitz, 1985; Harvath, 1994; Pohl, Given, Collins & Given, 1994; Archbold, Stewart & Greenlick, 1995; Tennstedt, 1999) necessitated that social workers and other health professionals, assist caregivers and recipients in formulating anticipatory strategies to understand their new roles in order to attain healthier outcomes. Caregivers need to be commended and appreciated for their effort and feelings (Levine, 1999). Support service also includes respect for caregivers' loss, emotions and grief as a result of guilt, anxiety, worry, and frustration that characterized caregiving. Caregivers need for information and guide is of important. Levine, (1999) and NAC (2004) revealed that many caregivers expressed need for information. Social workers assists caregivers to access information and services that suite them and allows a sense of mastery (Tennstedt, 1999). Health promotion activities are also encouraged among the caregivers by social workers so as to enables caregivers to know how important is the concern for their own physical and spiritual health (McLeod, 1999). Such activities include counselling to go for check-ups, screening and recruitment of other members of the family and friends to give them respite. Counselling services involve encouraging caregivers and their family members to join caregiver support group as it has been found to be a source of social support to caregivers (Suitor & Pillemer, 1996).

Additionally, caregivers are encouraged to engage in recreation activities with care recipients and other members of the family so as to have good time together and pleasant memories of time well spent (Archbold, Stewart, Greenlick & Harvath, 1995). Advocacy service is also part of the social services provided by social workers and it entails pressurizing for family-friendly policies and procedures such as family conferences, workplace support for caregivers, and reduction of barriers to information and services.

# CHAPTER FOUR

# METHODOLOY

## 4.1 Introduction

This chapter gives a vivid approach of how the research was carried out. It focuses on the research design that was adopted, the population of study, study area, sampling and sample size, research instrument, validity and reliability of research instruments, data collection procedure, method of data analysis, ethical consideration, and structure of the thesis.

## 4.2 The study area

The study was carried out in the South Western part of Nigeria. Nigeria is located on the West coast of Africa, north of the Atlantic Ocean and north of Niger Republic and Chad. The study area lies between longitude 300 and 70E and latitude 40 and 90N. The total land area is about 191, 843 square kilometres (Iloje, 1989). The people of the Yoruba ethnic group dominate the South Western part of Nigeria. The region is made up of six states which include Lagos, Ogun, Oyo, Osun, Ekiti and Ondo states and 36 senatorial districts (Iloje, 1989). Their economic activities include agriculture, commerce and industry and have about 40 million estimated populations each (Iloje, 1989).Oyo state has Ibadan as the capital and is the largest city of African origin south of the Sahara. It is a city in south-western Nigeria, capital of Oyo state and about 145km/ 90 northeast of Lagos state. The principal inhabitants of the city are Yoruba people (Iloje, 1989).The state is homogeneous and comprises the Oyos, the Ibadans and the Ibarapas all belonging to the Yoruba family and speak the same Yoruba language. The Oyo people are renowned for craftwork. There are over two hundred primary schools and over three hundred secondary schools in the state. Moreover, there are both public and private universities in the state. One of the oldest universities in Nigeria, University of Ibadan, is situated in the state. There are no tourist centres in the state (Iloje, 1989).

Lagos on the other hand, is the most populous city in Nigeria and also the most populous city in Africa. The metropolitan area is estimated to be 300 square kilometres, and a group of islands endowed with creeks and lagoons. The city is the economic and the financial capital of Nigeria (Iloje, 1989). The state is the most economically important of Nigeria. The indigenous inhabitants include the Aworis and the Eguns. Tourism is not particularly developed in Lagos state. Educationally there are about two hundred primary schools and more than three hundred secondary schools in the state. The state also has the presence of both public and private universities. University of Lagos is the oldest and the only public university in the state (Iloje, 1989).

Furthermore, Ondo state was also selected because it is sharing boundaries with Lagos and Oyo states. The state is a multi-ethnic one with the majority being Yoruba while there are also, the Ikales, the Iloajes, Arogbos and the Ijaws who are of Ijaw extraction. The state has eight hundred and eighty primary schools and one hundred and ninety secondary schools. There are a number of tertiary institutions both public and private. Federal university of technology is the highest institution in the state. Economically, it is agriculturally rich, contributing about seventy-five per cent of its gross domestic products (GDP). The main revenue yielding crops are Cocoa, Palm produce and timber. The creeks and the coastlands of the state are rich in prawns and lobsters and have a reserve for fish stock. Ondo state is also blessed with mineral resources such as Petroleum, Tar sand (bitumen), Kaolin clay, Iron ore, and Granite. The state does not have tourist centres (Iloje, 1989).

## 4.3 Research design

The study employed an expost facto research design and adopted a cross-sectional survey research design. The research design is the overall plan or structure of a study. The goal of a good research design is to insure internal validity and answer the question being asked. The only clear rule in selecting a design is that the question dictates the design. The term "Ex Post Facto", in simple English, means "After the Fact", or in other words, retroactive..Ex post facto design is a non- experimental research techniqueor causal comparative research which is useful whenever there are two groups which differ on an independent variable and to test hypotheses about differences on one or more dependent variables. It is also useful when pre-existing groups are compared on some dependent variables. The assignment of participants to the levels of the independent variable is based on events that occurred in the past. It is non- experimental research that is similar to an experiment because it compares two or more groups of individuals with similar backgrounds who were exposed to different conditions as a result of their natural histories (Lammers & Badia, 2005).

Cross-sectional research design on the other hand is a research method in which a large cross-section of the population is studied at one specific time and the differences between individual groups within the population compared. It is a research design that utilizes different groups of people who differ in the variable of interest, but share other characteristics such as socioeconomic status, educational background, and ethnicity. Cross-sectional studies are observational in nature and are known as descriptive research, not causal or relational. It is a type of research that can be used to describe characteristics that exist in a population, but not to determine cause-and-effect relationships between different variables. It is also often used to make inferences about possible relationships or to gather preliminary data to support further research and experimentation. Cross-sectional designs can be used in conjunction with both experimental and co relational studies (Creasey, 2006).

The purpose of the study was to conduct a survey of social support, socio-economic status and their influence on the psycho-social well-being of informal caregivers of physically challenged children. Therefore based on the above definition, the justifications for adopting an "ex post facto" design for the research include: the study cannot be carried out using experimental or quasi-experimental designs. Secondly, the focus on indicators of prior social support received and socio-economic status are link with psycho-social well-being; ex post facto analysis was a satisfactory and useful approach for this study.

### 4.4 Study population

Population can be defined as "the total collection of elements about which one wishes to make some inferences" (Welman et al, 2001: 46). In this study, the population was made up of informal caregivers of the physically challenged whose children are attending specials schools for the handicapped in three selected South-Western States of Nigeria (Lagos, Oyo and Ondo States).Caregivers are persons who take care of next of kin who cannot cope with everyday life due to an injury, illness or due to some other need of care (Reetta, 2012). Informal caregivers are family members such as mothers, fathers, brothers, sisters, daughters, relatives, friends and neighbours who assist individuals who cannot cope with activities of daily living (ADL). Therefore physically challenged children who are the children of these caregivers were excluded from the study as their own well-being is not covered by the study. There were no statistics to give the estimated population of informal caregivers in Nigeria.

## 4.5 Sample and sampling techniques

Gray (2004) defines a sample as a set of objects, occurrences or individuals selected from a parent population for a research study. The sample selected was a fairly large portion of the informal caregivers and was thus fairly well representative of the population. In this sense, the characteristics of the sample represent those of the entire population. The method used to collect the sample in this study was the stratified probability sampling method. Stratified probability sampling technique refers to the process of dividing members of the population of a study into different strata before sampling. The strata are mutually exclusive and collectively exhaustive i.e., every element in the population is assigned to only one stratum and no element of population is excluded. After the simple random sampling is applied within each stratum, the advantage is that it improves the representativeness of the sample by reducing sampling error and ensures that at least one observation is picked from each of the strata, even if probability of it being selected is far less than 1. Moreover, it produces a weighted mean that has less variability than the arithmetic mean of a simple random sample of the population (Yates, Daniel, David, Moore, Daren & Starnes, 2008).

A sample of 812 informal caregivers was selected from different special schools in three states in south-west of Nigeria. Random sampling was used because it ensures representativeness and venerability of results. Random sampling is a probability sampling method, whereby each element in the population has some known chance or probability of being selected as a subject (Uma, 2003).

Simple random technique is a subset of individuals i.e., it is a basic type of sampling chosen from a larger population. It allows for each individual to be chosen randomly and entirely by chance in a way that ensures individual same probability of being chosen at any stage during the sampling process. More also, it ensures that each subset of *k* individuals has the same probability of being chosen for the sample as any other subset of *k* individuals. Simple random sampling is the simplest of the probability sampling techniques. It requires a complete sampling frame, which may not be available or feasible to construct for large populations. Advantages of simple random sampling include freedom from classification error and requirement of minimum advance knowledge of the population. It also allows for easy interpretation of collected data and best suits studies where less information is available about the population (Yates et al. 2008).

Multi-stage sampling procedure was used to randomly select three states from the six states in the southwest geo-political zone. The second stage of the sampling procedure consisted of purposive selection of two senatorial districts in Oyo and Lagos while one was selected in Ondo state. Two senatorial districts from each state cover approximately 60 percent of the population in the state. Stage three involved the random selection of six special secondary schools from each of the two senatorial districts Oyo and Lagos while in Ondo only one senatorial district was selected as there were not many special schools located in this area. A total of 30 special secondary schools were selected for the study. Stage four comprised of randomly selecting 5 physically challenged students each from the six arms strata of the secondary schools selected for the study. The caregivers of the physically challenged were linked through their wards selected for the study during "open day activity" and their monthly visits to the schools. A total number of 812 caregivers accessed through their children participated in the study.

## Senatorial districts, secondary schools and selection of informal caregivers of physically challenged children.

### Table 1: Oyo South Senatorial District

| **SN** | **Name of school** | **Junior secondary one(Jss1)** | **Junior secondary two (Jss2)** | **Junior secondary three (Jss3 )** | **Senior secondary one (Ss1)** | **Senior secondary two (Ss2)** | **Senior secondary three (Ss3)** | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | OLuyole Cheshire High school | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 2 | Ijokodo School for the Deaf | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 3 | Ijokodo home School for the Handicapped | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 4 | Mthodist Grammar School | 5 | 5 | 5 | `5 | 5 | 5 | 30 |
| 5 | Ijokodo High School | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 6 | Lagelu Speical School | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
|  | Total | 30 | 30 | 30 | 30 | 30 | 30 | **180** |

**Table 2: Oyo north senatorial district**

| SN | Name of schools | Junior Secondary one (Js 1) | Junior Secondary two (Jss 2) | Junior Secondary three (Jss3) | Senior Secondary One (Ss1) | Senior Secondary two (SS2) | Senior Secondary three (Ss3) | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | Federal College Of Education (special unit | 4 | 4 | 4 | 4 | 4 | 4 | 25 |
| 2 | Okeholanna Grammar School | 5 | 5 | 5 | 4 | 4 | 4 | 27 |
| 3 | Awoyemi Commerical High School | 4 | 4 | 4 | 4 | 5 | 4 | 25 |
| 4 | L A School for the Handicapped | 4 | 4 | 5 | 4 | 4 | 4 | 25 |
| 5 | A D S High School | 5 | 4 | 4 | 4 | 4 | 4 | 25 |
| 6 | Muslim Co9mmunity High School | 4 | 4 | 4 | 4 | 4 | 5 | 25 |
|  | **Total** | 26 | 25 | 26 | 25 | 25 | 25 | **152** |

NB:Informal caregivers were accessed through their wards in selected special schools. In this particular senatorial district some children did not return their questionnaires; this explained the differences in the number in the table.

**Table 3: Ondo central senatorial district**

| SN | Name of schools | Junior Secondary One (Js1) | Junior Secondary two (Jss2) | Junior Secondary three (Jss3) | Senior Secondary one (Ss1) | Senior Secondary two (Ss2) | Senior Secondary three (Ss3) | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | Akure High School | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 2 | Ondo State School for the Hearing Impaired | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 3 | Government Technical College | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 4 | Bekkey Immaculate Group Schools | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
|  | **Total** | 20 | 20 | 20 | 20 | 20 | 20 | **120** |

**Table 4: Lagos central senatorial district**

| SN | Name of schools | Junior Secondary one (Jss1) | Junior Secondary two (Jss 2) | Junior Secondary three (Jss3) | Senior Secondary one (Ss 1) | Senior Secondary two (Ss2) | Senior Secondary three (Ss3) | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | Acess to Education for Childern | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 2 | Oshodi | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 3 | Army secondary school | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 4 | Children development centre | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 5 | Amuwo-Odofin Secondary school | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 6 | Methodist Secondary school | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
|  | **Total** | 30 | 30 | 30 | 30 | 30 | 30 | 180 |

**Table 5: Lagos west senatorial district**

| SN | Name of schools | Junior Secondary one (Jss1) | Junior Secondary two (Jss2) | Junior Secondary three (Jss3) | Senior Secondary one (Ss1) | Senior Secondary two (ss2) | Senior Secondary three | **Total** |
|---|---|---|---|---|---|---|---|---|
| 1 | Atundaolu school for the physically challenged | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 2 | Lagos state rehabilitation and training centre | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 3 | Modupe memorial school | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 4 | Paccelli school for the blind | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 5 | Hearth of gold for the handicapped | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
| 6 | Lagos Cheshire home | 5 | 5 | 5 | 5 | 5 | 5 | 30 |
|  | **Total** | 30 | 30 | 30 | 30 | 30 | 30 | **180** |

## 4.6 Biographical and occupational description of the sample

This section presents the demographic characteristics of the sample. These Characteristics include age, gender, marital status, educational qualifications, income and occupational status of informal caregivers. The age distribution of the respondents that participated in this study is illustrated in Figure 4, the gender distribution in Figure 5, the marital status distribution in Figure 6, the education qualification distribution in Figure 7, the distribution of occupational status in figure 8, and the distribution of income in Figure 9.

Figure 4, shows the age distribution of respondents. It shows that 2% of the respondents were between 30 and 39 years and 23 % were between 40 and 49. Furthermore, 61% were between 50 and 59 years while 14% were between 60 years and above.

**Figure 4: Age distribution of the respondents**

Figure 5 shows that 390 respondents (48.0%) were male and 422respondents (52.0%) were female.

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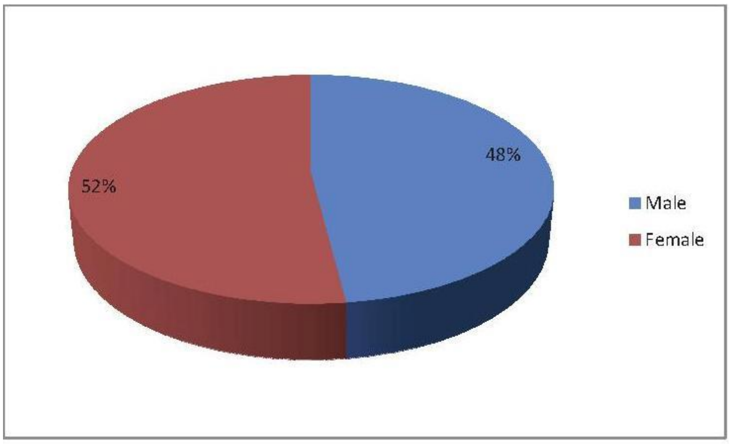

**Figure 5: Gender distribution of the respondents**

Figure 6 shows that 54% of the respondents are married couples, 35% are Single Parents, while 11% are divorced. Educational qualification of the respondents is shown on figure 4.

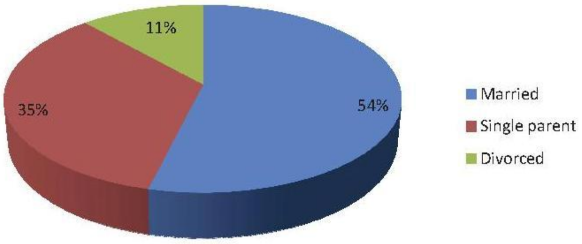

**Figure 6: Marital status of the respondents**

Figure 7 above shows that 2% of the respondents had no formal education, 13% had Primary education, 30% had Secondary education, 14% had WAEC and NECO certificate, 8% had Grade two certificates, 13% had NCE and OND certificate, 12% had HND and BS.C certificate while 16% had Postgraduate certificate.

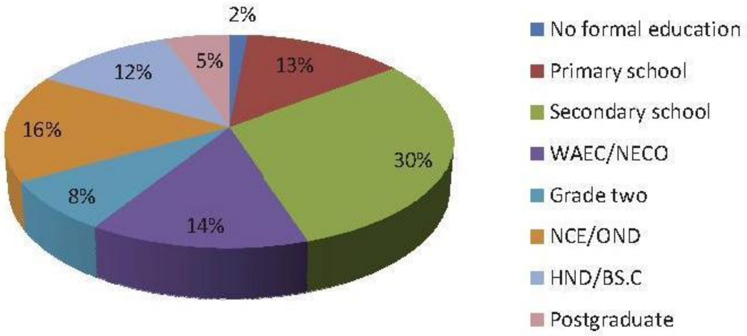

**Figure 7: Educational qualification of the respondents**

Figure 8 shows that 14% of the respondents are Professionals, 13% are Civil Servants, 5% are Pensioners, 33% are Self Employed, 5% are Full- Time House wives, 27% are Traders and Farmers, while 3% are Unemployed.

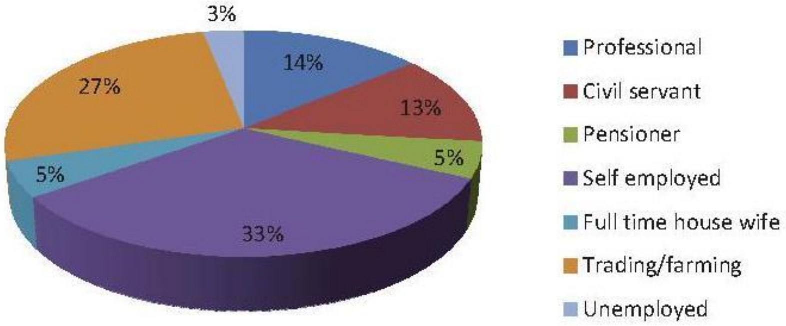

**Figure 8: Occupational status of respondents**

Figure 9 shows that 5% of the respondents earn more than NGN100, 000, 14% earn between NGN50, 000 and NGN100, 00, 14% earn between NGN30, 000 and NGN49, 999, 34% earn between NGN10, 000 and NGN29, 999, 26% earn between NGN5, 000 and NGN9, 999,

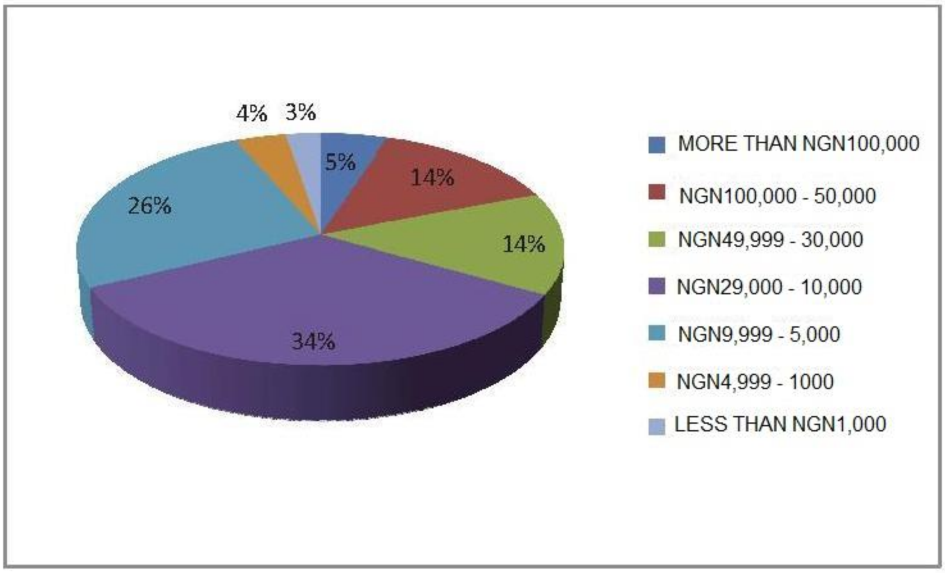

**Figure 9: Income distribution of respondents per year**

## 4.7 Research instrument

A three-part questionnaire was used to collect the data. Nachmias and Nachmias (1996) define a questionnaire as a list of questions that is presumably formulated, constructed and sequenced to produce the most constructive data in the most effective manner. Survey technique was used because questionnaires:

- translate the research objectives into specific questions that are asked of the respondents;
- Standardize the questions and the response categories so that all participants respond to identical stimuli;
- speed up the process of data analysis;
- ask the respondents the same questions;
- are less expensive; and
- offer greater anonymity.

The questionnaire used in this study was self-administered. It was accompanied by a covering letter addressed to the prospective respondents. The questionnaire consisted of the following three parts:

The Social Support Scale (SSS) developed by George, Blazer, Hughes and Fowler (1989), and was used to measure caregivers' social support and satisfaction. Internal consistency has been reported at 0.64 for social support (Dunst, 1985). The scale consists of items covering such sources of support as the immediate family, relatives, friends and others in the family's social network, social organizations, and specialized, generic professional services and other sources. The caregivers were asked to rate each source of support on a 5-point Likert scale (ranging from not at all helpful (1) to extremely helpful (5)). Past studies have indicated that the instrument is reliable (Dunst, Trivette, and Jenkins, 1994).

The caregivers' socio-economic status was measured using Socio-Economic Status Scale (Urban) by Kuppuswamy (1962). The scale measures socio-economic status on three main variables: Education, Occupation and Income. The range of scores which can be obtained is from 3 to 27. The norms which were established can only be applicable for urban population and cannot be used for a rural population. And the level of income was modified to show present economic conditions in Nigeria

The caregivers' psycho-social well-being was measured using the 18-item versions of Ryff’s (1989) psychological well-being scale. The scale has six subscales: autonomy, personal growth, positive relations with others, purpose in life and self-acceptance and environmental mastery. High scores indicate high level of psychological well-being. Previous studies indicated that the scale has a high reliability co-efficient (Ryff & Keyes, 1995). The measurement of this variable is important as it is the variable of interest to the researcher. Some of the items in the questionnaire were adapted and revalidated to fit into the Nigerian study.

## 4.8 Validity and reliability of research instrument

In quantitative research validation and reliability of instrument are of great importance as they give credibility to findings and explanations. Therefore in this study, it was ensured that the questionnaires used in collecting data were reliable. Joppe (2000) stated that reliability is the level to which results are consistent when tested over and over again and an accurate representation of the total population under study is referred to as representativeness. If the outcome of a study can be reproduced under the same methodology, then the research instrument is considered to be reliable. Moreover, a high degree of stability indicates a high degree of reliability, which means the results are repeatable. So in other words if an instrument is said to be reliable, it means that it can be used several times to test the same thing and producing same results (Rubin & Babbie, 1989). However, if results happen to change, the instrument can be said to be unreliable. Nonetheless, validity does not ensure accuracy like precision (Bell, 1993).

The type of reliability that the questionnaire was subjected to is stability reliability which is reliability across time. It answers the question "does the measure deliver the same answer when applied in different time period". This was done through test-retest method which ensures only external consistency and not internal consistency which is common in the physical sciences. It implied that the questionnaire had to measure the same phenomenon more than once. This was done through piloting of the questionnaire to fifty informal caregivers from other schools that were not in the main study and it was revealed that the questionnaire were reliable as it measured the same phenomenon over time with the same results.

Validity in quantitative research determines whether the questionnaires truly measure what it is intended to measure or how truthful the research results are. Furthermore, it means that validity determines whether the means of measurement are accurate and whether they are actually measuring what they are intended to measure (Winter, 2000). It should be noted that validity is difficult to achieve (no absolute confidence) because constructs are abstract ideas whereas indicators are concrete observations (Neuman, 1997). To ensure the validity of the data collection instrument (questionnaire), face validity was adopted. It refers to a type of validity that commonly accepted or agreed as a phenomenon (e.g. researchers may differ but agree on certain points of arriving at something). Most basic kind is the judgement by the scientific community that the indicator really measures the construct (De Vos, Strydom, Fouche & Delport 2005). It addresses the question "on the face of it, do people believe that the definition and method of measurement fit?" It is a kind of consensus method of measurement (Rubin and Babbie, 1989). Therefore, the questionnaire was judged valid by the supervisor and colleagues.

Although the instruments used are standardised scales and have been used in different studies, these instruments were subjected to pre-test. Before going to the field to administer the questionnaire, the investigator conducted a pre-test on the draft questionnaire whether the question will elicit the required response. For the pre-test a sample of 50 respondents was selected from special schools that were not part of those selected for the study. The selection was done at random in each state that was selected for the study. After the pre-test was over, the questionnaire was fine-tuned with modification wherever necessary and finalised. It was this finalized form that was used as the tool for data collection.

### 4.9 Data collection procedure

In this study, questionnaires were "self-administered." This means that the respondents were reached through their wards that were selected for the study. The covering letter was drawn carefully to convey the research objectives and to persuade respondents to give frank responses. The covering letter also explained the nature of the study, as well as assuring respondents of the confidentiality of all information provided. Respondents were also provided with detailed instructions as to how the questionnaires were to be completed and returned. The rationale behind providing clear instructions and assuring confidentiality of information was that this significantly reduces the likelihood of obtaining biased responses (Sekaran, 2003). Respondents' names were not asked for. This was done to give them an assurance that their responses would be kept confidential. This approach involves having direct contact with the respondents.

This method was adopted because it is less expensive, ensures anonymity of the respondents and has a high return rate as it allows for follow-ups for unreturned questionnaires. The main advantage of this method is that completed questionnaires can be collected within a short period of time. There were no difficulties in obtaining the data from the respondents. The questionnaire contains no items on personalised aspects of life and no item was distasteful. The respondents were free and cooperative in filling the questionnaire.

## 4.10 Method of data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected date. The data were edited, coded, cleaned and some consistency checks were made to assess the quality. The data collected from the survey were captured into the computer for analysis using Statistical Package for Social Sciences (SPSS). The demographic characteristics of the respondents' variables were analysed. For the inferential statistics the study employed the use of multiple regression analysis, one-way ANOVA, and Chi-square statistics for examining the research questions.

### 4.10.1 Descriptive statistics

Descriptive statistics describe the phenomena of interest (Sekaran, 2003). They include the analysis of data using frequencies, dispersions of dependent and independent variables and measures of central tendency and variability and to obtain a feel for the data (Sekaran, 2003). The mean and standard deviation was primarily used to describe the data obtained.

### 4.10.2 Inferential statistics

Inferential statistics allows for presentation of data obtained in research in statistical format to facilitate the identification of important patterns and to make data analysis more meaningful. According to Sekaran (2003), inferential statistics is employed when generalizations from a sample to the population are made. The statistical methods used in this research include Multiple Regression Analysis, the one-way ANOVA, and

Chi-square statistics for examining the research questions.

### 4.10.2.**1 Multiple regression analysis**

Multiple Regression Analysis: is a multivariate statistical technique that is used for studying the relationship between a single dependent variable and several independent variables. It provides a method to predict the changes in the dependent variable in response to changes in more than one independent variable. Hence, it allows for the determination of the relative importance of each predictor as well as to ascertain the collective contribution of the independent variables (Sekaran, 2003).

In this study multiple regression analysis was used to determine the impact of social support and socio-economic status (Independent variables) on the psycho-social well-being of informal caregivers of physically challenged children (Dependent variable). Through this statistical package, the relative importance of social support and satisfaction level on psycho-social well-being was singly and jointly determined. Furthermore, the impact of each social-economic variable family income, educational level, occupational status (Independent variables) were also singly determined on the psycho-social well-being of informal caregivers.

### 4.10.2.2 One way anova

One way Anova is frequently used to test equality among several means by comparing variance among groups relative to variance within groups (random error). The reason for doing an ANOVA is to see if there is any difference between groups on some variables. ANOVA allows for breaking up the group according to the grade and then see if performance is different across these grades and it is available for both parametric (score data) and non-parametric (ranking/ordering) data. It is the simplest version of ANOVA and can also be used to compare variables between different groups and tutorial performance from different intakes. A one way repeated measures ANOVA is used when you have a single group on which you have measured something a few times.

In this study one way Anova was used to further examine the impact of the independent variables on the dependent variable. It allows for the significant mean differences within groups in the study thereby showing the groups that have higher psycho-social well-being among the informal caregivers of physically challenged children.

#### 4.10.2.3 Chi-square

Chi-square is a statistical test commonly used to investigate whether distributions of categorical variables differ from one another. It is also referred to as chi-square test or *X* test. Ordinarily, categorical variable yield data in the categories and numerical variables yield data in numerical form. Chi-square test allows researcher to test for the null hypothesis which states that there is no significant difference between the expected and observed result (Sekaran, 2003).

However in this study Chi-square was used to answer the fifth and sixth research questions: How does marital status contribute to psycho-social well-being of informal caregivers and what is the significance of gender in psycho-social well-being of informal caregivers (Independent Variables).

## 4.11 Ethical consideration

According to Williams (2006) there are a number of key phrases that describe the system of ethical protections that the contemporary social research establishment has created to try to better protect the rights of their research participants. Ethical considerations are an important aspect of research, especially social science research. Ethical procedures are established in order to protect the physical and mental integrity of individuals, to respect their moral and cultural values as well as their religious and philosophical convictions, in addition to their other fundamental rights including respect for privacy whilst maintaining the highest level of confidentiality. Based on this assessment this study poses no harm to anybody. The questionnaire instrument was designed to give the respondents high level of anonymity, as personal identifiers such as name and address of the participants were not included in the questionnaire. Permission was sought from Forte Hare University Ethical Committee.

### 4.11.1 Informed Consent

According to Corti et al., (200), research should as far as possible be based on participants' free and voluntary informed consent. Patton, (2000) cited in De Vos (2011) suggests that before starting to collect data it should be communicated to participants that the information is important and the reasons for that importance, and the willingness to explain the purpose of the study to the respondents. The participants must be given a written informed consent that their participation in the study was voluntary and they were free to withdraw at any given point in time during the study. The informed consent made up the first part of the questionnaire and contains the objective, possible benefits of the study, time it would take to complete the questionnaire and assurance of privacy, confidentiality and anonymity.

### 4.11.2 Privacy, Anonymity and Confidentiality

Every individual has the right to privacy and has the right to decide when, where, to whom and to what extent his or her attitudes, beliefs and behaviours will be revealed. De Vos et al., (2005) argued that privacy implies element of personal privacy, while confidentiality indicates the handling of information in a confidential manner. It was made clear to the participants that whatever information the respondents were going to share was only going to be used for academic purposes and anonymity was maintained by ensuring that respondents' names were not going to be mentioned. These were clearly written on the letter of introduction.

Research should also avoid posing a threat to people's physical, mental and emotional health. Thus, in conducting the research, due care was taken in regards to ethics. This involved following a number of ethical practices:

- non-deception of research respondents
- debriefing of respondents regarding the study, that is, its purpose and duration
- contribution of the research to the general good of the organization
- obtaining respondents' consent that is fully informed and voluntary (done mainly by means of the covering letter)
- individual rights to privacy were observed, through confidentiality of research results
- transparency of research methods to allow for reliability

Attached to each copy of the study questionnaires was a covering letter. The covering letter was used to achieve some of the afore-mentioned ethical considerations.

# CHAPTER FIVE

# FINDINGS

## 5.1 Introduction

This chapter deals with the presentation and analysis of demographic information and the findings on social support as well as the level of satisfaction. The socio-economic factors and their impact on psycho-social well-being of informal caregivers of physically challenged children are also analysed in this chapter.

## 5.3 Presentation and analysis of findings based on psycho-social well-being, social support and level of satisfaction of social support

This sub-section of the chapter is a presentation of the findings according to psychosocial well-being, social support as well as the level of satisfaction regarding social support to informal care givers.

### 5.3.1 Psycho-social well-being of informal caregivers

A series of questions were asked to informal caregivers and this sub-section of the chapter is based on the findings thereof. The findings are presented according to Table 6

## Table 6: Responses of respondents on psycho-social well-being of informal caregivers of physically challenged children.

| **Psycho-social wellbeing** | | **Strongly disagree** | | **Disagree** | | **Undecided** | | **Agree** | | **Strongly agree** | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | N | **Freq** | **%** | **freq** | **%** | **freq** | **%** | **freq** | **%** | **freq** | **%** |
| When I look at the story of my life, I am pleased about how things have turned out. | 809 | 73 | 9.0 | 137 | 16.9 | 62 | 7.7 | 65 | 8.0 | 472 | 58.4 |
| I enjoy making plans for the future and working to make them a reality. | 809 | 20 | 2.5 | 29 | 3.6 | 17 | 2.1 | 65 | 8.0 | 678 | 83.8 |
| I think it is important to have new experiences that challenge how you think about yourself and the world. | 812 | 27 | 3.3 | 10 | 1.2 | 51 | 6.3 | 245 | 2.2 | 479 | 59.0 |
| I tend to be influenced by people with strong opinions | 811 | 139 | 17.1 | 108 | 13.3 | 212 | 26.1 | 243 | 29.9 | 109 | 13,6 |
| I judge myself by what I think is important, not by the values of what others thinks is important | 811 | 23 | 2.8 | 27 | 3.3 | 70 | 8.6 | 215 | 26.5 | 476 | 58.8 |
| have confidence in my own opinions,<br>even if they are contrary to the general<br>consensus. | 810 | 25 | 3.1 | 64 | 7.9 | 57 | 7.0 | 104 | 12.8 | 560 | 69.2 |
| When I think about it, I heven't really improved much as a person over the years | 809 | 95 | 11.7 | 113 | 14.0 | 79 | 9.8 | 153 | 18.9 | 369 | 45.6 |
| The demands of everyday life often get me down | 810 | 55 | 6.8 | 66 | 8.1 | 155 | 19.1 | 207 | 25.6 | 327 | 40.4 |
| In general, I feel I am in charge of the situation in which I live. | 811 | 71 | 8.8 | 113 | 13.9 | 178 | 21.9 | 212 | 26.1 | 237 | 29.3 |
| I feel like I get a lot out of my friendships I have not experienced many warm and trusting relationships with others. | 810 | 73 | 9.0 | 148 | 18.3 | 34 | 4.2 | 166 | 20.5 | 389 | 48.0 |
| Maintaining close relationships has been difficult and frustrating for me | 809 | 88 | 10.9 | 128 | 15.8 | 28 | 5.5 | 218 | 26,9 | 347 | 42.9 |
| I have a sense of direction and[ purpose in life. I don't have a good sense of what it is I am trying to accomplish in life | 811 | 31 | 3.8 | 18 | 2.2 | 22 | 2.7 | 230 | 28.4 | 510 | 62.9 |
| For me, life has been a continuous process of learning, changing and growth | 810 | 15 | 1.9 | 24 | 3.0 | 16 | 2.0 | 150 | 18.5 | 605 | 74.6 |
| I am quite good at managing the many responsibilities of my daily life. | 811 | 39 | 4.8 | 140 | 17.3 | 112 | 13.8 | 219 | 27.0 | 301 | 37.1 |
| Many days I wake up feeling discouraged about how I have lived my life. | 810 | 156 | 19.3 | 148 | 24.5 | 90 | 11.1 | 178 | 21.9 | 188 | 23.2 |
| In many ways I feel disappointed about my achievements in life. | 811 | 162 | 20.0 | 131 | 16.2 | 25 | 3.0 | 193 | 23.8 | 300 | 37.0 |

Respondents were asked if they were pleased about how things have turned out for them. Table 12 indicates that about 26% caregivers were not pleased with the ways things have turned out in their lives while 66.4% respondents said that they are pleased with the situation of things in their lives. The remaining 7.7% were unable to decide whether they should agree or disagree with the opinion. Respondents answers to the question that if they feel it is important to have new experiences that challenge how they think about themselves and the world, shows that 89.2% of caregivers agreed that they think it is important to have new experiences that challenge how they think about themselves and the world. About 5% of respondents disagreed that they do not think it is important to have new experiences that challenge how they think about themselves and the world. In addition to this assessment 6.3% were unable to decide whether they should agree or disagree with the opinion.

It further shows that 43.5% of respondents agreed that they tend to be influenced by people with strong opinion while 30.4% respondents disagreed. In addition, 26.1% were unable to decide whether they should agree or disagree. More also, it indicates that 64.5% of respondents agreed that they have improved much as a person over the years when they think about it, while 25.7% of respondents disagreed. Furthermore about 10% were unable to decide whether they should agree or disagree with the view. Further question on if they do often get down as a result of everyday life demands was responded to and result further illustrates that 66.0% of the respondents agreed that the demands of everyday life often get them down while 14.9% of respondents disagreed. In addition, 19.1% were undecided with the opinion. The result further reveals that about 70% of respondents agreed that their impression for maintaining close relationships has been difficult and frustrating while 26.7% of respondents disagreed, that it has not been difficult and frustrating for them. Finally 3.5 were undecided.

Another question about having a sense of direction and accomplishment in life was also answered by the respondents and findings shows that about 91% of the respondents agreed that they have a sense of direction and purpose to accomplish in their life. Moreover, 6.0% caregivers disagreed that they do not have a sense of direction and purpose to accomplish in their life and 2.7% are undecided. The question on about what life means to them, the results according to the findings show that 93.1% of respondents agreed that their life has been a continuous process of learning, changing and growth. It further shows that 4.9% of respondents disagreed that life has not been a continuous process of learning, changing and growth and 2.0% were undecided.

The result also indicates that about 64.0 % of respondents agreed that they were quite good at managing many responsibilities of their daily life while22.1% of respondents disagreed. The remaining 13.8% were undecided. Furthermore, the question if they feel discouraged about life every day reveals that 45.1% of respondents agreed that they feel discouraged about how they have lived their life when they wake-up every day. Finally, 43.8% of respondents disagreed and 11.1% were neutral. Result further reveals that 60.8% of the caregivers agreed that in numerous ways, they feel disappointed about their achievements in life. It was further obtained that 36.2% of respondents In many ways I feel disappointed about my achievements in life.disagreed, that in numerous ways, they do not feel disappointed about their achievements in life while 3.0% were undecided.

### 5.2.2 Social support to informal Caregivers

Social support to informal caregivers was measured through series of questions and this section analysis the result. Table reveals a summary of the findings or results which were analysed in the preceding paragraph

## Table 7: Responses of respondents on social support received by informal caregivers of physically challenged children

| **Social support** | | **Not at all helpful** | | **Sometime helpful** | | **Generally helpful** | | **Very helpful** | | **Extremely helpful** | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | **N** | **Freq** | **%** | **Freq** | **%** | **Freq** | **%** | **Freq** | | **Freq** | **%** |
| My parents | 812 | 205 | 25.2 | **94** | **11.6** | 307 | 37.8 | **99** | **12.2** | 107 | 13.2 |
| My spouse or partner's parents | 812 | **401** | **49.4** | 161 | 19.8 | 183 | 22.5 | **26** | 3.2 | **41** | **5.1** |
| My relatives/kin | 812 | 321 | 39.5 | 220 | 27.1 | 189 | 23.3 | **39** | **4.8** | **43** | 5.3 |
| My spouse or partner's relatives/kin | 812 | **96** | **11.8** | 52 | **6.4** | 361 | **44.5** | 137 | 16.9 | 166 | 20.4 |
| Spouse or partner | 812 | **74** | **9.2** | 139 | 17.1 | 217 | 26.7 | **126** | **15.5** | 256 | 31.5 |
| My friends | 812 | 289 | 35.6 | 242 | 29.8 | 183 | 22.5 | **42** | 5.2 | **56** | **6.9** |
| My spouse or partner's friends | 812 | 347 | 42.7 | 253 | 31.2 | 139 | 17.1 | **30** | **3.7** | **43** | 5.3 |
| My own children | 812 | 121 | 14.8 | 68 | 8.4 | 306 | 37.7 | 167 | 20.6 | 150 | 18.5 |
| Other parents | 812 | 78 | 9.6 | 68 | 8.4 | 337 | 41.5 | 147 | 18.1 | 182 | 22.4 |
| Co-workers | 812 | 78 | 9.6 | 64 | 7.9 | 346 | 42.6 | 152 | 18.7 | 172 | 21.2 |
| Parent groups | 812 | 98 | 12.0 | 72 | 8.9 | 341 | 42.0 | 119 | 14.7 | 182 | 22.4 |
| Social groups/clubs | 812 | 82 | 10.1 | 53 | 6.5 | 358 | 44.1 | 143 | 17.6 | 176 | 21.7 |
| Church members/minister | 812 | 263 | 30.2 | 237 | 29.2 | 195 | 24.0 | 67 | 8.3 | 67 | 8.3 |
| My family or child's physician | 812 | 325 | 40.0 | 255 | 31.4 | 146 | 18.0 | 47 | 5.8 | 39 | 4.8 |
| Early childhood intervention program | 812 | 62 | 7.6 | 75 | 9.2 | 324 | 39.9 | 179 | 22.1 | 172 | 21.2 |

Table 7 indicates that about82% of the caregivers find social support received from their spouse or partner's relatives/kin helpful while11.8% of respondents said that they do not find it helpful. In addition 6.4% said that it's sometime helpful. It shows from the table that 73.7% of the caregivers find social support received from their spouse or partner helpful while 9.2% of respondents said that they do not find it helpful. The remaining 17.1% said that it is sometime helpful.

Respondents were further asked on how helpful the support is from other parents. The table indicates that 82.0% of the caregivers find social support received from other parents helpful while 9.6% of respondents do not find it helpful. In addition 8.4 % said that it is sometime helpful. Caregivers also responded to question how helpful the support is from their co-workers. It also reveals that 82.5% of the caregivers find social support received from their co-workers helpful while 9.6% of respondents said that they do not find it helpful. However, about 8 % said that it was sometime helpful. The table further indicates that 79.1% of respondents find social support received from parent groups helpful while 12.0% of respondents said that they do not find it helpful. In addition 8.9% said that it is sometime helpful.

It shows from the table that 83.4% of respondents find social support received from their social groups/clubs groups helpful while 10.1% of respondents said it is not helpful. However, 6.5% said that it is sometime helpful. Finally, on social support caregivers were asked how helpful is the support from early childhood intervention programme was. Table 13 further reveals that83.2% of the respondents find social support received from early childhood intervention programme helpful while 7.6% of respondents said that social support received from their early childhood intervention program is not helpful. In addition 9.2% said that it Is sometime helpful.

### 5.2.3 Level of satisfaction of social support to informal caregivers

Level of satisfaction of social support among caregivers was also obtained. Some questions were asked and responses to these questions are analysed in this section. Table 14 shows a detailed summary of the findings.

**Table 14: Respondents' responses on the level of satisfaction of informal caregivers with social support**

| How satisfied are you with support from the following | | Not satisfied | | Generally satisfied | | Very satisfied | | Extremely satisfied | |
|---|---|---|---|---|---|---|---|---|---|
| | N | Freq | % | Freq | % | Freq | % | Freq | % |
| My parents | 812 | 118 | 14.5 | 67 | 8.3 | 63 | 7.7 | 564 | 69.5 |
| My spouse or partner's parents | 812 | 50 | 6.2 | 62 | 7.6 | 84 | 10.3 | 616 | 75.9 |
| My relatives/kin | 812 | 53 | 6.5 | 88 | 10.8 | 121 | 15.0 | 550 | 67.7 |
| My spouse or partner's relatives/kin | 812 | 42 | 5.2 | 70 | 8.6 | 91 | 11.2 | 609 | 75.0 |
| My spouse or partner | 812 | 138 | 17.0 | 137 | 16.9 | 151 | 18.6 | 386 | 47.5 |
| My friends | 812 | 57 | 7.0 | 107 | 13.2 | 125 | 15.4 | 523 | 64.4 |
| My spouse or partners' friends | 812 | 23 | 2.8 | 81 | 10.0 | 111 | 13.7 | 597 | 73.5 |
| My own children | 812 | 62 | 7.6 | 99 | 12.2 | 85 | 10.5 | 566 | 69.7 |
| Other parents | 812 | 46 | 5.7 | 44 | 5.4 | 129 | 15.9 | 593 | 73.0 |
| Co-workers | 812 | 47 | 5.8 | 58 | 7.2 | 109 | 13.4 | 598 | 73.6 |
| Parent groups | 812 | 59 | 7.3 | 48 | 5.9 | 68 | 8.4 | 637 | 78.4 |
| Social groups/clubs | 812 | 48 | 5.9 | 60 | 7.4 | 94 | 11.6 | 610 | 75.1 |
| Church members/minister | 812 | 80 | 9.8 | 76 | 9.4 | 157 | 19.3 | 499 | 61.5 |
| My family or child's doctor | 812 | 45 | 5.5 | 56 | 6.9 | 96 | 11.8 | 615 | 75.7 |
| Rehabilition centre/school for handicapped | 812 | 73 | 9.0 | 145 | 17.9 | 144 | 17.7 | 450 | 55.4 |

Table 14 reveals that 94.8% of respondents were satisfied with the support received from their spouse or partner's relatives/kin. The remaining 5.2% were not satisfied with the support received from their spouses or partner's relatives/kin.

Responses from Table 14 indicate that 83.0% of respondents were satisfied with the support received from their spouse or partner while 17.0% of respondents said that they were dissatisfied with the support received from their spouse. Respondents answer to question about satisfaction with support derived from their spouses or partners' friend's shows from the table that 97.2% of respondents were satisfied with the support received from their spouse or partners' friends while 2.8% of respondents said that they were dissatisfied with the support received from their spouse or partners' friends.

Further question about their satisfaction with support from co-workers, reveals from the table that 94.2% of respondents were satisfied with the support received from their co-workers. The remaining 5.8% of respondents said that they were dissatisfied with the support received from co-workers. Responses to the question about satisfaction with support from parent groups show that 92.7% of respondents were satisfied with the support received from parent groups while 7.3% of respondents said that they were dissatisfied with the support received from parent groups. Table 14 indicates that 94.1% of respondents were satisfied with the support received from their social group/clubs. In addition 5.9% of respondents said that they were dissatisfied with the support received from their social group/clubs.

Lastly, about 91.0% of respondents were satisfied with the support received from rehabilitation centre/school for handicapped. However, about 9.0% of respondents said that they were dissatisfied with the support received from rehabilitation centre/school for handicapped.

## 5.3 Analysis according to research questions

Under this section, findings are presented based on the objectives and research questions that were postulated in chapter one. Findings are presented in tables. The first research question was: What is the impact of social support on the psycho-socio well-being of informal caregivers and the level of satisfaction of the social support received? Table 15 shows the impact of social support and satisfaction level on psycho-social well-being of informal caregivers.

**Table 15: Impact of social support and satisfaction level on psycho-social well-being of informal caregivers.**

| Model 1 | S.E | **P** | T | Sig. | F-Ratio | Sig. | R | $R^2$ | Adj. $R^2$ |
|---|---|---|---|---|---|---|---|---|---|
| Social support | .025 | .288 | 8.559 | .000 | 73.253 | .000 | .288 | .083 | .082 |
| Model 2 | | | | | | | | | |
| Social support | .026 | .351 | 9.791 | .000 | 48.476 | .000 | .327 | .107 | .105 |
| Level of satisfaction with support received | .032 | .168 | 4.671 | .000 | | | | | |

***Significant at P <0.05***

Table 15 in the first model shows that social support predicts psycho-social well-being of informal caregivers of physically challenged children. This is because significant level *p*< 0.05 level of significance was achieved. Moreover social support accounted for 28.8% direct impact in relation to psycho-social well-being. In the second model social support and satisfaction level combined together have an impact on psycho-social well-being of informal caregivers of physically challenged children. This is also because significant level (P value) < 0.05 level was achieved. Social support and satisfaction level when combined together accounted for 35.1% direct impact in relation to psycho-social well-being of informal caregivers. The inclusion of the level of satisfaction with the level of social support increased the level of impact and prediction of sound psycho-social wellbeing.

The second research question runs thus: To what extent does occupational status contribute to psycho-social well-being of informal caregivers? Table 16 reveals a simple regression analysis on the impact of occupation on psycho-social well-being of informal caregivers

**Table 10: Summary of simple regression analyses on impact of occupation on psycho-social well-being of informal caregivers.**

| Model 1 | S.E | B | T | Sig. | F-Ratio | Sig. | R | $R^2$ | Adj. $R^2$ |
|---|---|---|---|---|---|---|---|---|---|
| occupation | .984 | .19 | 5.62 | .000 | 31.58 | .007 | .194[a] | .038 | .036 |

***"Significant at P <0.05***

Table 10 shows that occupational status significantly impacts on the psycho-social well-being of the informal caregivers of physically challenged children F (1, 808) = 31.58, $p < 0.05$. In the same table occupational status shows a strong contribution to the psycho-social well-being of informal caregiver ($R^2 = .04$, F (1, 808) = 31.58, $P < 0.01$).Occupational status contributes a significant 3.8% change observed in the variance of the reported psycho-social well-being of informal caregivers. Based on this it can be said that occupational status significantly determines psycho-social well-being of the informal caregivers of physically challenged children.

Table 11 indicates the multiple regression comparisons mean differences between occupations of informal caregivers.

**Table 17: Multiple comparisons on mean difference between occupations of Informal caregivers on psycho-social well-being.**

| Occupations | N | Mean | SD | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Professional | 114 | 62.60 | 6.86 | - | | | | | | |
| 2. Civil servant | 104 | 62.18 | 8.37 | .414 | - | | | | | |
| 3. Pensioner | 42 | 61.79 | 6.25 | .811 | .397 | - | | | | |
| 4 Self employed | 270 | 66.08 | 9.80 | -3.48* | -3.90* | -4.29* | - | | | |
| 5. Full time house wife | 42 | 64.64 | 6.70 | -2.05 | -2.46 | -2.86 | 1.44 | - | | |
| 6 Trading/farming | 215 | 65.51 | 8.99 | -2.91* | -3.32* | -3.72* | .571 | -.86 | - | |
| 7. Unemployed | 25 | 58.60 | 15.50 | 3.99* | 3.58 | 3.19 | 7.48* | 6.04* | 6.91* | - |
| Total | 812 | 64.41 | 9.15 | | | | | | | |

*mean difference is significant at the 0.05 level

Table 17 is further analysis using multiple comparison one way ANOVA LSD post hoc analysis which reveals that informal caregivers who are self-employed (X = 66.08) have significant higher psycho-social well-being followed by informal caregivers who were engaged in trading/farming (X = 65.51) compared to informal caregivers in other occupational category.

This is the third research question of the study: How does family income contribute to psycho-social well-being of informal caregivers? Table 18 is a simple regression analysis on the impact of family income on the psycho-social well-being of informal caregivers.

**Table 12: Summary of simple regression analyses showing significance impact of family income on psycho-social well-being of informal caregivers.**

| Model 1 | S.E | B | T | Sig. | F-Ratio | Sig. | R | | Adj. $R^2$ |
|---|---|---|---|---|---|---|---|---|---|
| Family income | 1.04 | .15 | 4.39 | .000 | 19.24 | .000 | .02 | .023 | .022 |

**_*Significant at_** $P <0.5$

From Table 18, the result also demonstrates that family income significantly contributes to the psycho-social well-being of the informal caregivers of physically challenged children F (1, 808) = 19.24, $p< 0.05$. The table also indicates that 5.2, family income demonstrates to be a significant predictor of informal caregiver psycho-social well-being ($R^2$= .02, F (1, 808) = 19.24, $P< 0.01$).The result suggests that family income contributes a significant 2.2% change observed in the variance psycho-social well-being of informal caregivers. This also shows that for every unit change in the psycho-social well-being of the informal caregivers the family income increases by 0.15 units ($p = 0.15$, t-value = 4.39, $p < 0.001$). Based on this, it can be said that family income significantly determined psycho-social well-being of the informal caregivers of physically challenged children.

Table 13 reveals multiple comparisons on mean difference between family incomes of informal caregivers.

**Table 19: Multiple comparisons on mean differences between family incomes of Informal caregivers.**

| | N | Mean | SD | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 More than NGN 100, 000 | 41 | 60.20 | 7 85 | - | | | | | | |
| 2. NGN 100, 000 - 50, 000 | 114 | 62.02 | 4 96 | - .8<br>1 1 | - | | | | | |
| 3. NGN 49, 999 - 30, 000 | 115 | 64.55 | 8 09<br>9 | -<br>4 35<br>* | -<br>2.53* | - | | | | |
| 4. NGN 29, 999 - 10, 000 | 280 | 66.21 | 8 92 | -<br>6 01<br>* | -<br>4.20* | - 66<br>1 | - | | | |
| 5. NGN 9, 999 - 5, 000 | 210 | 65.65 | 9 50 | -<br>5 45<br>* | -<br>3.64* | - 10<br>1 | .56 | - | | |
| 6. NGN 4, 999 - 1, 000 | 31 | 61.23 | 9 69 | - .0<br>1 3 | .78 | 3 32<br>. | 4.98* | 4.42* | - | |
| 7. Less than NGN 1, 000 | 21 | 53.38 | 16.96 | 6 81<br>* | 8.63* | 1 .17*<br>1 | 12.82* | 12.27* | 7.85* | - |
| Total | 812 | 64.41 | 9 14<br>8 | | | | | | | |

*Mean difference is significant at the 0.05 level

Table 19 shows one way ANOVA post hoc analysis and it reveals significant mean difference between family incomes of informal caregivers on psycho-social well-being. From the above table, the result of multiple comparisons indicates that informal caregivers who earn between NGN10000 to NGN29999 (X = 66.21) have significant higher psycho-social well-being followed by informal caregivers who earn between

NGN5000 to NGN9999 (X = 65.65) compare with other groups of family incomes.

Furthermore, another research question postulated to guide this study is: In what way does the level of education contribute to psycho-social well-being of informal caregivers? Table 20 indicates simple regression analyses on the impact of educational level on psycho-social well- being of informal caregivers.

**Table 14: Summary of simple regression analyses showing impact of educational levels on psycho-social well-being of informal caregivers.**

| Model 1 | S.E | B | T | Sig. | F-Ratio | Sig. | R | $R^a$ | Adj. $R^2$ |
|---|---|---|---|---|---|---|---|---|---|
| Education | -.63 | -.13 | -3.67 | .000 | 13.49 | .000 | .128 | .016 | .015 |

***"Significant at P <0.5***

Table 20 reveals that education attainment predict psycho-social well-being of the informal caregivers of physically challenged children F (1, 808) = 13.49, $p$< 0.05. In the same table educational attainment has a strong relationship with the psycho-social well-being of informal caregiver ($R^2$= .02, F (1, 808) = 13.49, P< 0.01).The result demonstrates that occupational status contributes a significant 2% change observed in the variance of the recorded psycho-social well-being of informal caregivers. For every unit change in the psycho-social well-being of the informal caregivers the level of educational decreases by 0.13 units (p = -0.13, t-value = -3.67, p < 0.01). Based on this it can be concluded that psycho-social well-being of the informal caregivers declines with higher educational qualification among informal caregivers of physically challenged children.

Informal caregivers on psycho-social well-being

**Table 15: Multiple comparisons on mean difference between educational level of informal caregivers on psycho-social well-being.**

| | N | Mean | SD | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Did not attend sch. | 12 | 58.92 | 6.74 | - | | | | | | | |
| 2. Primary school | 107 | 62.16 | 9.80 | -3.24 | - | | | | | | |
| 3. Secondary school | 246 | 65.21 | 9.58 | -6.29* | -3.05* | - | | | | | |
| 4 WAEC/NECO | 114 | 68.07 | 8.44 | -9.15* | -5.91* | -2.86* | - | | | | |
| 5. Grade Two | 64 | 65.91 | 8.38 | -6.99* | -3.75* | -.695 | 2.16 | - | | | |
| 6. NCE/OND | 132 | 62.78 | 9.67 | -3.86 | -.621 | -2.43* | 5.29* | 3.13* | - | | |
| 7. HND/B.SC | 94 | 62.35 | 7.46 | -3.43 | -.192 | -2.86* | 5.72* | 3.56* | .429 | - | |
| 8. Post Graduate | 43 | 64.58 | 5.59 | -5.66 | -2.42 | -.629 | 3.49* | 1.32 | -1.80 | -2.23 | - |
| Total | 812 | 64.41 | 9.15 | | | | | | | | |

* Mean difference is significant at the 0.05 level

Table 15 is further analysis of one way ANOVA on the direction of the impact. The table reveals a significant mean difference between educational levels of informal caregivers on psycho-social well-being. The table shows the result of multiple comparisons indicates that informal caregivers who possess WAEC/NECO qualification (X = 68.07) have significant higher psycho-social well-being followed by informal caregivers who possess grade two qualification (X = 65.91) and informal caregivers who also possess secondary school qualification (X = 65.21) compared with other groups of occupations.

Another research question of this study is: How does marital status contribute to psycho-social well-being of informal caregivers? Table 22 portrays the chi-square test on the relationship between marital status and psycho-social well-being of informal caregivers.

**Table 16: Summary table of Chi-square test on the relationship between the marital status and psycho-social well-being of informal caregivers**

| **Psycho-social well-being** | **Marital status** | | | **Df** | $\chi^2$ | **Sig.** |
|---|---|---|---|---|---|---|
| | **Married** | **Single parent** | **Divorced** | | | |
| | | | | **2** | **7.366** | **.025** |
| **Low** | **209** | **109** | **35** | | | |
| **High** | **228** | **172** | **59** | | | |

Table 16 shows that there is significant relationship between marital status and psycho-social well-being of informal caregiver which was tested using the Chi-square test of equality of proportion. The result obtained is $x^2$=7.366, df = 2, P< .05. This reveals that there is a significant relationship between marital status and psycho-social well-being of well-being of informal caregiver. Thus, differences exist between marital statuses with regards to the psycho-social well-being.

This is the last research question that was postulated to guide the study: What is the significance of gender in psycho-social well-being of informal caregivers? Table 23 shows chi-square test on the relationship between sex and psycho-social well-being of informal caregivers.

**Table 17: Summary table of Chi-square test of independence showing the relationship between sex and psycho-social well-being of informal caregivers**

| **Psycho-social well-being** | **Sex** | | **Df** | $\chi^2$ | **Sig.** |
|---|---|---|---|---|---|
| | **Male** | **Female** | | | |
| **Low** | **155** | **198** | **1** | **4.247** | **.039** |
| **High** | **235** | **224** | | | |

Table 23 reveals that there is significant relationship between sex and psycho-social well-being of informal caregiver having been tested using the Chi-square test of independent. The result obtained is $x^2$=4.247, df = 1, P< .05. This shows that there is a significant relationship between sex and psycho-social well-being of informal caregiver. Thus, differences exist between sexes with regards to the psycho-social well-being.

# CHAPTER SIX

# DISCUSSION OF FINDINGS

## 6.1 Introduction

In this chapter, findings of the study relating to the stated objectives and the outcomes relating to the research questions as presented in chapter one are discussed. The research questions postulated are what are the impact of social support and the satisfaction level of informal caregivers, the contribution of socio-economic factors (occupation, income and education) and the role of gender and marital status to psycho-social well-being of informal caregivers of children with disability. In addition, there is a discussion of these findings in relation to the current literature on psycho-social well-being of informal caregivers in south-western Nigeria. Furthermore, the findings on the impact of social support and satisfaction level of caregivers are discussed. Also the contribution of socio-economic factors and the role of gender and marital status in determining caregivers' well-being are also discussed.

## 6.2 Impact of social support and the level of satisfaction on the psycho-social well-being of caregivers

The result of finding on the research question one shows that social support has influence in determining psycho-social well-being of informal caregivers, so also is the satisfaction level of the support received. The result demonstrates that social support and satisfaction level made significant contribution to informal caregivers' psycho-social well-being. It was noted that when considering social support alone, psycho-social well-being improves, as the informal caregiver receives adequate support. The value of the standardized regression weights associated with variables respectively indicates that social support ($p = 0.351$, $p < 0.05$) is an effective contributor with 35.1 % contribution and satisfaction level with support receive ($p = 0.168$, $p =$

0.05) is also an effective contributor with 16.8 %. With the inclusion of satisfaction with social support received, the level of impact and prediction of psycho-social well-being improves showing that good social support that meets the immediate need and desire of the informal caregiver is of greater impact than giving unsolicited and less preferred support. Offering of social support and giving financial support may invoke lesser satisfaction compared to keeping the child under a foster care for a period of time to allow the parent to sort out some certain issues in their life and family.

Moreover the result shows that the highest social support comes from the social groups/clubs (83.4%) and follows by the early childhood (83.1%), co-workers (82.5%), other parents (82.0%), and spouse or partner relatives/kin (81.8%). The table further reveals that, parents group (79.1%), children (76.8%) and parents (63.2%), respectively. The implication of this is that, support groups are very important in meeting the needs of informal caregivers and there is need for caregivers to understand the role and usefulness of various social groups in the community in enhancing their psycho-social well-being. Members of these social groups can be parents whose children have disabilities so that they can share information on different issues that affect them as caregivers and also on issues that affect their children with disabilities. Government can also educate the public the more on the role and benefits of being a member of social groups and clubs in the society especially for the informal caregivers.

Early childhood intervention is also very important because this is the first intervention at the very first time that a parent discovers that his/her child has a disability and it goes a long way in minimizing the amount of anxiety and depression that comes with such discovery. In fact many parents do not know what to do with their children with disabilities at this stage. Parents at this stage need to be educated by professionals in the disability field and assisted in taking decision that will have a long term impact on the child. Social support from other sources is also very important as revealed by the result and this is an indication that social support is very crucial at enhancing psycho-social well-being of informal caregivers.

Results on the satisfaction level also reflect that caregivers find satisfaction from support received from different sources and with the highest level of satisfaction from spouse or partner's friend (99.2%). This also shows that married caregivers are more likely to enjoy positive psycho-social well-being than those who are not married. This is followed by satisfaction from spouse partner relative/kin (94.8%) and (94.3%) from other parents. The meaning of this is that support from partners and other parents who are close associate of caregivers are very helpful in the care of their children with disability. This suggests that caregivers who are single and divorced are more likely to experience negative psycho-social well-being as a result of not having partners to share burden of care with them. An intervention programme is required for this set of caregivers so that their well-being could be promoted.

Thus social support counts but the quality and satisfaction with the support received may go a long way in improving the life outcome of the informal caregiver. This can be in the form of respite care which allows caregivers opportunity to have a break so as to attend to some other personal issues. Through counselling a caregiver can be exposed to information on caregiving supports programmes and thereby make informed decisions about the type of social support programme that best suits their situation and how best their disabled children could be taken care of. Such informed decision could be very satisfactory as they see themselves as part of decision making concerning the interest of their children and themselves. In effect this poses a challenge to practitioners to what social support should be offered and in what capacity.

According to Shumaker and Brownell (1984) a clear distinction must be made between the content of supportive exchanges and the purposes or functions of social support. Because if this distinction is not made, the problem of how support is supposed to work, how it does work, and what its effects should be in care giving context. Caregivers must understand the nature of the social support available through various sources e.g., from friends and relatives, institutional support and community support, the potential impact and the intended outcome of these support on caregiving's activities. Studies on caregiver's social support often emphasize on social support network characteristics (e.g., size, density) not specifying the connections between networks and support. Yet most investigators do not recognize that issues relevant to interdependent relations and characteristics of all participants may significantly influence the phenomenon. So also, there is need for distinction to be made between harmful interpersonal relations and the potentially harmful effects of supportive exchanges. Finally, there is the necessity to consider the differences between the short- and the long-term effects of social support.

Shumaker and Brownell (1984) however recognize that support involves at least two individuals. The authors theoretically distinguish between the health-sustaining and the compensating (i.e., stress buffering) aspects of this phenomenon. This mean that it is believed that support is important to mental and physical health in the absence as well as in the presence of stress, and that support operates differently in these two situations. They consider the contextual nature of support. The authors argue that many phenomena cannot be adequately understood or investigated without a full consideration of the ecological factors that influence them. By considering context, they believed that researchers will be forced to distinguish clearly between dimensions of support (e.g., its specific functions and resources) and situational variables (e.g., organizational structure, physical design).

Shumaker and Brownell (1984) concluded in their study that Social support is an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the wellbeing of the recipient. Thus, identifying the fact that social support may not necessarily provide the buffering or compensatory effect as needed and may become harmful if not guided, qualitative and timely as needed by the caregivers. Social supports may differ in several ways from others. However what is consistent is the concept of exchange, the perceptions of at least two participants which outcome is tied to the perceived intentions of either participant, the actual effects the support received which may be positive, negative, or neutral; and may not be limited by the traditional social support network members nor by the care giving distress (Shumaker & Brownell, 1984).

Empirical evidence shows that social support may pose a potential threat to caregiver's well-being, for instance Gottlieb (1983) identified that social support pose a threat through inequity in supportive relationships, as Shinn et al. (1984) identified that an obligation to reciprocate might stress relations. Issues of reciprocity (Gouldner, 1960) and indebtedness (Greenberg, 1980) to those offering support and the recipient are particularly subjected to the motives and actions of the recipient in supportive exchanges. Reciprocity can be influenced by recipients' perceptions of providers' real costs and intentions in providing the benefit, as well as by the degree to which the benefit actually helps the recipient (Shumaker & Jackson, 1979). Greenberg (1980) takes the concept of reciprocity a step further by arguing that accepting a benefit may place the recipient in an uncomfortable state of tension (indebtedness): as a result, the recipient will want to reduce this discomfort by, for example, not accepting a benefit or by directly reciprocating it. Such options, however, are not always available. Sometimes people are forced to accept assistance when an opportunity to reciprocate in kind is limited or unavailable. When this occurs, people find alternative ways to reduce their discomfort. They may, for example, refuse to accept more help even though they continue to need it. They may also deride the person who helped them, help someone else if they cannot reciprocate directly, or re-evaluate the original exchange to decrease their perception of debt.

The implication of this is that if people feel they will not be able to return a benefit, they may be less likely to seek assistance or accept it when offered. In situations where help is needed over an extended period of time (in cases of disabled children), the recipient's inability to reciprocate fully may become increasingly apparent and asking for help may become especially difficult. Second, if reciprocity is prevented, then the relationship between providers and recipients may diminish. Recipients, for example, may derogate providers or the resources received to reduce feelings of discomfort. Over time this can cause social ties to disintegrate, and make recipients more vulnerable to poor psychological wellbeing. As such reducing the negative effects of perceptions of reciprocity may go a long way in reducing the after effect of social support for caregivers. First, providers can be sensitized to the recipients' needs to feel they are contributing equitably to the relationship. Second, recipients might be encouraged to assist someone other than the provider. Although available literature suggests that such opportunities do not eliminate a sense of debt, they do appear to reduce the tension associated with indebtedness (Shumaker & Jackson, 1979). Third, some of a recipient's burden can be moved from the informal network to a formal support system. For example, clergy, health professionals, and therapists may be valuable sources of support when circumstances cause disturbances in a relationship's normal balance between helping and receiving.

Formal support providers do not usually require reciprocity in the same way that informal support providers do. Furthermore, formal providers are less likely to be threatened by the needs of the recipient, require little effort to sustain the linkage, and are often able to provide the recipient with more expert information than informal providers (Shumaker, 1983). Finally, the recipient's needs can be shared among several such sources (Chesler & Barbarin, 1984).

When considering the findings and discussion of this study further, inference can be made to social support theory of Cassel (1976), psychological well-being theory of Ryff, (1989), subjective well-being theory of Cheng and Lam (2010) and social well-being theory of Keyes (1998) to make meaning of the impact of social support on well-being of informal caregivers of physically challenged children These theories postulate that factors such as environmental and institutional factors are very important in psycho-social well-being because they shield individuals from the harmful effect of stress. Emotional, informational, community, governmental and non- governmental supports are all products of environment and different institutions within the society which are very essential in ensuring well-being of informal caregivers. The findings in research question 1 indicate that social support received predicts psycho-social well-being and also adequate social support also enhances satisfaction level of informal caregivers. It could also be interpreted that lack of social support results in poor psycho-social well-being while inadequate social support leads to low satisfaction level. Adequate social support from community and institutions can reduce negative effect of caregiving thereby providing a high level of life satisfaction which can be seen as a high level of subjective well-being.

There is need for provision of adequate social support (tangible and non-tangible) to informal caregivers to buffer the effect of caregiving on them. This is because it is when their psycho-social well-being is ensured that they could provide quality care to their children with disability and thereby enhance their own children's psycho-social well-being. Positive psychological, physical outcomes among caregivers of children with physical disability can be enhanced through adequate social support drawn from network of social relationships and institutions that are available to them.

Based on this result, which is in concordance with Bozo and Demirtepe-Saygılı (2011) who submitted that caregivers who were more able to satisfy their basic needs, and perform their daily activities reported lower levels of psychological symptoms because they received enough social support. The result is also in support of the study on quality of social supports as it was demonstrated in the study of Lai and Thomson (2009) who demonstrated that perceived adequacy of social support is important to family caregivers as it lessens caregiving burden. Allan, Jordan, James and Maggie (2010) also agreed with the findings of this study that social support (the availability of persons with whom to talk or to socialize and the receipt of feelings of positive regard and self-esteem from others) were predictors of the life satisfaction among caregivers.

More also Tsai and Wang (2008) in agreement with this study affirmed that mothers with intellectually disabled children had a rather high level of strain as result of inadequate social support. Social support and strain had a significant and negative correlation. The result revealed that mothers' health status, social support and amount of time spent as a caregiver, as well as the intellectually disabled children's dependent degree of daily living activity, were major predictors of caregiver's strain. Furthermore the result of this study also concurs with that of Crammand and Nieboer (2011) who stated that psychological well-being of caregivers was strongly affected by parental stress and child's depressive feelings coupled with indirect relationship to restricted caregiver social activities. The researchers recommended that support services to parents and caregivers should address depressive feelings among children and facilitate the social activity of caregivers to protect their psychological well-being.

Wei, Chu, Chen, Hsueh, Chang, Chang and Chou (2012) also in support of these findings affirmed that caregivers benefit from participating in support group interventions in their study that shows that physical-psychological health (somatic, depressive and anxiety symptoms) of caregivers improved significantly after weeks of intervention programme.

A study done by Dyson (1997) also supports the present study that fathers and mothers of children with developmental disabilities experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities. They concluded that both parents' stress was associated with aspects of family functioning and family social support as perceived by themselves and their spouses.

Also in agreement with the study, Wanda and Amanda (1992) concluded that informal social supports have been consistently associated with the physical and mental well-being of the elderly. Also, adverse social contacts were associated with increased strain, while positive contacts were insignificant in their result. When sources of social support were examined daughters figured prominently as important sources of both positive and adverse social contacts. Their findings also emphasized the importance of interventions which include friends, neighbours, and others.

This finding is also consistent with Goodman (1991) who concluded that importance of social supports and the popularity of a self-help ideology have also resulted in professional initiation of support groups. She opined that support groups have become an important source of help particularly for caregivers of Alzheimer's victims. Another study that concurs with the present study is that of Nordtug, Krokstad, Sletvold and Holen (2011). These authors agreed that chronic obstructive pulmonary disease group who perceived more social support, reported less social withdrawal and higher numbers of helping persons. However, ill partners who displayed aggressive behaviour reduced perceived support. They conclude that differences in caregivers' needs for social support were related to their partner's disease.

The results which were observed in this study were also supported by Zipper and Simeonsson (2005) who affirmed that social support promotes healthy development among children with disability because as social inclusion is embraced they developmentally benefit socially through small group activities, incidental learning, and exposure to readiness skills that can easily be transferred to the academic world for use in communication, socialization and thought process skills. Papalia, Olds and Feldman (2004) affirmed in support of this study that social support naturally has the ability to offer parents of children with disability assistance and encouragement when they are overwhelmed by the burden of caregiving and become vulnerable.

This present study also confirms the findings of Dejong and Miller (1995) who stated that social support benefits the caregivers and student with disabilities by strengthening the ability of students with disabilities and reinforces community membership. Social support perceived and received by children with disabilities improves their academic performance and socialization process as they continue to live as adult members of the community and prevents alienation and repression by addressing the needs of all the people in the society.

However in contrast to the present result, Plumb (2011) findings indicate that higher levels of perceived social support were associated with increased parental stress. This may suggest that families who are experiencing clinically significant levels of stress seek out community supports at higher rates than other families. The findings of the study also suggest that some social connections may potentially elevate stress in parents of children with ASD.

### 6.3 The combination of occupational, educational level and income on psycho-social well-being of informal caregivers

The findings on the research questions 2, 3, and 4 as revealed in the result tables are discussed here. The results show that socio-economic factors have significant influence in determining psycho-social well-being of informal caregivers of physically challenged children. A caregiver's socio-economic status is based on family income, education level and occupation. Caregivers with high socio-economic status typically have access to a wide range of resources to promote their well-being as well as supporting their children's development. Socio-economic status of caregivers is one of the most consistent family factors found to be associated with health care of the physically challenged children. Generally, low socio-economic status and the factors associated with social economic status e.g. low social support and type of disability are significantly related to low levels of psycho-social well-being of informal caregivers. The findings of this study show that caregivers with little or low levels of education are more likely than educated caregivers to report a sound psychological well-being: this suggest a causative link between socio-economic status and psycho-social well-being of informal caregivers. Drawing from the capability theory, (Easterlin, 2001), financial capability is linked with psycho-social well-being.

Income which is determined by educational level and occupational status predicts psycho-social well-being of informal caregivers. A good income ensures financial capability which allows for control of financial and environmental situations that promote positive psycho-social well-being. This suggests that caregivers who have high educational qualifications and are in a good occupation are more likely to have high income which allows them to take care of the financial situation of their disabled children and themselves. On the contrary a low income earner caregiver as a result of low educational qualification and not in too good occupation are more likely not to control both financial and environmental situation and may not have positive psycho-social well-being. Income determines how well caregivers are able to provide for educational, health, housing, information and social needs of their children and that of their own. Ability to meet all these needs is what ensures psycho-social well- being of these caregivers.

Besides, the economic factor is one of the correlates and determinants of well-being as supported by subjective well-being theory (Cheng & Lam, 2010). This shows that income which determines the economic activities is very crucial in determining the psycho-social well-being of the informal caregivers. Drawing from the social well-being theory of Keyes, (1998), individuals with low socio-economic status are more likely to have negative well-being because they could not have access to good things of life while individuals with high socio-economic status are very likely to enjoy positive psycho-social well-being because of their ability to access good things of life. The implication of this for informal caregivers is that caregivers with low socio-economic status are most likely to have poor social well-being while caregivers with high socio-economic status are more likely to have positive social well-being due to the fact that they could have access to good things of life. The findings generally imply that social support and socio-economic factors are very important when considering psycho-social well-being of informal caregivers of physically challenged children. Their well-being becomes important because their ability to give quality care that will enhance the psycho-social well-being of their children with disability depends largely on their own personal well-being. In a situation where they themselves cannot take care of their own health due to pressure of caregiving their ability to give quality care is jeopardized and this has an effect of leading to early institutionalization of their children with disability which may not be in their best interest.

In the light of dwindling government resources and inability to provide quality special schools that can meet the needs of children with disability in Nigeria, it becomes important to strengthen informal caregivers of these children in areas of providing community, financial, emotional and health support which can be a catalyst to effective caregiving. Many of the caregivers are not well educated and do not have good jobs that can enhance their income generation and even if they want to work, their caregiving role is a hindering factor. Educating them also becomes very essential so as to make them have access to various sources of support that are available in the community which could be of help to them in their caregiving role.

The findings also demonstrate the importance of educational level and occupational status in the psycho-social well-being of caregivers which is in concordance with the subjective well-being theory that demographic characteristics are among the correlates and determinants of well-being. Demographic factors such as educational level and occupational status in association with other factors produce high level of life satisfaction and individual with high level of life satisfaction and positive effects are more likely to have subjective well-being. These findings suggest high educational levels and a good occupation is very important to caregiver's frequent experience of high levels of life satisfaction and overall total psycho-social well-being.

Based on these present findings, the result of this study is in agreement with Uskun and Gundogar (2010) who concluded that financial problems are the most important factors that affect the psychology of the parents of disabled people. Hence, they put forward that social programmes that will support the parents in respect of both financial matters and home-care facilities should be set up. Also in concordance with this finding Schofield et al. (1998) submitted that financial difficulties were associated with poorer well-being in the caregivers (as cited by Savage & Baile, 2004).

Quine and Pahl (1991) in consistent with these findings affirmed that being middle class with few financial worries appeared to protect the result of stressful behaviour for mothers of children with severe learning difficulties. A plausible explanation to caregivers' low psycho-social well-being may be that caregivers who believe there is little or nothing they can do as a result of their low level of education have little motivation to engage in what is typically viewed as health-engendering behaviours such as regular physician visits. Anastasi (2000) noticed that a large family at least in certain socio-economic levels of the caregivers would perhaps reduce the per capital income available for education, recreation, suitable housing, proper food and medical attention.

Caregivers of physically challenged children, whose self-report indicates that they are from low-socio-economic status, tend to be susceptible to low psycho-social well-being compared to those from high and medium socio-economic status irrespective of the type of disability of their children and challenges. Considerable evidence indicates that income and other measures of socio- economy status are associated with the wide variety of health outcomes. KapplanShema and Lynch (2008) concluded that psychological well-being increased with number of waves in which profit income was reported and with income over time.

Occupational status reflects the outcome of educational attainment, provides information about the skills and credentials required to obtain a job, and the associated monetary and other rewards. Occupational status is a promising measure of social position that can provide information about job characteristics, such as environmental and working conditions, and psychological demands of the job. Occupational status is directly linked to health because it positions individuals within the social structure, which defines access to resources and constraints that can have implications for health and general well-being. Burgard and Stewart (2003) affirmed that each particular job has its own set of demands and rewards that can influence health, such as physically hazardous or psychological stressful working conditions as well as effects of the job on individual's overall well-being.

## 6.4 The contributions of marital status and gender towards psycho-social well-being of informal caregivers.

The findings from this study extend the understandings of the impacts of sex and marital status of caregivers on psycho-social well-being. Gender is a strong predictor of becoming an unpaid caregiver. Women are far more likely than men to assume the role of unpaid caregiver in family. This is because women traditionally are assigned the role of caregiving in the home. The presence of a disabled child in the home could make this role to be more challenging for the women. Studies suggest that mothers were the ones looking after the children with disabilities and not the fathers. This was like a given responsibility for mothers while fathers supported from a distance.

In practice, mothers are the ones making decisions on what to do with their children with disabilities, although they may not be the head of the household because fathers do not want to be involved in the care process. Sex and marital status are social variables that influence people's life and play important role in determination of psychological well-being. The findings of this study show that more males have high psycho-social well-being than their female counterparts; while more married caregivers have high psycho-social well-being than both single and divorced caregivers. Drawing from the theoretical framework for this study, social well-being of Keyes (1998)) and subjective well-being of Cheng and Lam (2010), demographic factors such as sex and marital status are correlates and predictors of well-being in that they determine individual access to good things of life that bring life satisfaction. Men are placed in an advantageous position in the stratification hierarchy where they are the head to make provision for the rest of the family. Men are expected to go out and work and make money while women are to stay back at home and play the domestic role of taking care of the young and the old members of the family. This role denies women economic power that can enhance their psycho-social well- being. Their economic powerlessness, traditional role as caregiver and the presence of a child with disability in the home that requires additional care, places a great burden on women that usually give women negative outcomes. Being married also connotes that burden of care can be shared among the partners which could reduce the burden.

Married caregivers are more likely to have positive well- being than both single and divorced caregivers in that the latter are without partners with whom they could share responsibility of care with. Their lack of partners and the additional care responsibility placed on them by their children with disability pose as stressors that bring about their poor psycho-social well-being. This view is in agreement with Yee and Schulz (2000) who stated that female caregivers experience excess psychiatric morbidity attributed to caregiving and those women are at greater risk for psychiatric morbidity than men. Al-Kuwari (2007) concluded in support of these findings that educating mothers who care for a disabled child has a protective effect on developing psychiatric morbidity.

In a similar view, Roth et al. (2007) in corroborating this study stated that low psycho-social well-being is associated with lower perceived caregiver availability of being female, white, or unmarried, living alone, being older than 85, and having worse self-rated health, whereas white men showed the largest differential. Kersh, Hedvat, Hauser-Cram and Warfield (2006) confirmed in agreement with the findings that for both mothers and fathers, greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socio-economic status, child characteristics and social support. Marital quality also added significant unique variance for mothers but not for fathers, whereas, fathers' greater social support predicted increased parenting efficacy. They concluded that marital relationship to parental well-being is very important to consider in their psycho-social well-being.

The present findings are

upheld by Navaie-Waliser, Spriggs and Feldman, (2002) who concluded that informal caregivers, particularly women, are under considerable stress to provide a large volume of care with little support from formal caregivers. Goldscheider and Desiree (1999) also in confirmation of these findings stated that gender role norms are keys to caregivers' selection; the intimacy inherent in the care giving role renders an emotionally close marriage an important criterion to the selection of spouse as caregiver. Moreover, gender interacts with marital status to influence the composition of care giving networks. Barrett and Lynch (1999) also in contrast to the findings in this study concluded that widowed and people who never married have helping networks that are larger than those of married people. This may be attributed to sympathetic feelings expressed to them by close associates as a result of their loneliness. Young and Kahana (1989) also agreed that women, non-spousal caregivers, and daughters, in particular, experienced the most severe after effects. Also, in agreement with this study Wu and DeMaris (1996), uphold that family-based strains and economic hardship are significant predictors of higher distress in women.

A study done by Thoits (1992) corroborates this study that identity hierarchies of married and divorced men and women were remarkably similar. Psychological impacts of identities depend on their combinations, and differently by gender. The authors concluded that psychological well-being does not depend on the salience of particular identities that individuals hold. Abbeduto, Seltzer, Shattuck, Krauss, Orsmond and Murphy (2004), also in agreement with the present study, confirm that psychological well-being of mothers raising a child with a developmental disability varies with the nature of the disability. This is consistent with the notion that some parents have a genetic vulnerability for less than optimal outcomes and that this vulnerability is magnified by the challenges of raising a son or daughter with special needs.

It is pertinent that social support and socio-economic factors could determine the psycho-social well-being of informal caregivers but it is of important also to look into more other factors which could also be relevant in the determination of psycho-social well-being of informal caregivers of children with disability in the south-west of Nigeria.

# CHAPTER SEVEN

# SUMMARY OF FINDINGS, CONCLUSION, RECOMMENDATIONS

## 7.1 Introduction

This chapter deals with the summary of major findings, conclusions, recommendations, suggestions for further research, policy implications and limitations of study.

## 7.2 Summary

This study focused on determinants of psycho-social well-being of informal caregivers of physically challenged children in south-western Nigeria. The research employed ex-post facto design which involved a sample of 812 selected through multi stage sampling technique and on whom questionnaires were administered. Respective respondents answered four sets of questionnaires on demographic characteristics, social support, satisfaction level of social support received and psycho-social well-being. Multiple regressions, one way Anova, Chi-square, percentages and frequency counts were used to analyze the responses of the respondents. This section therefore, presents in summary the major findings

Social support has significant influence on the psycho-social well-being of informal care givers of physically challenged children. The impact of social support in determining the psycho-social well-being of informal caregivers of physically challenged children revealed by the study was 35.1%. This shows that social support is a major factor in determining psycho-social well-being of informal caregivers of children with disabilities. Social support and satisfaction level of social support received by the informal caregivers had significant influence on the psycho-social well-being of informal caregivers. The implication of this is that support received by the caregivers is adequate and this increases their satisfaction level which also enhances positive psycho-social well-being of the caregivers.

The study also revealed that occupation had significant influence on the psycho-social well-being of informal caregivers of physically challenged children. The impact of occupation in determining the psycho-social well-being of informal caregivers of physically challenged children is F (1, 808) = 31.58, $p < 0.05$. Occupational status of caregivers in this study is also found to be a major correlate in the determination of well-being of caregivers. Informal caregivers who were self-employed had the highest psycho-social well-being among the various occupational statuses. This may be due to the fact that self-employed people have more time to themselves to take care of their children with disabilities than those in paid jobs who may have to juggle between caregiving and work.

Family income had significant impact on the psycho-social well-being of informal care givers of physically challenged children. The impact of family income in determining the psycho-social well-being of informal caregivers of physically challenged children revealed by the study was F (1, 808) = 19.24, $p < 0.05$. The meaning of this is that income is a major factor contributing to the well-being of informal caregivers. Income is essential in meeting various needs of the caregivers as well as the needs of their children with disabilities. Such caregivers' needs include housing, food, health and informational need.

Educational level had significant impact on the psycho-social well-being of informal care givers of physically challenged children. The impact of educational level in determining the psycho-social well-being of informal caregivers of physically challenged children revealed by the study was F (1, 808) = 13.49, $p < 0.05$. Educational level of caregivers is also very important in their well-being. The level of education determines their level of awareness about the implication of caregiving to their health and their informational seeking ability about their children with disabilities. Caregiver with high level of education tends to take their health seriously and find it easier to access information more that those with low level education.

Sex had significant influence on the psycho-social well-being of informal care givers of physically challenged children. The influence of sex in determining the psycho-social well-being of informal caregivers of physically challenged children revealed by the study was $x^2 = 4.247$, df = 1, $P< .05$. The implication of this is that being male or female is also a contributing factor in caregivers' well-being. Men tends to have positive psycho-social well-being than women and this is because men tend to feel less concerned about issue of disability at home than women. Women carry more of the burden of caregiving at home and this tends to impact on their total well-being.

Marital status had significant impact on the psycho-social well-being of informal care givers of physically challenged children. The marital status in determining the psycho-social well-being of informal caregivers of physically challenged children revealed by the study was $x^{2=}7.366$, df = 2, $P< .05$. The findings show that married caregiver has a better psychosocial well-being than both single and divorced. The availability of a partner to share burden of caregiving with could have placed the married in a better position of well-being than their non-married caregivers.

## 7.3 Conclusion

The study aimed to investigate the determinant of psycho-social well-being of informal caregivers of physically challenged children in south-west Nigeria. The study has brought together the contributions of social support and socio-economic status to the overall well-being of informal caregivers. Different supports from different sources were measured and their satisfaction level on caregivers. The impact of socio-economic status such as income, occupational status, educational level, gender and marital status were also measured to know their contributions to caregivers' well-being. Informal caregivers are vulnerable to poor well-being due to the high level of stress that is involved in caring for a child with physical disability. Many caregivers themselves have poor health and getting involved in stressful activity such as caregiving can be very dangerous to their overall psycho-social well-being. In a society like Nigeria where there are no respite services for informal caregivers and institutionalization is the only form of rehabilitation for physically challenged children, the overall psycho-social well-being of these caregivers and their children is put into jeopardy.

The literature and the findings of this study have demonstrated the impact of social support and socio-economic status in the psycho-social well-being of informal caregivers of children with disabilities. The results obtained from this study demonstrate the significant positive association between social support, socio-economic factors (occupation, family income, educational level, gender and marital status) and psycho-social well-being of informal caregivers. The results also reveal that social support and satisfaction combine together significantly impacts on the psycho-social well-being of informal caregivers of physically challenged children. The results also demonstrated that socio-economic factors were significant important predictors of psycho-social well-being of informal caregivers of physically challenged children.

Further analysis revealed that differences exist between marital statuses and the sexes with regards to the psycho-social well-being. Women are far more likely than men to assume the role of unpaid caregiver in family due to the fact that women have been ascribed the traditionally role of caregiving in the home. This role is more likely to expose them to some psychological factors such as anxiety, depression, role conflict etc which may impact on their psycho-social well-being. The fact that social support and socio- economic factors predict psycho-social well-being of informal caregivers means that they are all equally important as probable determinants of psycho-social well-being of informal caregivers of physically challenged children.

The conclusions for this study are drawn from the findings of the study which include the following:

### 7.3.1 Social support from different sources is very essential to caregiver's psycho-social well-being.

The literature and the findings of this study have considerably shown the contributions of social support to well-being of informal caregivers of children with disabilities. The findings show that caregivers' need of support is very important and that not just any support but adequate support that leads to satisfaction level. Caregivers received support from various sources that were either helpful or not. Support from social groups/ clubs and early intervention were the highest while other sources followed them. The implication of this is that supports from various sources have their own contribution towards ensuring caregivers' well-being. While some supports are found not to be all that helpful, caregivers expressed satisfaction in them.

### 7.3.2 Adequate and satisfactory social support is required for psycho-social well-being of caregivers of children with disability.

Caregivers' needs are many and diverse. Their needs include emotional, financial, health, knowledge and education and any support that does not tilt towards meeting these needs may be inadequate and unsatisfactory. The findings reveal that the highest level of satisfaction from support comes from spouse or partner's friend and followed by other groups. Informal caregivers need to identify and strengthen their support based sources through effective close ties and adequate social network through which their overall psycho-social well-being can be enhanced.

### 7.3.3 Caregivers need financial assistance

Findings show that many caregivers belong to low socio-economic status and this is due to the fact that the majority of them have low educational qualification and belong to lowly rated occupation in the society. Findings reveal further that the majority of the caregivers are self-employed, traders and farmers. These economic activities can only generate little income for them. Many of them may also have to juggle between caregiving and their work which may not ensure maximum benefits from their business. Financial assistance from government can help them solve some of their health, informational and other needs problems. A good example is the grant for physically challenged people in South Africa which the South Africa government approved for all categories of people living with disabilities. In Nigeria such grants can be given to caregivers of children with disabilities who can effectively utilize them for their own and their children's well-being.

### 7.3.4 Psycho-social well-being of informal caregivers is generally satisfactory

The findings reveal that many caregivers score high on the well-being table. This is as a result of social support from different sources that assisted in their caregiving role. More important is that the support received is very satisfactory in that it is adequate and met the needs of the caregivers. Despite the fact that some supports received from some sources are not all that helpful, many caregivers still find them satisfactory. This may be due to the fact that any support received by them is never seen as waste and it has its own contribution towards their overall well-being.

Furthermore, the fact that both gender and marital status predict psycho-social well-being of informal caregivers, women and married couples with children with disabilities should be assisted in the area of coping with the challenges of caregiving so as to promote their psycho-social well-being.

## 7.4 Recommendations

The study warranted some recommendations which are subject to consideration on the part of the three tiers of government (local, state and national), policy makers and other stakeholders in the field of caregiving and disability.

1. There is need for deinstitutionalization of children with disability in special schools in Nigeria so as to comply with global trends of ensuring social inclusion for children with disabilities and shift to home care management for children with disability. This also becomes imperative in the light of the fact that government, as a result of inadequate funding, cannot ensure the well-being of these children through institutionalization.

2. There is need to mobilize parents of disabled children so that they form support groups to help each other. Parents supporting each other in their communities would be ideal to buffer the effect of caregiving on the parents. Also tied to the issue of support groups is the issue of skills. Some parents need skills on how to manage and care for their children with disabilities. This support group could be a good avenue where parents could acquire the required skills.

3. There is need for social mobilization targeted at fathers. In the study, fathers featured badly as being negative to disability. Yet fathers only come into the scene of the child with disabilities after the effect.

4. Many parents of children with disabilities need to be educated on the importance of taking care of their health through stress management skills which will ensure their well-being.

5. Parents of children with disabilities need to be mobilised and empowered to be able to demand support services from government.

6. Federal, state and local governments should support parents of children with disabilities by assisting them in the area of procurement of support devices and equipment that children with disabilities used such as wheelchairs, hearing aids, special boots, clutches through an effective government policy. This becomes important as many caregivers belong to low income groups which place them in a disadvantaged position to help their children.

7. Nigeria government needs to provide and improve on the present available social welfare services for both the caregivers and their children. Caregivers of children with disability's well-being are fundamental to the well-being of their children with disability. Children with disabilities are very expensive to manage and yet the majority of the care givers are poor.

## 7.5 Implication of findings for policy

Informal caregivers of physically challenged children are members of family of children with disability and for effectiveness of policies related to them, those psycho-social factors that determine their psycho-social well-being should be taking into cognizance. The findings of this study provide insight into formulation of framework that has to do with dealing with their psycho-social well-being.

In Nigeria there is no official documentation on care giving like the developed world where documentation exists on care giving activities. Thus this presents policy formulation problems i.e. what to provide, for whom to provide and how to provide. Lack of documentation prevents all the tiers of government from making adequate and effective policy on care giving or caregivers activity. The country's model of care giving and social welfare is still at its base level and based on the pre-colonial social welfare system. As such, informal caregivers in Nigeria do not have decision making powers because there were no varieties of support which they can draw on. Without informal caregivers, children with disabilities may not receive quality care in many low-income countries like Nigeria. Family caregivers remain the main caregivers of children with disabilities in community based rehabilitation. Yet many of these caregivers exist without any form of support to assist them in performing their responsibilities (Sen & Yurtsever, 2007).

In promoting health of community based resource personnel, there is need for strategies to support both caregivers and recipients putting into cognizance the inability of government to provide quality support through institutionalization of these children. An appropriate policy framework must ensure that caregiver's health is ensured through an intervention programme that covers the four domain definition of health such as physical, social, mental and spiritual well-being. Moreover, the needs of the caregivers should be put into consideration as they are the community resources for caregiving. Caregiver's needs include finance which is very important in maintaining a child with disabilities (Sandy, Kgole & Mavundla, 2013). Most caregivers belong to low-income groups which place them in a disadvantaged position. Some caregivers are without jobs as a result of giving 24 hours of care to their disabled children. Financial assistance is needed so that they can be able to provide for food, clothing, drugs, and for educational needs of their children. Close to this are education and training about various types of disabilities and how they can help their children with disability. Many informal caregivers lack knowledge of diseases or clinical courses such as knowledge about benefits of exercise, knowledge of services and other clinical aspects of caregiving activities that include measures of caregiver skills or competence, problem-solving ability, adherence to care guidelines and decision-making skills (Al-Krenawi, Graham & Gharaibeh, 2011).

However, this lack of knowledge has been attributed to source of anxiety and depression among caregivers (Järnsted, Kaivolainen, Laakso & Salanko-Vuorela, 2009). Adequate knowledge about disability facilitates understanding of their own need and that of their children. Supervision in terms of professionals who need to do home visitation so as to oversee caregivers performing their duties and probably assist if need be is also of importance. The need for partnership between the health professionals such as psychologists, nurses, and social workers and caregivers and recipients cannot be overemphasised. Quality care depends largely on this partnership as it enables caregiver's access to information about illness and treatment of their children with disability. It also removes frustration experience by caregivers as a result of lack of information about available services for their children. Designing a good policy framework also involves measuring both quantity and quality of care provided by caregivers. An understanding of these two terms gives a detailed explanation of the amount of care being provided and at what expense the care is been provided. This is important because the quality of care is directly related to caregiver's outcomes such as psychological health; physical health; utilization; and economic status and care recipient outcomes. Recipient outcomes may include disease management skills such as physically challenged children's efforts to care for themselves, social functioning (e.g., family functioning), and physical health and their health care utilization and economic status.

Governmental policy support without adequate record and data from which the government can draw from, makes it impossible for government to create respite or policy programme for informal caregiver. This is because there is no statistical number of informal caregiver carrying out informal care and as such, a way forward is to create a data base for informal caregivers who have their children institutionalized and those who are not 'towards improving the psycho-social wellbeing of caregivers.

Lack of an organized policy framework for designing and assessment of programmes especially programmes designed for caregivers and the recipients has hampered effective practice in Nigeria. As this study looks into the well-being of caregivers of physically challenged children, there is need to prepare caregivers for the challenges they face on a daily basis and also to maximize outcomes for both caregivers and recipients. There is need for creation and standardization of caregiver programmes or policies mandated at national, state, or local levels. To achieve this there is need for more information on the activities of caregiving in Nigeria. Evaluating measures of inputs into the caregiving process, that is all behaviour or tasks that are performed as a requirement of being a caregiver of a child with disability or dependent adult helps provide signals about the specific mechanisms that were affected by an intervention, which can be helpful when outcomes do not change (Reetta, 2012). As caregiver and care recipient outcomes affect each other the need for developing a policy framework for dealing with caregivers in Nigeria is long overdue. A good framework will put into consideration the following factors:

(1) Caregiver and care recipient baseline characteristics such as demographic characteristics, health status, economic status, health insurance, relationship type, and cultural norms.

(2) Caregiving activities which refer to clinical skills and knowledge, psychological skills, support seeking skills.

(3) Caregiver outcomes in the form of psychological health, physical health, health care utilization such as primary or specialty physician care, and economic status; and

(4) Care recipient outcomes in the form of disease management tasks, psychological health, physical health, health care utilization such as community-based or institutional long-term care, respite care, or primary physician care, and economic status.

Informal caregivers in Nigeria have no options than to accept the only available form of support which is the institutionalization of their disabled children, while in developed countries there are varieties of support in the form of respite homes for caregivers who decided to take care of their physically challenged children. This is because they prefer the comfort of staying in their own home or simply due to the immense financial burden that long-term facility placement can have on the family. An effective governmental policy is very essential so as to bring together federal, state, and local resources and funding streams to help support, expand and streamline the delivery of planned and emergency respite services. Furthermore, to provide recruitment and training of respite workers as well as caregiver training and empowerment. Provision of varieties of support to informal caregivers, also brings about options of support to caregivers. This is important as it helps to maintain physically challenged children in their homes for longer, reducing the need for institutionalization thereby contributing to reduced government costs on long term institutionalization.

The first policy implication has to do with the type and adequacy of the care support given. Literature has identified a paradox in which supportive services designed for children with developmental disabilities at times are in conflict with the interests of informal caregivers and other family members (Rosenau, 2000). Informal caregivers also face obstacles of carrying out activities that will preserve their own well-being and that of other family members while meeting the needs of a child with disabilities. Many informal caregivers would prefer social support that gives them decision-making power, flexibility, privacy and allow them to choose to accept or reject such support without unduly infringing on others. Informal caregivers also face obstacles to preserve their own well-being and that of other family members while meeting the needs of a child with disabilities. One such need is accepting respite from people. The nature and type of respite and how it is offered needs to be re-examined.

There is need for formal institutions and government to provide special programmes that offer respite and support to the informal caregivers. Parents of children with severe disabilities need options and information. Clear information that includes all of the rules about the waiver programmes should be available to caregivers not only the ones who ask. Time taken to perform caregiving responsibilities is time away from a person's own family responsibilities, social activities and personal relationships, all of which may add to a caregiver's emotional stress, sense of isolation, and feelings of being overwhelmed. Caregivers may miss either full or part days of work due to unpaid caregiving duties or may not accept promotions which would require increased time commitments at the paid workplace. Some may opt for part-time positions to balance work with care responsibilities. Thus individuals or groups giving support to informal caregivers may need to consult and counsel caregivers in order to understand their special needs. Unlike professionals who provide similar care in institutions, informal caregivers may not receive regular breaks from care giving. For example offering some token amount to an informal care giver may not have the same effect as offering such services such as babysitting, providing logistics and taking time -off to allow the care giver attend to important issues in their career or economic activities. Thus institution and government need to provide meaningful supports. Forms of relief, such as respite care, is one form of offering a short break from caregiving, and such relief is frequently cited as an unmet need by such informal caregivers (MaceDonald & Callery, 2007). Government must develop a thoughtful and thorough approach to determining the services that best meet the needs of caregivers (Talley & Crews, 2007). Programme, services and interventions that are shown to improve the life of caregivers are needed.

Literature has identified some support that could be offered to caregivers but it is not a size fit - all kind of solution in all cases. They include strengthening the capacity of families, respite care, family networking, counselling and training. Strengthening the capacity of families has become the emphasis of a number of programmes designed to support the relatives and caregivers of the seriously disabled. The goals of supportive programmes are to strengthen the capacity of families to care for the disabled as well as to improve the quality of life for caregivers (Heller, et al., 1999).

Respite services can be provided in two distinct ways; formal caregiving, provided by non-profit or for-profit agencies to give caregivers a short break from caregiving responsibilities. Informal respite care is care provided by relatives, family or friends who are not associated with any agency or organizational body to provide short term breaks to caregivers (Chan & Sigafoos, 2001; Damaini, et al. 2004). Counselling to individuals, groups or families, which might include medication management, help with transferring, and wound care or changing an intravenous line, making decisions or solving problems on behalf of the patient when necessary. Other areas where counselling may be useful include coping skills strategies that can help caregivers come to terms with their situation using psychological and practical strategies. Also including constructing a larger sense of the illness, praying for strength to keep going, reducing expectations, and reminding oneself that a care recipient's decline can be expected with aging. Self-efficacy, which includes task mastery, refers to confidence that one can perform a specified behaviour. Counselling offer often "stressed out" families an opportunity to deal with frustrations in an open and healthy manner. Counselling is also seen as a way to reduce potential health problems (Reetta, 2012).

Isolation adds to the burden of caregiving and often keeps families from sharing common problems and problem-solving techniques. Having opportunities for families to network with each other, via the internet or through face-to-face interactions, is shown to improve a sense of socialization and lessen the sense of isolation (Singer, et al., 2009). It can also help the caregivers in knowing outside resources that are available and whether these resources are available to the care recipients, how to secure and manage paid caregivers, when to involve other informal caregivers, and how to harness community resources (Reetta, 2012).

Training programs offer support in many different ways and the training can teach coping strategies, behavioural management, or employment training. Support for the impact of social support and socio-economic status on psycho-social wellbeing suggests the adoption of family centred approach in the Nigerian context. The overarching goal of the child welfare services system is to assure the long-term well-being of children, within their families whenever possible. However, the achievement of these objectives relies more on the informal caregiver than the formal caregivers in Nigeria. Unfortunately this study confirmed that the majority of the caregivers lack the necessary support and resources to achieve this feat. Faced with these conditions, many families need a broad array of services and supports to help them negotiate the challenges of family life and care adequately for their children. Viewed from the perspective of child protection, services for families fall into three major groups which are basic social services such as child care or health care services, family support and family preservation which is often referred to as "family centred". Out of these three, family centred approach one is of important because it responds to family needs and strengths.

Family centred approach is different from traditional approaches to childhood disability management, where the focus is on the child, and disability service providers are essentially the ones who make the key decisions on the type of services the child should receive. Essentially, family centred approach is based on the belief that the purpose of any work conducted with families who have a special needs child is to enhance the quality of life for the child and all members of the family. The guiding principles are the beliefs that each family should have the opportunity to decide their level of involvement in decision making for their child and that the involvement of family members should be supported and encouraged. However to adopt a family centred model of practice, government, non-governmental organizations and rehabilitation centres need to review the various aspects of the services offered. They also need to identify and address potential barriers that may impede the process. The outcome targeted in a family centred approach is focus on more than just the child's needs. A key premise of Family Centred Approach is that a special needs child achieves optimum function within a supportive family and community context, and that the child is affected (both positively and negatively) by the stress and coping abilities of other family members. Family-centred practice is a way of delivering services that recognize that each family is unique; recognizing that in most cases the family is the one constant factor in the life of a child. Through this approach experts must:

1. Identify and build on a family's existing strengths;
2. Recognize that the family's informal social support network is a primary resource for meeting the family's needs;
3. Target family-centred goals through supports and services; and
4. Emphasize and promote strengthening the parents' and family's ability to promote the child's development.

Finally, the individual or often the family must decide whether to accept the care giving role. This decision is influenced by many emotional factors but also includes an economic decision. Next, the working individual, if they decide to take on caregiving responsibilities, must then determine whether to remain in the labor force and how many hours per week they will devote to unpaid caregiving. The caregiver family must examine their current economic state and perhaps their multiple roles in the labour force. Most often it is the woman who must negotiate the possibility of maintaining or sacrificing her employment status. Non-governmental agencies and developed countries should do more in terms of lobbying the state labour movement to actively support informal caregiver in their role as job applicants, employees and bread winner. Informal care giving is central to long term care system, yet caregivers often make major sacrifices to help loved ones remain in their homes. A federal legislation in family caregiver support is needed now more than ever.

A national legislation is needed that:

1. Supports informal caregiver support programme to provide caregivers with information and assistance, counseling, support groups, respite, caregiver training and limited supplemental services.
2. Allow family informal caregiver to paid leave policies that increase financial support for workers providing essential care for family members.
3. Provide social security by recognizing the work informal caregivers who leave the workforce to provide full-time support and care for ill, disabled or family members.

## 7.6 Suggestions for further study

It is important that future researchers should pay attention on limitations of the present study and thus improve the generalibility of results. This study is valuable in that it took place in a developing country where caregiving has not received proper' attention. It is therefore absolutely necessary that the study be replicated in future research in other geo-political zone of Nigeria. There might be some other factors which are not included in this study that may contribute to caregivers' well-being. More importantly future research should use combination of qualitative and quantitative methodologies unlike the present study. This will ensure a deeper understanding of the subject under discussion through triangulation of research results. With triangulation research result could be more objective and reliable if different methods lead to the same result. Combination of methods has the potential of limiting errors and ensuring correctness of research result (Lammers & Badia, 2005). Finally, future research should look into other demographic factors like age, ethnicity, religious affiliation and work-family conflict as they could also play significant role in determination of informal caregiver's psycho-social well-being.

## 7.7 Limitations of the study

This study focused on the relationship between social support and psychosocial wellbeing, on the one hand, socio-economic factors and psychosocial wellbeing on the other among informal caregivers of physically challenged children in south-western Nigeria. It is important to note some of the limitations of this study. The study is cross-sectional survey in nature and as such assumption cannot be made at any direct causal-effect relationship between social support and psycho-social wellbeing, on the one hand, social-economic factors and psychosocial wellbeing on the other. Cross-sectional studies are observational in nature and are known as descriptive research, not causal or relational. Cross-sectional survey only assists investigators in giving support for the inferences of cause and effect. Cross-sectional survey is based on prevalent (existing) rather than incident (new) cases. The limitation of these cross sectional surveys is that they are confined to a specific point in time. That is, they provide us with a snapshot of a sample of a population at a single point in time. Since population characteristics constantly change over time, cross-sectional surveys for such situations do not reflect the actual situation.

The sample used for this study was from only one geo-political zone, that is, southwest Nigeria. Therefore it may not be quite justifiable to generalize the findings to other geopolitical zones in the entire country. Only self-administered questionnaires were used to gather data. This raises the possibility of common method variance. Common method variance refers to the amount of spurious covariance shared among variables because of the common method used in collecting data (Buckley et al., 1990). Common method variance has been a pervasively cited concern in organizational research because it clearly does affect observed correlations (Lammers & Badia, 2005).

Furthermore, non-availability of sufficient literature on informal caregiving in Nigeria is part of the limitation of study. Besides the researcher experienced a non-cooperative attitude of many of the informal caregivers as many of them demanded money before accepting to take part in the study. This is due largely to the erroneous belief of some of the caregivers that the researcher had collected money in the form of grant before embarking on the study.

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# APPENDICES

## Appendix 1 Questionnaire

**UNIVERSITY OF FORT HARE**
**DEPARTMENT OF SOCIAL WORK AND DEVELOPMENT**
**ALICE TOWN**
**SOUTH AFRICA**

**Dear Respondent,**

**This questionnaire is designed to investigate determinants of psycho-social well-being of informal caregivers of physically challenged children in southwest Nigeria.** The questionnaire is solely for research purpose alone. Thus your sincere and accurate response will be highly appreciated. Kindly read and provide answers to all the items listed below. You are assured of utmost confidentiality of all your responses.

### SECTION A

1. **Age:** ………………………….
2. **Sex:** Male [ ] Female [ ]
3. **Marital Status:** Married [ ] Single parent [ ] Divorced [ ] Widowed [ ]
4. **Educational Level :**
    - Did not attend any school [ ]
    - Primary school [ ]
    - Secondary school [ ]
    - Wasc/Neco [ ]
    - Grade two [ ]
    - Nce/Ond [ ]
    - Hnd/Bsc [ ]
    - Postgraduate { }
5. **Occupation :**
    - Professional [ ]
    - Civil Servant [ ]
    - Pensioner [ ]
    - Self employed [ ]
    - Full time house wife [ ]
    - Trading/Farming [ ]
    - Unemployed [ ]
6. **Family Income Per Month (in =N=)**

More than N 100,000 [ ]
N99,999 – 50,000 [ ]
N49,999 – 30,000 [ ]
N29,999 – 10,000 [ ]
N9,999 – 5,000 [ ]
N4,999 – 1,000 [ ]
Less thanN1,000 [ ]

## SECTION B

Instruction: For each of the following statements, tick ( √ ) the one out of the 5-point scale that best describes how the statement applies to you. The option that reflect the extent to do you experience . Respondents rate how much each of the items are true on a five point scale SD= Strongly Disagree, D = Disagree, U= undecided, A= Agree, SA = Strongly Agree

| **S/N** | | **Strongly Disagree** | **Disagree** | **undecided** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|---|
| 1. | When I look at the story of my life, I am pleased about how things have turned out. | 1 | 2 | 3 | 4 | 5 |
| 2. | I have not experienced many warm and trusting relationships with others. | 1 | 2 | 3 | 4 | 5 |
| 3. | I think it is important to have new experiences that challenge how you think about yourself and the world. | 1 | 2 | 3 | 4 | 5 |
| 4. | I tend to be influenced by people with strong opinions. | 1 | 2 | 3 | 4 | 5 |
| 5. | I judge myself by what I think is important, not by the values of what others think is important. | 1 | 2 | 3 | 4 | 5 |
| 6. | I have confidence in my own opinions, even if they are contrary to the general consensus. | 1 | 2 | 3 | 4 | 5 |
| 7. | When I think about it, I haven’t really improved much as a person over the years. | 1 | 2 | 3 | 4 | 5 |
| 8. | The demands of everyday life often get me down. | 1 | 2 | 3 | 4 | 5 |
| 9. | In general, I feel I am in charge of the situation in which I live. | 1 | 2 | 3 | 4 | 5 |
| 10. | I feel like I get a lot out of my friendships | 1 | 2 | 3 | 4 | 5 |
| 11. | Maintaining close relationships has been difficult and frustrating for me. | 1 | 2 | 3 | 4 | 5 |
| 12. | I have a sense of direction and purpose in life. | 1 | 2 | 3 | 4 | 5 |
| 13. | For me, life has been a continuous process of learning, changing and growth | 1 | 2 | 3 | 4 | 5 |
| 14. | I am quite good at managing the many responsibilities of | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | my daily life. | | | | | |
| 15. | Many days I wake up feeling discouraged about how I have lived my life. | 1 | 2 | 3 | 4 | 5 |
| 16. | In many ways I feel disappointed about my achievements in life. | 1 | 2 | 3 | 4 | 5 |
| 17. | I don’t have a good sense of what it is I am trying to accomplish in life. | 1 | 2 | 3 | 4 | 5 |
| 18. | I enjoy making plans for the future and working to make them a reality. | 1 | 2 | 3 | 4 | 5 |

## SECTION C

Listed below are people and groups that often times are helpful to members of a family raising a handicapped child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response the best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

| **How helpful has each of the following been to you in terms of raising your physically challenged child (ren)** | **Not Available** | **Not at All Helpful** | **Sometimes Helpful** | **Generally Helpful** | **Very Helpful** | **Extremely Helpful** |
|---|---|---|---|---|---|---|
| My parents | NA | 1 | 2 | 3 | 4 | 5 |
| My spouse or partner's parents | NA | 1 | 2 | 3 | 4 | 5 |
| My relatives/kin | NA | 1 | 2 | 3 | 4 | 5 |
| My spouse or partner's relatives/kin | NA | 1 | 2 | 3 | 4 | 5 |
| Spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| My friends | NA | 1 | 2 | 3 | 4 | 5 |
| My spouse or partner's friends | NA | 1 | 2 | 3 | 4 | 5 |
| My own children | NA | 1 | 2 | 3 | 4 | 5 |
| Other parents | NA | 1 | 2 | 3 | 4 | 5 |
| Co-workers | NA | 1 | 2 | 3 | 4 | 5 |
| Parent groups | NA | 1 | 2 | 3 | 4 | 5 |
| Social groups/clubs | NA | 1 | 2 | 3 | 4 | 5 |
| Church members/minister | NA | 1 | 2 | 3 | 4 | 5 |
| My family or child's physician | NA | 1 | 2 | 3 | 4 | 5 |
| Rehabilitation centre/school for handicapped | NA | 1 | 2 | 3 | 4 | 5 |