COLLEGE of HEALTH SCIENCES SCHOOL OF MEDICINE DEPARTMENT OF
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Quality of life and associated factors among caregivers of children with Down syndrome aged 6-month to 18 years and associated factors in Tikur Anbessa Specialized Hospital, Ethiopia

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For Specialty postgraduate thesis Submitted to the school of graduate studies of AAU, Department of Child, and Adolescent Health.

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Approval sheet

ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCESS

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I, the undersigned Pediatrics and Child health resident declare that I have submitted my original research on the title Quality of life and associated factors among caregivers of children with Down syndrome aged 6mo to 18 years in Tikur Anbessa Specialized Hospital, Ethiopia to TASH Addis Ababa, Ethiopia, 2023 in partial fulfillment of the specialty program. An institution based cross sectional study.

Submitted by:

Dr. Martha G/meskel ________ ____________

Name of resident Signature Date

This thesis work has been submitted with my approval as an advisor,

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Signature Date

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Acronyms

CHD: Congenital Heart Disease

DS: Down syndrome

HRQoL: Health Related Quality of Life

TASH: TikurAnbessa Specialized Hospital

QoL: Quality of Life

WHO: World Health Organizations

WHOQoL: World Health Organization Quality of Life

Abstract

Down syndrome (DS), also known as trisomy 21, is the most common chromosomal disease in humans and is caused by an extra copy of chromosome 21. Given that children with DS frequently have significant morbidities, this can place an immense burden on their caregivers and negatively affect their quality of life (QoL). Even though there are a sizable number of children with DS in our setup, there are no studies that specifically address the burden that having a child with DS puts on these caregivers.

Objectives: aim to assess the Quality of caregivers and associated factor among caregivers of children with DS.

Method: A cross-sectional study design was used to assess different variables of QoL among caregivers of children with DS at TASH. Data was collected using the WHOQoL-BREF tool through a modified face-to-face interview, and chart reviews for a calculated sample size of 292. Mean and SD were used to present continuous variables. Frequency and percentage are used to present categorical variables. The analysis will be done using SPSS Version 28, ANOVA, independent sample t-test, and Kruskal-Wallis test were used to compare continuous variables among different groups. Multiple linear regression analysis was used to determine factors independently associated with different domains.

Result Among the 285 included caregivers, the mean age was 37.8±7.99. Over half of caregivers were between 30-39 years old 155, (54.4%). The WHOQoL-BREF score findings in this study revealed that the mean scores for physical health and psychological domain were 53.43 and 58.05, respectively, which are relatively higher compared to the lower mean scores for Social relationship and Environmental domains which are 45.71 ±22.44 and 43.39 respectively. Caregiver education status, sex, household income and perceived severity of child illness showed significant association with the four domain of quality of life (P-value <0.05).

Conclusion and recommendation:-This study revealed that caregivers of children with Down syndrome have a significantly compromised quality of life in all the 4 domains of QoL, particularly in social relations and environmental health domains. Poor economic condition, sex of caregiver, lower education level and perceived severity of their children's illness are significant determinants of their QoL. This is indicative of the need for a coordinated care plan for children with down syndrome and their caregivers and we suggest further qualitative and case controlled studies to better define the kind of intervention these study group urgently requires.

Key words:- Down syndrome, quality of care, caregivers, Tikur Anbesa Specialized Hospital

1. Introduction

1.1 Background

Down syndrome (or trisomy 21), known as a genetic disease that results from an excess copy of trisomy 21 [1–3], is the most common genetic cause of mental retardation [1]. While the exact prevalence in Africa remains uncertain, Down syndrome is observed frequently in diverse international populations and has historically been identified as the most common chromosomal disorder [2, 3]. The severity of Down syndrome (DS) can vary significantly among individuals. Commonly, individuals with DS display physical features and experience intellectual challenges and lifelong delays in development. Furthermore, the condition can give rise to various consequences, including obstructive sleep apnea, hearing impairment, heart defects, ear infections, and eye conditions [3-5].

Although defining quality of life (QoL) has been a challenging task, it extends beyond mere health status, clinical symptoms, or functional capabilities [6-13]. Several definitions of QoL have been proposed, such as "a subjective evaluation of one's satisfaction with life" and "an individual's perception of their overall well-being considering their goals, expectations, values, and cultural context" [14, 23].

In addition to having a substantial morbidity on the affected children, DS can also have an impact on the quality of life (QoL) of their caregivers [4]. The term QoL has gained increasing acceptance as a key outcome measure in patients and caregivers of chronic illness [6]. It is a broad concept that is typically used to examine various domains of life [4]. The World Health Organization (WHO) defines it as an individual's view of their place in the world in relation to their cultural and value systems, as well as their goals, anticipations, and concerns [6, 14]. The concept encompasses notions such as psychological, physical, social, emotional, and environmental parameters that might be influenced by the patient’s health [4, 7].

Given that children with Down syndrome (DS) experience slower growth and require additional stimulation in their daily activities, parents often need to adjust their daily routines [5]. Research findings suggest that caregivers of children with DS experience lower levels of mental well-being compared to parents of children without chronic illnesses. This is evident in their lower scores in areas such as daily activities, vitality, and social and cognitive functioning [16].

The severity of a child's condition in Down syndrome (DS) can also have an impact on their quality of life (QoL), as some children with DS may require greater levels of care and medical interventions compared to others. By accurately assessing the dimensions of health-related quality of life (HRQoL), it is possible to identify the most vulnerable groups with the poorest outcomes in terms of their health [4, 16]. As a result, assessing HRQoL in parents of DS children may enable concerned bodies to create interventional programs that are appropriate for this population and improve QoL-related outcomes. This study will be carried out to determine whether or not having DS children can affect the various dimensions of the asses QoL of caregivers with DS attending follow up at TASH.

1.2 Statement of the Problem

Globally, approximately 7.9 million children are born annually with severe birth defects of genetic or partially genetic origin. Each year, a minimum of 3.3 million children under the age of 5 die from birth defects, and an estimated 3.2 million survivors may experience lifelong disabilities. According to Christianson [41], the onset of DS typically occurs during prenatal development [42], and it is estimated to affect approximately one in every 1,000 births. Diagnosis of DS is generally made prenatally or at the time of birth using methods such as cell-free prenatal screening with parallel sequencing of maternal plasma cell-free DNA or genetic karyotype testing [43, 44].

Individuals with Down syndrome (DS) are at an increased risk of developing infections, autoimmune disorders, and various hematologic and oncologic abnormalities [11]. DS represents a significant public health concern globally and places a substantial burden on families and society. Caregivers of children with DS face numerous challenges in providing care for their children, who experience multiple neuro developmental and physical difficulties. With advancements in medical care for individuals with DS and improved survival rates, there is a growing emphasis on enhancing the quality of life for both the children with DS and their caregivers, leading to extensive research in this area.

A scoping assessment has indicated that effective management of children with Down syndrome (DS) can be achieved through appropriate care coordination. Researchers have identified specific elements that are crucial for successful implementation of care coordination in primary care settings. These elements include a family-centered approach that addresses both the physical and psychological needs of individuals with DS [36]. However, there is a lack of research studies assessing the quality of life of caregivers of children with DS. In our particular setting, despite the presence of a specialized hospital

(TASH) that provides comprehensive care for DS patients, the burden experienced by caregivers across various domains of quality of life is often overlooked or neglected.

1.3 Rationale of the study

The quality of life (QoL) of caregivers to DS patients is compromised in various areas, with some contradictory findings in various studies conducted in Europe and the Middle East. However, pertinent research addressing the impact of caring for a child with DS on the QoL of caregivers in Ethiopia and generally in Africa is still lacking. To determine whether an intervention is necessary, it will be useful to have an organized understanding of the current QoL of caregivers of children with DS.

2. *Literature review*

Down syndrome (DS) is considered one of the most prevalent and severe developmental disorders associated with chromosomal abnormalities that allow survival beyond birth (1, 3, 8). Presently, there are millions of individuals worldwide who are affected by this condition. The intellectual functioning of adults with DS is typically comparable to that of an 8 or 9-year-old child (8). The World Health Organization (WHO) estimates that the incidence of DS ranges from 1 in 1000 to 1 in 1100 live births globally, with approximately 1 in 1250 live births in India (8, 34). However, it should be noted that there are conflicting reports regarding these statistics. In a study done in Nigeria in 2011 stated that there was difficulty in achieving accurate data on the exact prevalence of Down syndrome in developing countries in Africa attributable to many factors. True population-based data are difficult to generate; most of the data reported are hospital-based data and most are projected data from developing countries like Europe and US (2). Include factors affecting QOL in parents with children with chronic illnesses.

As highlighted in the literature, children with Down syndrome (DS) exhibit slower rates of development (4) and have unique needs that pose challenges for parents as they strive to prepare for their child's future (7-9). Consequently, these children require increased dedication from their parents, which can significantly impact family dynamics (4, 5). The moment parents receive the initial diagnosis of their child's condition is an emotionally charged and stressful event (1). In addition to the initial emotional impact, children with DS continue to have an ongoing influence on family life, as they require additional care throughout their lifespan, primarily provided by parents (3). While the repercussions of DS affect the entire family, the primary caregiver, often a parent, bears the responsibility of providing physical, emotional, and sometimes financial support to the affected individual (5, 9).

Numerous studies highlight the mother as the primary caregiver within the family, responsible not only for direct childcare but also for providing information regarding the child's overall development, health, and education (5, 9). The primary caregiver plays a crucial role in supporting individuals with special needs and ensuring their inclusion within the community, thus preventing situations of exclusion. However, caregivers often face challenging tasks without sufficient guidance, lacking support from healthcare institutions and social networks. The demands placed on caregivers, along with disruptions in their daily routines and the significant time commitment required for caregiving, can directly impact their personal, family, and social lives, thereby affecting their quality of life (9). Evidence in the literature indicates that caregivers to DS children have reduced mental health status, and usually require additional help to manage these children and enhance their psychological well-being. Another cross sectional study done in Saudi Arabia also indicated that caregivers to DS children have significantly higher stress levels as compared to others of normal children (4,29 ,30).

Studies conducted in both Western and Middle Eastern settings have consistently shown that raising a child with Down syndrome (DS) is associated with a decrease in health-related quality of life (HRQoL) across various domains, including cognitive functioning, social functioning, daily activities, and vitality (10). The term "quality of life" (QoL) encompasses a broad range of aspects that are typically assessed to evaluate overall well-being. In a more specific context, the term "HRQoL" is used to specifically address various parameters of life, such as psychological, physical, social, and emotional aspects, which may be affected by the individual's health status (23).

Quality of life is a comprehensive concept that encompasses various dimensions, including physical health, psychological well-being, level of independence, quality of social relationships, and one's relationship with important environmental factors (7, 34). As per the World Health Organization (WHO) definition, quality of life is determined by an individual's own perception of their overall life circumstances, taking into account cultural values and their goals, expectations, standards, and concerns (7, 9). Assessing quality of life based on this concept is subjective and multidimensional, incorporating both positive and negative evaluations (9).

Thoroughly evaluating the domains of health-related quality of life (HRQoL) can be instrumental in identifying the most vulnerable groups with poorer health outcomes. Consequently, measuring HRQoL in caregivers of children with Down syndrome (DS) can assist healthcare authorities in developing appropriate intervention plans aimed at improving quality of life outcomes (4). Numerous studies have identified factors that are linked to higher levels of stress and decreased well-being among parents of children with DS. These include socio-demographic factors like lower socio-economic status, a higher number of children and (higher or lower) age of the child with DS. The child’s functioning variables such as behavioral problems, communicative impairment, health problems and diminished self-sufficiency of the child were found to be of negative influence (10).

Finally, psychosocial factors such as maladaptive coping styles of parents, less dispositional optimism, lower quality of the (marital) relationship, and a lack of social support were associated with negative consequences (33, 10). Abbasi, S. and et al in their study in 2016 found that the quality of life among mothers of children with DS is not in a desirable condition. In their study, mothers gained the highest scores on the physical aspect explained by fatigue, time consumption, and stress that taking care of a child with DS brings upon the parents which was similar to the study done on care givers of children with cerebral palsy by Khanjani, and et al in 2010. In this study psychological health is the second component with the lowest score in this study after environmental health (7, 37).

A study conducted in India in 2020 highlighted the importance of improving health-related quality of life (HRQoL), with cognitive functioning and worry being identified as the least and most affected domains, respectively. The study also revealed that instrumental social support, active coping, and religious coping were the primary strategies used for coping (8). Another study conducted in Brazil found that parents/caregivers generally perceived their quality of life (QoL) as "good" and expressed satisfaction with their lives. The most affected domain was the Environmental domain, which was found to be correlated with socio-demographic factors such as education level and socioeconomic status (9).

A cross sectional study done in Netherland, also was done aiming to explore which socio-demographics, child functioning and psychosocial variables were related to the HRQoL domains of cognitive functioning, social functioning, daily activities and vitality in parents of children with DS. They found that psychological variables rather than Socio-demographics or child functioning showed most consistent and powerful relations to the HRQoL domains. Systematic screening of parents to detect problems timely, and interventions targeting the support network and the demands in time were recommended (10).

There is limited data about these outcomes in our set up which makes it difficult for the local healthcare authorities to identify the populations in need. Therefore, we plan this study to investigate whether or not having DS children can impact the different domains of the QoL of their caregivers in Ethiopia (4).

Conceptual frame work

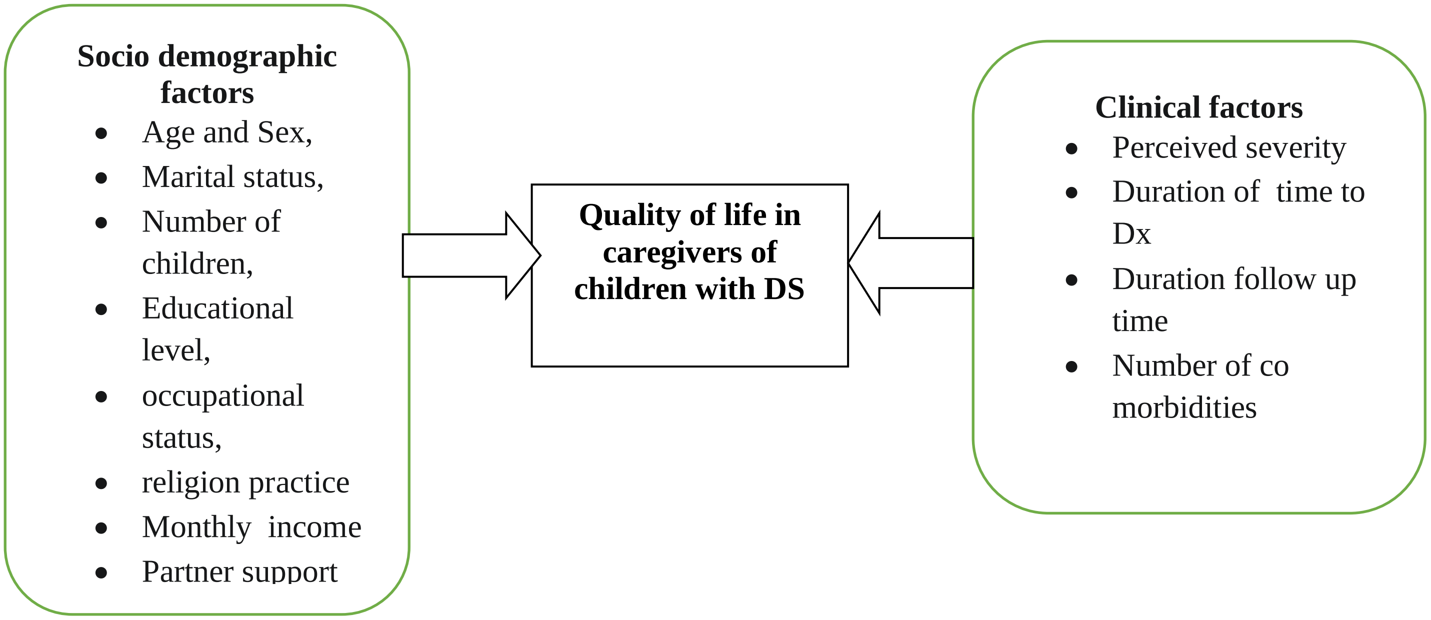


Figure 2.the conceptual framework of the factors assumed to affect heath related quality of life among care givers of child with DS (9-35).

3. Objectives

3.1 General objective

- To assess quality of life and associated factors among care givers of children with Down Syndrome on follow up at Tikur Anbesa Specialized Hospital.

3.2 Specific Objective

- To assess quality of life among care givers of children with Down syndrome age 6-month to 18 years on follow up at Tikur Anbesa Specialized Hospital.
- To assess factors affecting the Quality of life of care givers with Down syndrome children age 6-months to18 year on follow up at Tikur Anbesa Specialized hospital.

4. Methods

4.1 Study Setting

The study was conducted in Addis Ababa, Ethiopia at Tikur Anbessa Specialized Hospital. The hospital was established in 1974. It is the teaching hospital of Addis Ababa University, College of Health Sciences, and School of Medicine, located in Lideta sub-city. It is also the largest referral hospital in Ethiopia with a variety of specialties and sub-specialties. It has around 600 beds and serves about 250,000 patients as outpatients annually. It is one of the national referral centers for children with Down syndrome.

The pediatric Developmental, Neurology and Endocrine clinics often provide an outpatient follow-up care for children living with DS. The clinics work Half day in all the five working days of the week, and they are run by trained nurses, Pediatric and Child Health Residents, pediatric Neurology fellows and pediatric neurologists and a pediatric endocrinologist. Children in the range of 0-20 yrs of age attend these clinics to get the services these clinics provide. Currently, about 300 children attend the clinics monthly. The average number of children with DS and their care givers attending the clinics on a daily basis is around 20. Clinically stable patients are appointed to come every 3-6 months.

4.2 Study population

The study populations for the study were caregivers of children with DS attending the cardiac, developmental, neurology, and endocrinology clinics.

4.3 Study Design

Institution based cross-sectional study design was compute.

4.4 Sample size determination

The Sample size was calculated using the EPI info statistical package for sample size and power calculation. Plan is to estimate the mean of a continuous outcome variable in a single population, the formula for determining sample size is given below:

$$n = \left(\frac{Z\sigma}{E}\right)^2$$

Where: n = the desired sample size

d =3% (margin of error)

Z =1.96 (standard normal deviation value corresponding to 95% confidence level).

σ = standard deviation (26)

As we are assessing domains affecting QoL of caregivers to DS children, we have also calculated the sample size using different factors from several studies as shown in the table below.

Table -1 Sample size calculation by taking mean and SD of other study done

Author(s)		mean	Study Sample size (10% none respons)	Calculated Sample size
Fatima Saeed AlAhmari and et al	physical	15	261	105
	psychological	15		105
	social	10		46
	environmental	24		269
Emília de Faria Oliveira1	physical	15	31	105
	psychological	13		79
	social	26		292
	environmental	14		92

So, for this study sample size was taken from SD 26 from other similar study and calculated sample size was 266 and adding 10% none response rate the final sample size for this study become 292.

4.5 Sampling Method

The Cardiac, neurology, development and endocrine clinic follow up registries were used to generate the random list of DS patients under care and then simple random sampling technique through lottery method was employed to select the study participants. Patients ‘clinical ID numbers were used to avoid overlap sampling in different follow-up clinics. Willing study subjects were included in the study until the sample size is attained and the study period is finalized.

4.6 Inclusion and exclusion criteria

4.6.1 Inclusion criteria

- Consenting care givers who have clinically diagnosed children with down syndrome in the age range of 6 months to 18 years on follow-up at TASH.

4.7.2 Exclusion criteria

- Having other sick children in the family that needed care.
- any child with DS that also suffered from another dual diagnosis not related to Down Syndrome
- Caregivers who have lived with the child for 1 month or less.
- caregivers that suffered from mental health conditions prior to the diagnosis of the child

4.7 Study variables

4.7.1 Dependent variable: Quality of life

4.7.2 Independent variables: Age, sex, marital status, income, number of children, educational level, distance from follow-up, child age, child sex, co-morbidity, religious practice, perceived severity of illness etc.

4.8 Data collection tool:

World Health Organization Quality of Life Scale (WHOQoL-BREF) with modified questionnaires was used to assess the QoL of caregivers to DS children. WHO QoL BREF tool was developed by the World Health Organization as a quality-of-life assessment that would be applicable cross culturally. It is shorter version of WHOQoL-100, containing a 26 item self-reported measure where the scale is designed to measure the impact of disease and impairment on daily activities and behaviors, perceived health, disability, and functional capacity. It mainly measures four domains-physical, psychological, social, and environmental healths. The total score is presented between 26 and 156, where higher scores represent higher level of quality of life.

As well as raw scores being presented, a transformed score between 0 and 100 is computed based on methodology published in the WHOQoL-BREF manual. Higher transformed scores are indicative of higher level of quality of life and percentile 50 represents average quality of life (14). The tool is translated in more than 40 languages and has been successfully used in different studies**.** In this study the already available Summarized version of the expert translated Amharic version of the tool were used. It is scored as a Likert scale. And were interpreted as explained above (4, 14). The principal investigator reviewed and adjusted for any vague or difficult wording during translated questionnaire. Additional structured, pretested questionnaire on socio demographic and clinical questionnaire were prepared and used for data collection.

Piloting of both questionnaires was done in a sample of 9 caregivers which were excluded from the study. The questionnaires were modified based on the pretest findings.

4.9 Data collection Method

Four data collectors with medical background were recruited to collect data after they were trained on the WHOQoL-BREF manual. A structured, study questionnaire were administered to collect data on the socio-demographic characteristics, primary caregiver information, and health-related characteristics. Consent from primary caregivers was obtained. After information about the study and questionnaire were given, parents /care givers were taken to a separate room both questionnaires were filled by the data collectors. Any additional information needed or required was collected from charts and face-to-face interviews. For study participants who will fulfill the inclusion criteria, after ascertaining that the caregiver (parent) has lived with the child for at least the past 6 month, written informed consent was secured. Regular supervision at least 3 times per week was made by the primary investigator to assure quality and completeness of the data collected. Those caregivers with low QoL domains particularly on physical and psychological domains of life were linked to respective clinics in the hospital. Those requiring social support were linked to the hospital's social services and local NGOs working on Down syndrome.

4.10 Data analysis

Data from all participants were entered into a EPI data and then was imported to statistical software for analysis. There were no missing data. We used descriptive and inferential methods to assess QoL and factor associated with QoL. Normality assumptions were checked, and analysis of variance (ANOVA), independent sample t-test, and Kruskal-Wallis test were used to compare continuous variables among different groups. Continuous variables were expressed as the mean ± standard deviation and media wherever applicable. Categorical variables were described by frequencies (percent), and chi-square tests were used to identify associations between groups.

All tests were two-tailed, and p values less than or equal to 0.05 were considered statistically significant. QoL scores were transformed to a 100-point scale using methods detailed in WHOQOL-BREF manual [14]. Te internal consistency of QoL scores, measured by the WHOQOL-BREF instrument, was assessed using Cronbach's alpha. 0.815. Multiple linear regression analysis was used to determine factors independently associated with different domains of QoL. Prior to modeling for each individual domain, we checked multicollinearity using variance inflations factor (VIF).

4.11 Operational Definition

WHOQOL_ BREF Score: - is a condensed version of the WHOQOL-100, a scale created by the World Health Organization to assess quality of life and be cross-culturally applicable to assess the impact of disease and impairment on daily activities, behavior, perceived health, disability, and functional capacity.

HrQOL- a component of QoL that measures physical functioning, role limitations, social functioning, pain, mental health and vitality.

Down syndrome: is trisomy 21, which has a wide range of disease severity and a typical physical appearance. Symptoms typically include intellectual disabilities and lifelong developmental delays, as well as Co morbid conditions such as cardiac defects, obstructive sleep apnea, endocrine abnormalities, recurrent infections etc.

4.12 Ethical considerations

Respondents were clearly informed about the purpose of the study and the information required from them and that there is no risk or harm on the participants associated with the study. After securing consent, respondents were provided a separate room and given privacy to fill out respective questionnaires. They were also told that they have full right to not involve or withdraw from the study at any time. Participants' confidentiality was assured as there are no patient identifiers and data was decoded after collection. The children were received the same quality of health care service regardless of willingness of caregivers to participate in the study. Ethical approval for the study was sought from the department REC (Research and Ethics Committee).

4.13 Dissemination plan

The final reports of this study were submitted to the college of health sciences school of medicine, department of pediatrics and child health. The result of this study will be presented during thesis defense, as a specialty graduation thesis. Moreover, the findings of the study will be disseminated through publication in local and international journals.

5. Results

5.1 Socio demographic characteristic of respondent

The response rate of this study was 97.5% and the sex distribution of children in this sample was nearly balanced, with females representing a small majority. Of the 285 children, 139 (48.8%) were male and 146 (51.2%) were female. The majority of children 178, (62.5%) were under 5 years of age. Children aged 5-9 years comprised 73 of the sample (25.6%). Children aged 10-14 years and 15-19 years represented smaller proportions, with 27 children (9.5%) and 7 children (2.5%) respectively the mean age of the children were 4.9±3.7.

The majority of caregivers were female 242, (84.9%). Males comprised a small minority of caregivers 43, (15.1%). When we see the age distribution of the care givers mean age was 37.8±7.99. Over half of caregivers were between 30-39 years old 155, (54.4%). The second most frequent age group was 40-49 years, comprising 77 caregivers (27%). Thirty caregivers (10.5%) were aged 20-29 years. Smaller proportions of caregivers fell into the 50-59 years 16, (5.6%) and over 60 years 7, (2.5%) categories.

The majority of the respondents (214, 75.1%) were currently married. Forty-eight caregivers (16.8%) reported being single. Fifteen caregivers (5.3%) were separated or divorced. The remaining caregivers were widowed (8, 2.8%). The finding of this study revealed from the total respondent the highest proportion had completed grade 9-12 education (82 caregivers, 28.8%). Seventy-nine caregivers (27.7%) had education levels of grade 12 or above. Seventy-six caregivers' (26.7%) education was between grades 1-8. Thirty-seven caregivers (13%) reported having no formal education. The remaining 11 caregivers (3.9%) stated they could read and write.

Table:- 2 socio demographic status of the caregivers and their children with Down syndrome.

Sr.n	Variable		Frequency	Percent
1	Child sex	Male	139	48.8
		Female	146	51.2
		Total	285	100.0
2	Child age	<5	178	62.5
		5-9	73	25.6
		10-14	27	9.5
		15-18	7	2.5
		Total	285	100.0
3	Caregiver sex	Male	43	15.1
		Female	242	84.9
		Total	285	100
4	Caregiver age	20-29	30	10.5
		30-39	155	54.4
		40-49	77	27.0
		50-59	16	5.6
		>60	7	2.5
		Total	285	100.0
5	Caregiver marital status	Single	48	16.8
		Married	214	75.1
		Separated/Divorced	15	5.3
		Widowed	8	2.8
		Total	285	100.0
6	Caregiver education	Not Educated	37	13.0
		Able To Read And Write	11	3.9
		Grade 1-8	76	26.7
		Grade 9-12	82	28.8
		Grade 12 And Above	79	27.7
		Total	285	100.0
7	Total number of children	1	44	15.5
		2-3	148	51.9
		4-5	72	25.3
		>6	21	7.4

		Total	285	100
8	Income	<2000	55	19.3
		2001-4000	78	27.4
		>4000	152	53.3
		Total	285	100.0

The majority of caregivers 148, (52.1%) had 2-3 children. Seventy-two (25.4%) and 43 (15.1%) caregivers had 4-5 children and 1 child, respectively. The mean travel time was 2.5 hours with SD4.67 with a median of 1.5 hours. The majority 248, (87%) took 60 minutes or more to travel to the hospital. Thirty-seven caregivers (13%) reported being able to reach a hospital in under 60 minutes. When we see the religious practice of the care giver, over 90% (259) reported practicing a religion. Twenty-six caregivers (9.1%) indicated they did not practice any religious faith. Regarding employment status of the respondent, nearly half 130, (45.6%) reported being unemployed. Over one-sixth (47, 16.5%) were employed in government or non-governmental organizations. Approximately one-quarter (65, 22.8%) were self-employed. (Figure:-1)

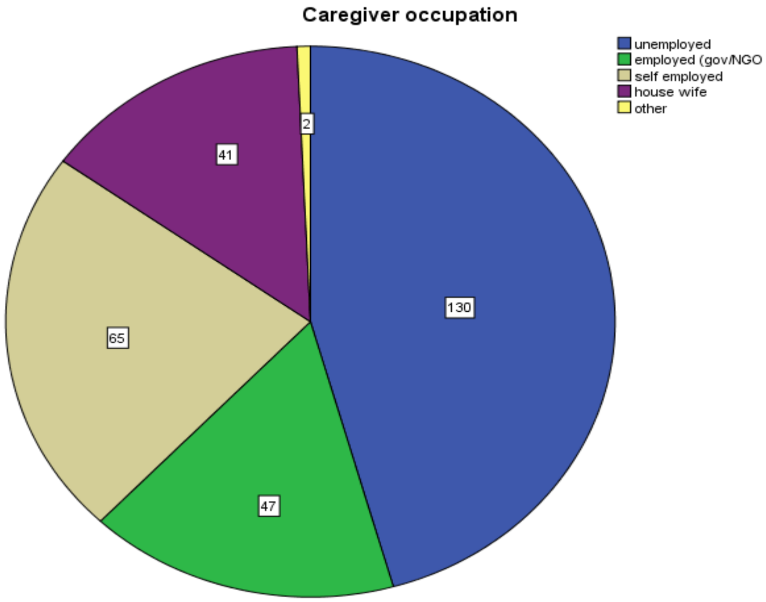
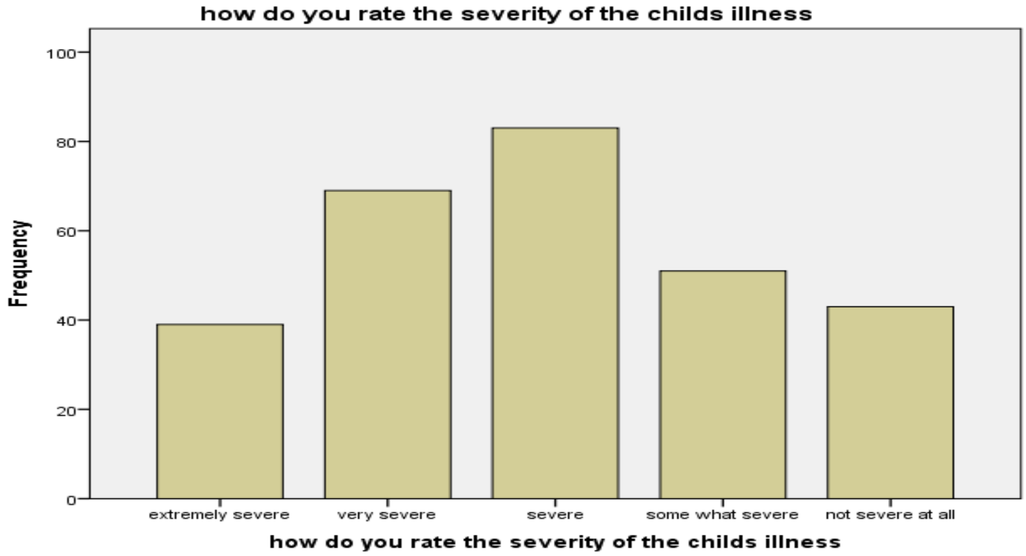


Figure 2: occupational status of caregivers of children with Down syndrome.

From the total children in the study the majority 202, (70.9%) had been diagnosed within the past 5 years. Over one-fifth 63, (22.1%) were diagnosed between 5-10 years ago and the rest 20, (7%) had been diagnosed 10 or more years ago. Regarding the time since the children's last clinical follow-up, the majority 205, (71.9%) had a follow-up within the past 5 years. Over one-fifth 60, (21.1%) were seen between 5-10 years ago the rest 20, (7%) had not been seen for 10 or more years.

The prevalence of co morbid conditions among the children is, the majority of children 270, (94.7%) were reported to have one or more co morbid medical issues. From the total children who report that they have Co-morbid (270), majority of children 212, (78.5%) were reported to have acyanotic CHD. Similarly, from the total children report having additional co-morbid, 15 (5.3%) were reported to have cyanotic CHD. Over two-fifths of children 116, (43%) were reported to have hypothyroidism and 11, (4.07%) were reported to have hyperthyroidism. Similarly, approximately one-fifth of children 60, (22%) were reported to have pulmonary hypertension. A small number of children 11, (4.07%) were reported to have GI abnormalities. Over one-tenth of children 34, (12.5%) were reported to have an"other" co-morbidity like.

Regarding the prevalence of other children or sibling with DS living in the household, the study revealed that the vast majority of children 284, (99.6%) did not have another sibling with DS. Only one child (.4%) was reported to have an additional sibling with DS and only two children (.7%) were reported to have an additional family member with a chronic illness. The study try to show Caregivers' perception of the severity of their child's illness and the largest group rated their child's condition as severe 83, (29.1%). Over one-quarter viewed it as very severe 69, (24.2%) or extremely severe 39, (13.7%).



[redacted]

Figure 3: caregiver perception of severity of their children illness

The result of this study showed that Figure 4 represent the distribution of caregiver ratings across different categories of general quality of life. It appears that the majority of caregivers (46%) rated the general quality of life as neither poor nor bad. Additionally, a significant proportion of caregivers rated it as poor (25.20%) or very poor (11.20%).

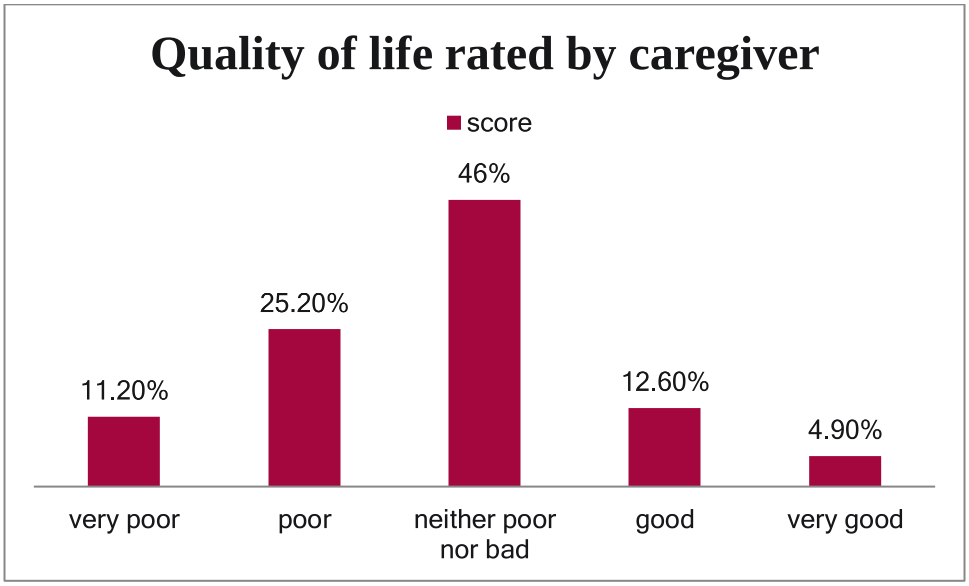


Figure 4:-Quality of life rated by caregivers of children with DS

From the total children in the study the majority 202, (70.9%) had been diagnosed within the past 5 years. Over one-fifth 63, (22.1%) were diagnosed between 5-10 years ago and the rest 20, (7%) had been diagnosed 10 or more years ago. Regarding the time since the children's last clinical follow-up the majority 205, (71.9%) had a follow-up within the past 5 years. Over one-fifth 60, (21.1%) were seen between 5-10 years ago. A small percentage 20, (7%) had not been seen for 10 or more years.

From the total 163 children who are eligible for education, who need special needs schooling 113, (69.3%) were not able to access special needs schooling. Approximately, one-fives (50, 30.67%) were able to access this resource. Responses from the subset of caregivers (n=113) who indicated they were not able to access special needs schooling for their child, over one-third 43, (38.1%) reported living far from home, slightly less than half 55, (48.7%) reported feeling limited in the number of schooling options, a small proportion 20, (17.7%) perceived the options to be expensive, and a small number 15, (13.3%) felt options did not provide sufficiently individualized or tailored training plans.

Table 3:- quality of life among caregivers with children Down syndrome.

Quality of life domains	Range	Mean	Std. Deviation
Physical health score	94.00	53.4386	17.845
Psychological health score	94.00	58.0526	15.989
social Relation score	100.00	45.7158	22.446
environmental health score	87.00	43.3930	15.460

The finding of this study reviled that the mean score for physical health is 53.4386, which suggests that the average individual in the study has a moderate level of physical health with standard deviation of 17.84. The mean score for psychological score is 58.0526, which suggests that the average individual in the study has a moderate to high level of psychological health with standard deviation of 15.98. Social Relation score: This variable assesses the social relationships of the individuals in the study. The mean score for this variable is 45.71 ±22.44, the last score, Environmental health score: This variable assesses the environmental health of the individuals in the study and the mean score for this variable is 43.3930, which suggests that the average individual in the study has a lower level of environmental health with SD of 15.46. Overall, the descriptive statistics suggest that the individuals in the study have moderate to high levels of physical and psychological health, moderate levels of social relationships, and environmental health.

5.2 factors associated with quality of life

Result from ANOVA showed Educational status of the care giver showed significant association in all four domains of quality of life ($p<0.05$). ANOVA results suggest that there are no statistically significant differences in any of the four health scores (physical, psychological, social relation, and environmental) between groups for marital status of the care givers (p>0.05).

Considering caregiver perception about the severity of their child illness, ANOVA results suggest that there are statistically significant differences in physical health scores, psychological health scores, and environmental health scores between the three groups, but no statistically significant differences in social relation scores (p=0.057).

The analysis reviled numbers of children the care givers have p = 0.173 for physical domain, is not statistically significant. Similarly In psychological score at p = 0.141, the difference in each group is not statistically significant. Overall, the results suggest that there are no statistically significant differences in physical health scores, psychological and social scores between the three groups, but statistically significant differences in environmental health scores (p=0.054)

This study reviled that care giver sex shows p value <0.05 for all QOL domains. So the result suggests that there is a statistically significant difference between groups in terms of physical health, psychological, social and environmental scores.

For variable that indicate the time that take to reach hospital the p-value exceeds the significance level (0.05), leading us to fail to reject the null hypothesis. This indicates that there is no statistically significant difference between groups in terms of physical, psychological, and social relation and environmental health scores.

Similar to the previous variables, religion practice of the respondent the p-value is greater than the chosen significance level. Therefore, we fail to reject the null hypothesis and conclude that there is no statistically significant difference between groups in terms of physical, psychological, social relation and environmental scores.

Table : 4 Results of ANOVA for comparing means of each dimension of “quality of life” among socio demographic and other clinical factors of mothers of children with Down syndrome.

Variables	**Physical health domain Mean(CI)**	**Psychological domain Mean(CI)**	**Social relation domain Mean(CI)**	**Environmental domain Mean(CI)**
Care giver age				
20-29	55.39	55.23	39.1	42.3
30-39	54.64	57.4	44.6	43.03
40-49	49.89	59.14	48.92	43.59
50-59	52.5	60.56	48.43	44.31

>60	60.4	66.85	55.28	52
Total	53.4	58.05	47.7	43.39
p-value	0.271	0.399	0.199	0.649
Education status				
Not Educated	43.08	49.01	37.3	35.42
Able To Read And Write	41.54	51.27	42.6	42.97
Grade 1-8	54.13	59.07	44.39	49.58
Grade 9-12	51.62	56.19	44.14	40
Grade 12 And Above	61.16	64.15	52.97	41.8
P value	**0.000***	**0.000***	**0.006***	**0.000***
Matrrital status				
Single	54.06	57	46	43.3
Married	53.88	58.30	46.27	43.7
Separated/Divorced	54.6	55	41.66	37.7
Widowed	52.37	63.25	36.75	44
pvalue	0.375	0.649	0.598	0.543
Number of child				
1	54.3	55.22	42.1	39.7
2-3	54.5	58.18	46.04	44.64
4-5	53.01	60.87	45.44	44.8
>6	45.38	53.3	51.8	37.04
p-value	0.173	0.141	0.44	**0.054***
Severity of case				
extremely severe	42.33	58.05	38.8	38.7
very severe	50.14	51.7	42.6	38.5
severe	53.92	55.71	46.4	42.9
some what severe	59.05	61	48.9	47.9
not severe at all	61.18	65.62	51.7	50.88
p-value	**0.000***	**0.001***	**0.057***	**0.000***
Child Sex				
Male	52.35	57.5	45.19	43.7
Female	54.47	58.4	46.21	43.06
P value	0.317	0.637	0.703	0.713
Care giver Sex				
Male	58.65116	62.67	59.65	49.04
Female	52.5124	57.23	42.23	42.38
p-value	**0.037***	**0.039***	**0.000***	**0.009***
Co-morbidity				
yes	52.53	58	45.27	43.4
no	51.86	54.2	53.66	43.14
p-value	0.727	0.337	0.159	0.947
Time to reach hospital				
<60	57.87	60.75	46.91	44.08
>=60	52.7	57.64	45.53	43.29

P value	0.104	0.271	0.727	0.772
Religion practice				
yes	53.69	58.03	46.35	43.6
no	50.92	58.26	39.38	41
P value	0.452	0.942	0.132	0.469
Able to get special need school				
Yes	51.16	57.68	48.3	42.3
No	53.16	58.17	46.9	44.39
p- value	0.504	0.983	0.345	0.636

Result from Kruskal –Wallis test

The output of Kruskal-Wallis Test suggests that there are significant differences in the four health scores (physical, psychological, social relation, and environmental) across the three groups defined by the income of the caregivers.

As the p-value is greater than the significance level for all quality domains, we fail to reject the null hypothesis. This indicates that there is no statistically significant difference in physical, psychological, social and environmental health scores among the groups defined by the variable child age.

Table 5:- Results of Kruskal –Wallis test for comparing means of each dimension of "quality of life" among of mothers of children with Down syndrome with independent variables.

Variables	**Physical health domain Mean rank**	**Psychological domain Mean rank**	**Social relation domain Mean rank**	**Environmental domain Mean rank**
Income				
0-2000	117.04	126.03	127.62	117.98
2001-4000	117.64	124.38	126.80	127.22
4001-1000000	165.41	158.69	156.88	160.15
p—value	**0.000***	**0.002***	**0.009***	**0.001***
Age of child				
<5	150.42	142.88	140.89	147.04
5-9	132.32	146.99	147.27	132.55
10-14	123.17	126.39	142.37	150.61
15-19	142.14	168.36	154.64	119.79
p-value	0.330	0.577	0.928	0.489

Occupational status				
unemployed	119.97	126.02	132.42	122.05
employed (gov/NGO	169.77	156.71	161.93	161.72
self employed	161.88	158.82	158.07	174.60
house wife	153.61	151.24	125.59	132.11
other	180.25	241.25	253.50	261.00
p-value	**0.001***	**0.012***	**0.015***	**0.000***
Time elapse DX				
<5 years	148.05	143.03	141.88	146.56
5-10 years	130.36	147.47	149.47	132.12
>=10 years	131.83	128.65	133.90	141.28
p- value	0.266	0.667	0.731	0.470
Time elapse for folloup				
<5 years	147.37	141.06	141.80	146.83
5-10 years	129.54	150.28	147.66	129.83
>=10 years	138.58	141.08	141.35	143.23
p-value	0.321	0.738	0.888	0.366
Partner support				
Yes	145.54	145.97	148.95	146.30
no	132.86	131.13	119.20	129.82
P value	0.295	0.219	0.014	0.173

Result from multiple linear regressions

After adjustment for socio-demographic characteristics, co morbidity and complication-related variables in multiple linear regression analysis, different sets of factors were found to be significantly associated with the four separate domains of the WHO-BREF QoL scale (Table 4). The coefficient for income is statistically significant at the 10% level, with a p-value of 0.07. This means that for every additional Birr of income, the BREF Physical health score is expected to increase by 0.158 points. The coefficient for partner support with child care is not statistically significant, with a p-value of 0.989. This means that the model does not have a significant effect on the BREF Physical health score. Similarly, caregiver sex is not statistically significant, with a p-value of 0.087.

Regarding care givers perception on severity of the child illness, the coefficient is statistically significant at the 1% level, with a p-value of 0.000. This means that for every additional point on the severity, the BREF Physical health score is expected to increase by 0.271 points. The model showed number of children that care givers have does not have a significant effect on the BREF Physical health score regarding with a p-value of 0.327. On the contrary, the coefficient for caregiver educational level is statistically significant at the 10% level, with a p-value of 0.01. This means that for every additional increment in the level of education, the BREF Physical health score is expected to increase by 0.197 points.(table 6)

Table 6:- Multiple linear regression analysis of physical domain of quality of life with independent variable .

Coefficients^a

model	**Unstandardized Coefficients**		**Standardized Coefficients**	**t**	**Sig.**	**95.0% Confidence Interval for B**		**Collinearity Statistics**	
	B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
(Constant)	35.210	8.246		4.270	.000	18.977	51.444		
income	3.603	1.317	.158	2.735	.007	1.010	6.196	.857	1.166
Partner support	.033	2.504	.001	.013	.989	-4.896	4.963	.905	1.105
caregiver sex	-4.650	2.704	-.093	-1.720	.087	-9.973	.673	.970	1.031
severity of the childs illness	3.849	.772	.271	4.985	.000	2.329	5.368	.970	1.031
number of children	-1.205	1.228	-.054	-.982	.327	-3.623	1.212	.939	1.065
caregiver educational level	2.723	.797	.197	3.417	.001	1.155	4.292	.862	1.160

a. Dependent Variable: BREF Physical health score

The coefficients for income and partner support are not statistically significant at the 10% level, with a p-value of 0.113 and 0.549 respectively. This means that the model does not have a significant effect on the BREF Psychological health score. Similarly, caregiver sex and number of children are not statistically significant, with a p-value of 0.096 and 0.130. This means that the model does not have a significant effect on the BREF Psychological health score.

In other way the model showed perceived severity of illness statistically significant at the 1% level, with a p-value of 0.000. Similarly, educational level is statistically significant at the 10% level, with a p-value of 0.000. This means that for every additional level of education, the BREF Psychological health score is expected to increase by 0.216 points. (Table-7)

Table 7. Multiple linear regression analysis of physiological domain of quality of life with independent variable .

Coefficients[a]

Model		**Unstandardized Coefficients**		**Standardized Coefficients**	**t**	**Sig.**	**95.0% Confidence Interval for B**		**Collinearity Statistics**	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)	38.079	7.670		4.965	.000	22.980	53.178		
	Income	1.950	1.225	.095	1.592	.113	-.461	4.362	.857	1.166
	Partner support	1.396	2.329	.035	.600	.549	-3.189	5.981	.905	1.105
	caregiver sex	-4.200	2.515	-.094	-1.670	.096	-9.151	.750	.970	1.031
	severity of the child's illness	2.744	.718	.215	3.821	.000	1.330	4.157	.970	1.031
	number of children	1.735	1.142	.087	1.519	.130	-.513	3.983	.939	1.065
	caregiver educational level	2.672	.741	.216	3.604	.000	1.213	4.131	.862	1.160

a. Dependent Variable: BREF Psychological health score

The finding of this study reviled caregiver sex and educational level are statistically significant at the 10% level, with a p-value of 0.012 and 0.000. The coefficient for does child's caregiver help with child care is not statistically significant, with a p-value of 0.172. This means that the model does not have a significant effect on the BREF Social Relation score. Similarly, care givers income does not show significant association with social relation domain. (Table 8)

Table 8;- Multiple linear regression analysis of social relation domain of quality of life with independent variable .

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)	50.141	10.743		4.667	.000	28.992	71.289		
	Income	1.870	1.716	.065	1.090	.277	-1.508	5.249	.857	1.166
	Partner support	-4.465	3.262	-.080	-1.369	.172	-10.887	1.957	.905	1.105
	caregiver sex	-14.247	3.523	-.228	-4.044	.000	-21.181	-7.312	.970	1.031
	severity of the childs illness	2.627	1.006	.147	2.612	.009	.647	4.606	.970	1.031
	number of children	2.606	1.600	.093	1.629	.104	-.543	5.755	.939	1.065
	caregiver educational level	2.613	1.038	.150	2.516	.012	.569	4.657	.862	1.160

a. Dependent Variable: BREF social Relation score

For environmental domain of quality of life caregiver sex and perceived severity of child illness showed significant association (p=0.026 and 0.000). On the contrary caregiver income and number of children were not statistically significant at the 10% level, Overall, the results suggest that the model has a significant effect on the BREF environmental health score, and that the coefficients for caregiver sex, severity of the Childs illness, and caregiver educational level are statistically significant.(Table 9)

Table 9:- Multiple linear regression analysis of Environmental domain of quality of life with independent variable.

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)	28.362	7.316		3.877	.000	13.959	42.764		
	newincome	1.880	1.169	.095	1.609	.109	-.420	4.181	.857	1.166
	Partner support	.483	2.222	.013	.218	.828	-3.890	4.857	.905	1.105
	caregiver sex	-5.384	2.399	-.125	-2.244	.026	-10.106	-.662	.970	1.031
	severity of the childs illness	3.003	.685	.244	4.384	.000	1.654	4.351	.970	1.031
	number of children	.923	1.089	.048	.847	.398	-1.221	3.067	.939	1.065
	caregiver educational level	2.548	.707	.213	3.604	.000	1.157	3.940	.862	1.160

a. Dependent Variable: BREF environmental health score

6. Discussion

This study aimed to assess the overall quality of life profile of caregivers of children with Down syndrome using the WHOQoL-BREF score and the associated factors. The study's findings, which are supported by other research, indicated that while social relations and the environmental domains of QoL showed below average scores, the physical health and psychological domains exhibited better scores. Similar findings about the highest score in the physical domain (7) were observed in an Iranian study.

Similar findings have been reported in a study (37), which aligns with our results. These findings demonstrate the potential strain that parents may experience due to the demanding, time-consuming, and stressful nature of raising a child with Down syndrome(5). Nonetheless, the comparatively higher scores on the physical and psychological domains are supported by the so called "DS advantage"in which parents reported greater personal reward, higher quality in their relationship with their children and subjective well-being. This is because parents of children with DS tend to adapt to their situation as these children exhibit positive qualities and fewer behavioral problems compared to children with other disabilities (9, 13, 45).

According to a study conducted in Saopaulo, Brazil, the environmental domain has the lowest mean score among the four QoL domains. This finding is in line with the results from (9) and with what we found. This might be due to the fact that caregivers of children with down syndrome had to cater to the special attention and time these children require that they will not have the time, mental space, comfortable working environment for themselves. Additionally, they won’t have the opportunity to advance in their careers, find fulfillment in their jobs and homes, or engage in entertainment (9,13).

Regarding the factors influencing quality of life, all domains of quality of life were found to be associated with the caregiver's perception of income, educational status, and perceived severity of their child's illness. The study also revealed that the scores in the physical, psychological, social, and environmental health domains were associated with the education level of the caregivers. Caregivers with higher levels of education could have easier access to information and resources related to their child's condition which could explain this association. They might be more knowledgeable about Down syndrome, its effects, and the resources available for assistance. This understanding may better equip them to deal with the challenges at hand and enjoy a better quality of life (40).

The findings of this study revealed a statistically significant association between caregiver's income and the physical health domain of quality of life. This finding aligns with the results from other studies, which indicate that cultural and socioeconomic disadvantages can impact the stress levels of parents/caregivers, leading to a strained relationship between parents and children (9, 20). The authors also emphasize that the education level of caregivers, particularly mothers, and cultural perspectives within the couple are associated with this particular domain of life.

Likewise, the study found that caregiver's perceptions of the severity of their child's illness were associated with all domains of quality of life. This finding is consistent with evidence indicating that caregivers may experience heightened levels of emotional distress, such as anxiety and depression, which can have a detrimental impact on their quality of life. The perception of the severity of their child's illness can further intensify emotional burden and increase stress, as caregivers often shoulder a significant portion of care-giving responsibilities, including managing medical appointments, therapies, and daily care. The perception of the severity of their child's illness can amplify the demands on their time, energy, and resources, potentially leading to burnout and reduced quality of life. This emotional challenge is a significant factor to consider (38).

In case of caregivers sex this study reviled that social relation domain of the quality of life have association with care givers sex this may be due to majority 85% of the study participant were female and around 50% of them were jobless. So, based on this study finding sex roles and societal expectations of women in many cultures, women are traditionally expected to take on caregiving responsibilities within the family. This can result in additional caregiving burdens for female caregivers, leading to increased stress, fatigue, and reduced personal time and autonomy, which can impact their quality of life. And also caring for a child with Down syndrome can be emotionally challenging. Female caregivers may experience higher levels of emotional distress, such as anxiety or depression, which can negatively affect their well-being and overall quality of life (36,39).

In the current study, no significant correlation was found between the age of parents/caregivers and the different domains of quality of life. However, previous studies (5, 10) have observed that age, particularly for mothers, can be considered a positive factor in enhancing the relationship between parents/caregivers and their children, as well as improving quality of life. Older mothers, who are often in a more mature phase of life, may bring certain advantages in caregiving. Similarly, in the present study, the domains of quality of life were also compared based on the ages of the children and adolescents, as some studies have suggested potential differences in outcomes (13, 16, 17). However, no significant differences were found between the groups in this regard.

7. Conclusion

This study revealed that caregivers of children with Down syndrome have average quality of life in physical health and psychological domains and lower in social relation and environmental health domains. Income, sex of caregivers, education level and perceived severity of the child’s illness are significant determinants of their QoL.

The results highlight the critical need of providing these caregivers with urgent support and intervention and the necessity of additional qualitative research and/or case control studies to better understand the impact of DS on QoL of caregivers of children with DS and related factors that may have an impact on QoL, to better clarify specific needs for intervention.

8. Recommendation

As the Social and environmental domains of QoL are most impacted, caregivers may feel less alone and anxious if they are assisted in starting and joining peer support groups, Down syndrome awareness and advocacy clubs, and other organizations. This will also aid in bridging the knowledge gap that appears to impact the QoL of these caregivers.

Facility-based coordinated care which integrates parental support and care with the care of the children with Down Syndrome, may be able to assist caregivers in overcoming challenges and teaching them coping skills. This is supported by a study that indicated that the person being cared for will experience much better care if the caregiver is healthy (46).

Finally, in order to more precisely establish the causal relationship between the independent factors and the QoL domains of caregivers of children with Down syndrome and to propose a specific intervention for this group, we recommend doing further qualitative and/or case control studies.

9. Reference

1. Ghosh S, Feingold E, Dey SK. Etiology of Down syndrome: Evidence for consistent association among altered meiotic recombination, non disjunction, and maternal age across populations. American Journal of Medical Genetics Part A 2009;149A:1415–20. https://doi.org/10.1002/ajmg.a.32932.
2. Adebari O. Down Syndrome in Nigeria Sub Saharan Africa [Internet]. Prenatal Diagnosis and Screening for Down Syndrome. InTech; 2011.
3. Christianson AL. Down syndrome in sub-Saharan Africa. J Med Genet. 1996 Feb;33(2):89-92. doi: 10.1136/jmg.33.2.89. PMID: 8929941; PMCID: PMC1051830.
4. F.S. AlAhmari et al., The quality of life of parents of children with down syndrome in a tertiary care hospital: A qualitative research study at Saudi Arabia, J.Annals of Medicine and Surgery 81 (2022) 104428
5. Leandro Loureiro Buzatto, Ruth Beresin, Quality of life of parents with Down syndrome children, einstein. 2008; 6(2):175-8
6. Vadakedom SS, Antony JM, Padma BK, et al. Quality of life of mothers of children with Down syndrome. J. Evolution Med. Dent. Sci. 2017;6(36):2939-2942, DOI: 10.14260/Jemds/2017/633
7. Abbasi, S., Sajedi, F., Hemmati, S., Najafi Fard, T., Azadchehr, M. J., &Poursadoghi. A.(2016). Evaluation of quality of life in mothers of children with Down syndrome. Journal of Practice in Clinical Psychology, 4(2), 81-88
8. Darla S, Bhat D, Health-related quality of life and coping strategies among families with Down syndrome children in South India, Medical Journal Armed Forces India, https://doi.org/10.1016/j.mjafi.2020.07.010
9. Oliveira Ede F, Limongi SC. Quality of life of parents/caregivers of children and adolescents with Down syndrome. J Soc Bras Fonoaudiol. 2011 Dec;23(4):321-7. English, Portuguese. doi: 10.1590/s2179-64912011000400006. PMID: 22231052.

10. Marchal JP, Maurice-Stam H, Hatzmann J, van Trotsenburg AS, Grootenhuis MA. Health related quality of life in parents of six to eight year old children with Down syndrome. Res Dev Disabil. 2013 Nov;34(11):4239-47. doi: 10.1016/j.ridd.2013.09.011. Epub 2013 Sep 28. PMID: 24083990.
11. Lee, A.; Knafl, K.; Van Riper, M. Family Variables and Quality of Life in Children with Down Syndrome: A Scoping Review. Int. J. Environ. Res. Public Health 2021, 18, 419. https://doi.org/10.3390/ ijerph18020419
12. Ajuwon, Paul M. "A Study of Nigerian Families Who Have a Family Member with Down Syndrome," Journal on Developmental Disabilities 18, no. 2 (2012).
13. Van Riper M, Knafl GJ, Barbieri-Figueiredo MDC, Caples M, Choi H, de Graaf G, Duarte ED, Honda J, Marta E, Phetrasuwan S, Alfieri S, Angelo M, Deoisres W, Fleming L, Dos Santos AS, Rocha da Silva MJ, Skelton B, van der Veek S, Knafl KA. Measurement of Family Management in Families of Individuals With Down Syndrome: A Cross-Cultural Investigation. J Fam Nurs. 2021 Feb;27(1):8-22. doi: 10.1177/1074840720975167. Epub 2020 Dec 4. PMID: 33272069; PMCID: PMC7897787.
14. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. Soc Sci Med. 1998 Jun;46(12):1569-85. doi: 10.1016/s0277-9536(98)00009-4. PMID: 9672396.
15. Chiracu A, Cosma G-A, Stepan AR, Cosma MA, Corlaci I, Călugăru EDC, Voinea F, Zăvăleanu M, Burileanu HA and Avramescu T (2023) Psychological capital, quality of life, and wellbeing in mother caregivers of individuals with down syndrome. Front. Psychol. 14:1145104. doi: 10.3389/fpsyg.2023.1145104
16. Senses Dinc G, Cop E, Tos T, Sari E, Senel S. Mothers of 0-3-year-old children with Down syndrome: Effects on quality of life. Pediatr Int. 2019 Sep;61(9):865-871. doi: 10.1111/ped.13936. PMID: 31267616.
17. Fucà E, Galassi P, Costanzo F and Vicari S (2022) Parental perspectives on the quality of life of children with Down syndrome. Front. Psychiatry 13:957876. doi: 10.3389/fpsyt.2022.957876
18. Ede MO, Okeke CI, Obiweluozo PE. Intervention for Treating Depression in Parents of Children with Intellectual Disability of Down's Syndrome: A Sample of Nigerian Parents. J Ration EmotCognBehavTher. 2022 Jul 21:1-25. doi: 10.1007/s10942-022-00471-1. Epub ahead of print. PMID: 35891632; PMCID: PMC9302872.
19. Rahimi T, Khazir Z. Perceived Experiences of Life Problems for Parents with a Down Syndrome Child. Health Education and Health Promotion. 2019;7(3):147-154.

20. Canbulat N, Demirgöz Bal M, Çoplu M. Emotional reactions of mothers who have babies who are diagnosed with Down syndrome. Int J NursKnowl. 2014 Oct;25(3):147-53. doi: 10.1111/2047-3095.12026. Epub 2014 Mar 7. PMID: 24602179.
21. R.; Batorowicz, B.; Dawud, S.; Aldersey, H.M. Family Quality of Life and Support: Perceptions of Family Members of Children with Disabilities in Ethiopia. Disabilities 2021, 1, 233–256. https://doi.org/ 10.3390/disabilities1030018
22. Newton R. Quality of life in Down syndrome: a matter of perspective. Dev Med Child Neurol. 2018 Apr;60(4):337-338. doi: 10.1111/dmcn.13706. Epub 2018 Feb 14. PMID: 29443380.
23. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? Pharmacoeconomics. 2016 Jul;34(7):645-9. doi: 10.1007/s40273-016-0389-9. PMID: 26892973.
24. The United Nations Convention on the Rights of the Child
25. Bull MJ, Trotter T, Santoro SL, et al; AAP Council on Genetics. Health Supervision for Children and Adolescents With Down Syndrome. Pediatrics. 2022;149(5):e2022057010
26. Haddad F, Bourke J, Wong K, Leonard H (2018) An investigation of the determinants of quality of life in adolescents and young adults with Down syndrome. PLoS ONE 13(6): e0197394
27. Anjali, K.G., Jose, T. T., Valsaraj, B. P., Nayak, A. K., Savitha, &Yashodharan, R. (2017). Quality of life of mothers having intellectually disabled children. Manipal Journal of Nursing and Health Sciences, 3(2), 67-72
28. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? Pharmacoeconomics. 2016 Jul;34(7):645-9. doi: 10.1007/s40273-016-0389-9. PMID: 26892973.
29. Weijerman ME, de Winter JP. Clinical practice. The care of children with Down syndrome. Eur J Pediatr. 2010 Dec;169(12):1445-52. doi: 10.1007/s00431-010-1253-0. Epub 2010 Jul 15. PMID: 20632187; PMCID: PMC2962780.
30. M.A. Roach, G.I. Orsmond, M.S. Barratt, Mothers and fathers of children with Down syndrome: parental stress and involvement in childcare, Am. J. Ment. Retard. 104 (5) (1999) 422–436.
31. Hedov G, Wikblad K, Annerén G. First information and support provided to parents of children with Down syndrome in Sweden: clinical goals and parental experiences. Acta Paediatr. 2002;91(12):1344-9. doi: 10.1111/j.1651-2227.2002.tb02832.x. PMID: 12578293.

32. Crowe TK, Florez SI. Time use of mothers with school-age children: a continuing impact of a child's disability. Am J OccupTher. 2006 Mar-Apr;60(2):194-203.
33. Greenberg JS, Seltzer MM, Krauss MW, Chou RJ, Hong J. The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or down syndrome on maternal well-being: the mediating role of optimism. Am J Orthopsychiatry. 2004 Jan;74(1):14-25. doi: 10.1037/0002-9432.74.1.14. PMID: 14769105; PMCID: PMC2396580.
34. Glanz BI, Healy BC, Rintell DJ, Jaffin SK, Bakshi R, Weiner HL. The association between cognitive impairment and quality of life in patients with early multiple sclerosis. Journal of the neurological sciences. 2010 Mar 15;290(1-2):75-9.
35. Siwach AK. Mapping of India’s contribution on “Down syndrome” during 40 years from 1973-2012. International Letters of Natural Sciences. 2015;7.
36. Skelton, B.; Knafl, K.; Van Riper, M.; Fleming, L.; Swallow, V. Care Coordination Needs of Families of Children with Down Syndrome: A Scoping Review to Inform Development of mHealth Applications for Families. Children 2021, 8, 558
37. Khanjani, M., Hatamizade, N., Hoseinian, M., Rahgozar, M., & Arjmand, M. Effects of training on how to care for children with cerebral palsy and their family caregivers’ quality of life (Persian). Journal of Rehabilitation 2010; 10(39), 38-42.
38. Malekpour, M., Farahani, H., Aghaei, A., & Bahrami, A. The effect of life-skills training on mothers stress having mentally retarded and normal children (Persian). Research on Exceptional Children 2006; 20(2), 661-676.
39. Koohsali, M., Mirzamani, M., Karimlo, M., & Mirzamani, M. Comparing of social adjustment in mothers of educable mentally retarded daughter (Persian). Journal of Behavioral Sciences 2008; 2(2), 165-172
40. Vadakedom S S, Mary Antony J, Krishnan Padma B, Saramma Mammen D, Palamkunnil Thankappan B. QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH DOWN SYNDROME. Journal of Evolution of Medical and Dental Sciences 2017;6:2939–42.
41. Christianson A, Modell B. MEDICAL GENETICS IN DEVELOPING COUNTRIES. Annual Review of Genomics and Human Genetics 2004;5:219–65.
42. Dierssen M. Down syndrome: the brain in trisomic mode. Nature Reviews Neuroscience 2012;13:844–58

43. Grieco J, Pulsifer M, Seligsohn K, Skotko B, Schwartz A. Down syndrome: Cognitive and behavioral functioning across the lifespan. American Journal of Medical Genetics Part C: Seminars in Medical Genetics 2015;169:135–49.
44. Bull MJ. Down Syndrome. New England Journal of Medicine 2020;382:2344–52.
45. Glidden LM, Grein KA, Ludwig JA. The Down Syndrome Advantage: It Depends on What and When You Measure. American Journal on Intellectual and Developmental Disabilities 2014;119:389–404.
46. Talley RC, Crews JE. Framing the Public Health of Caregiving. American Journal of Public Health 2007;97:224–8

Annex I Annex D Amharic version.

የመረጃወረቀት

ጤናይስጥልኝየእኔስም________________________________ይባላል፡፡የጥናቱመረጃሰብሳቢነኝ፡፡

በአዲስአበባዩኒቨርሲቲየጤናሳይንስኮሌጅየህጻናትእናታዳጊዎችህክምናክፍልየመጨረሻአመትተማሪየሆኑትዶ/ርማርታገ/መስ
ቀልበሚያካሂዱትጥናትእናምርምርላይመረጃሰብሳቢነኝ፡፡በዚህጥናትእናምርምርላይእንዲሳተፉበጣምእናበረታታለን፡፡
እርስዎምየሚሰጡትመረጃከዳውንሲንድረምጋርየሞኖሩልጆችአሳዳጊዎችየህይወትጥራትለማሻሻልግብዐትይውላል።ለ-
መጠይቁንለመጨረስከ10-20 ደቂቃዎችይወስዳል፡፡

የአማካሪዎችስም፡-ፐ/ርወርቅአበባአበበ፣ዶ/ርአዲስህይወትመለሰ

የድርጅቱስም፡- አዲስአበባዩኒቨርሲቲጤናሳይንስኮሌጅየህጻናትህክምናትምህርትክፍል

የጥናትናምርምርፕሮጀክትርዕስ፡-በጥቁርአንበሳሆስፒታል፣ኢትዮጵያ፣
ክትትልላይያሉከዳውንሲንድረምጋርየሞኖሩልጆችአሳዳጊዎችየህይወትጥራትደረጃምንነትየዳሰሳጥራት፣ 2015ዐ/ም

ዓላማ:- የዚህጥናትዓላማበጥቁርአንበሳሆስፒታል፣ኢትዮጵያ፣
ክትትልላይያሉከዳውንሲንድረምጋርየሞኖሩልጆችአሳዳጊዎችየህይወትጥራትደረጃምንላይእንዳለለማወቅረዳል፡፡
እርስዎሆኑልጆዎየሚሰጡትመረጃለጥናቱስኬታማነትብቻሳይሆንአገልግሎቱንለማሻሻልከፍተኛድርሻይኖረዋል፡፡
የጥናቱውጤትጉዳዩለሚመለከታቸውአካልይሰጣል፡፡

የአሠራርሂደት: -
ከላይየተጠቀሱትንዓላማዎችለማሳካትየሚያስፈልገውንመረጃከዳውንሲንድረምጋርየሞኖሩልጆችአሳዳጊዎችይወሰዳል፡፡
ይህምመረጃሙሉበሙሉየማይታወቅሚስጢራዊኮድተደረጎእናታሽጎለማንምሳይሰጥይቀመጣል፡፡
ይህምላሾችከእርስዎወይምለልጅዎከሚሰጥአገልግሎትጋርአይያያዙም፡፡
በዚህጥናትውስጥትክክለኛወይምየተሳሳቱመልሶችየሉም፡፡

አደጋ / ስጋት : - በዚህጥናትላይበመሳተፍጊዜዎንእንደምንሻማዎትሊሰሞዎትይችላል፡፡
ሆኖምግንየጥናቱውጤትሊያመጣዉ ለሚችለዉ ለውጥብለውእንደሚሳተፉእናምናለን፡፡
በጥናቱበመሳተፎምንምአይነትጉዳትአያደርስቦትም፡፡

ጥቅማጥቅሞች: - ለእርስዎበቀጥታጥቅምላይኖርይችላል:ነገርግንተሳትፎት ከዳውን ሲንድረም ጋር የሞኖሩ ልጆች አሳዳጊዎች
የህይወት ጥራት ደረጃለማሻሻልያግዛል፡፡በዚህፕሮጀክትለመሳተፍምንምዓይነትማበረታቻወይምክፍያአይኖሮትም፡፡

የአሳታፊዎቹቁጥር: -313ከዳውን ሲንድረም ጋር የሞኖሩ ልጆች አሳዳጊዎችንሪፖርትይወሰዳል፡፡

ምስጢራዊነት:-በዚህጥናትየተሰበሰበመረጃበሙሉምስጢራዊነትይጠበቃል፡፡ ሁሉምመዝገቦችእናሌሎችመረጃዎችምስጢርየተጠበቁናቸው፡፡የልጅዎየተጠበቀየጤናመረጃያለፍቃድጥቅምላይአይውልም፡፡ሁሉምየመረጃአሰባሰብመሳሪያዎችበቁጥርወይምበሌላመንገድልጅዎንለመለየትሊያገለግሉየሚችሉኮዶችይደረጋል፡፡

በጥናቱያለመሳተፍመብት:- በዚህጥናትመሳተፍወይምአለመሳተፍየእርስዎውሳኔይሆናል፡፡ በጥናቱውስጥላሉጥያቄዎችመልስአለመስጠትይችላሉ፡፡በማንኛውምሰአትከጥናቱ መሳተፍ ማቆምይችላሉ፡፡ ለጥናቱመረጃለመስጠትፈቃደኛከሆኑፈቃደኝነትዎን"አዎን"ብለውበመናገርማሳየትይችላሉ፡፡

የቃለመጠይቁጠያቂስም..............................ፊርማ..........................ቀን:................/.............../.......

በዚህጥናትውስጥጥያቄዎች, አቤቱታዎችወይምስጋቶችካሉዎትበሚከተለውስልክመደወልይችላሉ፡፡

ዶ/ርማርታገ/መስቀል

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የፈቃድ እና የስምምነትመግለጫቅፅ

1.የወላጅፈቃድ

ከላይየተዘረዘሩትንሁሉንምሁኔታዎችተረድቻለሁ፡፡በዚህጥናትውስጥየምሳተፈውሙሉበሙሉበፍቃደኝነትነው፡፡ እንደተነገረኝለጥያቄዎቹየምሰጠውመልሶችለሌላማንኛውምሰውተላልፈዉ አይሰጡም፡፡ እንዲሁምማንነትንለማንምአይገለጥም፡፡ስለሆነምበጥናቱላይለመሳተፍፍቃደኛነኝ፡፡

የጠያቂውስም______________________________ፊርማ__________________ቀን//(የቃለ-መጠይቁጠያቂፊርማተሳታፊውሙሉበሙሉፍቃደኛመሆኑንያረጋግጣል)

Annex IIWHOQOL-BREF Amharic translated version

ገለፃ

1.የለም2.በትንሽ3. መካከለኛ4. በጣም5. እጅግበጣም

1	የሕይወትዎንጥራትደረጃእንዴትይገመግሙታል?	1	2	3	4	5
2	በጤናዎምንያህልረክተዋል?	1	2	3	4	5
	የሚከተሉትጥያቄዎችባለፉትአራትሳምንታትህይወትዎላይያተኮሩናቸው					
3	ምንያህል (የአካል)ህመምማድረግካለብዎትነገርእንዳስተጓጎልዎትይሰማዎታል?	1	2	3	4	5
4	ምንያህልየህክምናዕርዳታየዕለትተዕለትእንቅስቃሴዎእንዳይጓደልያስፈልግዎታል?	1	2	3	4	5
5	ምንያህልበህይወትዎይደሰታለ?	1	2	3	4	5
6	ምንያህልህይወትዎትርጉምአለውብለውይገምታለ?	1	2	3	4	5
7	አእምሮዎንለማሰባሰብምንያህልዐቅምአለዎት?	1	2	3	4	5
8	በዕለታዊህይወትዎምንያህልደህንነትይሰማዎታል?	1	2	3	4	5
9	ምንያህልየአካልጤንነትይሰማዎታል? (Weather, noise, pollution, leisure)?	1	2	3	4	5
	የሚከተለትጥያቄዎችምንያህልበተሙዋላሁኔታላለፉትአራትሳምንታትአንዳንድነገሮችእንደተስማማዎትበማወቅላይያ ተኩራል					
10	ለዕለትተዕለትእንቅስቃሴዎበቂጉልበት አሎት?	1	2	3	4	5
11	የአካልዎንገጽታበፀጋተቀብለዋል?	1	2	3	4	5
12	ፍላጎትዎንለማሙዋላትበቂገንዘብአለዎት?	1	2	3	4	5
13	ለዕለታዊእንቅስቃሴዎአስፈላጊዉንመረጃያገኛሉ?	1	2	3	4	5
14	የመዝናኛእንቅስቃሴዎችየማግኘትችሎታዎምንያህልነው?	1	2	3	4	5
	የሚከተለትጥያቄዎችባለፉትአራትሳምንታትየህይወትገጠመኞችዎምጁህልየእርካታ፤የደስታ፤ ወይምየጥሩስሜትእንዳደረብዎየሚጠይቁናቸው					
15	ከቦታወደቦታበቀላለይዘዋወራለ?	1	2	3	4	5
16	ምንያህልበእንቅልፍዎረክተዋል?	1	2	3	4	5
17	ዕለታዊየኑሮእንቅስቃሴዎንበመምራትምንያህልረክተዋል?	1	2	3	4	5
18	በሥራችሎታዎምንያህልረክተዋል?	1	2	3	4	5
19	በራስዎምንያህልረክተዋል?	1	2	3	4	5
20	ከሰዎችጋርባለዎትግንኙነትዎምንያህልረክተዋል? (friends, relatives, acquaintances, peers)?	1	2	3	4	5
21	በወሲባዊህይወትዎምንያህልረክተዋል?	1	2	3	4	5
22	ከጓደኞችዎበሚያገኙትዕርዳታምንያህልረክተዋል?	1	2	3	4	5
23	በመኖሪያቦታዎምንያህልረክተዋል?	1	2	3	4	5
24	ለጤናአገልግሎትአቅርቦትያለዎትርካታምንያህልነው?	1	2	3	4	5
25	በመጓጓዣበኩልስ?	1	2	3	4	5
	የሚከተለውጥያቄለምንያህልበተደጋጋሚአንዳንድአዎንታዊስሜቶች፤ ለምሳሌየቤተሰብደህንነትወይምየጓደኛድጋፍወይምአለታዊስሜቶችእጁደህንነትአልባዓይነትተሰምቶዎት እንደሆነይጠይቃል					
26	ምንያህልበተደጋጋሚአለታዊስሜቶችእንደመከፋት፤ ተስፋመቁረጥጭንቀትወይምመደበትደረሶብዎትያውቃል?	1	2	3	4	5

27	ምንያህልበተደጋጋሚከእርስዎበፊትመጡሆያውይኖሩየነበሩሰዎችበደንብእንደማይቀርቡዎትይሰማዎታል?	1	2	3	4	5
28	ትምህርትሆመማርባጋጠመዎትዕድልምንያህልረክተዋል?	1	2	3	4	5
29	ሃይማኖትንወይምበዓላትንወይምየግልእምነትንሆመከተልባሆውአመቺሁኔታምንያህልረክተዋል?	1	2	3	4	5
30	ሥራሆማግኘትባሆዎትዕድልምንያህል	1	2	3	4	5
31	ወደሰብዓዊመብትአስከባሪድርጅትሆመቅረብምንያህልዕድልአግኝተዋል?	1	2	3	4	5
32	በመጡሆያውባለትየእድርናሌሎችማህበራትምንያህልይሳተፋለ?	1	2	3	4	5
33	በቀድሞሙያዎሆመሥራትምንያህልችሆዋል?	1	2	3	4	5

ይህን መጠይቅ ለመሙላት እገዛ አድርገዋል ወይ?

መጠይቁን ለምሙላት ምን ያህል ጊዜ ፈጇ?

ስለ መጠይቁ ተጨማሪ ሃሳብ አሎት ወይ?

Annex V ማህበራዊ፣ግላዊእናሕክምናነክጥያቄዎች

ለ) ማህበራዊ፣ ግላዊ ጥያቄዎች

ተ/ቁ	**ማህበራዊእናግላዊጥያቄዎች**	
1.	የልጅ ዕድሜ	
2.	የልጅ ጾታ?	1. ወንድ 2. ሴት
3.	የአሳዳጊዕድሜ? (በቦታውውስጥይሙሉ)	________ዓመት
4.	ጾታ?	1. ወንድ 2. ሴት
5.	የአሳዳጊየጋብቻሁኔታ	1. ያላገባ/ች 2. ያገባ/ች 3. የተፋታ/ች 4. አጋርበህይወትየለም
6.	የህይወት አጋሮት በልጆት ህክምና ሂደት ይሳተፋሉ ወይ?	1. አዎ 2. አይ
7.	የአሳዳጊየትምህርትደረጃ	1. ማንበብእናመጻፍአይችሉም 2. ማንበብእናመጻፍይችላሉ 3. 1ኛ-8ኛክፍል 4. ከ 9 ኛ - 12 ኛክፍል 5. ከ 12ኛእናከዚያበላይ
8.	የአሳዳጊስራ	1. ስራየላትም 2. የመንግስት / የግልሰራተኛ 3. የግልስራ 4. ሌላይግለጹ(____ _)
9.	የቤተሰብየወርገቢ? ________________________________	1. ዝቅተኛኳንታይል 2. 2ኛኳንታይል 3. መካከለኛኳንታይል 4. 4ኛኳንታይል 5. ከፍተኛኳንታይል
10.	የልጆችብዛትበቤተሰብውስጥ?	________ቁጥር
11.	መኖሪያ ቦታ ከህክምና ተቋም ምን ያህል ይርቃል/ ሰዓት ይፈጃል?	________________ ሰዓት
12.	የሃይማኖትተቋማትየሄዳሉ?	1. አዎ 2. አይ

ለ) ከሕክምናጋርየተገናኙጥያቄዎች

ተ/ቁ	**ከሕክምናጋርየተገናኙጥያቄዎች**	
13.	የልጅችግርከታወቀያለፈጊዜ	በ_______ዓመትወይም / ወር
14.	የልጅክትትልከጀመረያለፈጊዜ	________ዓመትወይምወር
15.	ልጅትከተጓዳኝህመምጋርይኖራልወይ? (የህክምናምረጃይታይ)	1. አዎ 2. አይ
16.	ለጥ/ቁ 15 አዎከሆነ፣ይገለጽ?(የህክምናምረጃይታይ)	1. የልብህመም a. cyanotic b. acyanotic 2. የሆርሞንችግር 3. GI anomalies 4. Pulmonary HTN 5. ያተነፋፈስ/እንቅልፍችግር 6. ሌላይገለጽ______________
17.	ከተመሳሳይችግርጋርየሚኖርሌላልጅያሳድጋሉወይ?	1. አዎ 2. አይ
18.	ከረጅምችግርጋርየሚኖርሌላልጅያሳድጋሉወይ?	1. አዎ 2. አይ
19.	የልጆትንየህክምናችግርምንያህልክብደትይሰጡታል?	1. እጅግበጣምከባድ 2. በጣምከባድ 3. በመጠኑአደገኛ 4. በተወሰነደረጃየከፋ 5. በከፋጉዳትአይደለም
20.	ለልጆት ተስማሚት/ቤትአግኝተዋል?	1. አዎ 2. አይ
21.	ለጥ/ቁ 20 አይ ከሆነ፣ምክያትይገለጽ?	1. ከመኖሪያይርቃል 2. ውድነው 3. ሌላ(ይግለጹ ________________________

Annex IIIconsent form information sheet

Hello. My name is______________________________and I am a data collector of the study Conducted by Martha G/meskel a final year resident at Addis Ababa university college of health sciences, conductingthisresearchforpartialfulfillmentofresidency in pediatrics and child health. We would very much appreciate your participation in this study.The information you provide will help us to know the quality of life of caregivers of children living with Down Syndrome. The interview takes between 10-20minutesto complete.

Name of advisers:- Prof. Workeabeba Abebe (pediatric infectious disease sub-specialist) and Dr. Addishiwot Melesse (Assistant professor of adolescent and child health)

Name of the organization: Addis Ababa University, College of Health Sciences,School of Medicine.

Name of the Sponsor: Addis Ababa University

Title of the Research Project: -Quality of health of caregivers of children living with Down Syndrome in TASH, Ethiopia, 2023

Purpose: The purpose of this study is to find out the quality of life of caregivers of children living with Down Syndrome in TASH. The information that you provide are very essential, not only for the successful accomplishment of the study but also for producing relevant information which will help in improving the provision of the service. I will provide research results to concerned body for intervention.

Procedure:To achieve the above objective, information which is necessary for the study will be taken from caregivers of children with Down Syndrome. Your responses will not affect the care of your child and are completely anonymous and confidential. There is no right or wrong answers in this study.

Risk/ Discomfort: - You may feel as though your time is being wasted by taking part in this study. With the expectation that this study leads to a positive change, we sincerely hope that you participate in the study. You are free to stop taking part at any moment.

Benefits: - Although there may not be a direct benefit to you, your involvement will probably help us determine the quality of life of parents of children with Down syndrome, which could determine whether an intervention is required in this population. You won't receive any form of payment or incentives for participating in this project.

Confidentiality: The information collected from this research project will be kept confidential and all records and other information obtained will be kept strictly confidential and your child's protected health information will not be used without permission. All data collection tools will be identified by number or otherwise coded to protect any information that could be used to identify your child or you.

Number of Participants:313care givers of children with DS will be participating in the study

Voluntary Participation: Taking part in the study is strictly voluntary. Refusal to participate in this research has no penalty or loss of benefits to which your child. This will not affect your relationship with the investigators. Saying "yes" will demonstrate your willingness to provide information for the study.

1. If yes, proceed to the next page 2.If no, thank you, and skip to the next participant Name of data collector __________________Signature of interviewer:--------- Date:------/-----/---------

If you have questions, complaints or concerns about this study, you can contact the principal investigator: Martha G/meskel

Email address:martha.hgb12@gmail.com.

Annex B: Consent and assent form

I am aware of all the aforementioned requirements. I am aware that my participation in the study is completely voluntary. I was offered the assurance that my answers wouldn't be shared with anyone else. I therefore agree to take part in the study.

1. Name of interviewer____________Signature_________date_______/_____/_____

(Signature of interviewer certifying that respondent has given informed consent verbally)

Annex IV WHOQoL-BREF English version

		Very poor	poor	neither good nor poor	good	Very good
1	How would you rate your quality of life?	1	2	3	4	5
		Very satisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5
The following questions ask about how much you have experienced certain things in the last two weeks.						
		Not at all	A little	A moderate amount	Very much	An extreme amount
3		1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment (weather, noise, pollution, leisures)?	1	2	3	4	5
The following questions ask about how completely you experienced or were able to do certain things in the last two weeks						
		Not at all	A little	moderately	mostly	completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
The following questions ask about how well or satisfied you felt about several aspects of your life in the last two weeks.						

		Very satisfied	dissatisfied	Neither satisfied nor dissatisfied	satisfied	Very satisfied
15	How well are you able to get around?	1	2	3	4	5
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships (friends, relatives, acquaintances, peers)?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5
The following question refers to how often you have felt or experienced certain things in the last two weeks.						
		never	seldom	Quite often	Very often	always
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did any one help you fill in this questionnaire?.......

How long did take to fill in this questionnaire?..

Do you have any comments about the questionnaire

Annex VI Questionnaire–Quality of life of parents with Down syndrome children

A. Socio-Demographic questioners

No	Question	Coding Categories
1.	age of child	
2.	Sex of child	1. Male 2. Female
3.	age of caregiver	______year
4.	sex?	1. Male 2. Female
5.	Marital status?	1. single 2. married 3. divorced/separated. 4. Widowed
6.	Does your partner involve in the child's medical care?	1. Yes 2. No
7.	Educational level?	3. Unable to read & write 4. Read and Write 5. Grade 1-8 6. Grade 9-12 7. Above 12
8.	occupation?	1. Unemployed 2. Government/private employee 3. Self-employed. 4. Other specify
9.	family income per months? _______birr	1. lowest 2. 2nd quantiles 3. Medium quantiles 4. 4th quantile 5. Highest quantile
10.	Family size (# of children)?	_________________
11.	Distance from home to the hospital in hours	_______hour
12.	Do you practice a religion	1. Yes 2. No

B) Medical related questioners		
13.	Time from 1st diagnosis of down syndrome?	____________year or/month
14.	Time since follow -up started in TASH?	____________year or month
15.	Is your child diagnosed with other comorbidities?	1) Yes 2) No
16.	If yes to Q#15 what type? (to be filled by the data collector, review chart, icare)	1) Cardiac a) Cyanotic b) acyanotic 2) Endocrine a) Hypothyroidism b) Hyperthyroidism 3) GI abnormalities a) Yes b) No 4) Pulmonary Hypertenstion a) Yes b) No 5) OSA a) Yes b) No 6) Other,specify___________
17.	Do you have another child living with Down syndrome	1. Yes 2. No
18.	Do you have a child living with other type of chronic illness at home?	1. Yes 2. No
19.	How would you rate your child's condition severity?Please check one answer.	1. Extremelysevere 2. Verysevere 3. Moderatelysevere 4. Somewhatsevere 5. Notat allsevere
20.	Is special need school available/accessible to your child?	1. Yes 2. No
21.	If No to Q#20, why	1. far from home 2. there are limited options. 3. is expensive. 4. other, specify_____________

Annex VII Table 1. WHOQOL domains and facets

Domain I Physical
1 Pain and discomfort
2 Energy and fatigue
3 Sexual activities
4 Sleep and rest
5 Sensory functions
Domain II Psychological
6 Positive feelings
7 Thinking, learning, memory and concentration
8 Self-esteem
9 Bodily image and appearance
10 Negative feelings
Domain III Level of independence
11 Mobility
12 Activities of daily living
13 Dependence on medicinal substances and medical aids
14 Dependence on nonmedicinal substances (alcohol, tobacco, drugs)
15 Communication capacity
16 Work capacity
Domain IV Social relationships
17 Personal relationships
18 Practical social support
19 Activities as provider/supporter
Domain V Environment
20 Freedom, physical safety and security
21 Home environment
22 Work satisfaction
23 Financial resources
24 Health and social care: accessibility and quality
25 Opportunities for acquiring new information and skills
26 Participation in and opportunities for recreation/leisure activities
27 Physical environment: (pollution/noise/transportation/climate)
28 Transport
Domain VI Spirituality/religion/personal beliefs
Overall quality of life and general health perception