RELATIONSHIP BETWEEN BURDEN OF CARE AND QUALITY OF LIFE AMONG CAREGIVERS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS (ASD) IN NAKURU LEVEL FIVE HOSPITAL, NAKURU COUNTY

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DECLARATION

This research dessertation is my original work and has not been presented for a degree at any other university.

Signed ………………………………Date ………………………………

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H56/86138/2016

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This research dessertation has been submitted for examination with our approval as the University Supervisors.

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DEDICATION

I dedicate this dessertation to my family for the support they have provided so far.

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ABSTRACT

Background to the Study: Autistic Spectrum Disorders (ASDs) remain an important public health problem due to associated behavioral and developmental challenges faced by affected children. Most people with ASDs and other developmental disorders live in Low and Middle Income Countries (LMICs); where they cannot access or afford treatment. Unfortunately, most of the knowledge about these conditions is based on research done in high-income countries. These burdens can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities; and can lead to suicide at its worst.

Objectives of the Study: The main objective of the study was to establish the relationship between burden of care and quality of life among caregivers of children with ASD in the African setting as seen in Nakuru Level Five Hospital, Kenya.

Study Design and Site: The study used a descriptive cross-sectional design incorporating quantitative research methods. This study was conducted in Nakuru Level five Hospital. Nakuru Level five Hospital is currently the fourth largest government referral hospital in Kenya.

Study Participants: The study population included all caregivers of children diagnosed with ASD, attending child psychiatry clinic at the Nakuru Level five hospital, Nakuru County.

Findings: On the general state of their social life, the study established that it was poor [2.34± 0.563] while their family relationships was fair [2.74±0.608] [x^2=104.9, $p<0.05$] while leisure activities were poor [2.32±0.556] [x^2=41.3, $p<0.05$] and their ability to function in their daily lives was fair [2.59±0.58] [x^2=82.05, $p<0.05$]. On their sexual drive, interest in it or performance, the study found that it was fair [2.98±0.56] [x^2=37.53 $p<0.05$] and their economic status was poor [2.38±0.66] [x^2=59.63, $p<0.05$] as well as living/housing condition was not good [2.67±0.56] [x^2=100.97, $p<0.05$]. Their ability to get around physically was good [3.64, .524] as well as their vision in terms of ability to do their hobbies/work [3.57±.543] though their overall sense of wellbeing was fair [2.73±.549] [x^2=139.1, $p<0.05$]. The respondents agreed that their current financial position was adequate to look after the child living with ASD to some extent [1.91±.874] and they were worried to some extent on child's future financial situation [2.4±.494. assessing their concern that they were largely responsible to meet the ASD child financial need, the study established that the respondents were to some extent [2.4±.48] and the same response was obtained on the query that if their family's financial situation had worsened since the diagnosis of the child with ASD [2.49±.50] . the study established that respondents had support from their family help in caring for the child to some extent [2.1±.303, x^2=56.6, $p<0.05$] and they further asserted that the child living with ASD cause disturbances in the home to some extent [2.4±.5] and they were able to care for others in their family to some extent [2.33±.47].

Conclusion: The findings of this study suggest that caring for children with autism spectrum disorders can overwhelm their family members, similarly to families of children with other developmental disorders. Overall, the research concluded that the family burden of care was very high leading to poor quality of life.

Recommendation: There is need for a longitudinal study in order to obtain more data to assess the caregiving burden and collaboration among stakeholders to come up with policy to support ASD children in order to lessen the burden of caregiving.

LIST OF ABBREVIATION

ASD	Autistic Spectrum Disorders
CDC	US Centers for Disease Control and Prevention
ADDM	Autism and Developmental Disabilities Monitoring
ASK	ASD Society of Kenya
APA	American Psychiatric Association
BAS	Burden Assesment Schedule
ESAT	Early Screening for Autistic Traits
KNH	Kenyatta National Hospital
LMIC	Low and Middle Income Countries
NACOSTI	National Commission for Science, Technology and Innovation
QoL	Quality of life
UoN	University of Nairobi
WHO	World Health Organization

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CHAPTER ONE

INTRODUCTION

1.1 Background Information

Autistic Spectrum Disorders (ASDs) remain an important public health problem due to associated behavioral and developmental challenges faced by affected children. These disorders belongs to a group of neurocognitive disorders which are characterized by signs and symptoms of decline in mental ability severe enough to interfere with independence and daily life functioning (American Psychiatric Assocciation, 2013). Moreover, there exists deficits in social interaction and communication which include response to social interactions as well as stereotyped behavioral mannerisms. These multiple developmental issues affect care givers negatively, increasing burden of care.

The burden of caregiving can be defined as a caregiver's personal suffering as a consequence of illness of a family member or friend (Kronenberg, Goossens, van Busschbach, van Achterberg & van den Brink, 2016). These caregivers' burden or strains were earlier defined as 'physical, psychological or emotional, social and financial problems that are experienced by caregivers' (George & Gwether, 1986). Caregiver burden is currently referred to as the problems and challenges confronting caregivers such as the symptoms of the child's illness, disturbed family relationships, limitations of the professional health care system, social stigma, economic/financial losses, decreased health of other family members and decreased social networks and support (Kronenberg, Goossens, van Busschbach, van Achterberg, & van den Brink, 2016). It has been found out that if the experienced burden exceeds the supportive powers of a caregiver, caregivers may develop physical, social and psychological exhaustion that eventually lead to poor quality of life (Akol et al., 2015).

At the family level, high burden levels could predispose to depression, substance abuse and anxiety in caregivers of children with ASD (Gandhi & Thennarasu, 2012). Family caregivers often manifest depressed mood which may affect their ability to perform desirable health-maintenance or self-care behaviors in response to symptoms (Shah, Wadoo & Latoo, 2010). This according to Koujalgi and Nayak (2016), may adversely affect their health and self–well-being. Consequently, the burden of family caregiving also causes family conflict and financial problem in individual, family, health care system, distorts the entire family functioning and the families under great stress would give up and reject the child with ASD who would become an outcast socially (Sintayehu, Mulat, Yohannis, Adera, & Fekade, 2015). Burden of caregiving is enormous and therefore a cause of poor quality of life among families living with ASD child. This study is designed to assess the relationship between burden of caregiver and quality of life.

1.1.1 Background to the Study

Globally, autism is estimated to affect 24.8 million people as of 2015 (GBD 2015 Disease and Injury Incidence and Prevalence, Collaborators, 2016). In the 2000s, the number of people affected was estimated at 1–2 per 1,000 people worldwide (Newschaffer et al., 2007). In the developed countries, about 1.5% of children are diagnosed with ASD as of 2017, Lyall et al., (2017) a more than doubling from 1 in 150 in 2000 in the United States (CDC, 2014). It occurs four to five times more often in boys than girls (CDC, 2014). The number of people diagnosed has increased dramatically since the 1960s, partly due to changes in diagnostic practice; the question of whether actual rates have increased is unresolved (Newschaffer et al., 2007). Worldwide, people with ASDs and other developmental disorders represent a vulnerable group (World Health Organization, 2013). They are often subject to stigma and discrimination, including unjust deprivation of health and education services, and opportunities to engage and participate in their communities. However globally, access to services and support for people with developmental disorders is inadequate, and families of those affected often carry substantial emotional, economic and care burdens (World Health Organization, 2013).

Most people with ASDs and other developmental disorders unfortunately live in low- and middle-income countries (LMICs); where they cannot access or afford treatment, most of the knowledge about these conditions is based on research done in high-income countries. The actual burden of ASD in sub-Saharan Africa is currently underestimated since prevalence of ASD in the African region and other low or middle income regions is still unclear as good-quality prevalence estimates on ASDs are not available (World Health Organization, 2013; Bakare & Munir, 2011). In Kenya, ASD has recently been recognized and therefore there is unclear data regarding its prevalence (Mutua & Dimiter, 2001).

Dimensions of the burden attributed to compromised mental health issues and mental disorders in children with ASD are not only enormous, but more evident and quantifiable (World Health Organization, 2003). According to Bonis (2016), parents of children with ASDs often experience a higher level of stress than parents of children without autistic disabilities, regardless of categories of disabilities. Caregivers play a vital role in material and emotional support to sick or disabled family members including those with mental disorders (Shah, Wadoo & Latoo, 2010). Amirkhanyan and Wolf (2013), concur that caregivers provide assistance with activities of daily living, emotional support to the patient, and dealing with incontinence, feeding, and mobility (Amirkhanyan & Wolf, 2013). These additional activities of caregiving increase stress, time and in turn cause poor quality of life to the family of a child with ASD. The entire aspect of caregiving for children with ASD impact negatively on the caregivers' life causing poor quality of life (World Health Organization, 2003)

1.2 Statement of the Problem

Kenya is ranked as a low- and middle-income country, with a very under-resourced mental health care system (Mbugua, Kuria & Ndetei, 2011). There are 92 psychiatrists nation-wide and most of them reside in or near major cities making it hard for majority of Kenyans to access mental health services according to the (Anon, 2018). This poses a very heavy load on care givers of children with ASD because of inaccessibility, unaffordability and inadequate services. ASD is a major depressive disorder and often has an onset and is associated with substantial psychosocial impairment on the caregiver as well as the entire community (Gladstone, Beardslee & O'Connor, 2011).

These burdens can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities; and can lead to suicide at its worst (Goodkind et al., 2015). Therefore the family living with children with ASD live a poor quality of life. Previous studies have focused on prevalence of depression among caregivers without keenly analyzing the care giving burden and quality of life in the African setting. In Kenya little is known about cost of care, lack of specialized support and facilities for children living with ASD. This enormous gap in caregiving increases burden of caregiving and emerges as a challenge faced by primary caregivers. The study is in a small section of Kenya, Nakuru County Level Five Hospital, and assessed care giving burden and quality of life attributed to caregivers of children with ASD.

1.3 Purpose of this Study

The purpose of this study was to assess the burden of caregiving and quality of life among caregivers of children living with ASD in Nakuru Level Five hospital, Nakuru County.

1.4 Research Questions

This study sought to answer the following questions;

i. What is the level of burden of care in families of children ASD and Quality of life?
ii. What is the distinction between objective and subjective dimensions of burden of care in children with ASD?
iii. What are the indicators of children living with ASD that are associated with burden of care and poor quality of life of caregivers of children with ASD in Nakuru Level Five Hospital?
iv. What is the relationship between burden of care and quality of life among caregivers of children with ASD?

1.5 Objectives of the Study

1.5.1 Broad Objectives

The main objective of this study was to establish the relationship between burden of care and Quality of life among caregivers of children with ASD in the African setting as seen in Nakuru Level Five Hospital, Kenya.

1.5.2 Specific Objectives

i. To establish the level of burden of care among caregivers of ASD and Quality of life.

ii. To assess the dimensions of burden of care and Quality of life of caregivers of ASD children.

iii. To determine indicators of children living with ASD which are associated with burden of care and poor quality of life of caregivers of children with ASD in Nakuru Level Five Hospital.

iv. To assess the relationship between burden of care and Quality of life among caregivers of children living with ASD.

1.6 Hypotheses of the Study

H0: There is no relationship between burden of care and quality of life among caregivers of children with Autistic Spectrum Disorders

H1: There is relationship between burden of care and quality of life among caregivers of children with Autistic Spectrum Disorders.

1.7 Summary

This chapter gave an overview of the research paper; it introduced the research, giving a background of the context. It also stated the problem that was being researched and highlighted areas where the research was of benefit to several stakeholders. The key terms were defined in this chapter and the chapter also covered the justification as to why this study was to be done, the scope of the study and the assumptions that had been made to this research.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter discussed the information from the available literature in the same field of study. The specific areas covered here include an empirical review, conceptual and theoretical framework. The literature review looked at available research on burden of care and quality of life among caregivers of children with ASD. There was a deliberate focus on caregivers of children with ASD who were the core subjects of the study. A review of literature to establish level of burden of care in ASD with a focus on objective and subjective dimensions of burden of care associated with ASD and Quality of life of caregivers of ASD children was done. A further literature search looked at indicators of people living with ASD which are associated with burden of care and poor quality of life of caregivers of children with ASD.

ASD is a pervasive developmental disorder in children characterized with deficits in both verbal and non-verbal communication, social interaction, restricted interests and behaviors. Much of the literature review was carried out from a Western perspective though globally there exists high prevalence of ASD (Mann, 2013). Moreover, there exists burden of care and poor quality of life of caregivers of children with ASD. This chapter presented a review of literature done on the areas under study.

While looking at the magnitude of caregivers' burden, Alzahrani, Fallata, Alabdulwahab, Alsafi and Bashawri (2017), contend that it is potentially augmented by factors related to the patients and households. Other scholars argue that caregiver burden can cause empty nest syndrome where the caregiver faces grief; loss of hope, dreams and expectations, and even despair in cases of relapse (Kronenberg, Goossens, van Busschbach, van Achterberg & van den Brink, 2016). It is therefore evident that significant levels of stress among caregivers can affect their overall quality of life including work, socializing and relationships (Shah, Wadoo & Latoo, 2010). As a result of the high burden and responsibilities vested upon caregivers, it was reported that caregivers experience poorer self-reported health, engaged in less health promotion actions than non-caregivers, and reported lower life satisfaction (Amirkhanyan & Wolf, 2013).

Socio demographic characteristics including caregiver age, gender, religiosity, marital status, and family income influenced the burden among caregivers (Oliveira et al., 2015). The burden according to Shah, Wadoo & Latoo (2010), is 50% higher for females than males especially mothers who typically struggle with feelings of incompetence, low self-efficacy, and a reduced ability for self-help (Bonis, 2016). Other factors that were thought to significantly influence caregiver burden included health status, ethnic and cultural affiliation (Shah, Wadoo & Latoo, 2010). Some communities' believed that mental illness is caused by supernatural powers and as a result, they tended to accept the condition and move on while others associated mental illness with presence of psychopathy. While looking at such affiliations, Estes et al., (2013) portend that closer relationship between caregivers and the person with mental disorders likely increased the burden on the caregiver. Provision of social and material support from family members and surrounding community influenced the burden among caregivers of people whose children were living with ASD (Oliveira et al., 2015).

The diagnosis of ASD usually occurred in childhood therefore, caring for a child with ASD was a lifelong undertaking as posited by (Seltzer, Shattuck, Abbeduto & Greenberg, 2004). Many children living with ASD needed services and support as they grew into adolescence and adulthood. About 1 in 68 children were identified with ASD according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network and ASD was reported to occur in all racial, ethnic, and socioeconomic groups (Christensen, Baio, Braun & et al, 2012). ASDs were characterized with displaying aggressive behavior that was likely to increase caregiver burden than those not displaying aggressive behavior (Fiske, 2009). Having more than one child with Autistic Spectrum Disorder multiplies challenging issues, limits family opportunities and is a risk factor for depression in parents who serve as caregiver (Bonis, 2016). In many cases, it was observed that factors including behavioral disturbances, functional impairments, physical impairments, cognitive impairments, and frequent attempted suicide were related to psychological distress in caregivers (Shah, Wadoo & Latoo, 2010). The duration of the illness and age of mentally disabled person were thought to be predominant determinants of caregiving burden (Byford, Barber, Fiander, Marshall & Green, 2011; Harvey, Burns, Fahy, Manley & Tattan, 2001).

A study on barriers encountered in diagnosis, treatment and management of ASD in Kenya in 2017 found out that autism is a relatively new field, and there is little to no research on interventions, there is also a lack of institutional support (Kamau, 2017). This study established that there were only a handful of government schools that had integrated special needs educations programs and of those only few had any special education teachers. According to the report, there is no accurate census on the number of children living with ASD in Kenya. In accordance with the WHO methodology, ASD Society of Kenya (ASK) gives an estimate of 800,000 people living with ASD in Kenya (Kamau, 2017).

2.2 Empirical Review

2.2.1 Burden of Care in ASD

The entire process involved in caring for children with ASDs is not only challenging, but affects family life in a great deal. Caregivers of children with ASD provide assistance with activities of daily living, emotional support, and dealing with incontinence, feeding, and mobility (Amirkhanyan & Wolf, 2013). This places a heavy burden of caregivers because they must sacrifice their time to ensure the child is made comfortable. Additionally, caregivers are forced to wake up earlier than usual so that they completes the tasks they have to undertake relating to caregiving just before they embarks on the other family chores. According to the World Health Organization (2003), mental disorders in children impact negatively on their care givers and is thought to lead to poor work output at places of work as well as poor quality of life in general. Caregivers usually face unfamiliar and unpredictable situations which increase stress and anxiety due to behavioral problems of children who cannot be successfully managed on a consistent basis.

Caregiving burden has been associated with certain demographic and other caregiver characteristics that either directly or indirectly increase the burden of caregiving. The main causes of psychological stress have been conceptualized as adjustment to change, daily hassles, and role strains (Shah, Wadoo & Latoo, 2010). However, it is thought that personality factors are the most powerful predictors of caregivers' well-being, psychological distress and overall quality of life (Möller-Leimkühler & Wiesheu, 2012). Other scholars have found out that caregivers who experience feelings of powerlessness, lack of control, and unpreparedness have higher levels of depression hence greater burden (Shah, Wadoo & Latoo, 2010). Beyond the caregivers, it has been found out that psychological distress among other family members increases burden in care givers (Oshodi et al., 2012) and these affect negatively the quality of life.

Previous studies have demonstrated that meeting the high care demands of affected children requires much time, effort and patience. Therefore, the provision of such care often results in psychological distress, depression, anxiety and other mental or physical health problems among their parents (Khanna et al., 2011; Stuart & McGrew, 2009). Beyond the psychosocial factors, many parents face financial problems, given high out-of-pocket health care expenses, underemployment or employment loss (Bromley, Hare, Davison & Emerson, 2004; Kuhlthau, Kahn, Hill, Gnanasekaran & Ettner, 2010). Not surprisingly, caregiving often bring a lot of strain to parents of children with ASDs often feel strained by caregiving (Stuart & McGrew, 2009).

More recent studies provide similar views on the burden on caregivers of children with ASD. In their study, Arfat and Dhafer (2017), found out that caregivers' of children with ASD reported more negative impact and poor psychological wellbeing. They appeared to be at great risk for depression, stress, anxiety and distress; and many caregivers have managed to overcome the constant challenge by using their patience and take the consequences to adapt well in the face of adversity.

2.2.2 Objective and subjective dimensions of burden of care associated with ASD

According to Montgomery, Gonyea and Hoonyman (1985), objective burden of care is viewed as a violation and encroachment of the caregivers day to day lifestyle which directly affects amount of time spent with the ASD child, which in turn interferes with personal space, recreational and socialization activities. Equally subjective burden refers to the magnitude to which the burden of care impacts negatively on the caregivers' lifestyle directly related to stress and strain as a whole.

Studies done here depict that the ASD children were unable to relate and adapt to situations because of behavioral impairments evidenced, therefore this placed a lot of strains on the caregivers lifestyle possibly interfering with their day to day schedules (Renske Hoefmam, n.d.). These called for enormous sacrifice and energy to take care of these challenges related to caregiving and additionally interferes with quality of life. According to Bonis (2016), the significant level of stress lead to poor work output, socialization and relationships.

Recent studies described the magnitude of subjective and objective care burden for informal caregivers to patients with ASD (Flyckt, Fatouros-Bergman, & Koernig, 2015). Patients with apparent abnormal behavior showed to increase the subjective caregiver burden (Grandon, Jenaro & Lemos, 2008). Similarly, factors reported related to caregiver depression were children's behavior problems, early onset of autism, low functioning of patients, inadequate social support that caregivers received and caregivers suffering from co-morbidity or disability (Tarabek, 2011). However, caregiving burden may be influenced by cultural aspects and differences in family and societal structures in different counties. Furthermore, factors relating to caregiver burden were severity of patient's symptoms, number of life problems of caregiver and low level of support that caregivers received (Stuart & McGrew, 2009).

2.2.3 Indicators of people living with ASD which are associated with burden of Care and poor quality of life

The American Psychiatric Association (2000), considers impairments in communication and reciprocal social interaction and restricted and repetitive behaviors and interests as the core symptoms of autism. Questions about the interactions between family context and the developmental trajectory of autism are relatively understudied, especially during adolescence. Some level of research has tried to address issues related to how families adapt to having a child with autism, and how these adaptations and their consequences shift as the person with autism ages (Seltzer, Krauss, Orsmond & et al., 2001).

2.2.4 Relationship between burden of Care and quality of life of caregivers of children with ASD

Research by Lee, Harrington, Louie and Newschaffer (2008) pins out that a family with an Autistic child experiences compromised quality of life as a result of stereotyped behavioral depictions experienced in ASD therefore the family may not get involved in activities outside the home because they need to monitor the child closely. Research by (Macelo, n.d.), found out that mothers are the key figures who are compounded to multi task between domestic responsibilities and caregiving for their ASD children. Possibly this heightens up to sudden and gradual physical mental health disorders leading to alienation and depression in addition to financial disequilibrium, reduction in sexual drive and self-blame. Moreover, in families who have a child suffering from ASD, it is common for the family to experience challenges including escalating family conflicts leading to break ups further impacting negatively on caregiving thus poor quality of life.

A research done in Qatar states that there exists increasing need to shed light on Autism because of the high burden directly associated with care as well as the societal constraint at large (Nadir, 2008). ASD cannot be cured but the family at large can be counseled on adaptive functioning and the caregivers' quality of life enhanced. However, no research has been done investigating on quality of life of caregivers of children suffering from ASD.

2.3 Theoretical framework

The study was based on the Family Systems Theory. According to Kerry (1988), individuality and togetherness are the two counter balancing life forces that are reflected from the operation of the families' emotional system. This support system focuses on the development of emotional and social relationship individuals and families, and how these family systems respond and make adjustments in relation to arising issues. ASD is an example of a dysfunction that can bear a significant impact on a family system.

The family systems theory is viewed as a three-person system which comprises of the father-mother-child triangle though the pattern can often change. One parent is passive, distant, or weak and leaves the conflict between the other parent and the child. The child is the weaker one of the two and often loses the battle and therefore comes to expect the loss. If the passive parent ever decides to attack or challenge the aggressive parent the child will eventually learn how to take the outside position and play the parents against each other (Bowen, 1985).

This theory is a human behavior theory that views the family as an emotional unit. It uses systems thinking to describe the complex interactions within the unit. According to the theory if one person in the family changes their functioning than it can be predicted then there was reciprocal changes in the entire functioning in the family. Bowenian's family systems theory is based on the idea that the emotional system will affect most all human activity and it is the principal driving force in the development of clinical problems (The Bowen Center, 2009).

2.4 Conceptual framework

A conceptual framework is a representation of research variables and tries to display their relationship (Punch, 2005). Conceptual framework is a logically developed, described and elaborated network of interrelationships among the variables deemed to be integral to the dynamics being investigated, explains the theory underlying these relations, and describes the nature and direction of the relationships (Matoko J.M. et.al 2009). While according to Mugenda and Mugenda (1999) conceptual framework refers to a situation where a researcher conceptualizes the relationship between variables in the study and shows the relationship graphically or diagrammatically.

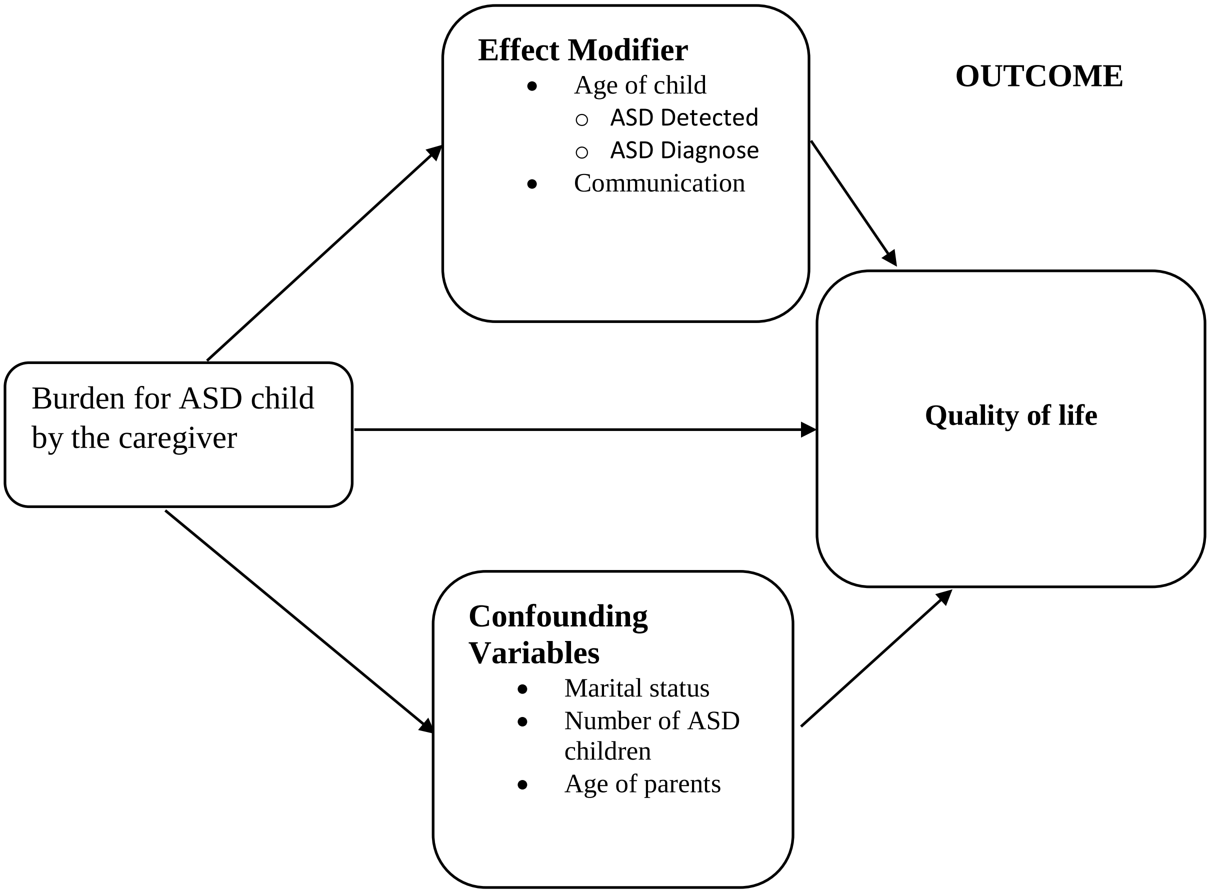

Figure 2.1: Conceptual framework
Source: Author [2018]

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the comprehensive methodology that this study followed in execution. Sections covered include the study design, target population, sample determination, sampling criteria, procedure of data collection, data management and analysis and ethical considerations.

3.2 Study design

The research design is a blueprint for conducting the research that specifies the procedures necessary to obtain the information needed to structure and solve the research problems. Research designs are also known as research strategies (Coldwell & Herbst, 2004). A good research design plans the research and seeks to explain how to find answers to research question and also explains how one will put the research strategy into action (Walsh & Wigens, 2003).

The study used a descriptive cross sectional design incorporating quantitative research methods. The design was appropriate since the researcher wished to test the degree of relationship between and among variables within a specific point in time (Best & Kahn, 2006).

3.3 Study site

This study was conducted in Nakuru Level five Hospital. Nakuru Level five Hospital is currently the fourth largest government referral hospital in Kenya in Nakuru County. The hospital was started as a military hospital in 1906 and has a total bed capacity of six hundred beds.

3.4 Study population

A population, also known as a “universe” refers to all the items in the field of inquiry (Kumar, 2008). In terms more direct to this research, a population can be defined as the entire group of individuals having a common characteristic (Mugenda & Mugenda, 2003). The target population refers to the population to which the researcher makes inferences to; this population should theoretically be countable, observable and exist within a specific time frame. The units of the target population must also be specified (Groves, Fowler, Couper, Lepkowski, Singer, & Tourangeau, 2009). The study population included all caregivers of children diagnosed with ASD, attending child psychiatry clinic at the Nakuru Level five hospital, Nakuru County.

3.5 Inclusion and exclusion criteria

3.5.1 Inclusion criteria

The study included;

1. Caregivers of children diagnosed with ASD attending child psychiatry clinic in Nakuru Level five Hospital;
2. Caregivers who have been caring for ASD children for over one year.
3. Caregivers who consented to participate in the study.

3.5.2 Exclusion criteria

The study excluded;

1. Caregivers who had been caring for ASD Children for less than one year period.
2. Caregivers who failed to consent

3.6 Sample Size Determination

The Sample Size was determined using Cochran's formula at a precision level of 5% and 95% confidence interval (Singh & Masuku, 2014) as shown below.

$$n = \frac{Z_{1-\propto}^{2} \times P(1-P)}{\partial^{2}}$$

n = Desired sample size when population is > 10,000

$\propto$= level of significance (5%)

Z = Standard normal deviate corresponding to 95% confidence level (1.96)

P = Assumed proportion of caregivers with depression- 79% (Kuria, Mbugua, & Ndetei, 2011), a study done in Kenya.

∂ =Degree of accuracy desired at 5%

$$n = \frac{1.96^2 \times 0.79(1 - 0.79)}{0.05^2} = 254.9 \approx 255$$

Since the target population is <10,000, the study sample was proportionally adjusted as follows:

$$nf = \frac{n}{1 + \frac{(n-1)}{N}}$$

Where,

nf is the proportionally adjusted sample size since population is < 10,000

n is the desired sample size when population is greater than 10,000

N is the population (100)

$$nf = \frac{255}{1 + \frac{(255-1)}{100}} = 72.03 \approx 72$$

The study used a sample of 80 caregivers inclusive of 10% attrition to cater for non-response.

3.7 Sampling Method

Sampling is the process of selecting a small number of individuals from the population size. This selection is intended to be a representation of the larger group (Mugenda & Mugenda, 2003). Convenience sampling technique was used to recruit the participants. The researcher purposefully recruited the participants on the basis of caring for children with ASD. This meant that all caregivers of children diagnosed with ASD visiting the facility for treatment or any other related services were approached for recruitment over the study period.

3.8 Data collection tools

1. A closed ended questionnaire of socio-demographic profile of the participants recording age of both ASD child and caregiver, gender for both child and caregiver, number of ASD children, marital status of caregiver, employment status of caregiver, education level and currently monthly income of caregivers.

2. Early Screening Tool for Autism spectrum disorder (ESAT). ESAT was developed for early screening of Autism because of its utmost sensitivity and specificity, a child with three or more negative scores is considered to be at high risk of highly Autistic.
3. Burden Assessment Schedule was used – the tool was first developed in India to measure objective and subjective burden. It is a relevant tool in assessment of consequences of caregivers' burden of an ASD child both qualitatively and quantitatively with emphasis on the study population. Inter- rater reliability exercises conducted indicated a Kappa value of 0.8 which confirms its quality of trust worthiness. Data was collected using structured questionnaire purposely prepared for this particular study.
4. Family Burden Assessment Schedule
5. The WHO- Quality of Life (QOL) - BREF standard tools.

3.8.1 Reliability and validity

3.8.1.1 Reliability

Reliability is a measure of degree to which a research instrument yields consistent results after a repeat trials (Mugenda & Mugenda, 2003), usually expressed as correlation co-efficient. Reliability coefficient varies between -1.00 and +1.00 with reliability of 0.75 and above indicates perfect reliability and 00 indicating no reliability, -1.00 to 0 show negative reliability (Orodho, 2005).

The coefficient indicates the extent to which a test is free from error of variance. The closer the reliability coefficient of a test is the value of 1.00, the more the test is free from error of variance and is a measure of the differences among proportions in the dimension assessed by the test (Borg & Gall, 2009).

In quantitative research, reliability refers to the consistency of the instrument and test administration in the study. To enhance reliability, the survey instrument was administered during the same time period to all participants. Cronbach's Alpha was used in the internal consistency reliability test in order to explain and interpret the reliability among the items surveyed (McDonald, Newton & Whetton, 2001).

3.8.2 Validity

The study used face, construct and content validity by seeking the opinion of supervisors on the adequacy of the research instruments in achieving the objectives of the study. Based on their opinions, the instrument was adjusted by deleting and adding some questions or by changing the structure or lexical density of questions as appropriate.

3.8.3 Pre-testing

Pre-testing of questionnaires was essential to avoid pitfalls after administering the data collection tool. Pre-testing is a screening method that allows the researcher to try the questionnaire on a smaller group of respondents initially to allow for feed-back and corrections (Zikmund & Babin, 2010). This approach helps the researcher to minimize on wrong answers due to misinterpretation of questions or blanks in questionnaires due to respondents misunderstanding of questions.

Pre-testing was done in this research to ensure that the questions are relevant, clear and understandable. The pre-testing aims at determining the reliability of the research tools including the wording, structure and sequence of the questions. A pretesting was done by the researcher two weeks prior to the actual study to assess the feasibility of the study. The pre-testing involved 10 respondents from the target population. The respondents were conveniently selected since statistical conditions are not necessary in the pilot study.

3.9 Data collection procedure

Letters of clearance were obtained from the KNH/UON Ethics and Research committee and the relevant authorities in the Ministry of Health Nakuru County Government and NACOSTI. In preparation for the actual data collection, the researcher requested for a memo from the hospital administrator informing the staff of the intended study and dates so as to be ready for the activity. The researcher's desk was positioned strategically so as not to miss an opportunity of recruiting participants. The researcher did self-introduction and explained the study objectives, procedure and benefits of the study, the inclusion and exclusion criteria were then be explained.

Those who met the criteria were requested to sign the consent form and given enough time to make informed choice in further participation in the study. The participants who signed the consent were then engaged in the interview by the researcher starting from the socio-demographic data. The researcher thanked the participants upon completion of filling in the questionnaire. Data collection took one month in accordance with the permission letter granted by the institution.

3.10 Data management and analysis

Data analysis was engaged in after all data had been collected in order to make sense of the data. The type of data analysis tool used is dependent on the type of data collected - qualitative or quantitative (Walsh & Wigens, 2003). The quantitative data in this research was analyzed by descriptive statistics using statistical package for social sciences SPSS v25. Descriptive statistics (frequency, proportions, and mean) was used to define variables. Inferential statistics [Pearson Chi Square and correlation] was done at 95% confidence intervals to establish the association between variables. Findings was presented in the form of text, charts, graphs, tables and verbatim.

Dummy Table

Statement	Indicator	Frequency	Percent	Chi Square	P value

3.11 Ethical consideration

Prior to commencement of the proposed study, the research protocol was approved by KNH/UoN Ethics and research committee. The aims and objectives of the study with its procedure, risks and benefits and the expected interview time was explained to the participants who then consented. The participants were informed of maintenance of confidentiality and that the data collected was meant for research purposes only. Participants were assured that findings from this research would help in developing policy to lessen caregiving burden and scale up quality of life of caregivers of children with ASD. The principle of autonomy was also applied which addressed the right of an individual to determine whether to or not to participate in the research. Additionally, harm reduction during the research was addressed openly to remove fear among participants. The researcher clearly explained to the participants that there was no monetary compensation for participation. Any other concerns regarding the study was answered and the researcher gave contact in case of future correspondences.

3.12 Data collection flow chart

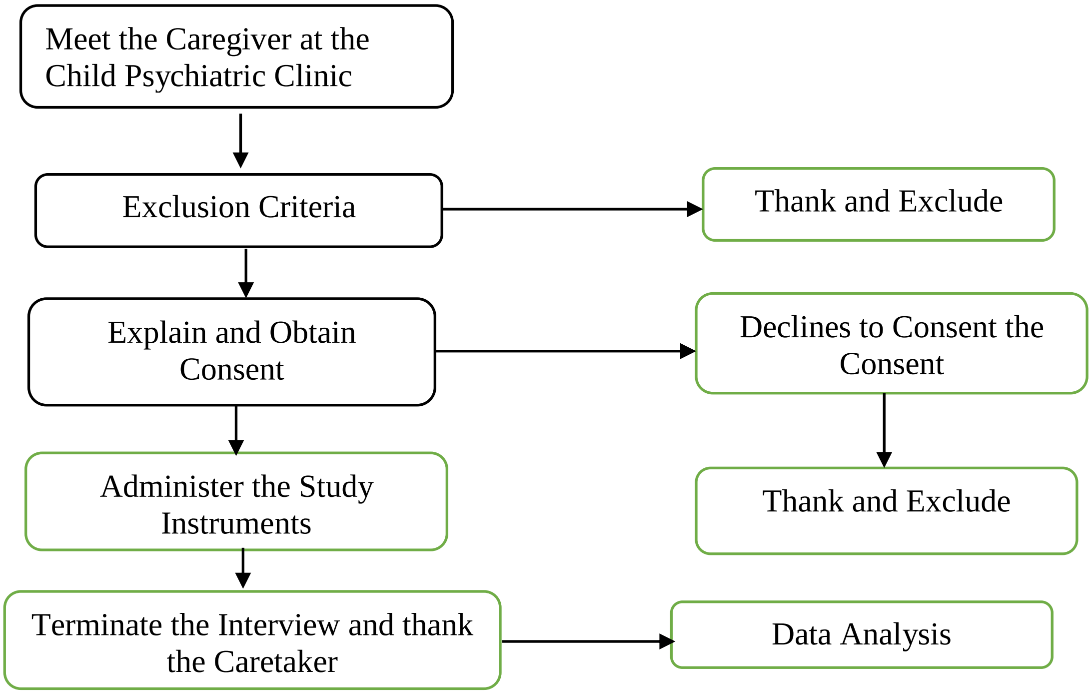

Figure 3.1: Data collection flow chart

3.13 Summary

This chapter introduced the topic of research, exploring on research design, types of data, data collection and analysis tools and ethical considerations considered during the research. The researcher used both primary and secondary data as information sources, and data was analyzed using both descriptive statistics and conceptual content analysis.

CHAPTER FOUR

DATA ANALYSIS AND PRESENTATION

4.1 Introduction

This section presents the data analysis and interpretation of the data collected. The first part covers the demographics of the respondents: the second part outlines the descriptive characteristics of both the dependent and independent variables according to the study objectives. The main objective was to assess and establish the relationship between burden of care and Quality of life among caregivers of children with ASD in the African setting as seen in Nakuru Level Five Hospital, Kenya.

4.2 Socio demographic charactersitics of the caregivers and ASD children

As presented in the Table 4.1, majority of the respondents (care givers) were between age brackets of between 31-50 years 64.9% (55) while those less than 30 years were 4.5% (5) and majority were females 75.9% (66). On the respondents highest education level attained, the study determined that majority 70.5% (62) had diploma level education compared to 21.6% (19) with primary level education. Among those who indicated they never married, they constituted 29.6% (26) as compared to those married 56.8% (50) and half 50% (44) earned less than Ksh 20,000 (<$ 66.7/day) compared to those who earned more than Ksh 20,000 (>$66.7/day). From the responses, about half had 1-4 children 48.8% (43) compared to 51.2% (45) who had more than 4 children.

Table 4.1: Socio-demographic Characteristics of caregivers

Socio Demographic Charactersitics of Caregivers

Covariate		N	%
Age bracket	Between 20-30 years	5	4.5
	Between 31-40 years	28	25.2
	Between 41-50 years	44	39.6
	More than 50 years	11	9.9
Gender (care givers)	Male	21	24.1
	Female	66	75.9
Education level	Primary	19	21.6
	Secondary	7	8.0
	Diploma	62	70.5
Marital Status	Never married	26	29.5
	Married	50	56.8
	Divorced/Separated/ Widowed	12	13.7
Income Bracket	Less than Ksh 10000	7	8.0
	Between 10001-20000	37	42.0

	Between 20001-30000	38	43.2
	More than 30000	6	6.8
size of your household	Three members	20	22.7
	Four members	23	26.1
	Five members	16	18.2
	Six members	16	18.2
	More than six members	13	14.8

The Table 4.2 present socio-demographic characteristics of children living with ASD. Majority of the children were under the care of their parent either mother or father 78.7% (70) and more than half of the children were aged 7-13 years old 55.1% (49) followed by 14-18 years old 31.5% (28). Most of the children 77.3% (68) were boys compared to 22.7% (20) who were girls. Slightly over a third were diagnosed with ASD at the age of six years 34.1% (30) and seven years 28.4% (25) while those diagnosed at 4 years were 29.5% (26).

Table 4.2: Child Socio-demographic characteristics

Child socio-demographic Characteristics

		Frequency	Percent
Relationship to the person cared for	Parents - mother/ father	70	78.7
	Grandparents	15	16.9
	Teacher	4	4.5
Age group of the child living	(3 – 6)	12	13.5
	(7 – 13)	49	55.1
	(14 – 18)	28	31.5
Gender	Female	20	22.7
	Male	68	71.9
Age child was diagnosed with ASD	4 years	26	29.5
	5 years	7	8.0
	6 years	30	34.1
	7 years	25	28.4

4.3 Early Screening for Autistic Traits (ESAT)

The Table 4.3 presents the Early Screening for Autistic Traits (ESAT) responses. Any child who scored 3 negative responses was regarded highly Autistic. Majority agreed that their children, ever brought objects over to them or show them something on their own accord 59.3% (53) and that showed to be interested in other children or adults 55.8% (48); liked to be cuddled 58.1% (50) or smiled at strangers 59.3% (51). They further agreed that when pointing at something, their children followed their gaze to see what they were pointing at 67.4% (58), their children ever used their index finger to point, to indicate interest in something and their children ever pretended, for example, to make a cup of tea using a toy cup and teapot, or pretend other things 75.6% (65).

Table 4.3: Early Screening for Autistic Traits (ESAT)

Early Screening for Autistic Traits (ESAT)

Statement		Frequency	Percent
Is your child interested in different sorts of objects, and not for instance mainly in cars or buttons?	Yes	49	57.0
	No	37	43.0
Can your child play with toys in varied ways (not just fiddling, mouthing or dropping them)?	Yes	49	57.0
	No	37	43.0
When your child expresses his/her feelings, for instance by crying or smiling, is that mostly on expected and appropriate moments	Yes	46	53.5
	No	40	46.5
Does your child react in a normal way to sensory stimulation, such as (coldness, warmth), light, sound, pain or tickling?	Yes	54	62.8
	No	31	36.0
Can you easily tell from the face of the child how he/she feels?	Yes	52	60.5
	No	34	39.5
Is it easy to make eye contact with your child?	Yes	51	59.3
	No	35	40.7
When your child has been left alone for some time, does he/she try to attract your attention, for instance by crying or calling?	Yes	46	53.5
	No	40	46.5
Is the behavior of your child without stereotyped repetitive movements like banging head or rocking his/her whole body?	Yes	53	61.6
	No	33	38.4
Does your child, on his/her own accord, ever bring objects over to you or show you something?	Yes	51	59.3
	No	35	40.7
Does your child show to be interested in other children or adults?	Yes	48	55.8
	No	38	44.2
Does your child like to be cuddled?	Yes	50	58.1
	No	36	41.9
Does your child ever smile at you or at other people?	Yes	51	59.3
	No	35	40.7
Does your child like playing games with others, such as peek a-boo, ride on someone’s knee, or to be swung?	Yes	52	60.5
	No	34	39.5
Does your child react when spoken to, for instance, by looking, listening, smiling, speaking or babbling?	Yes	58	67.4
	No	28	32.6
Does your child speak a few words or utter various babbling sounds?	Yes	53	61.6
	No	32	37.2
When you are pointing at something, does your child follow your gaze to see what you are pointing at?	Yes	58	67.4
	No	27	31.4
Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	62	72.1
	No	23	26.7
Does your child ever use his/her index finger to point, to ask for something?	Yes	57	66.3
	No	29	33.7
Does your child ever pretend, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?	Yes	65	75.6
	No	21	24.4

The Table 4.4 presents severity of ASD among children. The results indicated that slightly more than a third of the children in the study had moderate autism 38.4% (33) and mild autism 32.6% (28) respectively while 29.1% (25) had severe form of the disorder.

Table 4.4: ASD Severity

ASD severity

Covariate		Frequency	Percent
Categories	Mild Autism	28	32.6
	Moderate Autism	33	38.4
	Severe Autism	25	29.1

4.4 Financial and family burden

This section present the responses on financial and family of care using the burden assessment schedule (BAS); using Likert scale of 1- Not at all, 2- To some extent and 3-Sometimes. Table 4.5 present the financial aspect on BAS. The result showed that the respondents were not at all able to look after their family member with their current financial position [1.27±.638] [x^2=97.65, p<0.001] and further they were concerned that they were largely responsible to meet the ill family member's financial need [2.3±.462] [x^2=13.74, p<0.0501]. The result further showed that the respondents were worried about the ill family member's future financial situation [2.4±.48] and they agreed that their family's financial situation worsened since the diagnosis of their family member's illness [2.4±.49] [x^2=3.68, p<0.001. They indicated that the ill family member's condition prevented them from looking for a job [2.1±.59, p< 0.001] and felt that they were forced into going to work to support their ill family member [2.11±.575] [x^2=43.73, p<0.001]. The respondents agreed that the ill family member's condition affected their efficiency at work (at home/at work place) [2±00] [x2 =88.23], p<0.001.

Table 4.5: Financial burden

-*Financial Burden*

Statement	Mean	SD	x^2	P value.
Is your current financial position adequate to look after your ill family member?	1.27	0.64	97.65	<0.001
Are you concerned that you are largely responsible to meet the ill family member's financial need?	2.30	0.46	13.76	<0.001
Does the ill family member's future financial situation worry you?	2.35	0.49	5.50	<0.001
Has your family's financial situation worsened since the diagnosis of your family member's illness?	2.39	0.49	3.68	<0.001
Is the ill family member's	2.12	0.59	37.101	<0.001

condition preventing you from looking for a Job?				
Do you feel forced into going to work to support your ill family member?	2.11	0.58	43.72	<0.001
Does the ill family member condition affect your efficiency at work (at home/at work place)?	2	0.62	88.23	<0.001

The Table 4.6 presents the family wellbeing on the BAS. It was established that the respondents sometimes were satisfied with the way their ill family member looked after him/herself [2.84±.535] [x^2=29.97, p<0.001] and they indicated that they felt they had responsibility of ensuring that the ASD child had everything he or she needed [2.1±.305] [x^2=55.68, p<0.001]. Respondents agreed that they thought they had to compensate their family member's illness shortcomings in general [2.28±.453] [x^2=16.41, p<0.001] while they indicated that support from their family helped in caring for their family member's illness [2.23±455] [x^2=72.56, p<0.001]. The respondents agreed that patients caused disturbances in the home to some extent [2.39±.492] [X^2=368. P=0.01] and they were able to care for others in their family [2.28±.453] [x^2=16.40, p<0.001]. Concerning if their family stability had been disrupted by family member's illness (frequent quarrels, break-up), they agreed absolutely [2.34±.5] [x^2=51.70, p<0.001], although the family appreciated the way the respondents (care givers) handled their family member's illness [2.14±.433] [x^2=87.02, p<0.001] and they further indicated that their family member's illness prevented them from having satisfying relationship with the rest of their family [2.06±.423] [x^2=93.7, p<0.001] and their spouse helped with family responsibilities [2.05±.46] [x^2=80.88, p<0.001].

Table 4.6: Family well-being

Family well being

Covariate	Mean	SD	x^2	P value
Are you satisfied with the way- your ill family member looks after him/herself?	2.84	0.53	21.97	<0.001
Do you feel you have to take the responsibility of ensuring that the patient has everything he or she needs?	2.10	0.30	55.68	<0.001
Do you think you have to compensate your family member's illness shortcomings in general?	2.28	0.45	16.40	<0.001
Does support from your family help in caring for your family member's illness?	2.23	0.45	72.56	<0.001

Does the patient cause disturbances in the home?	2.39	0.49	3.68	0.01
Are you able to care for others in your family?	2.28	0.45	16.40	<0.001
Has your family stability been disrupted your family member's illness (frequent quarrels, break-up)?	2.34	0.50	51.70	<0.001
Do you think that your family appreciates the way you handle your family member's illness?	2.13	0.43	87.02	<0.001
Does your family member's illness prevent you from having satisfying relationship with the rest of your family?	2.06	0.42	93.70	<0.001
Does your spouse help with family responsibility?	2.05	0.463	80.88	<0.001

Table 4.7 present respondent's spouse relationship experiences. The result indicate that the respondents were able to fulfill their intimacy expectations by their spouse [2±.492] [x^2=75.67, p<0.001] as their spouses were still affectionate towards them [2.11±.317] [x^2=53.49, p<0.001]. Unfortunately the result showed that the quality of their marital relationship had declined since diagnosis of their child's ASD illness [2.3±.462] [x^2=15.36, p<0.001]. However caring for the ASD child did not make them feel easily tired and exhausted [2.40±49] x^2=2.90, p=0.088].

Table 4.7: Spouse relationship experiences

Spouse relationship experiences

Statement	Mean	SD	x^2	P value
Is your spouse able to fulfill you intimately?	2	0.49	75.67	.001
Is your spouse still affectionate towards you?	2.11	0.31	53.49	.001
Has the quality of your marital relationship declined since diagnosis of your family member's illness?	2.30	0.46	15.36	.001
Does caring for the patient make you feel easily tired and exhausted?	2.40	0.49	2.90	.088

Table 4.8 present emotional wellbeing of the respondents as they care for their ASD child. The respondents indicated that their workload did not increase since the diagnosis of the family member's illness [2.42±.496] [x^2=2.41, p=0.120. Respondents indicated that they thought their health had been affected because of their child's ASD illness [2.2±.623] [x^2=32.8, p<0.001]. Probing if they found time to look after their health, the respondents cited not at all [1.63±.756] [x^2=18.6, p<0.001. The same response was obtained indicating that they were not able to relax for some time during the day [1.42±.656] [x^2=20.82, p<0.001]. Respondents indicated that they felt depressed and anxious because of their child's ASD illness [2.76±.428] [x^2=20.04, p<0.001] and they felt that there was no solution to their child's illness [2.76±.428][x^2=13.13, p<0.001].

Respondents further showed that there was need for temporary separation from their child’s illness [2.03±.44] [x^2=88.93, p<0.001].

Respondents asserted that reducing the time spent with the ASD child to work/other activities did not help them [2.4±.50] [x^2=0.72, p=0.394] and further indicated that ASD child's unpredictable behavior disturbed them [2.34±.476] [x^2=8.91, p=0.003]. On the statement if their sleep was affected since the diagnosis of the child’s illness, they indicated it had [2.3±.45] [x^2=16.41, p<0.001] and that the child’s illness prevented them from having satisfying relationships with the friends [2.26±.44] [x^2=20.04, p<0.001]. Respondents further indicated that they felt lonely and isolated since the diagnosis of ASD illness in their child [2.37±.50] [x^2=48.29, p<0.001]. Respondents asserted that they received support from their friends who helped in caring for their child with ASD illness [2.11±.44, x^2=84.48, p<0.001]. Sharing their problems with others made the respondents feel better [2.1±.477], x^2=75.66, p<0.001] as they felt their friends appreciated the way they handled their child [2.11±.38] [x^2=105.59, p<0.001] as they did not often feel frustrated [2.4±.49] [x^2=3.50, p=0.061]. Respondents indicated that the improvement of their child’s illness was slow although they felt that they were doing more for the child to improve his/her condition [2.39±.49] [x^2=4.16, p=0.041]. Respondents further felt that their relatives understood and appreciated their effort to help their ASD child [2.29±.504, x^2=57.53, p<0.001] as they were satisfied with the amount of help they were getting from health professionals regarding their ASD child’s illness [2.12±.477, x^2=72.89, p<0.001].

Table 4.8: Emotional wellbeing of caregivers

Emotional wellbeing of caregivers

Statement	Mean	SD	x^2	P value
Has your workload increased since the diagnosis of your family member’s illness?	2.41	0.49	2.41	0.120
Do you think that your health has been affected because of your family member’s illness?	2.17	0.62	32.78	<0.001
Do you find time to look after your health?	1.63	0.75	18.60	<0.001
Are you able to relax for some time during the day?	1.42	0.65	20.81	<0.001
Do you sometimes feel depressed and anxious because of your family member’s illness?	2.76	0.42	24.04	<0.001
Do you sometimes feel that there is no solution to your family member’s illness?	2.30	0.46	13.13	<0.001
Do you feel sometimes the need for temporary separation from your family member’s illness?	2.03	0.44	88.93	<0.001

Does reducing the time spent with the patient (work/other activities) help you?	2.45	0.50	0.72	0.394
Does the patient's unpredictable behavior disturb you?	2.34	0.47	8.90	0.003
Has your sleep been affected since the diagnosed your family member's illness?	2.28	0.45	16.40	<0.001
Does your family member's illness prevent you from having satisfying relationships with the friends?	2.26	0.44	20.04	<0.001
Have you started feeling lonely and isolated since the diagnosis of your family member's illness?	2.37	0.50	48.29	<0.001
Does support from friends help in caring for your family member's illness?	2.11	0.44	84.48	<0.001
Does sharing your problems with others make you feel better?	2.10	0.47	75.66	<0.001
Do you feel that your friends appreciate the way you handle the patients?	2.14	0.38	105.59	<0.001
Do you often feel frustrated that the improvement of your family member's illness is slow?	2.40	0.49	3.50	0.061
Do you feel that you are doing more than the patient to improve his/her situation?	2.39	0.49	4.16	0.041
Do you have the feeling that your relative understands and appreciates your effort to help him/her?	2.29	0.50	57.53	<0.001
Are you satisfied with the amount of help that you are getting from health professionals regarding your relative's illness?	2.12	0.47	72.89	<0.001

Financial and family burden

Figure 1 present the total scores on financial and family burden calculated as total burden of giving care to a child living with ASD. From the scores, it was shown that almost all respondents experienced severe burden of care 97.7% (86) with only 2.3% (2) indicating moderate burden of care. This gives a right-skewed ("positively skewed") distribution, as scores computed fall to the right, positive side on the graph's peak (figure 1). The histogram is skewed to the right; the tail is long on the right than left, where the mode (86) and median (85) falls on the right of the mean (84.99).

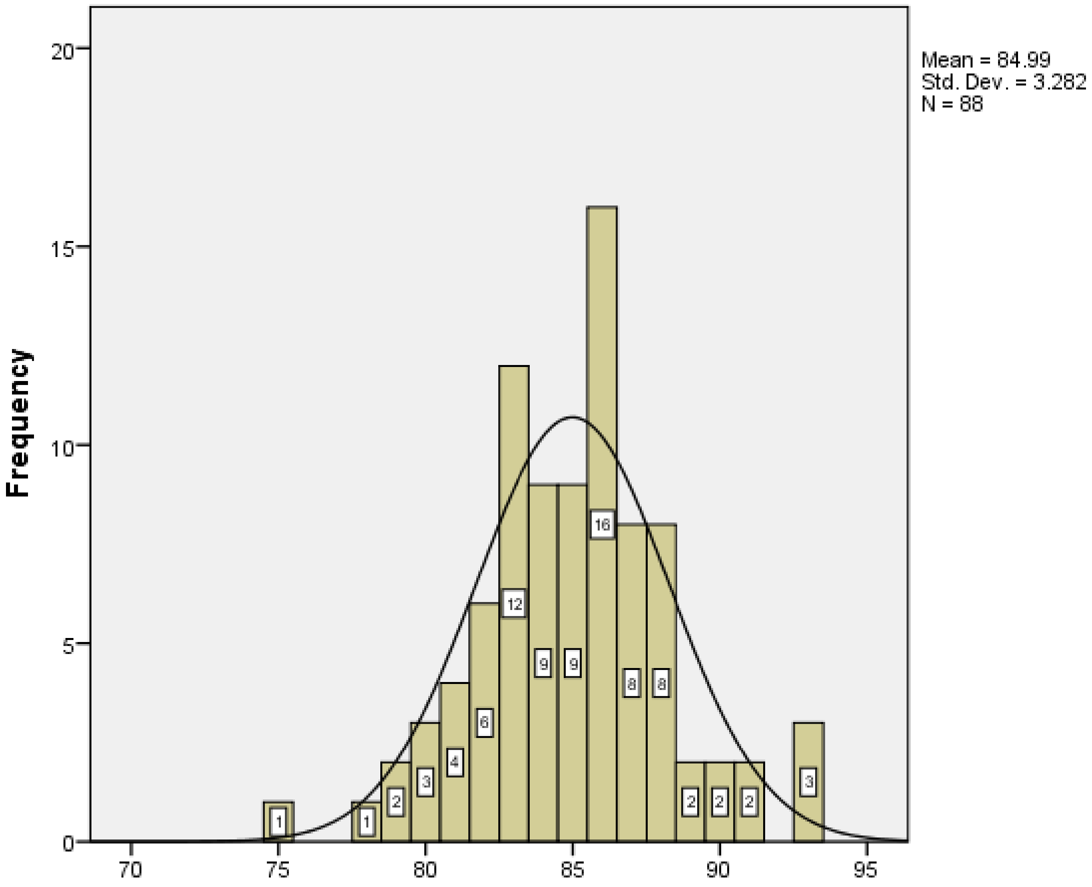

Figure 1: Family Burden of care scores

Figure 4.1: Financial and family support to the child with ASD

4.5 Financial and family support to the child with ASD

Table 4.9 presents primary caregiver's support to the child with ASD. The findings indicate that child's condition prevented respondents from looking for a regular job [2.0674±.53] [x^2=56.787, p<0.001. The respondents further indicated that the child's condition affected their efficiency at work (at home/at work place) [1.98±.38] [x^2=108.56, p<0.001], however they were satisfied to a little extent with the way the child looked after him/herself[1.30±.46] [x^2=13.7, p<0.001]. Respondents agreed that they had to take the responsibility of ensuring that the child living with ASD had everything he or she needed [2.1±.27] [x^2=63.20, p<0.001] and respondents compensated the child's shortcomings in general [2.07±.27] [x^2=63.20, p<0.001].

Table 4.9: Family support

Family Support

Statement	Mean	SD	x^2	P value
1. Is the child's condition preventing you from looking for a Job?	2.0674	0.53	56.787[a]	<0.001
2. Does the child's condition affect your efficiency at work (at home/at work place)?	1.98	0.38	108.56	<0.001
3. Are you satisfied with the way-the child looks after him/herself?	1.30	0.46	13.7	<0.001
4. Do you feel you have to take the responsibility of ensuring that the child living with ASD has everything he or she needs?	2.07	0.27	63.20	<0.001
5. Do you think you have to compensate the child's shortcomings in general?	2.07	0.27	63.20	<0.001

Table 4.10 presents family support to primary caregiver of the ASD child. Respondents had support from their family members who helped in caring for the child with ASD [2.1±.303, x^2=56.6, p=0.001and they asserted that the child living with ASD did not cause disturbances in the home [2.43±.49] and they were able to care for others in their family to some extent [2.33±.47]. They agreed that family stability was disrupted by the child's condition (frequent quarrels, break-up) to some extent [2.4±.5, x^2=39.5, $p<0.05$] and they thought that that their family appreciated the way they handle their children's condition to some extent [2.2±.49, x^2=66.42, $p<0.05$].

Assessing if the child's condition prevented them from having satisfying relationship with the rest of their family, the respondents indicated it did to some extent [2.3±.54, x^2=45.59, $p<0.05$] and that spouses helped them with family responsibility to little extent [1.85±.55 x^2=49.37, $p<0.05$] and their spouse able to fulfill them intimately to little extent [1.66±.47 x^2=49.37, $p<0.05$] and spouse still affectionate towards them [1.87±.65, x^2=22.9, $p<0.05$] though they indicated that their marital relationship quality had declined since diagnosis of their children's condition to some extent [2.38±.69 x^2=20.04, $p<0.05$].

Table 4.10: Family Support to Primary Caregiver

Family Support to Primary Caregiver

	Mean	SD	x^2	P value
1. Does support from your family help in caring for the child?	2.10	0.30	56.64	.001
2. Does the child living with ASD cause disturbances in the home?	2.43	0.49	1.36	.244
3. Are you able to care for others in your family?	2.33	0.47	9.44	.002
4. Has your family stability been disrupted by the child’s condition (frequent quarrels, break-up)?	2.42	0.54	39.52	.000
5. Do you think that your family appreciates the way you handle the child’s condition?	2.15	0.49	66.42	.001
6. Does the child’s condition prevent you from having satisfying relationship with the rest of your family?	2.28	0.54	45.59	.001
7. Does your spouse help with family responsibility?	1.85	0.55	49.37	.001
8. Is your spouse able to fulfill you intimately?	1.66	0.47	9.44	.002
9. Is your spouse still affectionate towards you?	1.87	0.65	22.94	.001
10. Has the quality of your marital relationship declined since diagnosis of the child condition?	2.38	0.70	20.04	.001

Table 4.11: Family support to primary caregiver

Family Support to Primary Caregiver

	Mean	SD	x^2	P value
21) Does caring for the child living with ASD make you feel easily tired and exhausted?	2.28	0.56	40.47	.001
22) Has your workload increased since the diagnosis of the child’s with ASD?	2.44	0.52	42.15	.000
23) Do you think that your health has been affected because of the child’s ASD condition?	2.50	0.50	01	.916
24) Do you find time to look after your health?	1.58	0.78	27.79	.000
25) Has your sleep been affected since the child was diagnosed with ASD condition?	2.26	0.44	18.88	.000
26) Do you sometimes feel depressed and anxious because of child’s ASD condition?	2.53	0.50	.55	.458
27) Do you sometimes feel that there is no solution to your child’s ASD condition?	2.30	0.46	13.76	001
28) Do you feel sometimes the need for temporary separation from the child?	2.05	0.43	91.0	001
29) Does reducing the time spent with the child living with ASD (work/other activities) help you?	2.08	0.57	44.58	001
30) Does the child living with ASD's unpredictable behavior disturb you?	2.04	0.67	19.16	001

It was observed that the respondents asserted that caring for their children made them feel easily tired and exhausted [2.28±.564, x^2=40.47, $p<0.05$] and their workload had increased since the diagnosis of the child’s ASD [2.44±.52, x^2=42.2, $p<0.05$]. They thought their health had been affected to some extent because of the child’s ASD condition [2.5±.5] and they found little time to look after their health [1.58±.78] while their sleep was affected to some extent since the child was diagnosed with ASD condition [2.26±.44 $x^2=18.88$, $p<0.05$.]. The respondents sometimes felt depressed and anxious to some extent because of the child's ASD condition [2.5±.50] and further, they indicated that sometimes they felt that there was no solution to their children's ASD condition [2.3±.46] though they still felt sometimes the need for temporary separation from their child to some extent [2.1±.43 , $x^2=91.03$, $p<0.05$] and this indicated that reducing the time spent with their child living with ASD (work/other activities) helped them to some extent [2.08±.57 $x^2=44.58$, $p<0.05$].

Table 4.12: Family support

	Mean	SD	x^2	P value
31) Are you able to relax for some time during the day?	2.13	0.64	25.43	.001
32) Does your child ASD condition prevent you from having satisfying relationships with the friends?	2.44	0.50	.91	.340
33) Have you started feeling lonely and isolated since the diagnosis of the child's condition?	2.16	0.37	39.11	.001
34) Does support from friends help in caring for the child living with ASD?	2.02	0.30	133.30	.001
35) Does sharing your problems with others make you feel better?	1.92	0.27	63.20	.001
36) Do you feel that your friends appreciate the way you handle the child living with ASDs?	2.17	0.48	67.43	.001
37) Do you often feel frustrated that the improvement of the child's condition is slow?	2.15	0.49	66.42	.001
38) Do you feel that you are doing more than the child living with ASD need to improve his/her situation?	1.96	0.51	66.89	.001
39) Do you have the feeling that your relative understands and appreciates your effort to help him/her?	1.89	0.50	68.11	.001
40) Are you satisfied with the amount of help that you are getting from health professionals regarding your child's condition?	2.01	0.53	59.62	.001
41) Are you worried that your child may not manage to take up a job?	1.96	0.41	99.52	.001
42)Are you worried that your child may not attain certain social skills	2.04	0.52	63.39	.001
43) Do your child stereotypical behaviors (if any) worry you?	2.01	0.46	82.27	.001
44) Are you worried that your child living with ASD may not entirely be independent in the future?	1.94	0.42	90.50	.001
45) Are you satisfied with the amount of help that you are getting from different professionals to your child your child's condition?	1.61	0.53	42.49	.001

46) Are you satisfied with the quality of schooling your child gets?	1.71	0.5878	34.40	.001

As presented, the respondents cited that they were able to relax for some time during the day to some extent [2.1±.64, x^2=25.43, $p<0.05$] and they indicated that their children's condition prevented them from having satisfying relationships with their friends to some extent [2.44±.50] though they agreed that they sometimes started feeling lonely and isolated since the diagnosis of the child's condition [2.2±.37 x^2=39.11, $p<0.05$].

Respondents agreed that support from friends helped in caring for the child living with ASD to some extent [2.02±.30, x^2=133.3, $p<0.05$] and that sharing their problems with others made them feel a little better [1.92±.27 x^2=63.2, $p<0.05$]. They often felt frustrated that the improvement of the children's condition was slow [2.1±.49 x^2=66.42, $p<0.05$] and felt that they were doing more than the child living with ASD needed to improve their situation [1.96±.51 x^2=66.89, $p<0.05$]. They further felt sometimes that they had a feeling that their relative understood and appreciated their effort to help their children [1.89±.50 x^2=68.11, $p<0.05$] though they were satisfied with the amount of help that they got from health professionals regarding their children's condition [2.01±.53 x^2=59.6, $p<0.05$].

On their children's future, the respondents were worried to some extent that their children may not manage to take up a job [1.96±.41 x^2=99.52, $p<0.05$] and as well as attaining certain social skills [2.04±.52 x^2=63.39, $p<0.05$]. The respondents were worried to some extent that their children may not entirely be independent in the future [1.94±.42 x^2=90.5, $p<0.05$] though they were little satisfied with the amount of help they got from different professionals to their children's condition [1.6±.58 x^2=42.5, $p<0.05$] and to a little extent respondents were satisfied with the quality of schooling their children got [1.7±.58 x^2=34.4, $p<0.05$].

4.5 Source of support to family living with ASD child

Table 4.13 present data on source of support to the families living with ASD child. Findings show that most respondents did not obtain State/ Government 88.8% (79) support for their child's ASD condition nor were attending a special school supported by the state 88.8% (79). Majority of the children with ASD were integrated in normal schools 78.7% (70). On the question about other support activities the child ASD was currently receiving, respondents indicated that occupational therapy topped the support activities 75.3% (67) compared to Speech therapy and applied Behavior Analysis 12.4% (11) each respectively.

Table 4.13: Source of support to family living with ASD

Source of support to the family living with an ASD child

Source of support		Frequency	Percent
Obtain State/ Government support for child's ASD condition	Yes	10	11.2
	No	79	88.8
The child currently attending a special school	Yes	10	11.2
	No	79	88.8
The school related to ASD	Yes	16	18.0
	No	70	78.7
Other support activities the child ASD currently receiving	Applied Behavior Analysis	11	12.4
	Speech therapy	11	12.4
	Occupational therapy	67	75.3

4.6 Quality of life

This section presents the quality of life enjoyment and satisfaction data. A likert scale of 1-very Poor, 2-Poor, 3-Fair, 4-Good and 5-Very Good was used and the responses are provided in the subsequent Table 4.14 for each item on the WHO- Quality of Life (QOL)-BREF questionnaire computing the mean, standard deviation and chi square. The first question assessed the respondents physical health, giving a mean of 2.6±0.649, indicating that their physical health was generally poor [x^2=73.73, p<0.001]. On their mood and work, the same trend was observed as the mean of 2.4±.54 [x^2=89.5, p<0.001] and 2.38±.489 [x^2=74.84, p=0.028] respectively. This implied that the respondents were affected by their ASD children conditions. The respondents also indicated that household activities were affected; 2.391±.57 [x^2=35.82, p<0.001]. Further, on the general state of their social life, the respondents indicated that it was poor 2.34± 0.56 [x^2=38.95, p<0.001] as well as their family relationships poor [2.73±0.60] [x^2=104.87, p<0.001]. Leisure activities were poor [2.32±0.55] [x^2=41.3, p<0.001] and their ability to function in their daily lives was also poor [2.59±0.58] [x^2=82.05, p<0.001]. On their sexual drive, interest or performance, respondents indicated it was poor [2.98±0.56] [x^2=37.53 p<0.001] and their economic status was also poor [2.38±0.66] [x^2=59.63, p<0.001] as well as living/housing condition was poor [2.67±0.56] [x^2=100.97, p<0.001]. Their ability to get around physically was good [3.64,

.524] [x^2=58.88, p<0.001] as well as their vision in terms of ability to do their hobbies/work [3.57±.543] [x^2=42.86, p<0.001]. The overall sense of wellbeing was poor [2.73±.549] [x^2=139.1, p<0.001] and getting medication for their ASD child was poor [3.13±.68] [x^2=58.88, p<0.001].

Table 4.14: Quality of life (QOL) – BREF Individual Scores

WHO- Quality of Life (QOL)-BREF individual scores

Level of satisfaction	Mean	SD	Chi-Square	P value
Physical health	2.600	0.64	73.73	**<0.001**
Mood	2.458	0.54	89.50	**<0.001**
Work	2.384	0.48	4.84	**0.028**
Household activities	2.391	0.57	35.82	**<0.001**
Social life	2.34	0.56	38.95	**<0.001**
Family relationships	2.73	0.60	104.87	**<0.001**
Leisure activities	2.32	0.55	41.30	**<0.001**
Ability to function in daily life	2.59	0.57	82.05	**<0.001**
Sexual drive, interest or performance	2.98	0.56	37.53	**<0.001**
Economic status	2.38	0.66	59.63	**<0.001**
Living/housing condition	2.67	0.56	100.97	**<0.001**
Ability to get around physically	3.64	0.52	58.88	**<0.001**
Your vision in terms of ability to do hobbies or work	3.56	0.54	42.86	**<0.001**
Overall sense of well being	2.72	0.54	139.10	**<0.001**
Medication	3.13	0.68	34.56	**<0.001**

Table 4.15 presents quality of life categories as assed on the BREF WHO questionnaire. All the health areas assessed; physical, psychological health, social health and environmental health were skewed to the right (positively) where all the medians and modes on the two different health categories were on the positive site of the mean. This results indicate that the quality of life in these areas were poor.

Table 4.15: WHO-Quality of life BREF-measure of central tendency categories

WHO-Quality of life BREF-measure of central tendency categories

Measure of central tendency	WHO quality of life categories			
	Physical Health	Psychological Health	Social Health	Environmental Health
Mean	51.77	29.05	29.95	13.24
Std. Error of Mean	.618	.431	.521	.152
Median	52.00	30.00	32.00	13.00
Mode	52	32	32	14
Std. Deviation	5.797	4.045	4.889	1.422
Range	28	16	28	7
Minimum	36	20	12	9
Maximum	64	36	40	16

Table 4.16: Correlations between burden of care and quality of life

Correlations between burden of care and quality of life

Covariate		Quality of Life	Environmental Health	Social	Physical Health	Psychological Health	Family Burden
Quality of Life	Pearson Correlation	1					
	Sig. (2-tailed)						
	N	88					
Environmental Health	Pearson Correlation	.236*	1				
	Sig. (2-tailed)	**.027**					
	N	88	88				
Social	Pearson Correlation	.663**	.230*	1			
	Sig. (2-tailed)	**.000**	.031				
	N	88	88	88			
Physical Health	Pearson Correlation	.682**	.319**	.094	1		
	Sig. (2-tailed)	**.000**	.002	.385			
	N	88	88	88	88		
Psychological	Pearson Correlation	.654**	.172	.295**	.167	1	
	Sig. (2-tailed)	**.000**	.109	.005	.120		
	N	88	88	88	88	88	
Family Burden of care	Pearson Correlation	.054	.030	.033	-.027	.136	1
	Sig. (2-tailed)	.617	.780	.761	.805	.207	
	N	88	88	88	88	88	88

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

The Table 4.16 presents the correlations between burden of care and quality of life. There was a significant positive relation on the various health parameters with the quality of life i.e. social health [rho=.663, p=0.00], physical health [rho=.682, p=0.000] and psychological health [rho=.654, p=0.000]. The environmental aspect of health [rho=.236, p=.027] indicates the magnitude of high burden and poor quality of life. Generally the family burden of care [p=.617] is very high leading to poor quality of life.

CHAPTER FIVE

DISCUSSION

The study provides a snapshot of impact of having a child with ASD on the lives of caregivers in Nakuru. The study had four objectives (1) establishing the level of burden of care among caregivers of ASD and quality of life (2) assessing the dimensions of burden of care and quality of life of caregivers of ASD children (3) determining indicators of children living with ASD which are associated with burden of care and poor quality of life of caregivers of children with ASD in Nakuru level five hospital, and (4) assessing the relationship between burden of care and quality of life among caregivers of children living with ASD.

Majority of autistic children are males (71.9%) and (22.7%) are females (Table 4.2), reflecting the higher prevalence of ASD in males compared with females. The findings are consistent with CDC (2014) report that ASD occurs four to five times more often in boys than girls. The findings of this study were further supported by David, John, & Susan, (2002); Bromley, Hare, Davison , & Emerson, (2004) and Benjak, Vuletic, & Simetin, (2009) who reported that the majority of the study subjects were males (80 %). Therefore, the males are more often diagnosed with ASD than females and the sex ratio of males to females with ASD is approximately 4:1. This evidence has predicted that psychosocial burden associated with autistic children of males will be highly perceived with children and their caregivers.

In order to identify children with ASD, the study utilized the Early Screening for Autistic Traits (ESAT) tool, consistent with similar studies (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006) where any child who scored 3 negative responses was regarded highly Autistic. The study found this tool very helpful in identification of ASD and overall translation into clinical practice requires that the process of monitoring for such early risk markers be operationalized to facilitate broad implementation.

The analysis of the current study indicated that slightly more than a third of the children in the study had moderate autism 38.4% and mild autism 32.6% respectively while 29.1% had severe form of the disorder. This results were contrary to Nikmatt, Mahadir, & Lai, (2008) who revealed that more than half of the parents perceived that their child had average to high severity of autistic symptoms. Of the 52 subjects, 29

(55.8%) subjects perceived that their child’s symptoms were within the severe level of ASD.

In this study, caregivers were predominantly women who had paid jobs and they asserted that they had difficulty in combining caregiving with their daily activities. Similarly, Macelo (n.d), found out that mothers are the key figures who are compounded to multi task between domestic responsibilities and caregiving for their ASD children. Findings concur with similar studies by (Hoefman, et al., 2014). In their study, they sought to provide insight in the impact of caregiving on parents of children with ASDs and found out that parents found it difficult to combine care tasks with daily activities such as work, household activities and family life. Findings from this study showed that the respondents were not at all able to look after their family member with their current financial position and further they were concerned that they were largely responsible to meet the ill family member’s financial needs. In line with other findings (Smith, Seltzer, Tager_Flusberg, Greenberg, & Carter, 2008), many caregivers of a child with an ASD experienced financial problems. The findings are in agreement with previous studies that have shown specific aspects of burden such as child health-related expenses and the adverse impact on parental work and on other children are significant in the families with a child affected by ASD (Lavelle, et al., 2013). Children with parent-reported ASD had higher levels of health care office visits and prescription drug use compared with children without ASD (P, .05). A greater proportion of children in the ASD group used special educational services (76% vs 7% in the control group, P, .05).

Results from this study show that despite the difficulties experienced by caregivers of children with ASD, the support from their family helped in caring for their family member’s illness. However, it was evident that family stability was disrupted by family member’s illness (frequent quarrels, break-up) and the family member’s illness prevented them from having satisfying relationship with the rest of their family. These results confirm that caring for a child with autism does have an impact on the psychosocial on the caregiver’s life (Nadir, et al., 2012).

The present study found out that most caregivers did not obtain State/ Government support for their child's ASD condition or nor were attending a special school supported by the state. Instead, majority of the children with ASD were integrated in normal schools. The findings are consistent with the (World Health Organization, 2018) report on autism spectrum disorders which indicate that globally, access to services and support for people with ASD is inadequate. Regarding other support activities targeting children with ASD, caregivers indicated that occupational therapy topped the support activities as compared to speech therapy and applied behavior analysis. A recent study conducted in Kenya (Kamau, 2017) found out that autism is a relatively new field in Kenya, and there is little to no research on interventions and there is also a lack of institutional support. Both the national government, through the ministry of Education, Health, Science and Technology nor county governments have solid positions on diagnosis, treatment and management of autism, or delivery of any allays of service options that would be beneficial to individuals with autism. This study also found that there were only a handful of government schools that had integrated special needs educations programs and of those only few had any special educations teachers. Therefore, increased recognition, understanding, and public awareness of autism, could absolutely create more social acceptability and widespread services for individuals with autism.

The results observed in this study indicated that the physical health was generally poor, caregivers were affected by their ASD children conditions, their household activities were affected, and the general state of their social life was poor while their family relationships were also poor. Leisure activities were poor and their ability to function in their daily lives was also poor. Further effect was seen on their sexual drive, interest or performance, which was generally poor and their economic status was poor as well, including living/housing conditions. The overall sense of wellbeing was poor and getting medication for their ASD child was poor. Overall, findings from the present study show that the family burden of care [p=.617] is very high leading to poor quality of life. Caring for children with autism can be associated with decline in physical and mental tasking job and resulting in compromised (QoL) of carers (Ganjiwale, Ganjiwale, Sharma, & Mishra, 2016). In agreement with the findings of this study, Hoefman, et al.,

(2014) reported the correlation between QoL scores and subjective burden level and found the impact of QoL positively associated with higher subjective and lower caregivers'' QoL. Caring for children with autism is challenging and has a high financial and family burden which leads to a poor quality of life for caregivers.

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATION

6.1 Introduction

This chapter presents summary research findings made in this study. Conclusions and recommendations are also drawn for action.

6.2 Summary of key findings

The researcher, while using the Early Screening for Autistic Traits (ESAT) tool to assess severity of ASD found out that slightly more than a third of the children in the study had moderate autism 38.4% (33) and mild autism 32.6% (28) respectively while 29.1% (25) had severe form of the disorder.

Most of the respondents were not at all able to look after their family member with their current financial position and they were concerned to some extent that they were largely responsible to meet the ill family member’s financial needs. The respondents were worried about the ill family member’s future financial situation. They agreed to some extent that their family's financial situation worsened since the diagnosis of your family member’s illness while they indicated that the ill family member’s condition prevented them from looking for a job to some extent. Respondents felt to some extent that they were forced into going to work to support their ill family member while they agreed that the ill family member’s condition affected their efficiency at work (at home/at work place) to some extent. The total scores on financial and family burden was calculated as total burden of giving care to a child living with ASD. The researcher found out that almost all respondents experienced severe burden of care 97.7% (86) with only 2.3% (2) indicating moderate burden of care.

Majority of the respondents did not obtain State/Government support for their child’s ASD condition and the children were not attending a special school as majority of these schools were not related to ASD. Regarding other support activities the child with ASD was currently receiving, the study established that occupational therapy topped the support activities compared to speech therapy and applied behavior analysis.

The physical health of the respondents was generally poor and the same trend was observed on their mood and work, implying that the respondents were affected by their ASD children conditions. On the general state of their social life, the study established that it was poor, although their family relationships were fair. Their leisure activities were poor, but were able to function in their daily lives fairly. On their sexual drive, interest in it or performance, the study found that it was fair, and their economic status was poor as well as living/housing condition was not good. Their ability to get around physically was good as well as their vision in terms of ability to do their hobbies/work though their overall sense of wellbeing was fair. Regarding quality of life categories, all the health areas assessed; physical, psychological health, social health and environmental health were skewed to the right (positively) where all the medians and modes on the two different health categories were on the positive side of the mean, indicating that the quality of life in these areas were poor. Overall, there was a significant positive relation on the various health parameters with the quality of life i.e. social health [rho=.663, p=0.00], physical health [rho=.682, p=0.000] and psychological health [rho=.654, p=0.000]. The environmental aspect of health [rho=.236, p=.027] indicates the magnitude of high burden and poor quality of life. Generally the family burden of care [p=.617] is very high leading to poor quality of life.

6.3 Conclusion

The study sought to establish the relationship between burden of care and quality of life among caregivers of children with ASD and therefore highlighted very important issue that may be neglected. The study focused on the caregivers of children with autism and the results described show that there is severe subjective burden from providing care for their children with autism and the caregiving absolutely affect their own quality of life. The findings of this study suggest that caring for children with autism spectrum disorders can overwhelm their family members, similarly to families of children with other developmental disorders. Finally, it is emphasized that acknowledging the factors which influence the burden of caregivers, constitutes another factor to be added into the care planning and intervention and can assist in developing strategies for guidance and assistance to patients and their caregivers. Overall, the research concluded that the family burden of care was very high leading to poor quality of life.

6.4 Recommendations

Based on the study objectives and findings, the researcher made the following recommendations:

1. There is need for a longitudinal study in order to obtain more data to assess the caregiving burden.
2. There is need for collaboration among stakeholders to come up with policy to support ASD children in order to lessen the burden of caregiving.

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APPENDICES

Appendix I: Consent form

University of Nairobi,
Department of Psychiatry
Dear Respondent

My names are Damaris Osoro, a masters student at University of Nairobi. Am undertaking a study on the ***relationship between burden of care and quality of life among caregivers of children with autistic spectrum disorders (asd) attending Nakuru Level Five Hospital, Nakuru County***. This research project is critical to strengthening service provision among ASD children as it will generate new knowledge in this area that will inform decision makers to make decisions that are research based.

Procedure to be followed

Participation in this study will require that I ask you some questions. I will record the information from you in a questionnaire check list. You have the right to refuse participation in this study. You will not be penalized nor victimized for not joining the study and your decision will not be used against you nor affect you at your place of employment.

Please remember that participation in the study is voluntary. You may ask questions related to the study at any time. You may refuse to respond to any questions and you may stop an interview at any time. You may also stop being in the study at any time without any consequences to the services you are rendering.

Discomforts and risks

Some of the questions you was asked are on intimate subject and may be embarrassing or make you uncomfortable. If this happens; you may refuse to answer if you choose. You may also stop the interview at any time. The interview may take about 20 minutes to complete.

Benefits

If you participate in this study you will help us to strengthen service provision on the children with ASD in Kenya and other Low-in- come countries in Africa. This research is critical to strengthening service delivery as it will generate new knowledge in this area of burden of service and quality of care that will inform decision makers to make decisions that are research based.

Rewards

There is no reward for anyone who chooses to participate in the study.

Confidentiality

Your name will not be recorded on the questionnaire and the questionnaires was kept in a safe place at the University.

Participant's Statement

The above statement regarding my participation in the study is clear to me. I have been given a chance to ask questions and my questions have been answered to my satisfaction. My participation in this study is entirely voluntary. I understand that my records was kept private and that I can leave the study at any time. I understand that I will not be victimized at my place of work whether I decide to leave the study or not and my decision will not affect the way I am treated at my work place.

Name of Participant: ………………………………………**ate**…………………………..

Signature……………………………………….

Investigator's Statement

I, the undersigned, have explained to the volunteer in a language s/he understands the procedures to be followed in the study and the risks and the benefits involved.

Name of Interviewer

Date……………………. **Interviewer Signature**………………………………………

Appendix II: Consent form [Kiswahili Version]

MAELEZO KUHUSU RIDHAA YA KUSHIRIKI KATIKA UTAFITI

Jina langu ni Damaris Osoro.Nasoma shahada ya uzamili ya saikolojia katika Chuo kikuu cha Nairobi Nafanya utafiti unaohusiana na mzigo wa kulea mtoto ambaye ameathiriwa na ugonjwa wa wigo wa autistic.Wsimamizi wangu ni Dr.Lincoln Khasakhala na Dr. Sobbie Mulindi ambao wote ni wahadhiri katika kitengo cha saikolojia,chuo kikuu cha Nairobi.Huu utafiti utafanywa na mimi mwenyewe chini ya wasimamizi wangu niliowataja hapo juu.Kupitia barua hii,ningeomba ushiriki wako katika utafiti huu wa kitabibu.pia ningependa kukueleza kwa ufupi kuhusu utaratibu mzima unaotumika katika utafiti wa kitaratibu.

a) Kushiriki kwako ni kwa hiari
b) Kukataa kwako kushiriki hakutaathiri kwa namna yoyote zile huduma za mtoto wako aliye chini ya uangalizi wako ambazo mnASDahili kupewa
c) Unaweza kusitisha ridhaa yako ya kushiriki wakati wowote na kitendo hiki hakitaadhiri kwa namna yoyote zile huduma ambazo motto aliye chini ya uangalizi wako anASDahili kupewa
d) Hakutakuwa kupewa hela ama zawadi zozote katika utafiti huu ila matokeo yake yatasaidia katika kuboresha huduma kwa watoto na walezi wa watoto walio na ugonjwa wa wigo wa autistic
e) Habari kuhusu huu utafiti zitabaki kuwa siri.Jina lako halitaandikwa popote katika ripoti itakayoandaliwa kufuatia utafiti huu,ila tu itakubidi kuandika jina lako katika fomu ya maridhiano ambayo itahifadhiwa tofauti na nyaraka zingine za utafiti.
f) Baada ya kuelezwa maelezo haya,usisite kuuliza maswali maswali endapo utahitaji ufafanuzi wowote.

Hatutakuwa na vitendo kama vile utolewaji wa damu katika utafiti huu na kwa hivyo hakutakuwa na athari zozote kwako.

Katika utafiti huu utaulizwa maswali kwa njia ya dodoso na zoezi zima litachukua kama dakika 20 mpaka 30.

FOMU YA RIDHAA YA KUSHIRIKI KATIKA UTAFITI

Mimi…………………………………………………………………….(jina la mtu anayemtunza mtoto)vaina mimi na mtoto huyu ni ifuatavyo:mimi ni(i)mzazi,(ii)mtu wa familia moja naye,au(iii)mlezi.

Nimekubali kwa hiari yangu kushiriki katika utafiti unaoongozwa na Damaris Osoro unaoitwa“RELATIONSHIP BETWEEN BURDEN OF CARE AND QUALITY OF LIFE AMONG CAREGIVERS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS (ASD) ATTENDING NAKURU LEVEL FIVE HOSPITAL.”Nimeelezwa kuhusu kuhusu lengo na utaratibu za utafiti huu kwa kiwango cha kuridhisha.

Sahihi au alama ya kidole gumba…………………………………………………………………Tarahe………………………..

Anwani………

Namba ya simu…….

Namba ya utafiti……

Shahidi (Damaris Osoro)…………………………………………..Namba ya Simu: 0721612361

Appendix III: Tools

Questionnaire

Section A: Social demographic information

1. Age……………..
2. Gender: Male [ ] Female [ ]
3. Level of education completed:
    a. None [ ]
    b. Primary [ ]
    c. Secondary [ ]
    d. Certificate [ ]
    e. Diploma [ ]
    f. Degree [ ]
    g. MASDers [ ]
    h. PhD [ ]
4. Marital status:
    a. Never married [ ]
    b. Married [ ]
    c. Divorced/Separated/ Widowed [ ]
5. What is your household monthly income (Ksh):……………..
6. What is the size of your household (number of persons who cook together)………….

Child's demographic factors

7. DOB: / /
8. Gender: Male [ ] Female [ ]

Section C: BURDEN ASSESSMENT SCHEDULE

BURDEN ASSESSMENT SCHEDULE (BAS)

Instruction for caregivers: *The questions above reflect how a person sometime feels when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There is no right or wrong answer.*

Section B

	Not at all	To some extent	Sometimes
1) Is your current financial position adequate to look after your ill family member?	3	2	1
2) Are you concerned that you are largely responsible to meet the ill family member's financial need?	1	2	3
3) Does the ill family member's future financial situation worry you?	1	2	3
4) Has your family's financial situation worsened since the diagnosis of your family member's illness?	1	2	3
5) Is the ill family member's condition preventing you from looking for a Job?	1	2	3
6) Do you feel forced into going to work to support your ill family member?	1	2	3
7) Does the ill family member condition affect your efficiency at work (at home/at work place)?	1	2	3
8) Are you satisfied with the way- your ill family member looks after him/herself?	1	2	3
9) Do you feel you have to take the responsibility of ensuring that the patient has everything he or she needs?	1	2	3
10) Do you think you have to compensate your family member's illness shortcomings in general?	1	2	3
11) Does support from your family help in caring for your family member's illness?	1	2	3

12) Does the patient cause disturbances in the home?	1	2	3
13) Are you able to care for others in your family?	1	2	3
14) Has your family stability been disrupted your family member’s illness (frequent quarrels, break-up)?	1	2	3
15) Do you think that your family appreciates the way you handle your family member’s illness?	1	2	3
16) Does your family member’s illness prevent you from having satisfying relationship with the rest of your family?	1	2	3
17) Does your spouse help with family responsibility?	3	2	1
18) Is your spouse able to fulfill you intimately?	3	2	1
19) Is your spouse still affectionate towards you?	1	2	3
20) Has the quality of your marital relationship declined since diagnosis of your family member’s illness?	1	2	3
21) Does caring for the patient make you feel easily tired and exhausted?	1	2	3
22) Has your workload increased since the diagnosis of your family member’s illness?	1	2	3
23) Do you think that your health has been affected because of your family member’s illness?	1	2	3
24) Do you find time to look after your health?	3	2	1
25) Are you able to relax for some time during the day?	3	2	1
26) Do you sometimes feel depressed and anxious because of your family member’s illness?	1	2	3
27) Do you sometimes feel that there is no solution to your family member’s illness?	1	2	3
28) Do you feel sometimes the need for temporary separation from your family member’s illness?	1	2	3
29) Does reducing the time spent with the patient (work/other activities) help you?	3	2	1

30) Does the patient's unpredictable behaviour disturb you?	1	2	3
31) Has your sleep been affected since the diagnosed your family member’s illness?	1	2	3
32) Does your family member’s illness prevent you from having satisfying relationships with the friends?	1	2	3
33) Have you started feeling lonely and isolated since the diagnosis of your family member’s illness?	1	2	3
34) Does support from friends help in caring for your family member’s illness?	3	2	1
35) Does sharing your problems with others make you feel better?	3	2	1
36) Do you feel that your friends appreciate the way you handle the patients?	3	2	1
37) Do you often feel frustrated that the improvement of your family member’s illness is slow?	1	2	3
38) Do you feel that you are doing more than the patient to improve his/her situation?	1	2	3
39) Do you have the feeling that your relative understands and appreciates your effort to help him/her?	3	2	1
40) Are you satisfied with the amount of help that you are getting from health professionals regarding your relative’s illness?	3	2	1

Adopted and modified from Burden Assessment Schedule of SCARF (1998)

KISWAHILI TRANSLATION OF (FBAS)

MCHANGO WA UFUNZO WA BURDEN (BAS)

Maelekezo kwa watunza huduma: Maswali hapo juu yanatafakari jinsi mtu anavyohisi wakati wa kutunza mtu mwingine. Baada ya kila taarifa, duru neno ambalo linaelezea mara ngapi unavyohisi kwa njia hiyo. Hakuna jibu sahihi au sahihi.

Sehemu B

Si kwa wakati mwingine Wakati mwingine

1) Je, msimamo wako wa kifedha unaofaa kwa kumtazama mwanachama wako wa mgonjwa? 3 2 1
2) Unajihusisha kuwa wewe ni wajibu mkubwa wa kukutana na mahitaji ya kifedha ya mwanadamu mgonjwa? 1 2 3
3) Je! Hali ya kifedha ya familia ya mgonjwa hukuhangaikia? 1 2 3
4) Je! Hali ya kifedha ya familia yako imepungua tangu ugonjwa wa mwanadamu wako? 1 2 3
5) Je, hali ya familia ya mgonjwa inakuzuia kutoka kwa kutafuta Ayubu? 1 2 3
6) Unajisikia kulazimika kwenda kufanya kazi ili kumsaidia mshirika wako wa mgonjwa? 1 2 3
7) Je, hali ya familia mbaya huathiri ufanisi wako wa kazi (nyumbani / mahali pa kazi)? 1 2 3
8) Je! UnASDahili na njia - mjumbe wako wa mgonjwa anajiangalia mwenyewe? 1 2 3
9) Unajisikia unapaswa kuchukua jukumu la kuhakikisha kwamba mgonjwa ana kila kitu anachohitaji? 1 2 3
10) Unadhani unapaswa kulipa fidia mapungufu ya wagonjwa wako kwa ujumla? 1 2 3
11) Je msaada kutoka kwa familia yako unasaidia katika kutunza ugonjwa wa mwanadamu? 1 2 3
12) Je, mgonjwa husababisha mvurugo nyumbani? 1 2 3
13) Je, unaweza kuwatunza wengine katika familia yako? 1 2 3

14) Je utulivu wa familia yako umevunja ugonjwa wa mwanadamu wako (ugomvi mara nyingi, kuvunjika)? 1 2 3

15) Je! Unafikiri kwamba familia yako inakubali jinsi unavyohusika na ugonjwa wa mwanadamu wako? 1 2 3

16) Je ugonjwa wa mwanadamu wako hukuzuia kuwa na uhusiano unaofaa na familia yako yote? 1 2 3

17) Je, mwenzi wako husaidia kwa wajibu wa familia? 3 2 1

18) Je! Mwenzi wako anaweza kukufanyia ufanisi? 3 2 1

19) Je, mwenzi wako bado ana upendo kwako? 1 2 3

20) Je, ubora wa uhusiano wako wa ndoa umeshuka tangu utambuzi wa ugonjwa wa mwanadamu wako? 1 2 3

21) Je, kumtunza mgonjwa hufanya uhisi uchovu na uchovu? 1 2 3

22) Je, kazi yako imeongezeka tangu utambuzi wa ugonjwa wa mwanadamu wako? 1 2 3

23) Unadhani kuwa afya yako imeathirika kutokana na ugonjwa wa mwanachama wako? 1 2 3

24) Je! Unapata muda wa kuangalia afya yako? 3 2 1

25) Unaweza kupumzika kwa muda fulani wakati wa mchana? 3 2 1

26) Je, wakati mwingine hujisikia unyogovu na wasiwasi kwa sababu ya ugonjwa wa mwanadamu? 1 2 3

27) Je! Wakati mwingine huhisi kwamba hakuna ugonjwa wa ugonjwa wa mwanadamu? 1 2 3

28) Je! Unasikia wakati mwingine haja ya kujitenga kwa muda mfupi na ugonjwa wa mwanadamu wako? 1 2 3

29) Je, kupunguza muda uliotumiwa na mgonjwa (kazi / shughuli zingine) kukusaidia? 3 2 1

30) Je! Tabia ya mgonjwa haitabiriki inakukosea? 1 2 3

31) Je usingizi wako umeathiriwa tangu ugonjwa wa mwanadamu wako umegundua? 1 2 3

32) Je! Ugonjwa wa mwanadamu wako hukuzuia kuwa na mahusiano ya kuridhisha na marafiki? 1 2 3

33) Je! Umeanza kujisikia upweke na kutengwa tangu utambuzi wa ugonjwa wa mwanadamu wako? 1 2 3
34) Je msaada kutoka kwa marafiki husaidia katika kutunza ugonjwa wa mwanadamu wako? 3 2 1
35) Je, kugawana matatizo yako na wengine kunawezesha kujisikia vizuri zaidi? 3 2 1
36) Je, unahisi kwamba marafiki zako wanathamini jinsi unavyowahudumia wagonjwa? 3 2 1
37) Je! Mara nyingi unahisi kuwa huzuni kuwa uboreshaji wa ugonjwa wa mwanadamu wako ni polepole? 1 2 3
38) Je! Unahisi kuwa unafanya zaidi kuliko mgonjwa ili kuboresha hali yake? 1 2 3
39) Je, una hisia kwamba jamaa yako inaelewa na inakubali jitihada zako za kumsaidia? 3 2 1
40) Je, unakidhi na kiasi cha msaada unachopata kutoka kwa wataalamu wa afya kuhusu ugonjwa wa ndugu yako? 3 2 1

Ilikubaliwa na kurekebishwa kutoka Ratiba ya Tathmini ya Burudani ya SCARF (1998)

FAMILY BURDEN ASSESSMENT SCHEDULE (FBAS)

QUESTIONNAIRE

Introduction to Questionnaire

Introduction: In the field of autism spectrum disorder ASD care, attention has been concentrated almost exclusively on the patients. In recent years, however, more concern has been shown towards the families, friends and others involved. You too are involved in the care of someone with mental health problems and this questionnaire has been designed to assess the personal consequences of such a situation for carer like yourself.

Completing the questionnaire: The questionnaire is divided into two sections, each representing a different aspect of caring. Each part is headed by a brief explanatory paragraph to lead you into the theme of the section. Only *one answer* is possible for each question, unless otherwise indicated please tick accordingly. In some cases, we will ask you to fill in a few personal details, such as your age. It is quite possible that in some cases, a question will not be relevant to your particular circumstances. The questionnaire will clearly indicate, therefor, which questions you can ignore and at which point you should start again.

The consequences of your caring for a child with ASD condition might have existed for several years already, but it is important to bear in mind that this questionnaire is mostly concerned with an analysis of the *current* situation. Most of the questions, therefor, cover your experiences during the *pASD four weeks,* whilst a few questions are about your more long-term experience. The questions themselves will make this clear

All information was treated confidentially, and you do not have to give your name if you do not wish to. If there are questions which you would prefer not to answer, we will, of course, respect your wishes - in this case, however, please write or respond *'no answer'* next to the question. Take your time to answer each question in turn and remember that what matters most of all is that your answers truly reflect your own personal experience.

Before we turn to the matter of your own experiences, we would first like to have some general information about you personally and about the relative/friend you are caring for.

CLIENT AND INFORMANT DETAILS

1. *What is your age group? (years)*
    - a) (15 – 24) ☐
    - b) (25 – 34) ☐
    - c) (35 – 44) ☐
    - d) (45 – 54) ☐
    - e) (55 – 64) ☐

2. *What's your gender?*
    - a) Female ☐
    - b) Male ☐

3. What's your highest Educational?
- a) Primary school level ☐
- b) Secondary school level ☐
- c) Post-Secondary level ☐
- d) other (specify) ☐

4. What is your civil status (marital status)?
- a) single ☐
- b) married ☐
- c) Separated ☐
- d) Divorced ☐
- e) Widowed ☐
- f) Living with a partner ☐
- g) Others (specify) ☐

5. What is your relationship to the person you are caring for?

I am her/his
- a) Parents - mother/father ☐
- b) Step and foster parents ☐
- c) Sibling - sister/brother ☐

7. What's the gender of the child living with ASD?
- a) Female ☐
- b) Male ☐

8. At what age was your diagnosed with ASD? ……………………………

9. Do you get State/ Government support in addressing your child's ASD condition?
- *a)* Yes ☐
- b) No ☐

10. Is the child currently attending a special school yes or no

11. Is the school related to ASD?
- *a)* Yes ☐
- *c)* No ☐

d) Grandparents ☐
e) Neighbor ☐
f) Other (please indicate) ☐

6. What is the age group of the child living with ASD?(years)

a) (3 – 6) ☐
b) (7 – 13) ☐
c) (14 – 18) ☐
d) Less than 3 years? ☐

12. What other support activities is the child living with ASD currently receiving?

a. Applied Behaviour Analysis ☐
b. Speech therapy ☐
c. Physiotherapy ☐
d. Homeopathy ☐
e. Occupational therapy ☐
f. Nutritional therapy ☐
g. Others (please name them) ☐

FAMILY BURDEN ASSESSMENT SCHEDULE

Instruction for caregivers: *The questions above reflect how a person sometime feels when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There is no right or wrong answer.*

Section B

	Not at all	To some extent	Sometimes
1) Is your current financial position adequate to look after the child living with ASD?	3	2	1
2) Does the child's future financial situation worry you?	1	2	3
3) Are you concerned that you are largely responsible to meet the ASD child financial need?	1	2	3
4) Has your family's financial situation worsened since the diagnosis of the child with ASD?	1	2	3
5) Is the child's condition preventing you from looking for a Job?	1	2	3
6) Do you feel forced into going to work to support the child's condition?	1	2	3
7) Does the child's condition affect your efficiency at work (at home/at work place)?	1	2	3
8) Are you satisfied with the way-the child looks after him/herself?	1	2	3
9) Do you feel you have to take the responsibility of ensuring that the child living with ASD has everything he or she needs?	1	2	3
10) Do you think you have to compensate the child's shortcomings in general?	1	2	3
11) Does support from your family help in caring for the child?	1	2	3

12) Does the child living with ASD cause disturbances in the home?	1	2	3
13) Are you able to care for others in your family?	1	2	3
14) Has your family stability been disrupted by the child's condition (frequent quarrels, break-up)?	1	2	3
15) Do you think that your family appreciates the way you handle the child's condition?	1	2	3
16) Does the child's condition prevent you from having satisfying relationship with the rest of your family?	1	2	3
17) Does your spouse help with family responsibility?	3	2	1
18) Is your spouse able to fulfill you intimately?	3	2	1
19) Is your spouse still affectionate towards you?	1	2	3
20) Has the quality of your marital relationship declined since diagnosis of the child condition?	1	2	3
21) Does caring for the child living with ASD make you feel easily tired and exhausted?	1	2	3
22) Has your workload increased since the diagnosis of the child's with ASD?	1	2	3
23) Do you think that your health has been affected because of the child's ASD condition?	1	2	3
24) Do you find time to look after your health?	3	2	1
25) Has your sleep been affected since the child's was diagnosed with ASD condition?	1	2	3
26) Do you sometimes feel depressed and anxious because of child's ASD condition?	1	2	3

27) Do you sometimes feel that there is no solution to your child’s ASD condition?	1	2	3
28) Do you feel sometimes the need for temporary separation from the child?	1	2	3
29) Does reducing the time spent with the child living with ASD (work/other activities) help you?	3	2	1
30) Does the child living with ASD's unpredictable behaviour disturb you?	1	2	3
31) Are you able to relax for some time during the day?	3	2	1
32) Does your child ASD condition prevent you from having satisfying relationships with the friends?	1	2	3
33) Have you started feeling lonely and isolated since the diagnosis of the child’s condition?	1	2	3
34) Does support from friends help in caring for the child living with ASD?	3	2	1
35) Does sharing your problems with others make you feel better?	3	2	1
36) Do you feel that your friends appreciate the way you handle the child living with ASDs?	3	2	1
37) Do you often feel frustrated that the improvement of the child’s condition is slow?	1	2	3
38) Do you feel that you are doing more than the child living with ASD need to improve his/her situation?	1	2	3
39) Do you have the feeling that your relative understands and appreciates your effort to help him/her?	3	2	1

40) Are you satisfied with the amount of help that you are getting from health professionals regarding your child’s condition?	3	2	1
41) Are you worried that your child may not manage to take up a job?	3	2	1
42)Are you worried that your child may not attain certain social skills	3	2	1
43) Do your child stereotypical behaviours (if any) worry you?	3	2	1
44) Are you worried that your child living with ASD may not entirely be independent in the future?	3	2	1
45) Are you satisfied with the amount of help that you are getting from different professionals to your child your child’s condition?	3	2	1
46) Are you satisfied with the quality of schooling your child gets?	3	2	1

Adopted and modified from Burden Assessment Schedule of SCARF (1998)

Kabla kuzungumzia hisia zako cha awali habari za kimsingi kukuhusu na mwanao/jamaa yako unae mtizama

TAARIFA ZA WATEJA NA WAHOJIWA

1. Taja rika lako? (miaka) a) (15-24) b) (25-34) c) (35-44) d) (45-54) e) (54-64)	7. Mtoto anayeishi na usonjo (ASD) ni wa jinsia gani? a) Kike b) Kiume
2. Taja jinsia yako? a) Kike b) Kiume	*8. Usonjo wa mwanao ulitambuliwa akiwa na miaka ngapi?* ……………………………
3. Taja kiwango chako cha juu cha elimu? e) Kiwango cha shule ya msingi f) Kiwango cha shule ya sekondari g) Kiwango cha baada ya sekondari h) Nyingineo (fafanua)	8. Je unapata usaidizi wa serikali katika uangalizi wa hali ya usonjo (ASD) ya mtoto wako? d) Ndio e) Hapana
4. Taja hali yako ya ndoa? h) Sijaoa i) Nimeoa/Nimeolewa j) Tumetengana k) Nimeachika l) Nimefiwa m) Ninaishi na mwenza (bila ndoa) n) Nyingineo (fafanua)	9. Je mtoto huyo yupo katika shule maalaum a) Ndio b) Hapana

5. Taja uhusiano wako na mtu unayemchunga? Mimi ni g) Mzazi wake – baba/mama h) Mzazi wa kambo na mzazi mlezi i) Ndugu – dada/kaka j) Babu/Nyanya k) Jirani l) Mwingineo (tafadhali taja)	10. Je shule hio inahusiana na usonjo (ASD)? a) Ndio b) Hapana
6. Je ni mtoto anayeishi na usonjo (ASD) ana rika gani? (miaka) a) (3-6) b) (7-13) c) (14-18) d) Chini ya miaka mitatu (3)?	11. Kuna shughuli nyingine za kimsaada mtoto aishie na usonjo anazipata kwa sasa? a. Uchambuzi shirikishi wa kitabia b. Tiba ya kuzungumza c. Tiba ya kimwili d. Tiba ya nyumbani (homoetherpy) e. Tiba ya kikazi f. Tiba ya kimlo (chakula) g. Nyinginezo (tafadhali zitaje)

JEDWALI LA TATHMINI YA MZIGO WA FAMILIA

Maelekezo kwa watoa huduma: Maswali haya yanaeleza jinsi mtu kwa nyakati nyingine anahisi anapokua akimhudumia mtu mwingine. Baada ya kila taarifa, tia alama neno ambalo linaelezea jinsi unavohisi. Hamna jibu sahihi wala lisilo sahihi. **Sehemu B**

	Hapana Kabisa	Kwa kiasi fulani	Kwa mara nyingine
1) Je hali yako ya sasa ya kiuchumi inakuwezesha kumhudumia kabisa mtoto anayeishi na usonjo (ASD)?	3	2	1
2) Je hali ya kiuchumi ya baadae ya mtoto inakuogopesha?	1	2	3
3) Je una wasiwasi kwamba unajukumu kubwa la kukidhi mahitaji ya kifedha ya mtoto aliye na usonjo (ASD)	1	2	3
4) Je hali ya kiuchumi ya familia yeny imetetereka baada ya kugundua hali ya usonjo (ASD) ya mtoto?	1	2	3
5) Je hali ya mtoto iankuzuia kutafuta kazi?	1	2	3
6) Je unalazimika kwenda kufanya kazi ilikumsaidia mtoto huyo?	1	2	3
7) Je hali hio ya mtoto inaathiri ubora wa kazi yako (nyumbani ama kazini)?	1	2	3
8) Je unaridhishwa na jinsi mtoto anajitunza?	1	2	3
9) Je unahisi una wajibu wa kumhudumia na kuhakikisha mtoto anayeishi na usonjo (ASD) ana kila kitu anachohitaji?	1	2	3
10) Je unadhani unabidi kufidia mapungufu ya mtoto huyo kwa ujumla?	1	2	3
11) Msaada kutoka kwa familia yako unasaidia katika kumhudumia mtoto?	1	2	3
12) Je mtoto anayeishi na usonjo (ASD) analeta usumbufu nyumbani?	1	2	3

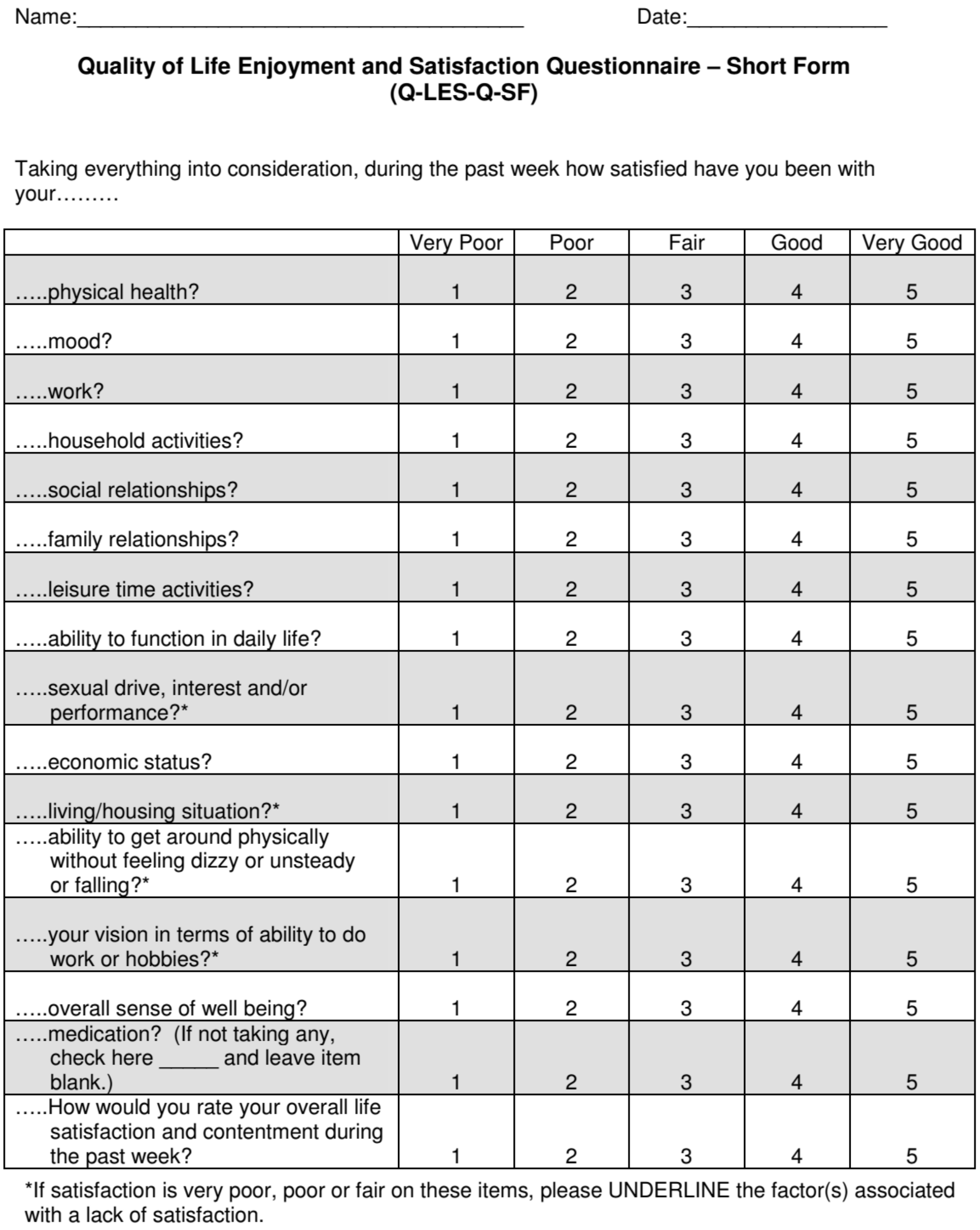
13) Unaweza wa kuwahudumia wengine katika familia?	1	2	3
14) Utulivu wa familia yako umevurugwa na hali ya mtoto (malumbano ya mara kwa mara, utengano)?	1	2	3
15) Unadhani familia yako inathamini jinsi unavyoichukulia hali ya mtoto?	1	2	3
16) Je hali ya mtoto inakuzuia kuwa na uhusiano wa kutosheleza na wengine katika familia yako?	1	2	3
17) Je mwenza wako anasaidia katika majukumu ya kifamilia?	3	2	1
18) Mwenza wako anaweza kukutosheleza kimapenzi?	3	2	1
19) Je mwenza wako bado anavutiwa na wewe?	1	2	3
20) Je hali yenu ya ndoa imezorota baada ya kugundulika kwa hali ya mtoto?	1	2	3
21) Je kumhudumia mtoto anayeishi na usonjo (ASD) kunakufanya uchoke haraka?	1	2	3
22) Je kazi zako zimeongezeka baada ya kugundulika kwa hali ya usonjo (ASD) kwa mtoto?	1	2	3
23) Je unadhani hali yako ya afya imeathirika kutokana na hali ya usonjo (ASD) ya mtoto?	1	2	3
24) Je unapata nafasi ya kuchunguza afya yako?	3	2	1
25) Je usingizi wako umeathirika tangia kugundulika kwa hali ya usonjo (ASD) ya mtoto?	1	2	3
26) Je kwa wakati mwingine unahisi msongo wa mawazo au wasiwasi kutokana na hali ya usonjo (ASD) ya mtoto?	1	2	3
27) Je wakati mwingine unahisi kama hamna suluhisho la hali ya usonjo (ASD) ya mtoto wako?	1	2	3
28) Je kwa wakati mwingine unahisi uhitaji wa kutengana kwa muda na mtoto?	1	2	3

29) Je kupunguza kwa wakati unaotumia na mtoto anayeishi na usonjo (ASD) (kazi/ama shughuli nyingine) kunakusaidia?	3	2	1
30) Je tabia isioleweka ya mtoto anayeishi na usonjo (ASD) inakusumbua?	1	2	3
31) Je unaweza kupumzika kwa muda wakati wa mchana?	3	2	1
32) Je hali ya usonjo (ASD) ya mtoto wako inakuzuia kuwa na uhusiano mzuri na marafiki zako?	1	2	3
33) Umeanza kuhisi mpweke na kutengwa tangia kugunduliwa kwa hali ya mtoto?	1	2	3
34) Je usaidizi kutoka kwa marafiki kunasaidia kumhudumia mtoto anayeishi na usonji (ASD)	3	2	1
35) Je kutaja matatizo yako kwa wengine kunakufanya ujisikie afadhali?	3	2	1
36) Unahisi marafiki zako wanathamini jinsi unavomhudumia mtoto anayeishi na usonjo (ASD)?	3	2	1
37) Je wakati mwingine unahisi kukata tamaa ukidhani kuimarika kwa hali ya mtoto inachukua muda?	1	2	3
38) Je unahisi kwamba unafanya zaidi ya jinsi kuimarika kwa hali ya mtoto mwenye usonjo (ASD)?	1	2	3
39) Je unahisi kwamba ndugu zako wanaelewa na kuthamini jitihada zako za kumsaidia mtoto?	3	2	1
40) Je unaridhishwa na kiwango cha usaidizi unachopata kutoka kwa wataalam wa afya kuhusiana na hali ya mtoto wako?	3	2	1
41) Je unahofu kwamba mtoto wako anaweza asifanye/asipate kazi?	3	2	1

42) Unahofu mtoto wako huenda asipate baadhi ya stadi za kijamii?	3	2	1
43) Je tabia fulani (kama zipo) za mtoto zinakupa wasiwasi?	3	2	1
44) Je una wasiwasi kwambo tatizo la usonjo (ASD) la mtoto wako litamfanya asiweze kujimudu peke yake siku za baadae?	3	2	1
45) Unaridhishwa na kiwango cha usaidizi unachokipata kutoka kwa wataalam mbalimbali kwajili ya hali ya mtoto wako?	3	2	1
46) Unaridhishwa na ubora wa kufundishwa (elimu) anayopata mtoto wako?	3	2	1

Adopted and modified from Burden Assessment Schedule of SCARF (1998)

Section D: WHO- Quality of Life (QOL)-BREF



Name:______________________________________ Date:_________________

Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF)

Taking everything into consideration, during the past week how satisfied have you been with your………

	Very Poor	Poor	Fair	Good	Very Good
…..physical health?	1	2	3	4	5
…..mood?	1	2	3	4	5
…..work?	1	2	3	4	5
…..household activities?	1	2	3	4	5
…..social relationships?	1	2	3	4	5
…..family relationships?	1	2	3	4	5
…..leisure time activities?	1	2	3	4	5
…..ability to function in daily life?	1	2	3	4	5
…..sexual drive, interest and/or performance?*	1	2	3	4	5
…..economic status?	1	2	3	4	5
…..living/housing situation?*	1	2	3	4	5
…..ability to get around physically without feeling dizzy or unsteady or falling?*	1	2	3	4	5
…..your vision in terms of ability to do work or hobbies?*	1	2	3	4	5
…..overall sense of well being?	1	2	3	4	5
…..medication? (If not taking any, check here _____ and leave item blank.)	1	2	3	4	5
…..How would you rate your overall life satisfaction and contentment during the past week?	1	2	3	4	5

*If satisfaction is very poor, poor or fair on these items, please UNDERLINE the factor(s) associated with a lack of satisfaction.

Scoring the Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF)

The scoring of the Q-LES-Q-SF involves summing only the first 14 items to yield a raw total score. The last two items are not included in the total score but are stand-alone items. The raw total score ranges from 14 to 70. The raw total score is transformed into a percentage maximum possible score using the following formula:

$$\frac{\text{(raw total score} - \text{minimum score)}}{\text{(maximum possible raw score} - \text{minimum score)}}$$

The minimum raw score on the Q-LES-Q-SF is 14, and the maximum score is 70. Thus the formula for % maximum can also be written as (raw score −14)/56. The table below converts total raw scores into % maximum scores.

Raw Score	% Maximum	Raw Score	% Maximum	Raw Score	% Maximum	Raw Score	% Maximum
14	0	28	25	42	50	56	75
15	2	29	27	43	52	57	77
16	4	30	29	44	54	58	79
17	5	31	30	45	55	59	80
18	7	32	32	46	57	60	82
19	9	33	34	47	59	61	84
20	11	34	36	48	61	62	86
21	13	35	38	49	63	63	88
22	14	36	39	50	64	64	89
23	16	37	41	51	66	65	91
24	18	38	43	52	68	66	93
25	20	39	45	53	70	67	95
26	21	40	46	54	71	68	96
27	23	41	48	55	73	69	98
						70	100

Jina: ____ Tarehe: __________________

Swali la Maisha ya Kufurahi na Uradhi - Fomu fupi (Q-LES-Q-SF)

Kuchukua kila kitu kuzingatiwa, wakati wa wiki iliyopita ulikuwa umeridhika na ....

	Mbaya	maskini sana	kadri	Nzuri	Nzuri sana
	1	2	3	4	5
... afya ya afya					
... ..mood?					
... kazi?					
... .. shughuli za nyumba?					
... mahusiano ya kijamii?					
mahusiano ya familia?					
shughuli za wakati wa burudani?					
.. uwezo wa kufanya kazi katika maisha ya kila siku?					
gari la ngono, maslahi na / au utendaji?					
... hali ya kikononi?					
hali / nyumba hali					
uwezo wa kuzunguka kimwili					
bila hisia ya kizunguzungu au isiyojumuisha au kuanguka?					
... maono yako katika suala la uwezo wa kufanya kazi au utamani?					
ufahamu zaidi wa kuwa vizuri?					
dawa? (Kama si kuchukua yoyote, angalia hapa _____ na uondoe kipengee tupu.)					
.. Je, unaweza kiwango cha maisha yako yote kuridhika na kuridhika wakati wiki iliyopita?					

* Ikiwa kuridhika ni maskini sana, kuna maskini au haki juu ya vitu hivi, tafadhali UNDERLINE sababu (s) inayohusishwa na ukosefu wa kuridhika.

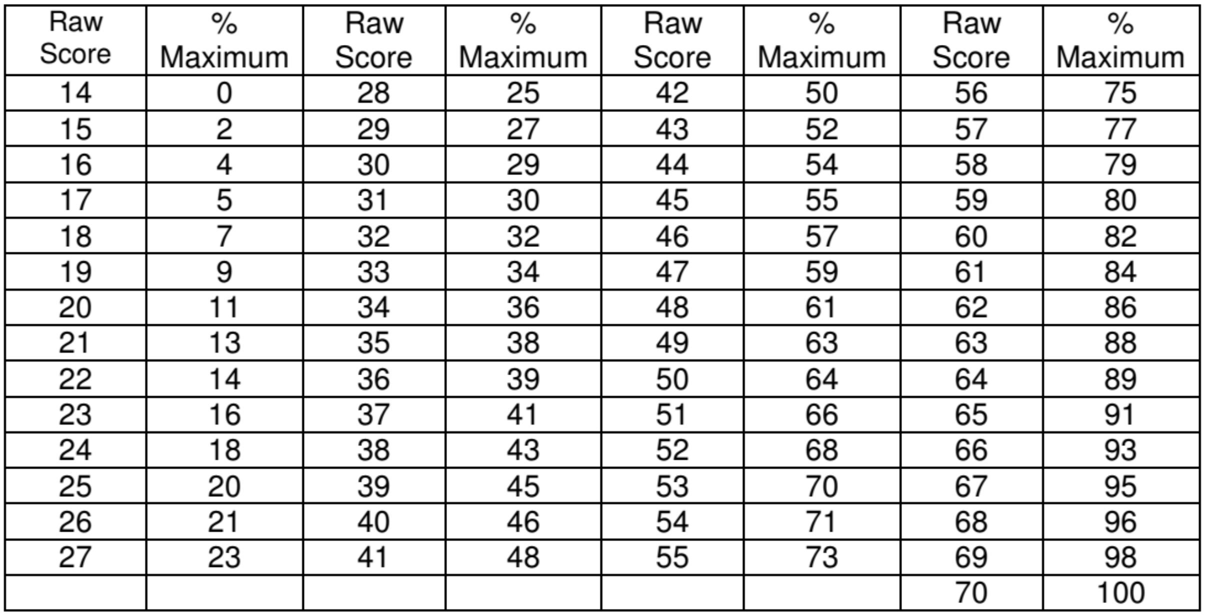
Kutoa Ubora wa Maisha ya Furaha na Uradhi - Fomu fupi (Q-LES-Q-SF)

Makosa ya Q-LES-Q-SF yanahusisha kuhesabu tu vitu 14 vya kwanza ili kutoa alama ya jumla ya ghafi. Vipengele viwili vya mwisho havijumuishwa kwenye alama ya jumla lakini ni vitu vinavyosimama. Kiwango cha jumla cha alama ya ghafi kutoka 14 hadi 70. alama ya jumla ya ghafi inabadilishwa alama ya kiwango cha asilimia inayowezekana kwa kutumia formula ifuatayo:

(alama ghafi ya alama-kiwango cha chini)

(kiwango cha juu cha alama za kiwango cha chini cha alama)

Alama ya chini ya Q-LES-Q-SF ni 14, na alama ya kiwango cha juu ni 70. Hivyo formula ya% ya juu inaweza pia kuandikwa kama (ghafi alama -14) / 56. Jedwali hapa chini inabadilisha alama za ghafi za jumla kwa alama ya kiwango cha juu.



Raw Score	% Maximum	Raw Score	% Maximum	Raw Score	% Maximum	Raw Score	% Maximum
14	0	28	25	42	50	56	75
15	2	29	27	43	52	57	77
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22	14	36	39	50	64	64	89
23	16	37	41	51	66	65	91
24	18	38	43	52	68	66	93
25	20	39	45	53	70	67	95
26	21	40	46	54	71	68	96
27	23	41	48	55	73	69	98
						70	100

Tahadhari ya Hakimiliki: Maswala ya Ustawi na Ustawi wa Ubora - Fomu fupi (Q-LES-Q-SF) imechukuliwa na Jean Endicott, Ph.D. Ruhusa imetolewa ili kuzalisha wadogo kwenye tovuti hii kwa waalimu kufanya matumizi yao na kwa watafiti kutumia katika tafiti zisizo za sekta. Kwa matumizi mengine ya kiwango, mmiliki wa hakimiliki anapaswa kuwasiliana.

Early Screening for Autistic Traits (ESAT) /

Kuchunguza mapema kwa sifa za Autistic (KMAT)

No.	Swali	Yes/ Ndiyo	No/ Hapana
1.	Is your child interested in different sorts of objects, and not for instance mainly in cars or buttons? Je, mtoto wako anavutiwa na aina mbalimbali za vitu, na si kwa mfano hasa katika magari au vifungo?		
2.	Can your child play with toys in varied ways (not just fiddling, mouthing or dropping them)? Je, mtoto wako anaweza kucheza na vidole kwa njia mbalimbali (sio tu kuzungumza, kuzungumza au kuacha)?		
3.	When your child expresses his/her feelings, for instance by crying or smiling, is that mostly on expected and appropriate moments? Wakati mtoto wako akielezea hisia zake, kwa mfano kwa kulia au kusisimua, ni kwamba hasa wakati uliotarajiwa na unaofaa?		
4.	Does your child react in a normal way to sensory stimulation, such as (coldness, warmth), light, sound, pain or tickling? Je, mtoto wako anaitikia kwa njia ya kawaida ya kuchochea hisia, kama vile baridi (joto, joto), mwanga, sauti, maumivu au kicheko?		
5.	Can you easily tell from the face of the child how he/she feels? Je! Unaweza kusema kwa urahisi kutoka kwa uso wa mtoto jinsi anavyohisi?		
6.	Is it easy to make eye contact with your child? Je, ni rahisi kumwomba mtoto wako kwa macho?		
7.	When your child has been left alone for some time, does he/she try to attract your attention, for instance by crying or		

	calling? Wakati mtoto wako ameachwa peke yake kwa muda fulani, anajaribu kukuvutia, kwa mfano kwa kulia au wito?		
8.	Is the behavior of your child without stereotyped repetitive movements like banging his/her head or rocking his/her whole body? Je, ni tabia ya mtoto wako bila harakati za kurudia mara kwa mara kama kumpiga kichwa chake au kugonga mwili wake wote?		
9.	Does your child, on his/her own accord, ever bring objects over to you or show you something? Je, mtoto wako, kwa kibinafsi, analeta vitu juu yako au kukuonyesha kitu?		
10.	Does your child show to be interested in other children or adults? Je mtoto wako anaonyesha kuwa na hamu kwa watoto wengine au watu wazima?		
11.	Does your child like to be cuddled? Je, mtoto wako anapenda kuwa cuddled?		
12.	Does your child ever smile at you or at other people? Je, mtoto wako anakuchemshe au wewe au watu wengine?		
13.	Does your child like playing games with others, such as peeka-boo, ride on someone’s knee, or to be swung? Je, mtoto wako anapenda kucheza michezo na wengine, kama vile peeka-boo, wapanda magoti ya mtu, au kurusha juu na jini kama ameshikwa?		
14.	Does your child react when spoken to, for instance, by looking, listening, smiling, speaking or babbling? Je, mtoto wako anaitikia wakati akizungumzwa naye, kwa mfano, kwa kutazama, kusikiliza, kusisimua, kuzungumza au kupiga kelele?		

15.	Does your child speak a few words or utter various babbling sounds? Je! Mtoto wako anazungumza maneno machache au kusema sauti mbalimbali za kupiga sauti?		
16.	When you are pointing at something, does your child follow your gaze to see what you are pointing at? Unapoelezea jambo fulani, je, mtoto wako hufuata macho yako ili kuona kile unachozungumzia?		
17.	Does your child ever use his/her index finger to point, to indicate interest in something? Je! Mtoto wako hutumia kidole chake cha kuashiria, kuonyesha nia ya kitu?		
18.	Does your child ever use his/her index finger to point, to ask for something? Je, mtoto wako hutumia kidole chake cha kuashiria, kuomba kitu?		
19.	Does your child ever pretend, for example, to make a cup of tea using a toy cup and teapot, or pretend other things? Je, Mtoto wako anajifanya, kwa mfano, kufanya kikombe cha chai kwa kutumia kikombe cha toy na teapot, au kujifanya vitu vingine?		

Appendix IV: Turnitin Originality Report

RELATIONSHIP BETWEEN BURDEN OF CARE AND QUALITY OF LIFE AMONG CAREGIVERS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDERS (ASD) ATTENDING NAKURU LEVEL FIVE HOSPITAL, NAKURU COUNTY by Damaris Osoro

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