UNIVERSITY OF NAIROBI

HEALTH-RELATED QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSYAT KENYATTA NATIONAL HOSPITAL

A research dissertation in partial fulfillment for the degree of Masters of Medicine (Paediatrics and Child Health), University of Nairobi.

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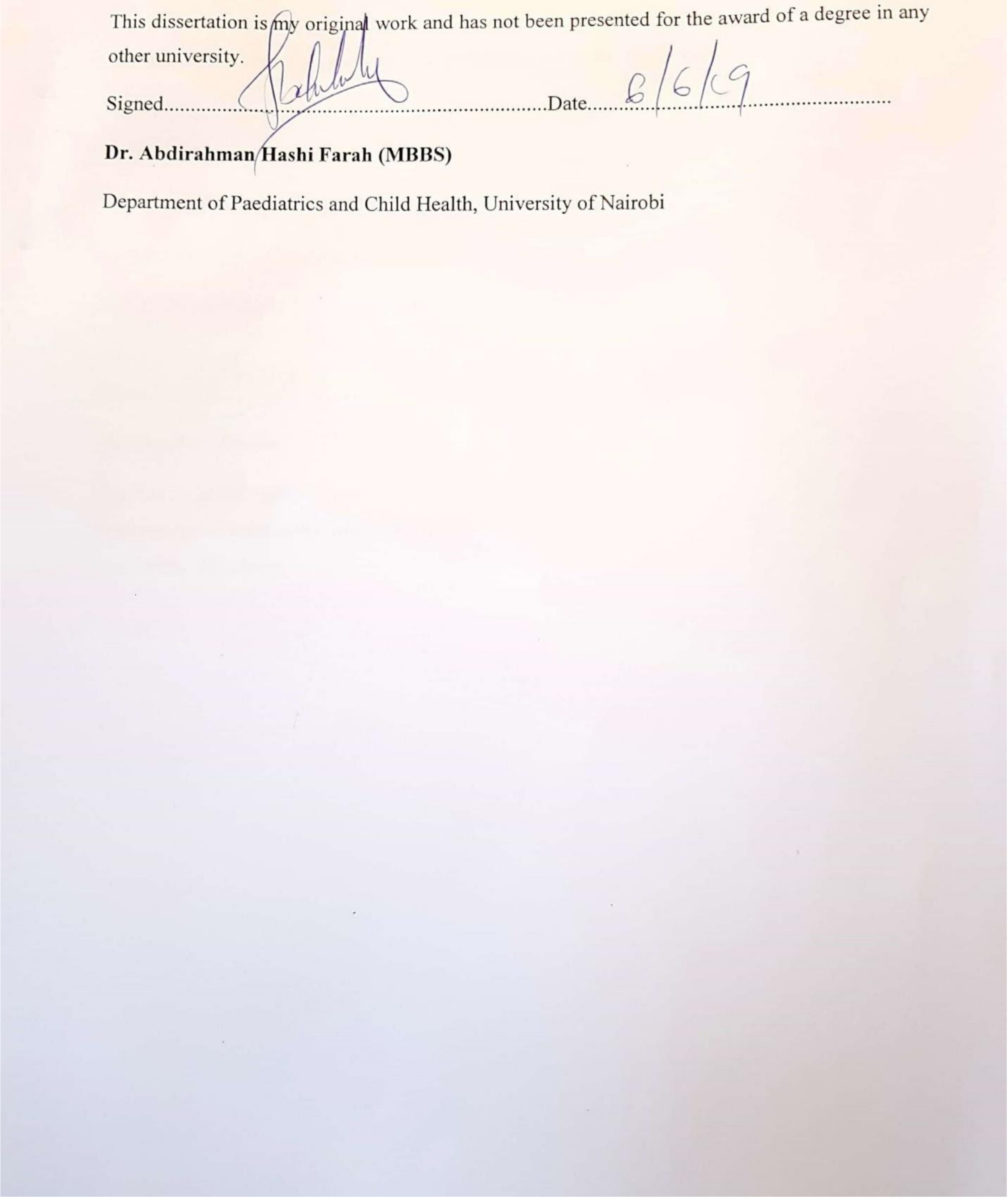
Student's Declaration



This dissertation is my original work and has not been presented for the award of a degree in any other university.

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Abbreviations

BDI – Beck Depression Inventory

CDC – Centers for Disease Control and Prevention

CP – Cerebral Palsy

CPSK – Cerebral Palsy Society of Kenya

ENT – Ear, Nose and Throat

GMFCS – Gross Motor Function Classification System

HRQoL – Health-related Quality of Life

KNH – Kenyatta National Hospital

KNH-UON ERC – Kenyatta National Hospital – University of Nairobi Ethics and Research Committee

LQoL – Low Quality of Life

MOH – Ministry of Health

PI – Principal Investigator

QoL – Quality of Life

SF-36 – 36-Item Short Form Health Survey

sd – Standard deviation

UON – University of Nairobi

WHO – World Health Organization

Definitions:

Health-related Quality of Life: Health-related quality of life (HRQOL) is a multi-dimensional concept that is used to assess the impact of health status on quality of life. The terms Quality of life and Health-related Quality of life are often used interchangeably.

Caregiver: According to The Kenya National Council for Children's Services (2011) a caregiver is defined as a person responsible for the care and wellbeing of children in all contexts.

Primary Caregiver: can be biological parents, children in the family, relatives and house helps (ayahs).

Chronic Illnesses: According to Center for Disease Control and Prevention (CDC), chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.

Abstract

Background

Providing care to any sick child involves the use of extensive resources. There is more demand for these resources when the child involved has a disability. Children suffering from cerebral palsy have physical, mental, emotional and social disabilities and require long-term specialized care in order to meet their needs. This cans adversely affect the health-related quality of life of their caregivers.

Broad Objective: To determine the health-rated quality of life of primary caregivers of children with cerebral palsy at Kenyatta National Hospital.

Methodology: Hundred primary caregivers (50 caregivers of children with CP and 50 caregivers of children without chronic illnesses) took part in this cross-sectional study. In both groups, the participants had their health-related quality of life (HRQoL) evaluated using Short Form Health Survey (SF-36). Interviewer-administered questionnaire was used to gather socio-demographic characteristics of the caregivers. Functional ability of children with cerebral palsy were assessed using Gross Motor Function Classification System (GMFCS).Data was analyzed using SPSS version 23.0. HRQoL scores were analyzed and presented as means with standard deviations. Tests of associations and comparison of means were analyzed using fisher's exact test, Chi-square, independent t-test and ANOVA with P value set at 0.05.

Results: Primary caregivers of 50 children with CP were studied and compared with an equal number of primary caregivers of children without chronic illnesses. The mean age of the caregivers of children with CP was 32.7 years (sd 6.7 years) and 96% females taking care of children with CP with an average age of 4.7 years (sd 2.9 years) and 52% females. Unemployment rate was 50%for the caregivers with children suffering from CP with 60% earning less than kshs20,000 a month. The mean HRQOL score of caregivers of children with CP was 67.5 (sd 17.3) which was lower than the comparison group (p=0.001). The scores for the domains of vitality, mental health and social functioning as well as those of physical functioning and role limitations due to emotional problems were also lower in the study group. Caregivers of children with CP with GMFCS levels and V scored higher than the others in the domain of general health. Caregivers' age and their monthly income influenced the health-related quality of life scores of caregivers with children suffering from CP.

Conclusions: The health-related quality of life of primary caregivers with children suffering from cerebral palsy was noted to be significantly lower than that of caregivers of children without chronic illnesses. The negative impact was apparent in the domains of vitality, mental health, social functioning, physical functioning, role limitations due to emotional problems, and the overall HRQoL. Factors such as caregivers’ income and age significantly correlated with low HRQoL in caregivers of children suffering from CP.

Chapter one: Introduction and Background

1.0. Background/Introduction

Cerebral palsy (CP) is a condition that affects the development of movement and posture leading to limitations in activities which are attributed to non-progressive disturbances that occur in the brain of a fetus or an infant. The disturbances of motor in cerebral palsy can also be accompanied by impairments in cognition, perception, sensation, communication and/or seizure disorder.(1).

CP is a common cause of disability in children in the world, with the greatest burden occurring in countries of the developing world(2). It is estimated to affect 2-2.5 of 1000 live births globally (3) while in Africa, prevalence varies from one country to another from approximately 2-10 per 1000 live births(4–6).Functional challenges resulting from physical, social, emotional and cognitive disorders make children suffering from CP unable to perform their duties in society(7,8). They often depend on others for their activities of daily living including basic self-care (9,10), while those who require assistance with movement demanding more time from their caregivers(11). Children with CP also require specialized multidisciplinary care, physiotherapy, occupational therapy as well as continuous medical checkups(11).

Caring for a child is a responsibility that every parent faces in their life. This responsibility takes a different meaning when the child involved has functional deficits. The main challenge encountered by caregivers of children with cerebral palsy is to choose between dealing with their children's chronic health problems and focusing on their lives(12). Caregivers often sacrifice their personal ambitions in life in order to dedicate their time caring for their children(13). The longstanding commitment to the care of children with cerebral palsy can have a negative effect on the health-related quality of life (HRQoL) of caregivers(14).

The World Health Organization (WHO) defines quality of life as the way an individual perceives their position in life according to their culture and values and how they connect to their expectations and goals in life(15).HRQoL involves domains that include physical, mental, emotional, and social functioning (16). The terms quality of life and health-related quality of life have been applied interchangeably in literature(17).The evaluation of HRQoL has been and continues to be a subject of study involving different medical conditions in which various instruments of measurement have been employed(18).

The existence of low health-related quality of life among primary caregivers of children with cerebral palsy has been documented in literature(19–21)and shows that caregivers are being affected negatively in various domains. A study by *Halim et al* (2013) explains that caregivers caring for children suffering from CP scored lower in the mental, social, emotional and vitality aspects of SF-36 compared with those with healthy children(22). All these(22) negatively affect the health-related quality of life of the family members and in particular that of the immediate caregivers.

In Kenya, various studies have looked at the impact other diseases such as cerebral malaria have on the quality of life of the mother and the affected child and also how cerebral palsy affects the quality of life of the child (23–26), however; no comprehensive study has been done to evaluate the impact cerebral palsy has on the health-related quality of life of the primary caregivers who nurse these children.

According to cerebral palsy society of Kenya, 3 in 100 children are living with cerebral palsy and they require full- time care which mostly comes from their mothers. Some of the mothers are forced to quit their jobs and assume full responsibility of taking care of these children. Others get sacked from employment due to lack of government protection. All these are likely to affect the psychological and emotional wellbeing of these caregivers. The end result is poor health and/or low quality of life for the primary caregivers(27). It is on this premise that the study seeks to establish the health-related quality of life of primary caregivers having children suffering from cerebral palsy and also to identify factors that are associated with health-related quality of life among caregivers of children suffering from cerebral palsy.

Chapter Two: Literature Review

2.1. Health-related quality of life of primary caregivers of children with Cerebral Palsy

Caring for a child that is suffering from a chronic disability such as cerebral palsy can have an adverse effect on the health-related quality of life (QoL) of caregivers. Different facets of the health-related quality of life of primary caregivers of children suffering from cerebral palsy are affected including physical, mental, emotional and social domains (22).

In the study of *Yilmaz et al* (2013) that investigated the QoL of 137 mothers of children having cerebral palsy compared with 140 mothers of children that were healthy, the mothers of children with CP scored significantly lower in the mental, social, emotional and the vitally aspects of SF-36 health survey compared to controls ($p<0.001$). It was also observed that mothers of children suffering from cerebral palsy scored poorly in the Beck Depression Inventory (BDI) than controls, a 21-item scale that assesses key symptoms of depression, with those scoring BDI ≥ 17 evaluated in favour of depression. Depressed mothers scored poorer in all the domains of SF-36 survey(22).

Primary caregivers of children with cerebral palsy exhibit physical pain depending on the degree of motor disability in their children. Those caring for more dependent children were found to have worse bodily pain compared to those caring for less dependent children. This becomes more evident as the child becomes older and heavier (28,29). *Brehaut et al*. (2004) studied 468 caregivers of children suffering from cerebral palsy compared with the general population, and reported that caregivers of children with CP described more chronic physical conditions ranging from back pain, headaches and arthritis than the general population(30). Similar findings were reported by *Kaya* (2010) by comparing physical pain, depression and quality of life of mothers with children suffering from CP against mothers with children that were healthy. According to the study, more physical pain were reported in mothers caring for children suffering from cerebral palsy, with more severe pain experienced by those with higher levels of depression(10).

According to a qualitative study on psychological effects of cerebral palsy in African families, Participants reported that good knowledge of CP contributed positively in coping with the demands of caring for children suffering from CP. On the other hand, 38.5% of participants reported that they were accused of being the reason that their children developed cerebral palsy. They also reported experiencing problems that include loss of job, family disintegration, and financial constraints(31). Similarly, *Singogo et al*. reported that mothers with children suffering from CP were elatedly their families and the community at large. They were assumed to cause their children to develop the condition. Additionally, mothers also reported that their marriages suffered because of their children (32). On the contrary, *Sen et al*. (2007) and *ones et al*. (2005) have explained that mothers with children suffering from a disability blame themselves more and avoid engaging in social activities, and this affects their social life(33,34).

2.2. Factors associated with health-related quality of life of primary caregivers of children with cerebral palsy

Health related and demographic factors are associated with QoL of children suffering from cerebral palsy and their caregivers (13). Factors such as functional status of the child, the age of the caregiver, their sex, educational level, level of income, as well as religiosity consistently emerge in literature (20,35,36).

The increase in disability and presence of complications were shown to lower the QoLof the child (13), while low quality of life of the child was shown to significantly affect their caregiver's quality of life(20). Contradictory findings exist in literature regarding the association of GMFCS, a measure of severity in functional disability in Children suffering from CP, and the caregivers' QoL. *Shirmard et al*. found a negative association between GMFCS and QoL of caregivers, showing that severe disability in children correlated with parental stress, which could be a cause for lower QoL (35). Two other studies reported an association between QoL of caregivers and the degree of disability in their children based on GMFCS(22,37). However, other studies failed to demonstrate a relationship between caregivers' QoL and the disability status in their children(9,34).

Studies by *Huang* (2014) and *Lv* (2019) (38,39) have proven linkage between caregivers' age and QoL while in others found no significant correlation between the two(9,19). A study by *Wu et al*. in Anhui, China, investigated the QoL of primary caregivers of children suffering from CP that included52 grandmothersand125 mothers. The QoL of mothers and grandmothers of children suffering from CP were both found to be poorer than in the general population in both components of SF-36 health survey. Grandmother caregivers scored poorer than mother caregivers in all aspects(40).

Higher education levels in caregivers of children suffering from CP led to lower stress levels (41). Educated caregivers have the ability to obtain more information and develop a more positive attitude compared to illiterate caregivers (42). Caregivers with less education find it more difficult to access support services which in turn increases their burden of care (43). On the other hand, *Adegoke et al*. in Nigeria studied 40 mothers with children suffering from CP comparing with 40 mothers with normally developing children and found no significant correlation between caregivers' education level and their quality of life and further reported that the educational status of caregivers did not affect their ability to deal with the demands arising from their roles as caregivers (19). Interestingly, Lawako and Soares concluded that level of education influenced QoLof caregivers of children suffering from chronic conditions, in their study caregivers that attained university education scored the lowest QoL(36).

A correlation was found to exist between family income and caregivers' social health and their quality of life (35). *Khayatzadeh* (44)reports that the socioeconomic status affects all domains of QoL of caregivers with children suffering from cerebral palsy. *Berhaut* (30) explains that most of the caregivers of children suffering from CP are not employed in full-time jobs and have lower incomes because they dedicate most of their time caring for their children. Furthermore, These mothers are primarily concerned about the care of their family members when working for a pay and prefer to engage in an informal work arrangements in order to enjoy more flexibility(45). *Tekinarslan et al*(46) observed that increase in family income improved QoL of caregivers. However, despite acknowledging that overspending of money and time on caring for the child, leaving little resources to be used in other household needs, *Ribeiro et al*. were not able to prove any relationship between family income and caregivers quality of life(45).

The difference in gender among caregivers of children suffering from CP was shown not to influence their QoL according to *Shirmard* (2017), a comparison was made between 64 parents of children suffering from CP and 64 parents of healthy children matched for their age and gender. While mothers of children suffering from CP scored significantly lower QoL than mothers with healthy children, no significant difference in QoL between fathers and mothers was observed in each group(35). Similarly, *Davis et al.*(9) found no differences in Qol among fathers and mothers of children suffering from cerebral palsy. Other studies evaluating the QoL of caregivers of children suffering from CP also reported similar findings (45,47,48). However, *Byrne* (2010) explains that since mothers stayed more with the children suffering from cerebral palsy they were more likely to report a worse health outcome(28).

Religiosity and spirituality help caregivers develop positive attitude towards care giving stress and assist them to cope with the challenges arising from care giving (49). Religion also preaches optimism and people who are optimistic cope well in stressful events (50). *Morano* and *King* reported that caregivers who are religious have less depression because of their religious involvement (48). However, *Adegoke et al* (2014) found that religion had no impact on the caregiver's HRQoL. Caregivers in their study practiced one form of religion or the other, that is Christianity or Islam(19).

2.3. Conceptual/ theoretical framework

2.3.1. Family Systems and Resource exchange theories

The study had been conducted and data analyzed based on two fundamental cognitive theories; the family systems theory(51), which recognizes the interdependence between family members, oneness of the family and the complex interactions between them and that the wellbeing of each family member depends on others; Resource exchange theory (52)was used to study family relationships, wellbeing and the resource exchanges that occur in the family interactions. The exchange of resources such as love, services, goods, money and information between family members for whatever reason will result in a gain or a loss of some sort among family members. The decision taken by a mother or a caregiver to provide care services to a chronically ill child or any other member of the family is an expression of love to that sick child and in exchange the mother expect that when the child gets well he or she will return the favour in future in the form of one of the resources(53).

2.3.2. Conceptual Framework

Based on the family systems and resource exchange theory, the relationship between health-related quality of life of primary caregivers as a dependent variable and predictors or independent variables (health related and socio-demographic factors) were presented using the following conceptual framework which has been adopted with modification from the conceptual Framework used by *Crom et al*. (1999) to assess patient-related factors and cancer-related factors on the health outcomes and QoL of pediatric solid tumor survivors.

Independent variables intervening variables dependent variable

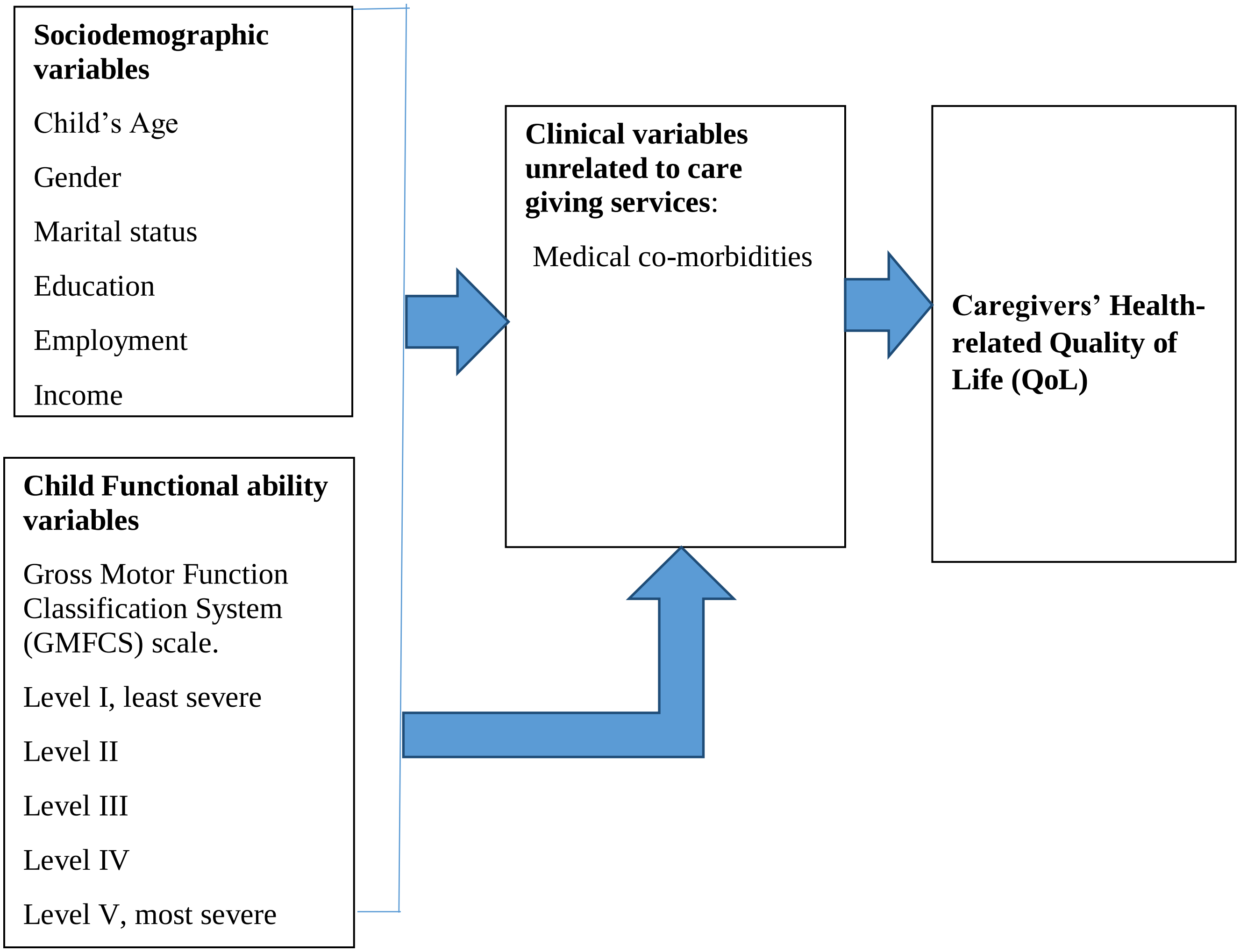


Figure 1.Modified Conceptual Framework for the relationship between health-related quality of life of caregivers of children with CP and its predictors, Crom (1999).

2.4. Justification/ significance of the study

The HRQoL of primary caregivers of children suffering from CP or any other chronic condition is not always the main target of healthcare workers during the treatment of these children. The information about the quality of life of the caregivers can give a better comprehension of how, if enough attention is given to these caregivers, they can form an integral part in the long-term treatment of their children's condition. While measures of HRQoL have been widely applied in many areas of healthcare practice, the general health of caregivers of children suffering from chronic conditions are rarely assessed. The study findings will be very key to both policy makers as well as healthcare practitioners, in that the knowledge generated through the research will inform the development of strategies and healthcare interventions which can assist primary caregivers of children suffering from cerebral palsy to cope with the challenges that result from caring for these children which negatively affects their HRQoL.

2.5. Objectives

2. 5.1.Primary Objective

To determine the health-related quality of life of primary caregivers of children with cerebral palsy at Kenyatta National Hospital

2.5.2. Secondary Objectives

1. To determine factors associated with health-related quality of life of primary caregivers of children with cerebral palsy.

Chapter 3: Methodology

3.1. Study design

This was across-sectional study

3.2. Study area description

The study was done at Kenyatta National Hospital. The hospital is one of the largest national referral facilities, situated in Nairobi. The hospital has a good number of specialized clinics and therefore attends to a large number of patients with different health conditions from a across the country. The study was conducted among patients visiting pediatric neurology, pediatric outpatient and inpatient (wards 3A, 3B, 3C, 3D) departments, physiotherapy and occupational therapy clinics. These clinics have been selected because it is in these clinics that the diagnosis and treatment of chronic conditions including cerebral palsy are being handled.

3.3. Study population

The study population consisted of primary caregivers of children aged 2-12 years who visited Kenyatta national hospital for care. The cases were caregivers with children aged 2-12 years and have been diagnosed with cerebral palsy after visiting paediatric neurology, paediatric outpatient and inpatient departments, physiotherapy and occupational therapy clinics. The comparison group consisted of primary caregivers of children without chronic illnesses aged 2-12 years who came to the outpatient clinic for care.

3.3.1 Inclusion Criteria

- The inclusion criteria for primary caregivers with children suffering CP was to have only one child having CP aged 2-12 years, staying with the child, not pregnant, not having any chronic physical or mental illness, and not caring for another person suffering from a chronic illness or a disability. Whereas for primary caregivers of children without chronic illnesses was to have a child in the same age group without any chronic illness, staying with the child, not having chronic physical or mental disorder, not pregnant and not caring for another person suffering from a chronic illness or a disability.

3.3.2 Exclusion Criteria

- The exclusion criterion for both groups was to have any chronic mental or physical disorders, pregnant or caring for another person suffering from a chronic illness or a disability.

3.4. Sample size calculation

The sample size for this study was estimated to detect a mean change of HRQoL between primary caregivers with children suffering from CP and primary caregivers of children without chronic illnesses based on findings of a study by *Glinac* 2017(37). In this study that was done in Bosnia and Herzegovina, it compared the QoL of 71 mothers with children having cerebral palsy and 70 mothers with healthy children. It was reported that the QoL of mothers with children suffering from cerebral palsy was poorer than that of mothers with healthy children. The study also established that the difference in median scores for the two groups was 23.53, the inter-quartile range of the quality of life scores was 12.56 and 17.36 for the exposed versus non-exposed respectively(37). Assuming 80% power to detect the minimum effect, 5% level of precision, 95% confidence interval, a minimum of 41 mothers would be required in each group. Considering a 20 percent lack of response rate the sample size would be 50 per group, totaling 100 overall.

3.4.1. Sample Size Calculation formula

The sample size has been estimated adopting the procedures described below for a continuous outcome variable. It was assumed that QoL will be calculated as scores and based on assumptions of study by *Glinac et al* 2017 (37)which reported median scores and interquartile rate, the following formula has been adopted

$$n=\frac{(u+v)^2(\sigma_1{}^2+\sigma_0{}^2)\frac{r+1}{r}}{(\mu_1-\mu_0)^2}$$

$\mu_1 - \mu_0 =$ Difference between the means/ medians [88.89-65.36] =23.53

σ_1, σ_0 = Standard deviations of exposed and non-exposed/ exposed [exposed [50.06-77.92] =12.56 vsnon-exposed [IQR] [79.86-97.22] e=17.36]

u = power = 80%, u is 0.84 (for all cases)

v = Percentage point of normal distribution corresponding to the (two-sided) significance level (95% confidence interval) e.g. for significance level of 5%, v = 1.96

r is the ratio of sample size between the exposed and non-exposed group assumed to be 1:1 (r=1)

$u = 1.28$

$v = 1.96$

$\sigma_1 = 17.36$ [Glinac et al 2017(37)

$\sigma_0 = 27.86$ [Glinac et al 2017(37)]

$\mu_1 - \mu_0 = 23.53$

$$n = \frac{(u+v)^2(\sigma_1^2 + \sigma_0^2)}{(\mu_1 - \mu_0)^2}$$

$$n = \frac{(0.84 + 1.96)^2\,(17.36^2 + 27.86^2)}{(23.53)^2} = \frac{10.3 \times [301.4 + 776.2]}{553.7} =$$

$$n = \frac{(11103.1)}{553.7} = 41$$ minimum sample size per group

A total of **100**caregivers (50 per group) were required.

3.5. Sampling procedure.

It is estimated that a total of about 100 primary caregivers of children with Cerebral Palsy visit the hospital monthly. So as to achieve the required sample size of 50 primary caregivers with children aged 2 to 12 years and having Cerebral Palsy, the primary caregivers were selected consecutively to arrive at the required sample size. The same procedure was followed to select the primary caregivers of children without chronic illnesses until the right sample size was attained. The cases were 50 caregivers drawn from the population of primary caregivers having children who have been diagnosed with cerebral palsy and the comparison were 50 caregivers drawn from the population of primary caregivers whose children do not suffer from any chronic illnesses. A total of 100 primary caregivers were sampled for the study.

The recruitment of controls was done in three blocks comprising children under5, 5-10 years and those above 10 following recruitment of cases. This was to ensure normal distribution on ages between cases and controls

3.6. Recruitment and consenting procedures

Ethical approval to proceed with the study was obtained from the Kenyatta National Hospital/University of Nairobi Ethics Committee. The ethical approval was then used to seek permission from the in-charges of the paediatric outpatient and inpatient departments, paediatric neurology, physiotherapy and occupational therapy clinics. The primary caregivers of children having CP were recruited from the departments of paediatric outpatient and inpatient, paediatric neurology, physiotherapy and occupational therapy clinics on daily basis until sample size was achieved. The principal investigator explained the study to the participants. The primary caregivers were screened to ascertain their eligibility to participate in the study. The caregivers who met all the inclusion criteria and accepted to participate in the study were taken to a separate room where the consent form was read to each one of them individually. The consent form was in a language that the caregiver was able to understand comfortably. The caregivers were free to ask any questions and the research assistant answered or explained to his/her satisfaction. It was explained to them that they were free to accept or refuse to participate and refusal to participate was not going to affect the services they have been receiving from the clinics. The primary caregivers were recruited into the study after having signed a written consent form. Primary caregivers who did not know how to read and write signed their consent forms using their finger mark in the presence of a literate witness who had been taken through the normal consenting procedure. The primary caregivers of children without chronic illnesses were recruited from the paediatric outpatient clinic on daily basis until sample size was achieved and the same recruitment and consenting procedures were followed as the caregivers with children suffering from CP. The cases and the controls were recruited simultaneously.

3.7. Data collection procedures

The principal investigator administered the data collection tools to the primary caregivers to collect quantitative data. HRQoL data was collected using short form 36 (SF-36) health surveys. Functional ability of the children with cerebral palsy was assessed using Gross Motor Classification System (GMCS). A pre-coded individual questionnaire was administered to primary caregivers in both cases and controls to collect socio-demographic data from the primary caregivers and the children.

3.7.1. Data collection Tools

3.7.1.1 Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)

SF-36 survey form is generic, standardized and validated tool that has been used to evaluate HRQoL of caregivers with children suffering CP(22,54). This form is non- specific to any age group, disease or condition and it consists of 36 questions with 8 sub-sections or domains namely general health perceptions, physical function, bodily pain, physical role functioning, emotional role functioning, vitality, social role functioning and mental health. The reliability score of SF-36 in a study conducted in Ghana was estimated to be more than 0.80 and there was a great internal consistency and reliability of SF-36 that was used (55), similarly other studies have also been used to validate SF-36 in different contexts including Kiswahili, the national language of many countries in East Africa including Kenya(15,56,57).It has also been applied in studies done in Kenya to evaluate the QoL of patients suffering from chronic conditions such as HIV and Rheumatoid Arthritis(58)(59). RAND 36- Item Health survey 1.0 scoring system was adopted for analysis in this study. Each item was recorded on a linear scale of (0 – 100) in which case 0 represented having a problem doing the activity while 100 represent not having a problem doing the activity. The items were scored so that a higher score represented a more favorable health condition while lower scores represented unfavorable health conditions. The overall scores were measured as the mean of the responses(37) with its standard deviation and 95% confidence interval(CI=95%).

3.7.1.2 Gross Motor Function Classification System (GMFCS)

Functional ability of the child was assessed using Gross Motor Function Classification System (GMFCS) for the cases only. GMFCS normally assesses the ability move and it is scored on a five- level ordinal scale (I-V), whereby those patients who are in group (I) can move without limitations while those who are in group (V) are children whose movements are only possible with the support of a wheelchair or a device. Gross Motor Function Classification System is a valid and reliable tool to assess functional status of children having cerebral palsy(54,60), based on the severity of the condition. The outcome of functional ability assessment was used as an independent variable to assess the relationship between the level of a child’s functional ability and the health-related quality of life of the caregiver.

3.8. Data Storage and Security

Each questionnaire was checked to ensure that they do not contain any personal identifiers in order to protect confidentiality of the participants. All personal identifiers were removed. The questionnaires were safely locked in a cabinet that was only accessible to the principal investigator. This was to protect the participants of the study and the information obtained from them to ensure confidentiality.

3.9. Data management and analysis

Completed questionnaires were checked for inconsistencies, inaccuracy and missing data immediately after the interviews and clarifications made from the respondents. The statistical analysis was performed using SPSS version 23.0. The primary caregivers were described by summarizing socio-demographic characteristics into means and percentages for continuous and categorical variables respectively. Comparison of characteristics between caregivers of children with CP and those of children without chronic illness was tested using independent t test, chi square test of association and fisher's exact test for small figures (expected count less than 5). Child's functional ability was analyzed and presented as percentage of children with CP. The overall quality of life and the sub-scale scores of the caregivers were calculated and presented as means with standard deviations. Quality of life score was calculated against each level of GMCFS and the difference tested using ANOVA test. The mean QoL scores were also correlated with socio-demographic characteristics and child's functional status by comparing mean scores across groups and testing using independent t and ANOVA tests as appropriate. Statistical significance was determined at 5% level (p value less than or equal to 0.05).

3.10. Ethical consideration.

Ethical approval was granted by the Kenyatta National Hospital/University of Nairobi Ethics Committee. Participation was on voluntary basis and consent of the recruited primary caregivers was sought through a written informed consent form. Permission to do the research in Kenyatta National Hospital was obtained from relevant departmental heads .It was explained to the caregivers that their participation in the study was voluntary and that they could leave the study at any time of their choice .Refusal to join the study has not affected the services they have been getting from the clinics or any other department at the hospital

3.11. Risks

Risks like emotional breakdown among the caregivers were mitigated by a counselor who was informed about the study. There were no invasive procedures that were carried out. Refusal to participate in the study has not affected the services the caregivers and their children have been receiving from the hospital.

3.12. Benefits

The findings of this study will be shared with the ministry of health and other healthcare stakeholders to inform the development of policies and interventions to assist caregivers with children suffering from cerebral palsy.

3.13. Dissemination of the study results and findings

1. The results of this study will be disseminated to Kenyatta National Hospital in order to establish a support system for the caregivers with children suffering from cerebral palsy.
2. The findings will also share with the department of paediatrics at the University of Nairobi.
3. The healthcare practitioners will be given copies of the study results so that they develop a more holistic approach towards these caregivers.
4. The results of the research will be published in a peer review journal.

Chapter 4: Results

The study groups were 50 caregivers of children suffering from CP who were compared with equal number of caregivers of children without chronic illnesses. As indicated in Table 1, the mean age of the study group was 32.7 years (sd 6.7 years) and 96% females taking care of children with CP with an average age of 4.7 years (sd 2.9 years) and 52% females. Majority of the study group caregivers were mothers (84%), married ((72%) and with secondary level of education (48%). A half (50%) were unemployed and 60% earned less than 20,000 a month. Majorities (92%) were Christians and 90% did not receive any support from external source. The comparison group were significantly older (mean 35.6 years, p=0.039), had higher proportion of fathers taking care of their children (28%, p=0.003), had lower rates of unemployment (12%, p<0.001). The CP children were mainly in GMFCS of level V (32%), level IV (26%) and level II (26%).

Table 1: Socio-demographic characteristics of primary caregivers

Variable	**Children with CP**	**Children without chronic illnesses**	**P value**
Caregiver's age in years, mean (sd)	32.7 (6.7)	35.6 (6.9)	**0.039**
Caregiver's sex			
Male	2 (4.0)	15 (30.0)	**0.001**
Female	48 (96.0)	35 (70.0)	
Child's age in years, mean (sd)	4.7 (2.9)	5.5 (2.9)	0.141
Sex of the child			
Female	26 (52.0)	27 (54.00	0.841
Male	24 (48.0)	23 (46.0)	
Relation with the child			
Father	2 (4.0)	14 (28.0)	**0.003**
Mother	42 (84.0)	32 (64.0)	
Sibling	2 (4.0)	0	
Relative	2 (4.0)	1 (2.0)	
Friend	0	1 (2.0)	
Other	2 (4.0)	2 (4.0)	
Marital status			

Single	10 (20.0)	10 (20.0)	0.920
Married	36 (72.0)	34 (68.0)	
Widowed	1 (2.0)	1 (2.0)	
Separated	3 (6.0)	5 (10.0)	
Employment			
Fulltime	8 (16.0)	15 (30.0)	<**0.001**
Part time	3 (6.0)	3 (6.0)	
Self-employed	14 (28.0)	26 (52.0)	
Unemployed	25 (50.0)	6 (12.0)	
Education			
Primary	12 (24.0)	4 (8.0)	0.085
Secondary	24 (48.0)	31 (62.0)	
University/college	14 (28.0)	15 (30.0)	
Income			
Less than 20000	30 (60.0)	11 (22.0)	<**0.001**
More than 20000	20 (20.0)	39 (78.0)	
Religion			
Christian	46 (92.0)	49 (98.0)	0.426
Muslim	2 (4.0)	1 (2.0)	
Atheist	2 (4.0)	0	
Support			
Church	0	1 (2.0)	0.598
Government institution	3 (6.0)	3 (6.0)	
NGOs	2 (4.0)	0	
None	45 (90.0)	46 (92.0)	
GMFCS			
Level I	5 (10.0)		
Level II	13 (26.0)		
Level III	2 (4.0)		
Level IV	14 (28.0)		
Level V	16 (32.0)		

Health-related quality of life (HRQOL)

As shown in Table 2, caregivers with children having CP had a mean HRQOL score of 67.5 (sd 17.3) which was significantly lower than mean of 78.2 (sd 13.0) in the comparison group (p=0.001).

Table 2: Overall HRQOL of the caregivers

Group	N	Mean overall HRQOL score (sd)	P value
Caregivers of children with CP	50	67.5 (17.3)	**0.001**
Caregivers of children without chronic illnesses	50	78.2 (13.0)	

Health-related Quality of life by domain

As indicated in Table 3, HRQoL scores were lower across all aspects for caregivers of children suffering from CP. HRQoL was significantly lower in relation to physical functioning, social functioning, and role limitations due to emotional problems, vitality and mental health.

Table 3: Health-related Quality of life domains of caregivers

Variable	Children with CP Mean (sd)	Children without chronic illnesses Mean (sd)	P value
Physical functioning	90.8 (17.8)	99.3 (22.9)	**0.041**
Role limitations due to physical health	64.0 (43.8)	72.5 (39.8)	0.313
Role limitations due to emotional problems	52.0 (46.7)	84.0 (34.5)	**<0.001**
Energy and fatigue (vitality)	60.4 (12.8)	66.5 (12.7)	**0.019**
Emotional wellbeing (mental health)	63.6 (14.3)	75.5 (12.1)	**<0.001**
Social functioning	66.8 (23.5)	77.0 (18.1)	**0.016**
Bodily pain	73.3 (24.2)	81.1 (21.2)	0.088
General health	69.4 (17.0)	69.5 (14.1)	0.969

Factors associated with HRQOL in caregivers of children with CP

Relationship between HRQoL and the functional ability of the children with CP

As shown in Table 4, overall HRQOL was not significantly related to the GMFCS level of children with CP (p=0.343). Similarly, all except the domain of general health did not significantly correlate with GMFCS (p>0.05). Caregivers with children suffering from CP with GMFCS levels I and V scored significantly higher than the others in the domain of general health (p=0.028).

Table 4: Functional ability and correlation with HRQoL of caregivers of children with CP

Variable	**GMCFS**	**n (%)**	**P value**
Overall QOL score	I	76.3 (14.7)	0.343
	II	67.2 (16.2)	
	III	72 (6.8)	
	IV	60.2 (17.5)	
	V	70.9 (18.7)	
Physical functioning	I	90 (14.6)	0.899
	II	91.9 (14.8)	
	III	100	
	IV	92.1 (13.4)	
	V	87.8 (25.0)	
Role limitations due to physical health	I	85 (33.5)	0.254
	II	53.8 (48.8)	
	III	100	
	IV	50 (43.9)	
	V	73.4 (41.3)	
Role limitations due to emotional problems	I	60 (54.8)	0.462
	II	66.7 (43.0)	
	III	50 (23.6)	
	IV	33.3 (47.1)	
	V	54.2 (48.5)	
Energy and fatigue (vitality)	I	71 (8.9)	0.300
	II	60 (11)	
	III	65	
	IV	60.4 (15.5)	
	V	56.9 (12.4)	
Emotional wellbeing (mental health)	I	72.8 (8.7)	0.374
	II	58.5 (6.0)	

	III	58 (2.8)	
	IV	63.7 (16.6)	
	V	65.5 (18.0)	
Social functioning	I	70 (14.3)	0.773
	II	70.2 (15.8)	
	III	62.5 (17.7)	
	IV	59.8 (27.4)	
	V	69.5 (28.5)	
Bodily pain	I	83.2 (23.4)	0.183
	II	71.7 (20.8)	
	III	71 (12.7)	
	IV	61.7 (28.4)	
	V	82 (21.5)	
General health	I	78.2 (14.2)	0.**028**
	II	65 (13.9)	
	III	69.5 (3.5)	
	IV	60.4 (17.5)	
	V	78 (16.4)	

Age of the child and their caregivers' HRQoL

As shown in Table 5, overall HRQOL was not related to the age of the child (p=0.312). However, social functioning and bodily pain scores were significantly different for caregivers with CP children in different age groups. Caregivers of children who were more than 10 years had the highest social functioning scores (mean 87.5) compared to those with younger children (p=0.003). Caregivers of children less than 5 years scored significantly higher (mean 81.2) than the others in the domain of bodily pain (p=0.003).

Table 5: Age of children with CP and their caregivers ‘HRQoL

Variable	**Age in years**			
	<5	5-10	>10	P value
Overall HRQOL score, mean (sd)	69.6 (16.8)	62.0 (18.3)	74.4 (14.1)	0.312
Physical functioning, mean (sd)	90.5 (20.1)	90.7 (13.3)	97.5 (3.5)	0.867
Role limitations due to physical health, mean (sd)	66.7 (41.8)	60.0 (48.0)	50.0 (70.7)	0.804
Role limitations due to emotional problems, mean (sd)	48.5 (46.5)	53.3 (48.5)	100	0.322
Energy and fatigue (vitality) , mean (sd)	61.7 (11.9)	57.3 (15.2)	62.5 (3.5)	0.547
Emotional wellbeing (mental health) , mean (sd)	65.9 (13.4)	57.9 (15.7)	68.0 (11.3)	0.178
Social functioning, mean (sd)	70.8 (21.1)	55.0 (25.4)	87.5 (17.7)	0.039
Bodily pain, mean (sd)	81.2 (21.8)	56.8 (22.6)	68.0 (8.5)	0.003
General health, mean (sd)	71.9 (15.1)	64.7 (20.2)	62.0 (21.2)	0.326

Age of caregivers of children with CP and their HRQoL

As shown in table 6, the overall HRQoL of caregivers younger than 30 years was significantly higher than those above 30 years (p=0.002), they also scored significantly higher in the domains of role limitations due to physical health, social functioning, bodily pain and general health.

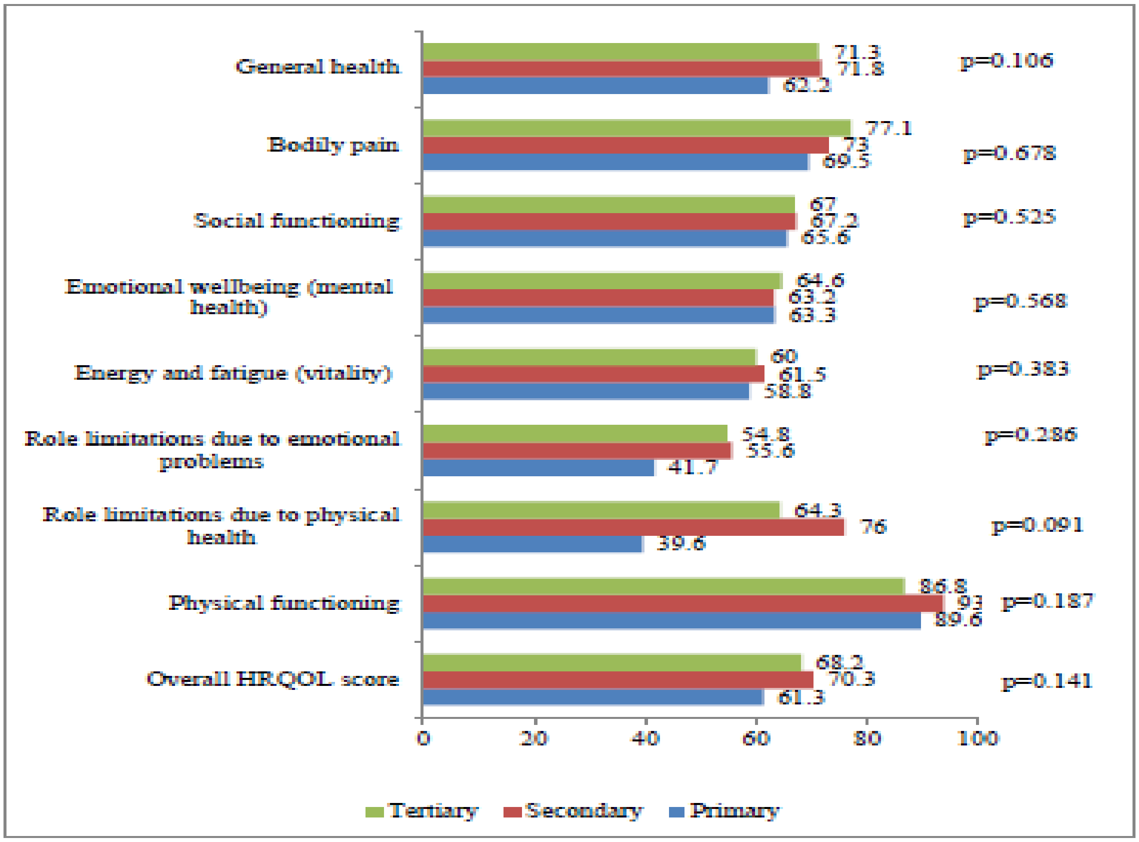
Table 6: Age of caregivers of children with CP and their HRQoL

Variable	**Age in years**			
	<30	30-39	40+	P value
Overall HRQOL score, mean (sd)	78.1 (11.8)	64.8 (17.4)	52.0 (13.6)	0.002
Physical functioning, mean (sd)	95.6 (10.5)	90.0 (20.4)	81.7 (18.6)	0.249
Role limitations due to physical health, mean (sd)	82.8 (35.0)	62.5 (43.3)	20.8 (40.1)	0.009
Role limitations due to emotional problems, mean (sd)	68.8 (43.0)	42.9 (46.1)	50.0 (54.8)	0.211
Energy and fatigue (vitality) , mean (sd)	65.0 (10.5)	59.5 (13.4)	52.5 (12.1)	0.103
Emotional wellbeing (mental health) , mean (sd)	68.0 (10.7)	61.9 (15.9)	60.0 (14.1)	0.323
Social functioning, mean (sd)	82.8 (17.6)	59.8 (23.4)	56.3 (17.2)	0.002
Bodily pain, mean (sd)	87.6 (15.8)	71.3 (24.0)	44.5 (14.1)	<0.001
General health, mean (sd)	73.8 (15.1)	70.9 (15.3)	50.2 (18.6)	0.008

Education and quality of life

As shown in figure 1, education did not significantly associate with the overall HRQoL and also did not influence individual domains in the SF-36 (p>0.05).

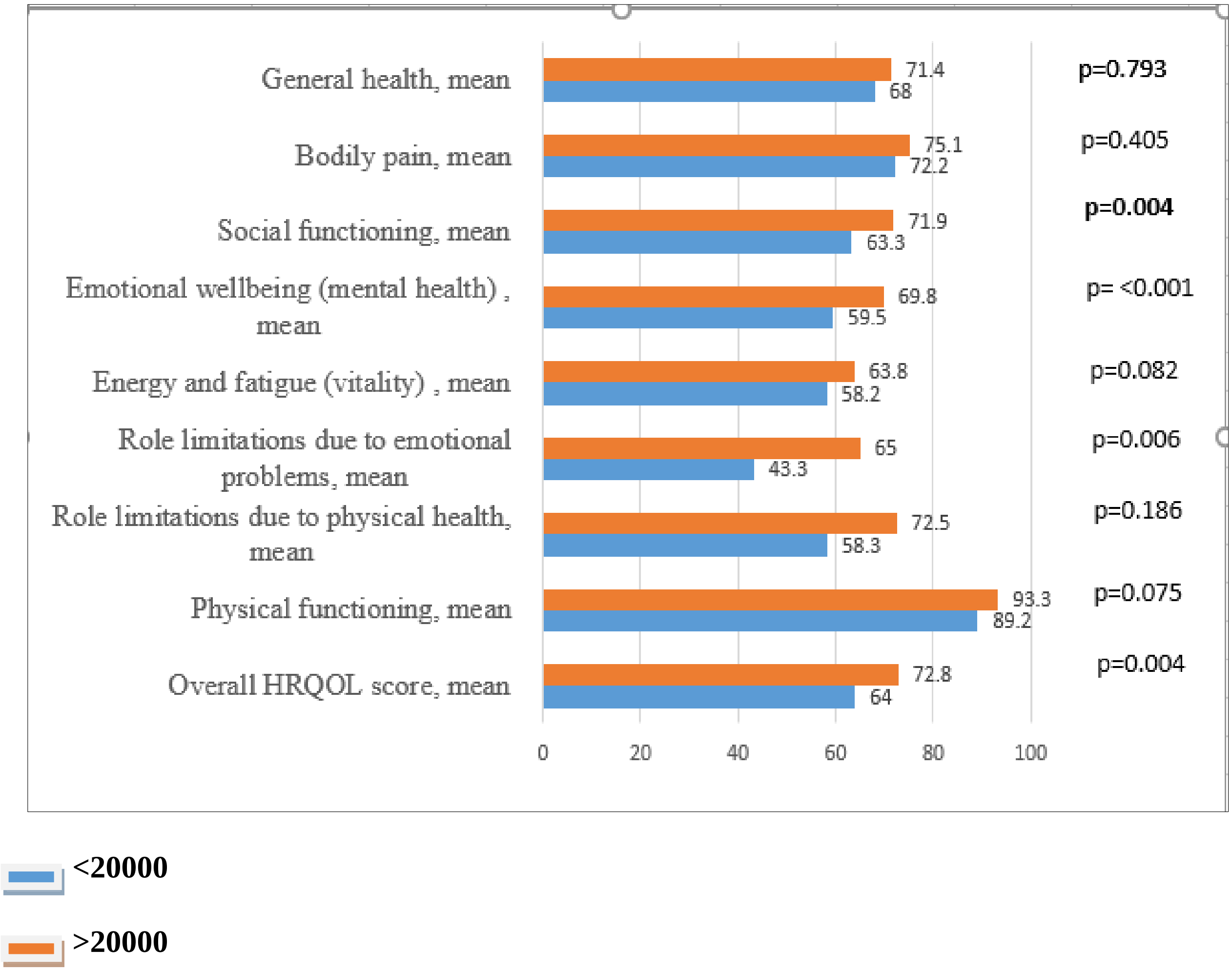
Figure 1: Education and caregivers' HRQoL



Income and HRQoL

As shown in figure 2, the mean overall HRQoL was significantly lower in those earning less than 20,000 compared to the ones earning higher (p=0.004). Similarly, role limitations due to emotional problems, vitality and social functioning scores were significantly lower in those earning less than 20,000 per month (p<0.05).

Figure 2: Income and HRQoL



Chapter 5: Discussion

This study compared the HRQoL of 50 primary caregivers of children suffering from CP against 50 primary caregivers of children without chronic illnesses. There existed differences between the two groups on the basis of their age, occupational status and income but otherwise had similar characteristics. Caregivers with children suffering from CP were younger; many of them were unemployed and earned less than the comparison group. The overall HRQoL of primary caregivers with children suffering from cerebral palsy (CP) was significantly poorer than that of caregivers of children without chronic illnesses. The scores for caregivers with children suffering from CP were also poorer in all the domains of SF-36 though significantly in the domains of physical functioning, role limitations due to emotional problems, vitality, mental health and social functioning. The results of this study are similar to results from other studies(19,20,22) that reported lower HRQoL of primary caregivers with children having CP. The overall scores of HRQoL of primary caregivers of children with CP were lower than their controls in all the studies(19,20,22).It is likely the differences between the two groups from the outset might have contributed in the outcome.

The functional levels of children suffering from cerebral palsy did not influence the overall HRQoL of caregivers with children having CP, a significant correlation was demonstrated only in the area of general health. The findings of this study appear similar to those found by other studies (9,34). On the contrary, in other studies a negative correlation was reported between the functional disability of the child assessed using GMFCS and caregivers' quality of life (13,37), this was more evident in the domain of social functioning. The caregivers' spent most of their time caring for their disabled children with little time left to socialize.

According to our study, the age of the child was not found to influence the overall HRQoL of caregivers with children suffering from CP. However, a negative association was found to exist between caregivers' HRQoL and their age. Our findings were similar to what was found in other studies (38,39) that compared caregivers' age and their quality of life, while in other studies authors found no connection between the two (9,19). The adverse effect of increasing age on the caregivers' quality of life can also be explained by the strain the ageing process can have on the physical and social life of the caregivers.

Caregivers’ education level did not influence the overall HRQoL of caregivers with children suffering from CP. A similar finding was reported in a another study (40). On the other hand, a few other studies reported a correlation between caregivers’ education level and their quality of life (42,43), it was explained in these studies that educated caregivers had a better chance of accessing social and medical resources that contributed to the improvement in their QoL.

The income of caregivers of children suffering from CP was significantly poorer than that of caregivers of children without chronic illnesses in our study. This is consistent with findings of previous other studies (30,35,44). However, there are studies that showed no significant connection between caregivers’ income and their quality of life (20,45). In our setting caregivers who are mostly mothers prefer to spend more time caring for their children with reduced availability to work for pay, this is further compounded by the lack of social welfare.

5.1. Conclusion

According to the findings of our study, the HRQoL of primary caregivers of children with cerebral palsy was noted to be significantly lower than that of caregivers of children without chronic illnesses. The negative impact was more on the domains of physical functioning, role limitations due to emotional problems, vitality, mental health, social functioning and the overall HRQoL. It was also shown that caregivers’ age and income significantly correlated with low HRQoL in caregivers with children having CP.

5.2. Study Limitations

Since we conducted our study in only one health facility it will not be possible for the findings to be generalized to other settings. Another limitation is that this study generalized children with CP and does not take into account the different types of CP.

5.3. Recommendations

Measures to improve the HRQoL of caregivers with children having CP should be incorporated in the care of these children.

Provision of financial support to caregivers of children with cerebral palsy to ease their financial burden.

Creation of labour laws and regulations that favor caregivers of children with disabilities.

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Appendices

Appendix 1: Short Form-36 Health Survey questionnaire, validated version.

Questionnaire No: ____________________

Date of the interview ___________________________Age: _________

Gender: 1. Male 2. Female

Please answer the 36 questions of the **Health Survey** completely, honestly, and without interruptions.

GENERAL HEALTH:

1. In general, would you say your health is?

1. Excellent 2.Very Good 3.Good 4. Fair 5. Poor

2. Compared to one year ago, how would you rate your health in general now?

1. Much better now than one year ago
2. Somewhat better now than one year ago
3. about the same
4. Somewhat worse now than one year ago
5. Much worse than one year ago

LIMITATIONS OF ACTIVITIES:

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing football

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

5. Lifting or carrying groceries

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

6. Climbing several flights of stairs

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

7. Climbing one flight of stairs

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

8. Bending, kneeling, or stooping

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

9. Walking more than a kilometer

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

10. Walking several blocks

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

11. Walking one block (200 metres)

1. Yes, Limited a Lot 2. Yes Limited a Little 3. No, not limited at all

12. Bathing or dressing yourself

1. Yes, Limited a Lot 2. Yes, Limited a Little 3. No, not, limited at all

PHYSICAL HEALTH PROBLEMS:

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

13. Cut down the amount of time you spent on work or other activities

1. Yes 2. No

14. Accomplished less than you would like

1 Yes 2. No

15. Were limited in the kind of work or other activities

1. Yes 2. No

16.Had difficulty performing the work or other activities (for example, it took extra effort)

1. Yes 2.No

EMOTIONAL HEALTH PROBLEMS:

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

17. Cut down the amount of time you spent on work or other activities

1. Yes 2. No

18. Accomplished less than you would like

Yes 2. No

19.Didn't do work or other activities as carefully as usual

1. Yes 2. No

SOCIAL ACTIVITIES:

20. Emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

1. Not at all2. Slightly 3.Moderately 4.Severe 5. Very Severe

PAIN:

21. How much bodily pain have you had during the past 4 weeks?

1. None 2. Very Mild 3.Mild 4. Moderate 5.Severe 6.Very Severe

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

1 Not at all 2. A little bit 3. Moderately 4.Quite a bit 5. Extremely

ENERGY AND EMOTIONS:

These questions are about how you feel and how things have been with you during the last 4 weeks. For each question, please give the answer that comes closest to the way you have been feeling.

23. Did you feel full of pep?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

24. Have you been a very nervous person?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

25. Have you felt so down in the dumps that nothing could cheer you up?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

26. Have you felt calm and peaceful?

1. All of the time
2. Most of the time
3. A good Bit of the Time

4. Some of the time
5. A little bit of the time
6. None of the Time

27. Did you have a lot of energy?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

28. Have you felt downhearted and blue?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

29. Did you feel worn out?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

30. Have you been a happy person?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time

6. None of the Time

31. Did you feel tired?

1. All of the time
2. Most of the time
3. A good Bit of the Time
4. Some of the time
5. A little bit of the time
6. None of the Time

SOCIAL ACTIVITIES:

32. during the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

1. All of the time
2. Most of the time
3. Some of the time
4. A little bit of the time
5. None of the Time

GENERAL HEALTH:

How true or false is each of the following statements for you?

33. I seem to get sick a little easier than other people

1. Definitely true 2. Mostly true 3. Don’t know 4.Mostly false 5. Definitely false

34. I am as healthy as anybody I know

1. Definitely true 2. Mostly true 3. Don't know 4. Mostly false 5. Definitely false

35.I expect my health to get worse

1. Definitely true 2. Mostly true 3. Don't know 4. Mostly false 5. Definitely false

36. My health is excellent

1. Definitely true 2. Mostly true 3. Don't know 4. Mostly false 5. Definitely false

Appendix 2: Primary Caregivers' individual Questionnaire

Questionnaire No. ________________

Date of interview__________________

Age ____________________ Sex___________________

Residence__________________

Socio-demographic characteristics

1. Gender of the child

1. Male 2. Female

2. Age of the child ___________

3. What is your relation to the child?

1. Father
2. Mother
3. Sibling
4. Relative
5. Friend
6. Others _____________

4. Are you the primary caregiver of the child?

1. Yes 2. No

5. What is your marital status?

1. Single
2. Married
3. Widowed
4. Separated

6. What is your form of employment?

1. Full time
2. Part-time
3. Self-employed.
4. Unemployed

7. What is highest level of education completed?

1. Primary
2. Secondary
3. University/college

8. On average, what is your family’s total Income in a month?

1. less than Ksh. 20,000

2. more than Ksh. 20,000

9. What is your religion?

1. Christian
2. Muslim
3. Hindu
4. Atheist

10. Apart from your family members or relatives where else do you get the support to take care of your child?

1. Church
2. Government institution
3. NGOs
4. None

Answer Question 12 if your child has cerebral palsy

12. Based on the scale of Gross Motor Function Classification System (GMFS), in which of the following five levels does your child belong to? **Probe to classify correctly**

1. Level I: Walks without Limitations
2. Level II: Walks with Limitations
3. Level III: Walks Using a Hand-Held Mobility Device
4. Level IV: Self-Mobility with Limitations; May Use Powered Mobility
5. Level V: Transported in a Manual Wheelchair

Appendix 3: English Consent form for primary caregivers of children with cerebral palsy.

Title of the study: Health-related Quality of life of primary caregivers of children with cerebral palsy at Kenyatta National Hospital (KNH).

Investigator's Statement

I am studying for a Master's degree in Medicine at the University of Nairobi. As part of my course I am carrying out a research about the quality of life of primary caregivers of children with Cerebral palsy, their experiences of living and taking care of these children and what are the predictors of caregivers' quality of life. As such I am requesting you as the primary caregiver of the child to take part. In the research I hope to highlight issues that the caregivers think are very important in addressing the plight of caregivers providing care to children with cerebral palsy. These issues can then be used to inform clinical practice which may lead to a more holistic and a better understanding of the plight of caregivers with children having cerebral palsy.

What is the purpose of the study?

Whereas a lot of research has been done about Cerebral Palsy, most of this research has concentrated on the quality of life of the children suffering from cerebral palsy, ignoring the fact that caregivers of these children do get affected. This study seeks to evaluate general health of primary caregivers with cerebral palsy children (HRQoL), their experiences with providing care to these children and factors influencing their health-related quality of life. The current research will focus on the views of primary caregivers as appertain to their quality of life which has been ignored by earlier research.

Why you are invited to participate?

As you are the main caregiver of the child your views on care giving is very important for this research and I request you to participate in the study. It is up to you to decide to join the study. The study will be described to you in detail. If you agree to take part, you be will be asked to sign a consent form. You are free to withdraw at any time, without giving any reason. This will not affect the standard of care you have been receiving from this hospital.

What is the study procedure?

If you consent to participate in this study, our research assistant will ask you some questions about your General health, including limitations of activities, emotional and physical health problems. You will also be asked questions related to social activities, energy and emotions. In addition, you will be asked questions about your age and the age of your child, relation to the child and your marital status. Finally you are also going to be asked about your employment status, education, religion and average monthly income. The interview will take at least 1 hour.

What are Risks and Benefits of participating in the study?

Benefits: The results of the study will be shared with the ministry of health and other stakeholders for any intervention required assisting primary caregivers nursing children with cerebral palsy. Result will be further utilized to advocate for the plight and challenges being faced by these caregivers.

Risks: You might be emotionally overwhelmed during the interview; a counselor will be available to help you in case you are affected. There will be no invasive procedures carried out on you. Refusal to participate in the study will in no way affect the services you and your child have been receiving from this hospital.

Voluntariness: Your participation in the study is absolutely voluntary. It is up to you to decide to join the study. You are free to withdraw at any time, without giving any reason. This will not in any way affect the standard of care you and your child have been receiving from this hospital.

Confidentiality: The information obtained about you, your child and your family will be kept in strict confidence. No specific information regarding you, your child or your family will be released to any person without your written permission. We will, however, discuss general overall findings regarding all primary caregivers of the children but nothing specific will be discussed regarding you or your child. We will also, not reveal the identity of you or your child in these discussions.

Contact of the Principal Investigator

If you ever have any questions about the study or about the use of the results you can contact the principal investigator, **Dr. Abdirahman Hashi Farah - 0780596850**

If you have any questions on your rights as a research participant you can contact the Kenyatta National Hospital Ethics and Research Committee (KNH- ERC) by calling 2726300 Ext. 44355.

Consent Form: Participant's Statement:

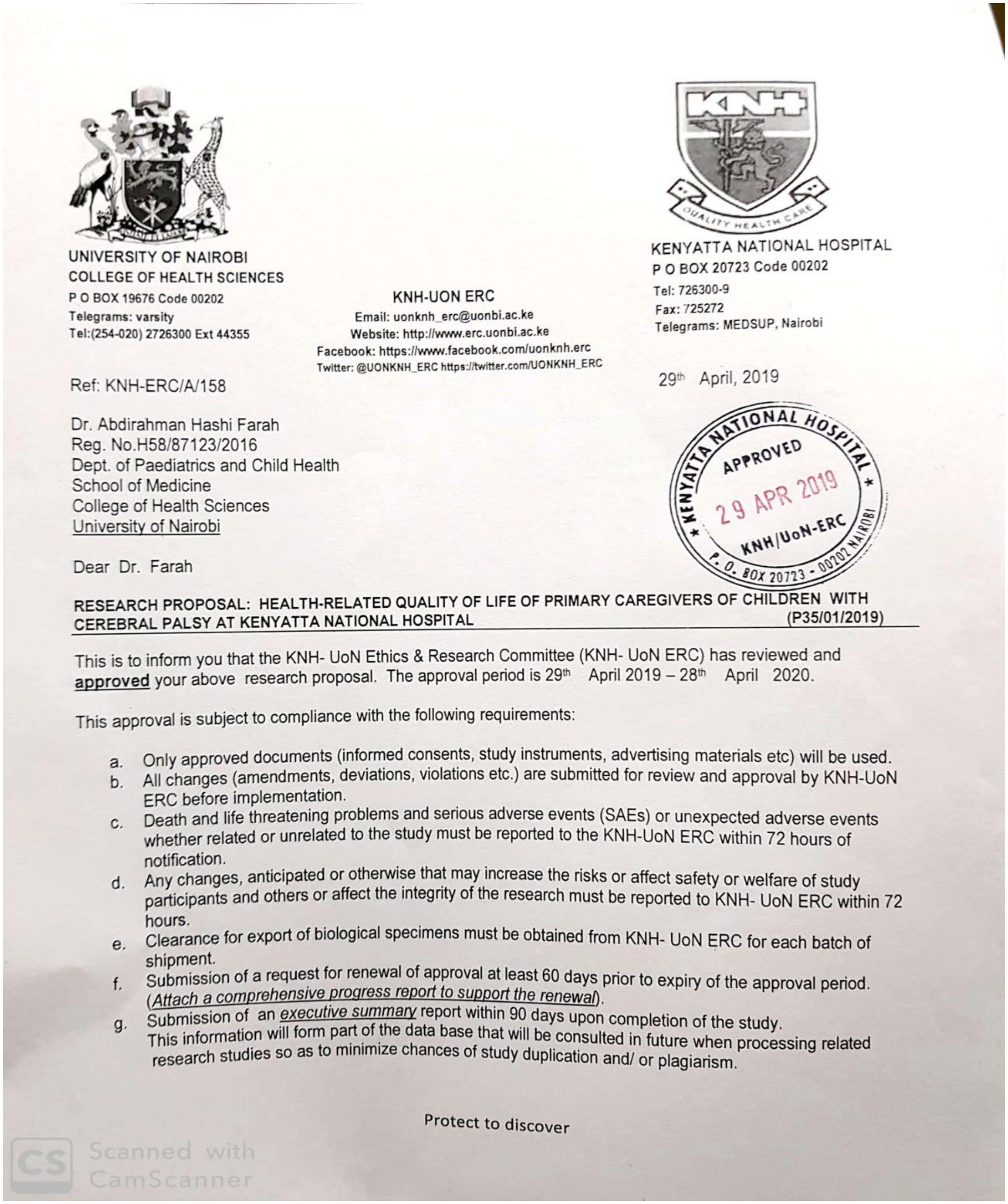
I ____having received adequate information regarding the study research, risks, benefits hereby AGREE / DISAGREE (Cross out as appropriate) to participate in the study. I understand that my participation is fully voluntary and that I am free to withdraw at any time. I have been given adequate opportunity to ask questions and seek clarification on the study and these have been addressed satisfactorily.

Parents Signature: _____________________________ Date ___________________

I ____ declare that I have adequately explained to the above participant, the study procedure, risks, and benefits and given him /her time to ask questions and seek clarification regarding the study. I have answered all the questions raised to the best of my ability.

Interviewers Signature _________________________Date ____________________

Appendix 4: KNH-UON ERC Approval Letter



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29th April, 2019

Ref: KNH-ERC/A/158

KENYATTA NATIONAL HOSPITAL
APPROVED
29 APR 2019
KNH/UoN-ERC
P. O. BOX 20723 - 00202 NAIROBI

Dr. Abdirahman Hashi Farah
Reg. No.H58/87123/2016
Dept. of Paediatrics and Child Health
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Farah

RESEARCH PROPOSAL: HEALTH-RELATED QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL (P35/01/2019)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 29th April 2019 – 28th April 2020.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

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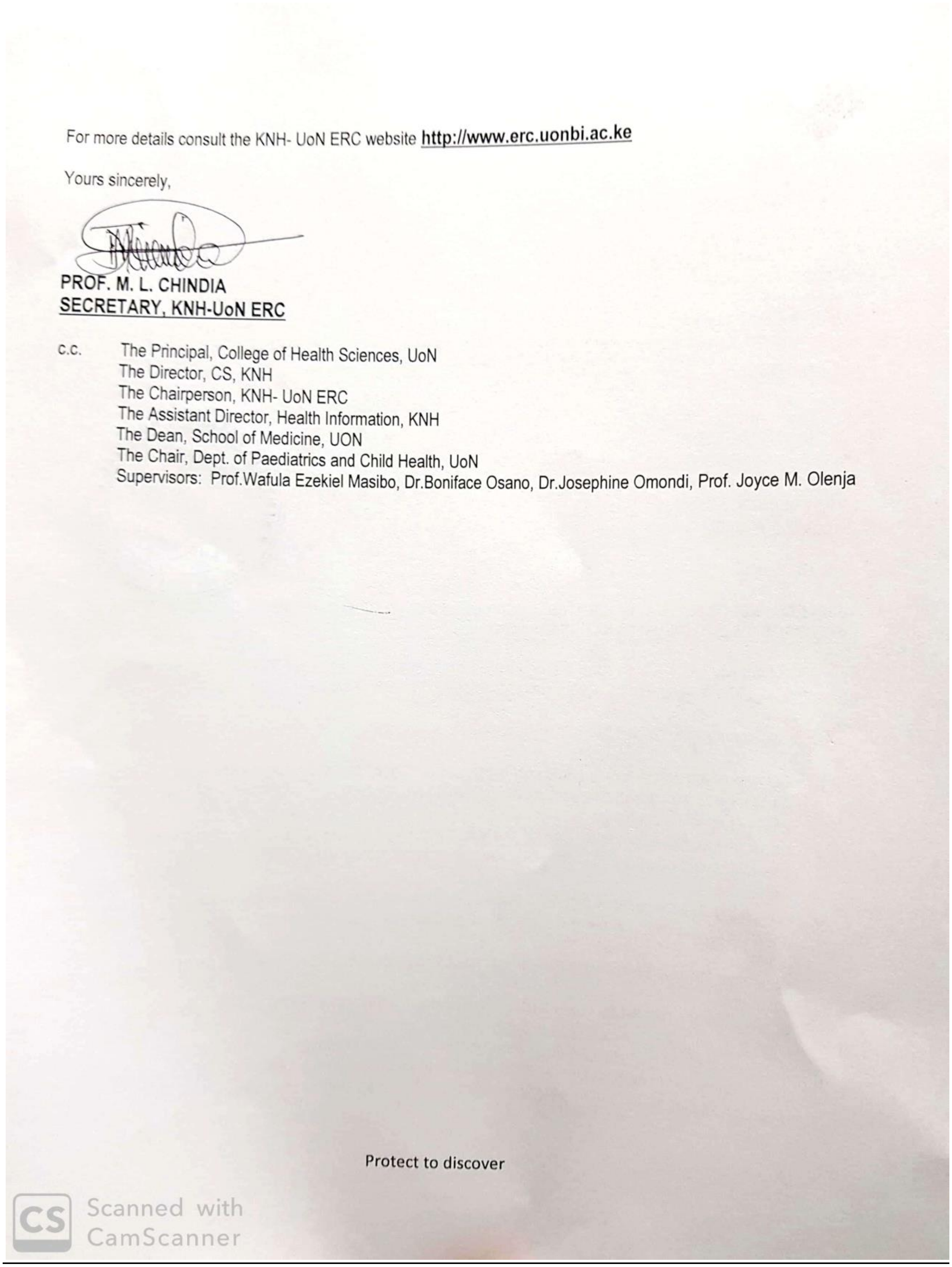

For more details consult the KNH- UoN ERC website **http://www.erc.uonbi.ac.ke**

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UON
The Chair, Dept. of Paediatrics and Child Health, UoN
Supervisors: Prof.Wafula Ezekiel Masibo, Dr.Boniface Osano, Dr.Josephine Omondi, Prof. Joyce M. Olenja

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