# **Addis Ababa University**

# **Collage of Education and Behavioral Studies**

# **Department of Special Needs Education**

Lived Experiences of Adults with Late Blindness in View of Psychosocial Problem and Coping Mechanisms: The Case of Addis Hiwot Center of Blind

By

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June, 2020

Addis Ababa, Ethiopia

Lived Experiences of Adults with Late Blindness in view of Psychosocial Problem and Coping Mechanisms: Case of Addis Hiwot Center of Blind

# $\mathbf{BY}$

# **Mihiret Ayele**

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# ADDIS ABABA UNIVERSITY COLLEGE OF EDUCATION AND BEHAVOURAL STUDIES

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# Acronyms

AHCB Addis Hiwot Center of Blind

AMD Age-related macular degeneration

CRPD United Nations Convention on the Rights of Persons with Disabilities

DR Diabetic retinopathy

VA Visual Acuity

VI Visual Impairment

WHO World Health Organization

# **Abstract**

Adventitious blindness including late blindness refers to vision loss that occurs after five years of age and above in which those who faced the vision problem at their late age may have visual memory. The study aims to investigate the lived experiences of adults with late blindness focusing on their psychosocial problems and other related themes such as the conditions how the study adults with late blindness reacted to the occurrence of their vision problem, the impact of vision problem of the study adults with late blindness on their psychosocial conditions, the kinds of coping mechanisms applied to mitigate the psychosocial problems of adults with late blindness and the aspiration of adults with late blindness on their future life. research method with particular emphasis on phenomenological research design was employed to conduct the study. Face to face interview was applied to generate data from the interviewees using semi-structured interview with a view to maintaining the consistency and quality of the interview. A total of 11 interviewees (six males and five females) were identified and selected purposively as study participants from senior members of Addis Hiwot Center for the Blind, the only center/association established by adults with late blindness in Ethiopia who had shared vision on the issues related to late blindness. The data analysis was carried out based on the thematic areas organized in interview guides as core questions. In addition, as a part of the study two coherent case stories were prepared. The finding showed that the participants confirmed that their vision problem affects their psychosocial wellbeing and living conditions. The finding of the study further revealed that the occurrence of the vision problem at their late age adversely affected the psychosocial and economic conditions of the participants and their problem was aggravated by lack of opportunity to access rehabilitation services on coping mechanisms. The finding of the study signified the need that both government and non-state actors should work together at policy and grass roots level with a view to make difference in the lives of people with late blindness and ensuring the continuation of their independent living within the new situation they encountered.

# **Chapter One**

#### Introduction

# 1.1. Background of the Study

It is the reality of any society that there are hundreds of millions of people with disabilities throughout the world. The joint global report of World Bank and WHO, (2011) confirmed that nearly 80% of people with disabilities live in low-income countries.

Accordingly, the estimated prevalence of visual impairment is placed next to physical and hearing impairment in the context of Ethiopia. The rapid assessment conducted by Federal Ministry of Health in collaboration with different consortiums and organizations working on eye sight health, (2005-2006) revealed that there are 1.2 million people with total blindness and 1.7 million people with low vision in Ethiopia.

Studies conducted on vision and vision problems disclosed that the occurrence of vision problem can be either congenital of acquired. Hence, Late blindness belongs to the type of vision problem categorized in acquired impairments most likely appear in late ages.

People who lose their sight after the age of two retain some memory of what they had seen. The later the disability occurs, the more they remember. Visual memory is an important factor in learning for it can influence one's development of concepts and other aspects of important learning. Blindness is a general term for individuals with some significant degree of visual impairment. Approximately 2% of Americans over the age of 45 report being blind in both eyes. The degree of blindness is usually broken down into three categories: totally blind, legally blind, and visually impaired or "low vision." Blindness may be either congenital or adventitious. Blindness may be the result of dysfunction within the eye itself, in the optic pathways, or in the brain. Dysfunction in the latter is known as "cortical blindness." Adventitious blindness is a visual impairment developed sometime after birth. It may be the result of injury, illness, or emotional trauma (Gregory, 2003).

Visual impairment might result in serious difficulties, because human beings depended on visual perception to get most of their information from the world around them. It might also trigger a psychological crisis that could promote an intention to seek "death," (Ueda, 2018). Acquired visual impairment can compromise mobility and daily living, and consequently lead to a greater

reliance on informal and formal care. Another, but no less important, aspect of acquired visual impairment is the psychosocial impact and adjustment (Samuel Robert Nymanr, 2012, p. 971).

Vision loss has a significant impact on the lives of those who experience it as well as on their families, their friends, and society. The complete loss or the deterioration of existing eyesight can feel frightening and overwhelming, leaving those affected to wonder about their ability to maintain their independence, pay for needed medical care, retain employment, and provide for themselves and their families.

#### 1.2. Statement of the Problem

Adventitious blindness affects many areas of life and will require the individual to make significant and often unwelcome changes. New ways of performing everyday tasks (such as reading, writing, and cooking) must be learned. The loss of driving privileges may be particularly traumatic. New techniques must be learned to meet the current job demands of most individuals, while a few persons will need to develop new career goals.

Age itself has its own effect on visual ability. As the age increase the problem have a chance to occur rather than early ages. But this does not mean that visual impairment will not may occur because of different situations. Having a visual impairment might present a risk to young adults for reduced participation and social exclusion (Ellen and Gerardus et al, 2016).

Adults with late blindness have been facing different challenges because of their late vision problems. Vision problem comes with different economic, social and psychological challenges. People with blindness may suffer from repudiation, umbrage, inferiority complex, anxiety, depression and similar psychological problems because of their incapacity in comparison to healthy people or due to the feeling of low self-esteem (Lindo & Nordholm, 1999). In Ethiopia there are a lot of people with late blindness who experience vision problem at later age. Most of people with late blindness found at the older age. The vision problem have mostly similar cases like trachoma, cataract and others. Experiencing vision problem lately has impact on the person's life as well as his/her family's life. Most of them will suffer to accept the problem as it is and to start new chapter of their life. The vision problem has impact on their daily activities. Also Mary (2010) stated that the psychosocial adjustment to disability has a significant effect on a person's ability to live independently. If individuals with disabilities such as visual impairment are unable to overcome psychosocial barriers they may be unable to live autonomously.

This study attempts to assess the lived experiences of adults with late blindness from psychosocial perspective. Adults with late blindness faces different psychological and social problems because of the impairment. They may not able to work independently, in some situations they may lose their work because of the impairment, they experience isolation and discrimination from the society. Because of those some social and economic problems they will experience different psychosocial problems which are temporary and permanent. So, the purpose of this study is to understand and explore the lived experiences of adults with late blindness. By using phenomenological approach, semi structured interview will be conducted with different adults with late blindness.

Researches has not been available which are conducted on the lived experiences of adults with late blindness in view of psychosocial problems and coping mechanisms recently. Those adults will faced different psychosocial problems throughout their life span. Therefore, the aim of this study is to explore the lived experiences of adults with late blindness in view of psychosocial problem and coping mechanisms deeply.

# 1.3. Objectives of the Study

The objective of this study was to assess the lived experience of adults with late blindness in view psychosocial problems and its coping mechanisms.

#### **Research Questions**

- 1. What are the common causes of late blindness and the first impression of families of adults with late blindness in the context of the study?
- 2. How adults with late blindness reacted to the occurrence of their vision problem?
- 3. How did their vision problem impact to their psychosocial conditions? And?
- 4. What kind of coping mechanisms was applied to mitigate the psychosocial problems of adults with late blindness?
- 5. What aspiration did adults with late blindness have about their future life?

#### 1.4. Scope of the Study

This study focuses on adults with late blindness. The study selects Addis Hiwot center for the blind. Addis Hiwot Center for the Blind established in 1992 E.C. The center is located in Arada sub-city, woreda 2 of Addis Ababa City Administration. This center is the only center which is

established for person with late visual impairment or acquired visual impairment. The reason why this center was selected is because it is the only center in Ethiopia.

#### 1.5 Significance of the Study

The result of this study will be helpful for people for whom it may concern about people with visual impairment and also for people with visual impairment themself to understand the psychosocial problems and psychosocial effect of visual impairment. Also, this study puts some recommendations and suggestion for different stakeholders on how they can treat those people and also how can they help adults with late blindness by showing different ways to cope psychosocial problems.

There are no much researches which is related with adults with blindness especially on their lived experience. So, this study will give some insight for different centers and researchers. Therefore, they can conduct different researches deeply which is related with this study. Also, those centers can focus on this issue and also investigate different studies to give appropriate services for adults with late blindness. The other thing is this study will help Addis Hiwot center by providing different suggestions to improve the services that they are giving now for the member of the center and also for the community.

#### **1.6 Operational Definition**

**Late blindness:** -It is type of visual impairment that happen after birth because of different reasons like different accidents, diseases.

**Adults:** -An adult is a mature, fully developed person. An adult has reached the age when they are legally responsible for their actions. And in this study adults are a person whose age is above 25.

**Lived experience:** -an experience which refers to a representation of the experiences and choices of a given person, and the knowledge that they gain from these experiences and choices.

**Psycho-social problems:** a problem that affect the social and psychological wellbeing of individuals.

# **Chapter Two**

#### **Review of Related Literature**

# 2.1 Definition and Basic Concepts of Late Blindness (Acquired Visual Impairment)

#### 2.1.1 Introduction

Visual impairment can interfere with the development of learning, mobility, social growth and adjustment (Sarah, 2018). Visual impairment is an impairment in vision that, even with correction adversely affects a person's daily activities including education and work (Johnson-Jones, 2017). According to Hassan and et al... (2017) VI is a global problem with important socio-economic consequences that have proven effects on the quality of life of individuals, and usually impose great family-related and socio-economic losses. Visual impairment, also known as vision loss, is a decreased ability to see to a degree that causes problems not fixable by usual means, such as glasses Some also include those who have a decreased ability to see because they do not have access to glasses or contact lenses. Visual impairment is often defined as a best corrected visual acuity of worse than either 20/40 or 20/60. The term blindness is used for complete or nearly complete vision loss. VI may cause people difficulties with normal daily activities such as driving, reading, socializing, and walking. Visual impairment results in several educational, social and psychological effects.

The estimated number of people visually impaired in the world is 285 million, 39 million blind million having low vision; 65 % of people with visual impairment and 82% of all blind are 50 years and older. (WHO, 2012) Naipal and Rampersad 2018 state that studies have reported on the prevalence of VI. More than 90% of individuals with VI live in developing countries. This geographical disparity may be attributed to a higher prevalence of conditions related to poverty or environmental conditions and poor access to health care services in developing countries. In terms of gender, women are at a higher risk of visual impairment because of longer life expectancies and lack of access to health care services especially in rural areas. Furthermore, the global prevalence of blindness is greater in women than in men. Interestingly, Stevens et al. (2013) found that for blindness, this gender disparity is highest in high-income regions and lowest in Sub-Saharan Africa. The authors hypothesized that this low gender disparity in Sub-Saharan Africa may be because of onchocerciasis, which is more prevalent in men than women in endemic African regions.

#### 2.1.2 Definition of Late Blindness

An adventitious impairment or late blindness is often accompanied by an element of surprise, trauma and depression that requires a certain accommodation period. The shock usually affects the individual and the family and communication between both parties is essential. Training or experience should also be considered, as functional and positive self-development will depend on the individual's mastery of the other senses and/or residual vision for the organization of information and active participation in society (Schinazi, 2007).

Adventitious blindness refers to an individual who becomes blind after five years of age, meaning individuals with this type of blindness will probably have some visual memory and can use visualization (Sardegna, Shelly, Rutzen, &Steidl, 2002). In general, adventitious blindness is the terminology used to refer to vision loss after years of sight. It is a visual impairment developed sometime after birth. It may be the result of injury, illness, or emotional trauma (although none of the participants in the present study had an etiology of emotional trauma for their blindness).

Late or adventitious visual impairment partial or total visual impairment that results from injury or illness following a period of normal visual ability. Onset of the impairment can produce severe grief, mourning reactions, and dependency. As a consequence, any residual visual capacity may not be used effectively, exacerbating psychological and social-adjustment problems. Also called acquired visual impairment.

Ageing is the primary risk factor for many eye conditions. The prevalence of presbyopia, cataract, glaucoma and age-related macular degeneration increase sharply with age (28, 30, 32, 33). Genetics also play a role in the development of some eye conditions including glaucoma, refractive error and retinal degenerations such as retinitis pigmentosa (34-36). Ethnicity (30) is an example of another non-modifiable risk factor that is related to a greater risk of developing some eye conditions (WHO, 2019).

#### 2.2 Causes, types and Prevalence of Visual Impairment

Several recent studies around the world on the prevalence of visual impairment and blindness, as well as the major causes and the parameters used to define them in populations with 40 years and older. Cataract is the main cause for 47.8% of blindness in the world. Cataract surgery is

considered one of the most cost-effective intervention to restore sight. Glaucoma (12.3%), agerelated macular degeneration (AMD) (8.7%), corneal opacities (5.1%) and diabetic retinopathy (4.8%) are also important causes of blindness, besides childhood blindness (3.9%), trachoma (3.6%) and onchocercosis (0.8%)Refractive errors were not considered an important blindness cause since most studies used best-corrected visual acuity (VA) for distance as their main outcome measure.

#### 2.2.1. General Causes and Types of Visual Impairment

The cause of visual impairment is different and the causes are so many. Visual impairments may be congenital (present at birth) or acquired (occurred after birth). Almost half of the children who are blind are disabled because of prenatal factors, mostly hereditary. Researchers are beginning to identify genes that cause some forms of blindness. These are the common cause of visual impairment but these are not only cause for visual impairment.

#### 2.2.1.1. Refractive errors

The light rays that enter the eye do not fall exactly on the retaina and myopia (nearsightedness) results. Nearsighted persons can see things that are near to them, but they cannot distinguish images at a distance. When the eyeball is too short, the images fall at the back of the regain and hyperopic (farsightedness) occurs. Farsighted persons see things better at a distance; however, the effort to view things better at a distance; requires excessive accommodation of the lens curvature and can cause fatigue and restlessness.

# 2.2.1.2. Astigmatism

This refers to distorted or blurred vision caused by irregularities in the cornea or other surfaces of the eye; both near and distant objects may be out of focus. Astigmatism is a common type of refractive error. It is a condition in which the eye does not focus light evenly onto the retina, the light-sensitive tissue at the back of the eye. It can affect both children and adults. Some patients with slight astigmatism will not notice much change in their vision.

Astigmatism occurs when light is bent differently depending on where it strikes the cornea and passes through the eyeball. The cornea of a normal eye is curved like a basketball, with the same degree of roundness in all areas. An eye with astigmatism has a cornea that is curved more like a

football, with some areas that are steeper or more rounded than others. This can cause images to appear blurry and stretched out.

# 2.2.1.3. Amblyopia/Lazy Eye

Refers to a dimension of vision in one eye, causing suppression of the weaker eye and the use of only stronger eye. The condition may be due to eye muscle imbalance, refractive errors, or other Amblyopia is a leading cause of vision impairment in children and usually begins in infancy or childhood. It is a condition resulting in poor vision in an otherwise healthy eye due to unequal or abnormal visual input while the brain is developing in infancy and childhood. The condition is sometimes called "lazy eye".

#### **2.2.1.4.** Cataract

Cataract is a condition of cloudiness in the lens of the eye that blocks the light necessary for seeing clearly. Vision loss depends on where the cataract is located on the lens and how dense the clouding is. Treatment (Surgery and Eye glasses or contact lenses) can be effective.

According to the latest assessment, age related cataract is responsible for 48% of world blindness, which represents about 18 million people. Although cataracts can be surgically removed, in many countries surgical services are inadequate, and cataract remains the leading cause of blindness. As people in the world live longer, the number of people with cataract is growing. Cataract is also a major cause of low vision in both developed and developing countries. Even where surgical services are available, low vision associated with cataract may still be prevalent, as a result of the long period spent waiting for operations and barriers to surgical uptake, such as cost, lack of information, and transportation problems.

#### 2.2.1.5. Glaucoma

Glaucoma can be regarded as a group of diseases that have as a common end point a characteristic optic neuropathy which is determined by both structural change and functional deficit. The medical understanding of the nature of glaucoma has changed profoundly in the past few years and a precise comprehensive definition and diagnostic criteria are yet to be finalized. This is a condition in which the normal fluid of the eye (aqueous humor) does not drain properly. This causes pressure within the eye, which may damage the optic nerve and result I severe loss

of sight or tunnel vision. The person sees only the center of the visual field. If detected early enough, glaucoma can be treated by controlling the pressure in the eye.

The number of persons estimated to be blind as a result of primary glaucoma is 4.5 million, accounting for slightly more than twelve per cent of all global blindness. Risk factors are those limited to the onset of disease and those associated with progressive worsening in already established disease. The primary risk factors that are linked to the individual and the onset of the disease are age and genetic predisposition. The incidence of POAG rises with age and its progression is more frequent in people of African origin. ACG is the common form of glaucoma in people of Asian origin (WHO, 2010).

#### **2.2.1.6.** Trachoma

Trachoma is one of the oldest infectious diseases known to mankind. It is caused by Chlamydia trachomatis a microorganism which spreads through contact with eye discharge from the infected person (on towels, handkerchiefs, fingers, etc.) and through transmission by eye-seeking flies. After years of repeated infection, the inside of the eyelid may be scarred so severely that the eyelid turns inward and the lashes rub on the eyeball, scarring the cornea (the front of the eye). If untreated, this condition leads to the formation of irreversible corneal opacities and blindness (WHO, 2010).

Trachoma affects about 84 million people of whom about 8 million are visually impaired. It was once endemic in most countries. It is responsible, at present, for more than 3% of the world's blindness but the number keeps changing due to the effect of socio-economic development and current control programs for this disease. In spite of this, trachoma continues to be hyper endemic in many of the poorest and most remote poor rural areas of Africa, Asia, Central and South America, Australia and the Middle East. Adult women are at much greater risk of developing the blinding complication of trachoma than are adult men. This increased risk has been explained by the fact that women generally spend a greater time in close contact with small children, who are the main reservoir of infection (WHO, 2010).

#### 2.2.1.7. Onchocerciasis (river blindness)

Onchocerciasis is an insect-borne disease caused by a parasite Onchocerca volvulus and transmitted by black flies of the species Simulium damnosum. Onchocerciasis is often called

"river blindness" because the black fly which transmits the disease abounds in fertile riverside areas that frequently remain uninhabited for fear of infection. Volvulus is almost exclusively a parasite of man. Adult worms live in nodules in a human body where the female worms produce high numbers of first-stage larvae known as microfilaria. They migrate from the nodules to the sub-epidermal layer of the skin where they can be ingested by blackflies. They further develop in the body of the insect from which more people can be infected.

Eye lesions in humans are caused by microfilariae. They can be found in all internal tissues of the eye except the lens where they cause eye inflammation, bleeding, and other complications that ultimately lead to blindness.

Onchocerciasis is a major cause of blindness in many African countries. As a public health problem, the disease is most closely associated with West and Central Africa, but it is also prevalent in Yemen and six countries in Latin America. Onchocerciasis has in the past greatly reduced the economic productivity in infected areas and left vast tracts of arable land abandoned. It is estimated that there are about half a million blind people due to river blindness (WHO, 2010).

#### 2.2.1.8. Childhood blindness

Childhood blindness refers to a group of diseases and conditions occurring in childhood or early adolescence, which, if left untreated, result in blindness or severe visual impairment that are likely to be untreatable later in life. The major causes of blindness in children vary widely from region to region, being largely determined by socioeconomic development, and the availability of primary health care and eye care services. In high-income countries, lesions of the optic nerve and higher visual pathways predominate as the cause of blindness, while corneal scarring from measles, vitamin A deficiency, and the use of harmful traditional eye remedies, ophthal mianeonatorum, and rubella cataract are the major causes in low-income countries. Retinopathy of prematurity is an important cause in middle-income countries. Other significant causes in all countries are congenital abnormalities, such as cataract, glaucoma, and hereditary retinal dystrophies.

# 2.2.1.9. Diabetic retinopathy

Diabetic retinopathy is composed of a characteristic group of lesions found in the retina of individuals having had diabetes mellitus for several years. The abnormalities that characterize diabetic retinopathy occur in predictable progression with minor variations in the order of their appearance. DP is considered to be the result of vascular changes in the retinal circulation. In the early stages vascular occlusion and dilations occur. It progresses into a proliferative retinopathy with the growth of new blood vessels. Macular oedema (the thickening of the central part of the retina) can significantly decrease visual acuity.

It is estimated that in 2002 DR accounted for about 5% of world blindness, representing almost 5 million blinds. As the incidence of diabetes gradually increases, there is the possibility that more individuals will suffer from eye complications which, if not properly managed, may lead to permanent eye damage (WHO, 2010).

# 2.2.1.10. Corneal opacities

Corneal visual impairment encompasses a wide variety of infectious and inflammatory eye diseases that cause scarring of the cornea, the clear membrane that covers the outside of the eye. Significant scarring ultimately leads to functional vision loss.

The 4th cause of blindness globally (5.1%), corneal blindness is one of the major causes of visual deficiency after cataract, glaucoma and age-related macular degeneration (AMD). Trachoma is responsible for nearly 4.9 million blinds, mainly as a result of corneal scarring and vascularization. Ocular trauma and corneal ulcerations are significant causes of corneal blindness. They are often underreported but they are estimated at 1.5 to 2.0 million new cases of unilateral blindness every year. Among the causes of childhood blindness

Even though the control of onchocerciasis and leprosy are public health success stories, these diseases are still significant causes of blindness, affecting approximately 250,000 individuals each. Traditional eye medicines have also been implicated as a major risk factor in the current epidemic of corneal ulceration in developing countries. Corneal visual impairment is encompassing a wide variety of infectious and inflammatory eye diseases that cause corneal scarring, which ultimately leads to functional vision loss (WHO, 2010).

# 2.2.1.11. Genetic eye diseases

Genetic eye diseases include a large number of ocular pathologies which have in common the transmission from parents to children by their genetic inheritance. All do not cause visual impairment. Knowledge about genetic eye diseases has increased dramatically during the last twenty years. Although there are no global statistics which let us know the extent of the burden of visual impairment from genetic causes, it does seem that genetic eye pathology represents a significant percentage of the causes of blindness in industrialized countries.

#### 2.2.2. Age related blindness and its causes

Visual impairment (VI) is common in older adults, with the prevalence increasing with age (Congdon et al., 2004). The number of people with moderate/severe VI worldwide is estimated to increase from 217 million in 2015 to 588 million by 2050(Bourne et al., 2017).

Visual impairment among the elderly is a major health problem. With advancing age, the normal function of eye tissues decreases and there is an increased incidence of ocular pathology. Demographic studies have shown that age is the best predictor of blindness and visual impairment (K Y Loh and J Ogle, 2004).

# 2.2.2.1 Age related macular degeneration

Age-related macular degeneration (AMD) is a condition affecting people over the age of 50 and involves the loss of the person's central field of vision. It occurs when the macular (or central) retina develops degenerative lesions. It is thought that circulatory insufficiency, with reduction in the blood flow to the macular area, also plays a part. Several forms of AMD exist.

Globally, AMD ranks third as a cause of visual impairment with a blindness prevalence of 8.7%. It is the primary cause of visual impairment in industrialized countries. The main risk factor is ageing. Other risk factors may include the use of tobacco, genetic tendencies, the degree of pigmentation (with light colored eyes being at higher risk), arterial hypertension, the ultraviolet rays, and consumption of a non-balanced diet.

# 2.2.2.2 Retinitis pigmentosa

Retinitis pigmentosa is a group of inherited retinal disorders that affects the photoreceptors and the retinal pigmentary epithelium. In some disorders the rods are affected first and the cones later (termed rod-cone dystrophy) or the reverse (cone-rod dystrophy). Rod-cone dystrophy is the most common form of RP, in which the first manifestation is night blindness, followed by decreasing visual fields and eventually leading to blindness after several decades. The prevalence of RP is 1 in 3000 to 1 in 5000. Majority of the disorders have a genetic basis and involve photoreceptor cell death by apoptosis. (M Prem S, J Khadka and K Pesudovs, 2017).

#### **2.2.2.3** Low Vision

Low vision is a visual impairment that is not corrected by standard eyeglasses, contact lenses, medication, or surgery that interferes with the ability to perform everyday activities like reading, shopping, or watching TV.

Low vision is a condition that involves a minimal ability to see (particularly central vision) which is usually 6/18 or worse that is unresolved or uncorrected with traditional eyeglasses, contact lens, intraocular lens implants or corrective surgery. Low vision is not the same as blindness. Unlike a person who is blind, a person with low vision has some useful sight. However, low vision usually interferes with the performance of daily activities such as reading or driving (Liz S, 2008). A person with low vision may not recognize images at a distance or be able to differentiate colors of similar tones (Sudesh and Sunandan 2010).

According to WHO statistics (Resnokoff et al, 2004 cited in Sudesh and Sunandan 2010), there are about 45 million blind and 135 million low vision individuals, together comprising a total of 180 million visually- impaired people all over the world. A majority (90 %) of these individuals live in the least developed countries.

Although low vision can occur at any stage in life, it primarily affects the elderly. However, low vision is not a natural part of aging. Although most people experience some physiological changes with age (presbyopia), these changes usually do not lead to low vision. Most people develop low vision because of eye diseases. The common causes of low vision and blindness in the young are retinitis pigmentosa, hereditary macular degeneration, cataract, optic atrophy and glaucoma. Diabetic retinopathy, glaucoma and age-related macular degeneration account for 70 % of the global burden of blindness in the elderly age group. Although, in most cases, persons with low vision have disabled central vision (also called reading vision), there are other types of low vision which may include disabled or partial peripheral vision, disabled or partial color

vision, disabled or partial ability to adjust to different light settings and disabled or partial ability to adjust to different contrasts and glared vision. When vision impairment is recognized early, treatment can be more effective, enabling people to maintain as much independence as possible.

Cataract and trachoma also will be cause for late or age related visual impairment but most of the time they are taken as vision problem causes on any age.

# 2.3. Visual impairment in Ethiopia

Ethiopia launched the Vision 2020 Initiative in September 2002. The long-term aim of this important initiative is to develop a sustainable comprehensive health care system to ensure the best possible vision for all people and thereby improve their quality of life. Blindness is not only incapacitating to the individual but also can adversely affect several aspects of poverty reduction strategies. Approximately 80% of blindness in Ethiopia was believed to be avoidable; i.e., preventable or curable (Yamane, Alemayehu, Abebe and Wondu, 2008).

It is very important to note that elderly people, women, and rural residents are at a greater risk of low vision and blindness. Although age is a biological risk factor gender and residency reflect on the social inequalities in promoting health and accessing health services. Emphasis need to be given to minimize the gender differences.

Trachoma, both active Trachoma and Trachoma toustrichiasis (TT), is concentrated in some regions of the country (Amhara, Oromia and SNNPR) that also account individually and collectively for the large proportion of the country's population. These regions have large rural population and environmental and hygienic conditions that favor trachoma transmission. The above facts clearly indicate eye problems in Ethiopia are among the major public health problems of the country and pose huge economic and social impact for affected individuals and to the society and the nation at large (Yemane, Alemayehu and Abebe, 2006).

In our country visual impairment is not new word for the majority of the society because there are many people with visual impairment. Ethiopia is believed to have one of the world's highest rates of blindness and low vision. Ethiopia is believed to have one of the world's highest rates of blindness and low vision. However recent data were lacking to accurately determine the magnitude of eye problems in the country.

The Federal Ministry of Health along with several non-governmental organizations are working in various parts of the country on blindness prevention and control programs focusing mainly on cataract surgery and trachoma control through the SAFE Strategy (surgery, antibiotics, facial cleanliness and environmental improvement). Planning and tracking the progress of these programs were difficult due to lack of appropriate information on the magnitude of the problems. In order to direct national priorities for blindness control programs and to have a baseline data for program monitoring and evaluation it was imperative to conduct a national survey on blindness, low vision and their causes (Yemane, Alemayehu and Abebe, 2006).

Based on the current estimated population size of Ethiopia, which is 75 million, overall there are 1.2 million blind people, 2.8 million people with low vision, 9 million children 1-9 year of age with active trachoma, and 1.3 million adults with Trachoma toustrichiasis. Over all about one million people are blind from avoidable causes. Cataract alone account for over 600, 000 blind individuals, and for over 1.1 million people with low vision. About a million individual with low vision need spectacles to correct their vision (Yemane, AlemayehuWorku and Abebe, 2006E.C). Eye care is a major health issue throughout developing countries where 90 percent blindness is reported. Ethiopia has the reputation of having the highest rate of blindness and impaired vision, and unfortunately, 80 percent of it is believed to be preventable or curable.

The majority of eye disease is found in rural areas where climate, poor ventilation, overcrowding and close proximity to livestock are contributing factors. Women are most affected either due to their work in smoky, wood-burning kitchens or because they have less access to eye care than men, due to their place in society. Illiteracy prevents ability to read instructional materials and slows down education about eye care. Lack of adequate clean water and sanitation also contribute to diseases as does lack of income, a situation exacerbated when the blind person in the family cannot work. Caring for dependent family members can also keep people from full-time employment, again making access to care almost economically impossible. The expense of travel to larger cities where the majority of doctor's work can also prevent needed care (Joyce, 2016).In Ethiopia there are common causes for visual impairments some of them are the following;

1. Cataract: The incidence of this condition is the same as in other parts of Africa. Most cataracts are related to aging. Cataracts are very common in older people. By age 80, more

than half of all Americans have either a cataract or have had cataract surgery. A cataract can occur in either or both eyes. It cannot spread from one eye to the other. Developing cataracts is a normal part of growing older. Most people start to develop cataracts after the age of 65, but some people in their forties and fifties can also develop cataracts.

- ❖ Certain things make it more likely that you will develop cataracts:
  - A. **Diabetes** people who have diabetes often develop cataracts earlier.
  - B. **Trauma** having an eye injury can cause the injured eye to develop a cataract.
  - C. **Medications** some prescription drugs can cause cataracts, for example steroids.
  - D. **Eye surgery** surgery for a retinal problem will likely lead to cataracts in the affected eye at some point in the future.
  - E. **Other Eye conditions** other eye conditions, such as retinitis pigmentosa, glaucoma or uveitis, may also cause cataracts.
  - F. **Having high myopia** (being very short sighted) may cause cataracts.
- 2. Trachoma: Recurrent infections by the organism which is spread by flies moving from person to person feeding from eye and nose secretions eventually cause scarring of the lids. The lids turn inwards and the eyelashes rub the front of the eye cause painful scarring. Management includes access to water for face washing, use of a cheap antibiotic eye ointment locally, donated oral antibiotic tablets and surgery when the eyelids turn in.
- 3. Childhood Blindness: At certain times children are tipped over into frank Vitamin A deficiency. This causes a very rapid onset of eye signs leading to melting of the front surface of the eye. Treatment depends on spotting the eye signs early (or the night blindness) and giving Vitamin A capsules which are very cheap. This problem can be easily corrected if it is identified at right time for the treatment and the child is not going be visually impaired.
- **4. Refractive errors:** Uncorrected refractive errors are the main cause of low vision and the second cause of blindness. Although refractive errors (myopia, hyperopia and astigmatism) can be easily diagnosed and corrected with spectacles or other refractive corrections to attain normal vision. They affect the whole spectrum of the population irrespective of age, gender, and ethnic group. Uncorrected refractive errors have severe

consequences for the individual, family and society. Myopia in particular, can have an impending negative impact on career choice, ocular health, and sometimes self-esteem. School-aged children constitute a special vulnerable group, where uncorrected refractive error may have a remarkable impact on learning capability and educational potential, as well as economic cost to the family and government (Nebiyat, Alemayehu and Tigist, 2015).

"The impact of blindness due to refractive errors is considered in terms of blind-person-years, a person becoming blind due to refractive error at a young age and which is not corrected, would suffer many more years of blindness than a person becoming blind from cataracts in old age and would place a greater socio-economic burden on society. Uncorrected refractive error is easily correctable by a pair of inexpensive spherical or/and cylindrical spectacles. The most accessible and acceptable way to correct visual disorder in children is to embed vision-testing programs in the schools to identify cases and to provide spectacles free-of-charge or at low cost" (Zelalem and Abdirahman, 2013).

#### 2.4. Psycho-Social Problems

#### 2.4.1. Psychosocial implication of blindness and low vision

Individuals who are blind or have low-vision must face the constant challenge of psychologically and socially adjusting to their disability. The age of onset blindness or impairment can have a significant effect on the affective development of individuals (Rosa, 1993 cited in Schinazi, 2007). Impaired vision significantly reduces activities associated with participation in society and religion, mobility, recreational and daily living etc. Vision loss in later life contributes to limitations on physical activity, reduces independent mobility, causes vision impairment and falls, imbalance, entails risks of hip fracture, mortality and underlines the need for community and/or family support.

People with blindness may suffer from repudiation, umbrage, inferiority complex, anxiety, depression and similar psychological problems because of their incapacity in comparison to healthy people or due to the feeling of low self-esteem (Ishtiaq, Chaudhary, Rana, and Jamil 2016). Visually impaired adults are concerned with securing and maintaining employment, productivity, and independence, as well as maintaining a home and fulfilling family and social obligations. Older adults who have new visual impairment face a significant challenge at a time

when they may also be experiencing other major life changes, such as general health limitations or loss of a spouse. Loss of independence and the ability to enjoy leisure activities are predominant concerns of the older adult with a visual impairment.

Wolffe & Candela, (2002) confirmed that "Unemployment is a serious problem for adults with visual impairment, with 69% of the blind and 56% of working age adults with low vision unemployed. Reasonable job accommodations support the employment of individuals with visual impairment. Such accommodations may include modification of equipment and materials, task restructuring, providing drivers or readers, and creating accessible work environments" (Wolffe & Candela, 2002).

#### 2.5. The legal and Policy Frameworks

Any country must ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- ❖ To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- ❖ To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- ❖ To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs.

#### 2.5.1. International legislations

# 2.5.1.1. The universal declaration of human rights (1948)

The universal declaration of human rights states that everyone has the right of equal access to public services in general and education in particular. It also establishes the principle of free basic compulsory education for citizens to support the full development of human personality, and to strengthen respect for human rights and fundamental freedoms.

#### Article 26 of universal declaration of human right

Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional

education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

# 2.5.1.2. The declaration on the rights of Person with disability (1975)

It calls for international and national actions to ensure the rights of the disabled to all services, enable them to develop their capabilities and skills to the maximum possible, and hasten the process of their social integration.

The declaration states that all persons with disabilities have an inherent right to respect for their human dignity. Persons with disabilities, whatever the origin, nature and seriousness of their impairments and disabilities have the same fundamental rights as their fellow-citizens of the right to enjoy a decent life as normal and full possible.

# 2.5.1.3. Disability Discrimination Act

The act has been amended several times since being passed. It now provides protection from discrimination in relation to employment and occupation (including being a counselor); trade organizations and qualifications bodies; education; the provision of goods facilities and services; premises (both residential and commercial); and private clubs. From December 2006 all the functions of public bodies (such as arresting someone) will be covered, as well as the provision and use of certain transport vehicles.

Changes will be made to enlarge the scope of the counselor provisions, those relating to housing, private clubs, and qualifications bodies. The act will also impose a duty to promote disability equality on public authorities, including NHS trusts. At the heart of the act lies the duty to make what are known as "reasonable adjustments." This means that those covered by the act. Also employers, educators, service providers, e t c ... must make "reasonable adjustments" to barriers which hinder disabled people in their access to employment, education, service provision, etc.

# **2.5.1.4.** The standard rules on the equalization of opportunities (1993)

It recognizes the principle of equal primary, secondary and tertiary education; opportunities for children, young people and adults with special needs in an integrate setting; the education of persons with special needs as an integral part of the education system. It establishes appropriate,

adequate and accessible support services accommodate educational provisions for persons with special needs in an inclusive setting.

Integrated education and community-based programs should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities. National community-based programs should encourage communities to use and develop their resources to provide local education to persons with disabilities. In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered. It should be aimed at preparing students for education in the general school system.

#### 2.5.1.5. The World Education Forum Dakar (2000)

It is about making the right to education a reality as it is enshrined in the 1948 Universal Declaration of Human Rights. It is the extension of the education for all movement and aimed at turning the vision of education for all into a reality; meet basic learning needs for all, including those children and young people with special needs. Ensuring that the learning needs of all young people including children with disabilities and adults are met through equitable access to appropriate learning and life skill programs.

# 2.5.1.6. The UN convention on the rights of persons with disabilities

States parties shall take all necessary measures to ensure that full enjoyment by children with disability of all human rights and fundamental freedoms on an equal basis with other children, in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. Also the convention States parties shall ensure that children with disabilities have the right to express their views freely in all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate to realize that right.

#### 2.6 National legal Documents

Through the world there are many agreements and declarations to create best grade score achievable children. As much as possible, all children must put in least restrictive place of education in order to join helpful educational experience. (MOE, 1992) The following

international and national declarations and conventions took from ministry of education special needs education strategy.

Article 41(5) of the 1995 Constitution sets out the state's responsibility for the provision of necessary rehabilitation and support services to 'the physically and mentally disabled'. The wording of the article is outdated and reflects a narrow, medical understanding of disability. However, under Article 9(4) and Article 13(2) of the Constitution, all international agreements ratified by the Ethiopian government automatically become part of the law of the land. The state is therefore obliged to ensure the rights of persons with disabilities as prescribed in the CRPD.

The Proclamation 568/2008 Concerning the Rights of Disabled Persons to Employment, which aims to protect and promote the rights of persons with disabilities to appropriate training, employment opportunities and salaries, and to prevent workplace discrimination.

The Developmental Social Welfare Policy of 1997, which makes reference to the inclusion, participation and independence of persons with disabilities, including children. Implementation strategies include creating accessible physical environments, promoting positive attitudes towards disability, and assisting NGOs working on the issue.

The Ethiopian Building Proclamation of 2009 makes it mandatory for public buildings to be physically accessible for persons with disabilities.

The National Plan of Action for the Inclusion of Persons with Disabilities 2012 – 2021 is an ambitious policy framework that aims to mainstream disability issues in all fields of society. It makes provision for comprehensive rehabilitation services, equal opportunities for persons with disabilities in education, skills training and work, as well as full participation in the lives of their families, communities and the nation.

Ethiopia's Growth and Transformation Plan (2010-2015) identifies disability as a crosscutting development issue. This is the third, 5-year term Poverty Reduction Strategy Paper formulated by Ethiopia since 2000, and it is the first to expressly address disability. It focuses on education and training, rehabilitation and equal access to services and opportunities for persons with disabilities, as well as strategies to prevent disability. In spite of the policy advances above, formal commitment has not yet sufficiently manifested in action (Yibeltal 2013). There are still legislative and policy gaps. For example, Ethiopia has not signed the Optional Protocol to the

CRPD, which would allow persons with disabilities whose rights have been violated to bring individual complaints to the Committee on the Rights of People with Disabilities. Several domestic laws still have to be harmonized with the CRPD, as required by article 4 of the treaty. In addition, monitoring of disability policy implementation, especially in rural areas, remains weak. In recent years, some restrictive policies and legal frameworks that impede activities of disabled peoples' organizations (DPOs) and other civil society organizations in Ethiopia have been adopted. The Charities and Societies Proclamation of 2009 requires all non-governmental organizations working on rights-based advocacy to generate 90% their operational funding only from local sources and not from international collaborations of any sort.

Ethiopia's Growth and Transformation Plan (2015 -2020) in Social Welfare and Labor Affairs issues indicates that with regard to Social welfare, the major strategic directions pursued were creating opportunities for the disabled, the elderly and vulnerable population groups to participate and equitably benefit from the political, economic and social activities of the country and to increase citizen's social security service coverage. Thus, to ensure the benefits for persons with disabilities from physical rehabilitation services, three new physical rehabilitation centers were established. Similarly, seven existing centers were equipped and strengthened with equipment and raw materials where all of them have been providing services. Regarding establishment of a system for the effectiveness of the sector's activity, service delivery standards for physical rehabilitation and for the elderly, and guideline for National Coordinating Committee for the convention of the Rights of Persons with Disabilities were prepared and implemented accordingly. In addition, Social Protection Policy was prepared and ratified by the government and the National action plan for elderly persons was revised.

Social security services which used to be provided only for government organization employees is now being provided for private organization employees as well. It was planned to provide social welfare services to 1,530,606 citizens. Accordingly, the service was provided to 1,632,607 citizens. Although significant efforts have been made to accomplish the objectives of the plan, the services have not been adequate to ensure the benefit for persons with disabilities and coverage and accessibility of social security for citizens. Thus, all stakeholders should work hard to bring long lasting solutions.

It is well known that a healthy and stable employee and employer relationship is vital to ensure industrial peace and in turn for industrial development expansion and realization of structural transformation. Thus, strengthening institutional capacity ahead of time is fundamental. In line with this, a number of activities were undertaken during the plan period.

#### 2.6.1 Ethiopian labor proclamation

In this proclamation the Ethiopia approved labor right special for people with disability in general which has protection for their employment and also when they are on work. It allows them to have employment right.

#### Article 29. Reduction of Workforce

1/ In this Proclamation "reduction of workforce" means termination of workforce of an undertaking for any of the reasons provided for by Article 28 (3) of this Proclamation workers representing at least ten percent of the number of workers employed or, in the case where the number of workers employed in an undertaking is between twenty and fifty, termination of at least five employees over a continuous period of not less than ten days.

2/ The expression "number of workers" referred to in Sub-Article (1) of this Article means the average number of the workers employed by an employer concerned within the twelve months preceding the date when the employer took measures of reduction of workers.

3/ whenever a reduction of workforce takes place in accordance with Article 28 (3) of this Proclamation, the employer shall conduct consultation with a Trade Union or workers' representatives in order to retain workers having skills and higher rate of productivity in their posts. In case of comparable skill and rate of productivity, the workers to be affected first by the reduction shall be in the following order:

- a) Those having the shortest length of service in the Undertaking;
- b) Those having fewer dependents;
- c) The reduction shall affected first workers except those that are listed under
- d) Up to (e) of this Sub-Article;
- d) Those employees with disability;
- e) Those who sustained employment injury in the Undertaking;

- f) Workers' representatives; and
- g) Expectant mothers and mothers within four months post-natal.

Those legislation were focused on the right of people with disabilities on education and job. As they explained people with disabilities have the right to get education, employment opportunities, and workplace accessibilities in different ways based on their special needs in general. People with visual impairment will be suffered on education and workplaces because the stakeholders and some institutions don't allow them to know their rights.

The government of Ethiopia has taken a number of legislative and policy steps that indicate commitment to advancing the rights of persons with disabilities. In terms of international instruments, these steps include:

Signing and ratifying (in 2010) the **United Nations Convention on the Rights of Persons with Disabilities (CRPD)**, the first international, legally binding treaty aimed at protecting the human rights of persons with disabilities.

Signed and ratified other treaties that advance the rights of people, including those with disabilities, for example the UN Convention on the Rights of the Child, the African Charter on Human and People's Rights, the Convention on the Elimination of All Forms of Discrimination against Women, and the Beijing Platform for Action all of which make some reference to protecting the rights of persons with disabilities to fair treatment, appropriate care, inclusion and full participation in society. The African Commission on Human and Peoples' Rights has drafted a Protocol on the Rights of Persons with Disabilities. It was released for comment in April 2014 and once finalized, is likely to become part of Ethiopia's policy framework for advancing disability rights. Other important upcoming tools in 2014 are the CRPD Toolkit for Africa and the Accountability Framework for Africa which is part of the Common African position for Post 2015 Development. In terms of national laws and policies, the following have the most direct bearing on the rights of persons with disabilities:

**Article 4** - A National Plan of Action on Human Rights (2013–2015) has been issued by the Ethiopian Council of Ministers and House of Peoples' Representatives in order to promote the full realization of all human rights in the country, persons with disabilities included. In addition to the political, social environmental and developmental rights, the National Plan of Action has

devoted one chapter/thematic area regarding the rights of vulnerable sectors of the population such as women, children, persons with disabilities and people affected by HIV/AIDS. A national steering committee composed of high government officials and chaired by the Minister of Justice has been established. The steering committee is currently exhibiting its fullest engagement in implementing the plan at federal and regional level.

Article 5 - The employment right law also provides for reasonable accommodation to ensure equality right in employment. On the basis of this law, a number of employees with visual impediment, especially those who are in the public sector have got readers and assistants at office. The Government pays salary for the clerks and secretaries supporting the employees with visual impairment. In certain cases, transport services are provided. The Ministry of Science and Information has for instance assigned a vehicle for three people with visual impairment and two persons with physical disabilities staff to transport them from and to office. The Government has also employed a sign language interpreter for people with hard of hearing official at the central statistics authorities. An assistant has been assigned and employed for an honorable member of the House of Peoples' Representatives to facilitate his public responsibility on equal basis with other members. Despite the low number of beneficiaries of such service, the practice may serve as one positive experience to be learned and followed by other institutions. In certain cases, persons with disabilities enjoy special benefits secured by law. In a recently issued of Addis Ababa city administration directive on the prohibition of leasing government houses for commercial purposes, it was specially provided that persons with disabilities who may have rented the government house for some commercial purpose will not lose the benefit and maintain the house and use it as a means of income.

#### **Unit Three**

#### **Research Methods**

#### 3.1. Research Design

This study explores the lived experience of adults with late blindness in view of psychosocial problems and coping mechanisms. Qualitative research approach was used to conduct the study due to the fact that it deals with "....in-depth understanding about a certain phenomenon through exploration instead of measurement" (Bernard, 2008, P.69). Qualitative research approach can be described as an effective approach that occurs in a natural setting that enables the researcher to develop a level of detail from being highly involved in the actual experiences (Creswell, 2003).

One of the relevant methods in qualitative research is phenomenological approach. Hence, Phenomenological research design were implemented for this study due to the nature of the thematic area of the research. To be specific, the vital reason why this approach is preferred is owing to the fact that the lived experiences of individuals as a phenomenon will be described by the individuals themselves (Creswell, 2014). Hence, this approach is believed to be appropriate and suitable mechanism for the conduct of the study which is intended to acquire the experience of targeted adults with late blindness.

The purpose of phenomenological study is "to understand the experience of the participants from their" point of view" (Leedy & Ormrod, 2001, p. 157). The focus is on the participant's perceptions of the event or situation and the study tries to answer the question of the experience. Creswell (1998, p. 52) points out that the essence of this study is the search for "the central underlying meaning of the experience and emphasize the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on the memory, image, and meaning". Phenomenological research generally deals with people' perceptions or meanings, attitudes and beliefs and feelings and emotions.

# 3.2. Description of Research Site

The study site were selected purposively. The study was conducted at Addis Hiwot Center for the Blind. The center is located in Arada sub-city, woreda 2 of Addis Ababa City Administration. The center has been engaged in providing relevant support services for hundreds of members with late blindness as of its foundation. Hence, the center was selected for the purpose of the

study due to the reason that the organization is the only center in the country established by the founding members with late blindness for the provision of pertinent services considering the specific needs and challenges of persons who face blindness at their later age.

#### 3.3. Research Participants

The only legitimate informants in phenomenological research are those who have lived the reality or those who passed through the experience related to the targeted thematic issue of the study (Creswell, 1998). Hence, the recruitment process has been conducted in consultation/collaboration with the management of the targeted center focusing on individuals who had lived experience being adult with late blindness. The study is planned with an intention to illustrating the lived experience of adults with late blindness from psychosocial perspective. The registration profile of the center indicated that there are more than 500 members of the association with appropriate gender proportion. Accordingly, the study participants were identified/selected purposively based on the following criteria:

- > Adults with are late blindness;
- Adults with late blindness over the age of 25;
- > Senior and founding members who had shared vision and initiative for the foundation of the center; and
- Adults with late blindness who reside in different sub cities of the city if applicable.

#### 3.4. Sampling Techniques

Purposive sampling and snowball sampling was used to identify the respondents who are adults with late blind to explore their experience. Purposive sampling was a commonly used sampling strategy, in that participants are recruited according to pre-selected criteria relevant to a particular research question. Sometimes, this sampling technique may be referred to as 'judgment sampling'. The condition that the participant of the study was selected purposively based on their experience enables the author of the research to access their rich information to show the real picture of the thematic issue of the research (Elmir et al, 2010).

In addition, snowball sampling was employed to address the founding members of the association who are not currently active beneficiaries of the center and facilitate them to be involved in the center as key informants considering their hand on and rich experience on the process of the foundation of the center.

Using this type of approach which is snowball sampling to sampling enables researchers to identify a greater number of individuals affected by the phenomenon and also yields rich information about the social networks, grassroots of the individuals involved in sampling (Noy, 2007). Those sampling helps methods help the researcher to investigate the real experience of the study participants who are adults with rich experience on the targeted thematic area of the research. In the context of this study, the author of the research were thoroughly investigate and analyze the lived experience of adults with late blindness identified using purposive and snowball sampling based on the criteria stated above.

#### 3.5. Sample Size

Sample size in qualitative research should be adequate to achieve data saturation, richness of data and not too large that it is difficult to undertake in-depth, meaningful analysis. Regarding the number of participants in qualitative studies, a common range is usually somewhere from 8 to 15 participants, but it may vary widely both inside and outside this range ((Violeta L. and Dean, 2013). As per the recommendation of Creswell (2007), a total of 10 study participants as sample size are adequate for the conduct of the research that uses phenomenological approach. In addition, phenomenological studies are not interested in how many? ", who have had a particular experience, but how many times the phenomenon makes its presence in the description (Giorgi, 2009). For the purpose of this study the selected participants was 15 participants were selected from total targeted population with the above criteria which are listed in the research participant part through telephone. But from those 15 only 11 of them were willing and 4 of them were not available. The study select only those number of participant because this research method only allow 8 up to 15 participants.

#### 3.6. Data Collection Tools and Procedure

The following data collection tools were applied to generate information for the conduct of the study:

- Face- to-face interview with key informants; and
- Case stories selected from key informants.

In the course of the interviews, a friendly approach was applied in order to probe the interviewees' internal and external realities including their feelings. All interviews were held at the convenient places or the office of the center based on the consent of the informants.

A four-page semi structured guide to the interview questions were prepared and used to maintain interview consistency and quality. Each interview was last one hours on average and was recorded on an audio-digital recorder with the interviewee's consent.

Another reason why semi-structured interviews are required to have an interview guide is related to the importance of providing a set of questions for discussion. The questions are set to ensure the research questions or objectives are covered. However, there is freedom to ask any questions in any order, following tangents or seeking clarification of previous answers or elaboration of responses. In other words, semi-structured interviews direct the interview yet allow for flexibility (Violeta and Dean, 2013). The approach of phenomenological research itself facilitates the interviewees to be active participant and expert in their own life, validating their knowledge and contributing to the research process (Gill & Liamputtong, 2009).

The question guides for the interview are prepared in English and then translated into Amharic, to facilitate the contribution and active engagement of the participants in the study.

### 3.7. Data Analysis

The analysis were presented based on thematic areas organized in the interview guide. The response of the interview was presented under each thematic area using descriptive approach which is highly relevant for interpretative phenomenological data analysis method as stated in the research design section of the research. All interview guidelines was designed based on the research questions and the data that was collected were analyzed thematically and some basic information were written by narrating what has been said.

According to Creswell (2007, p. 74), "using interviewees own words to illustrate themes enables the reader to assess the pertinence of the interpretations, and it retains the voice of the participants personal experience."

#### 3.8. Ethical Issues

Research ethics deals primarily with the interaction between researchers and the participants of the study. Professional ethics deals with additional issues such as collaborative relationships among researchers, mentoring relationships, intellectual property, fabrication of data, and plagiarism, among others.

Whenever we conduct research on people, the well-being of research participants must be our top priority. The research question is always of secondary importance. This means that if a choice must be made between doing harm to a participant and doing harm to the research, it is the research that is sacrificed.

Furthermore, the interviewees were well informed about the confidentiality of the information they provided and the fact that their privacy is fully respected. In accordance with Janet Boddy (2013, P. 54) "The confidentiality of information supplied by research subject and the anonymity of respondent must be respected".

Fortunately, choices of that magnitude rarely need to be made in qualitative research! But the principle must not be dismissed as irrelevant, or we can find ourselves making decisions that eventually bring us to the point where our work threatens to disrupt the lives of the people we are researching. So, based on these the researcher puts in to consider the following things:

- ➤ Any data which is collected from the participants was used only for the purpose of the study;
- The researcher tries to keep every personal information of the participant;
- The researcher didn't push the participant to get information;
- ➤ The researcher tries to respect the idea and personality of all participants;
- The researcher does everything with consensus with the participant; and
- > The researcher informed the participant about every step in the data collection procedure.

So, the researcher put those things to consider while in the data collection procedure.

### **Chapter Four**

### **Results**

This study aims at exploring the lived experiences of adults with late blindness in view of psychosocial problem and coping mechanisms. Accordingly, this chapter presents the main research findings obtained from the semi structured interview process with the adults to discover their lived experiences of the participants. The key finding of the study has been presented in three sections:

- The profile of the participants;
- Lived experiences of adults with late blindness categorized in five thematic areas; and
- Two case stories.

**Table 1 Profile of the informants/respondents** 

No	Respon dents	Sex	Age	Marital Status	Academic Qualificati on	Occupation	Onset of the impairment	Sever	el of rity of ne rment	Responsibi lity in the study center	Date of membersh ip in the association
								Total Blind	Low vision		
1	R1	F	28	Single	Grade 12	Student	At age of 18 in 2003		<b>✓</b>	Member	2004
2	R2	M	44	Widowed	Grade 12	No job	At age 40 in 2008	<b>✓</b>		Member	2008
3	R3	M	62	Widowed	Degree in Law and governance	No job (pensioner)	At age of 53 in 2003	<b>✓</b>		Braille teacher	1998
4	R4	M	32	Single	Grade 11	Electrician	At age of 28 in 2008	<b>√</b>		Member	2008
5	R5	F	50	Single	Grade 6	No job	At age 40 in 2002	<b>√</b>		Member	2011
6	R6	M	32	Single	Grade 8	lottery Vending	Age 15 in 1997		<b>✓</b>	Member	2005
7	R7	F	30	Single	Grade 6	No job	At age 14 in 1998	<b>✓</b>		Member	2011
8	R8	M	44	Married	Grade 12+2	No job	2004(age 36)- left eye and 2008(age 40)- Right eye.	<b>✓</b>		Member	2010
9	R9	M	38	Married	Diploma	No job	At age 32 in 2006	<b>√</b>		Member	2010
10	R10	F	29	Married	Not educated	No job	At age 9 in 1992	<b>✓</b>		Member	2011
11	R11	F	44	Single	MA on social work	General Manger	Age 24 in 1998		<b>√</b>	General Manger	2003

### 4.1. The lived Experience of Adults with Late Blindness Categorized in Five Thematic Areas

# 4.1.1. The Common Causes of Late Blindness and the First Impression of Families of Adults with Late Blindness in the Context of the Study

As indicated on Table 1 that shows the profile informants, a total of 8 participants of the study were adults with total blindness, and the remaining 3 respondents were also adults with low vision. Accordingly, all participants of the study were asked the question related to the cause of their blindness and their first impression or reaction of their respective families towards the occurrence of their vision problem. In their response, 10 respondents confirmed that they were aware of the cause of their impairment, where as one of the interviewees reported that they were not informed about the reason why she lost her vision. As per the information generated from those interviewees who were aware of the cause of their visual impairment, tumor, glaucoma, measles, fluid in the brain, retina problem, scar in the brain and accident were the ground reasons of their vision problem. As stated above, as one of leading causes of visual impairment of the interviewees, human-made accidents caused the loss of vision of the respondent at their late age as described hereunder. In the course of the interview, R4 explained that:

I lost my sight while I was in work. I am a paraprofessional in maintenance of electronics devices such as stove, juice blender, oven, percolator, refrigerator, Injera makers etc. In addition, I have been engaged in electricity installation for many years using my experience working on repairing electronics devices. While I was repairing a refrigerator, the gas of that old refrigerator accidently percolated in my eyes and on my hands too. Thereafter, I was supported to access medical treatment both in emergency and regular wards in the hospital. Even though the medical treatment succeeded in curing my hands, the severity of the damage that affected my left eye required further treatment of surgery. Unfortunately, the ophthalmologists could not restore my sight regardless of concerted effort they made to retain my sight. Even though I am not well informed about the situation, the same problem was observed on my right eye shortly that forced the ophthalmologists to conduct surgery as they did for my left eye. The process of the surgery was not successful as the ophthalmologists expected. Immediately after the surgery, my right eye sight was in state of decline. Finally, I lost my sight through such gradual process of decline of my vision, and presently, I only project dark and light, and

sometimes the shape of objects too. Regardless of this situation, there is no doubt that I am functionally blind.

It was in one of the government hospitals specialized in eye care and treatment that I received medical treatment to restore my sight reversing the damage on my eyes caused by the accident. I objectively believe that I did not receive proper attention and appropriate treatment from most of medical doctors and other personnel in the course of the diagnosis and medication. This situation forced me to visit privately owned clinics and invest a lot of money for the treatment seeking the swift restoration of my sight. Unfortunately, I could not succeed in achieving my wish rather one of my doctors informed me that he detected the symptom of diabetes in my blood that adversely affected my emotion. I believe that the success of such complicated medical treatment is 50 percent: this is what happened regarding my vision problem.

As confirmed by the interviewees, 10 out of 11 participants of the study tried to get medical treatment as much as possible. Of these respondents who received medical treatment, 5 interviewees reported that they underwent surgical treatment without visible success. To be specific, 3 of them noted that they have been forced to pass through repeated surgery. As a result, 2 study participants reported that the failure of the medical treatment urged them to search another option for the restoration of their sight. Accordingly, they have repeatedly used traditional medication such as holly water and witchcrafts.

With regard to the first reaction of the families of the study participants towards the occurrence of their vision problem, all the respondents unanimously concurred that the response of their families to the loss of their sight was appalling believing that the consequence of the problem was devastating for the family as a whole.

However, 2 interviewees reported that the reaction of their families towards the loss of their sight at their late age was not shocking as expected; rather they confirmed that their families made relentless effort with a sense of stability and tranquility to facilitate them to access medical treatment on time and accept the situation as it is.

The respondent was asked if there was the same vision problem that affected one of their family members or close relatives. In their response, all study participants unanimously corroborated that there was no person who was contracted with the same vision problem from their family members and relatives.

With regard to the situation how the respondents lost their sight, they were asked whether they lost their sight accidently or by the long lasting impact of a disease that gradually affected their vision acuity. A total of 8 interviewees reported that they lost their sight suddenly as a result of unknown reasons. Whereas, the other 2 respondents explained that it was in a state of decline that they ultimately lost their sight due to chronic eye disease. The remaining respondent, however, was not aware of the situation and the reason too how she lost her sight.

One of those interviewees who lost their vision abruptly expounded the process how he encountered vision problem as follows:

As I have tried to explain the situation, I lost my sight suddenly without experiencing any kind of sight problem or chronic eye disease. Once up on a time I was watching TV in my home at night with my family. In that occasion, I have realized that I could not properly read short messages written on the screen of the TV. I can assure you that I have never ever faced such kind of problem in the past. Shortly after my problem was detected, I have tried to access medication seeking appropriate treatment and solution for my progressive sight problem. Then I have visited two hospitals searching better medical facility and treatment. Finally, the ophthalmologists underwent laser cleaning on my cloudy lens with an intention to curing the impact of cataract and restoring my sight. To be honest, I have observed improvement on the range and acuity of my vision for a while. Unfortunately, this progress could not perpetuate any more due to the reason that I have lost once again my sight after two months of the treatment.

## 4.1.2. The Conditions How the Study Adults with Late Blindness Reacted to the Occurrence of their Vision Problem

Considering the advent of the breakthrough in the life of the study participants following incidence of visual impairment at their late age all respondents were asked about their reaction to the occurrence of their vision problem. Regardless of their different answer to the question, all respondents did not hesitate to explain their true feeling that they were highly frustrated and disappointed when they became blind at their late age. They further explained the situation that they felt bitter grief when they recognized the fact that they lost their sight.

As stated above the range of reaction of the study participants towards the new experience and mode of life they faced following the loss of their vision was quite different. As a result, some of the respondents reported that they had difficulty to accept the new scenario of their life emanated from the loss of their vision. Accordingly, three interviewees showed their miserable experience related to their late blindness explaining their notorious memory that they have tried to commit suicide.

One of these respondents reported the scar of this painful experience as follows:

I remember that when I face the vision problem, I was emotionally ill and exclusively incapable to control and manage my disturbance and hopelessness. I had expectation that there may be a medical solution for my sudden eye sight problem. Unfortunately, my expectation came to an end without success following the failure of the medication to restore my sight. Shortly after my return to home from the hospital, my preference was to die, and that is why I have tried to commit suicide. This is due to the reason that I have been forced to stay at home for 8 consecutive months isolating myself from the rest of the world. I hope that it will not be difficult to understand my situation and feeling how terrible it was. In this confusing situation I was asking myself why I have been here. Because, the world is not mine since I do not belong to any one. It is true that anyone will not accept the vision problem but through time my feeling changed when I saw my mother's conditions and my friend life experience who is a famous musician that helped me to cope with my challenges.

The other interviewee, respondent 9 also briefly described his experience how he reacted to the occurrence of his vision problem as follows:

I remember that I detected my vision problem while I was working in my workshop.

Meanwhile, I felt severe headache that lasted for many hours.

Simultaneously, I could not operate and manage my hands that forced me to stop my work due to the sudden inoperativeness of my upper limbs. Shortly, I faced the same impairment or paralysis on my leg and after a while I lost my sight too. Thereafter, I have tried to get medical treatment for my multiple impairments that I have faced accidently. Thanks to the relentless support and treatment of my doctors I have enjoyed the success of the medication that brought cure on my temporarily impaired hands and legs.

However, I could not get healing for my vision problem as I have expected from the concerted effort made by the ophthalmologists to restore my sight. As a result, I faced painful frustration and lack of stamina/motivation to continue my work so that my workshop was get closed and all properties including machineries of the workshop were brought and stored in my house for a long period without operational service. I myself became idle being dependent up on my families and my physical and mental health was in state of decline for many months after the occurrence of my vision problem. Finally I have decided to commit suicide hiding myself from my family as if I have accepted the new situation of my life wholeheartedly. However, once up on a time, my wife discovered a rope from my pocket that disclosed my hidden plan of suicide. Following this terrible event and heart breaking grief and bitter weep of my wife I have decided to cool my frustration down and cope with the new situation. Then, I have tried to get cure for my vision problem using holy water. Even though I could not succeed in achieving my wish while I was in one of the churches where I received the traditional treatment using the holy water, I was able to meet people with visual impairment who came to the church for the same purpose. This occasion was a turning point in my life that I became aware of my capacity and the opportunities that would enabled me to lead my independent life sharing the life experience of my kindred' with visual impairment. After I have returned back home, I have joined Addis Hiwot Center for Blind (AHCB) to access the rehabilitation services including learning braille reading writing which have particular relevance for the life career of late blind people.

A total of 10 interviewees reported that regardless of the multiple and painful emotional, economic and social problems they faced associated with their late blindness tried to be acquainted and familiarize themselves with the new situation through receiving adaptive skills such as: braille reading and writing, orientation and mobility, and counseling service from AHCB.

As confirmed by the study participants, all interviewees had passed through multifold challenges related to their late blindness that adversely affected their emotion and blurred their aspiration too. Some of them tried to commit suicide; the others also found difficulty to harmonize themselves with the society they live in. They confirmed that all these challenges they experienced were exclusively attributed to the lack of resilience and determination to accept their

visual impairment and its adverse effects on their future life. The other reason that exacerbated their problem as per their information was that they were not aware of the facts related to visual impairment in their former life.

A total of 10 interviewees acknowledged that they had no any kind of experience or contact with individuals having visual impairment that limited possibilities for them to have awareness about the life of people with low vision. One of the respondents (R4), however, noted that he had the opportunity in his life experience prior to the occurrence of vision problem to establish close friendship with one of famous musicians with visual impairment and get experience on the life of people with blindness. In his information, he further depicted the overall situation of his intimacy with his visual impaired friend as follows.

As I said, I was an intimate friend of a famous vocalist with visual impairment who produced consecutive albums in the last two decades. I was one of his assistants while he was preparing and releasing his album. My friend was closely treated by my parents and siblings being deemed as one of the members of our family. I am proud of witnessing the help of my friend with visual impairment and my former experience and lesson that I have earned for my present day self-esteem and confidence in leading independent living in this new atmosphere of life.

When they assess their situation or feeling to live in the two entirely different worlds being a sighted and blind person, as they clarify their feeling the situation is different and it is like the difference of dark and light. Before they were blind they can do different things like they will work any kind of work by moving from one place to another place but now after they lost their sight their movement is restricted due to the occurrence of the problem. The problem created different kind of challenges in the life of the participants. As they mentioned, they automatically get into economic dependency.

# 4.1.3. The Impact of Vision Problem of the Study Adults with Late Blindness on their Psychosocial Conditions

Based on the central theme of this section intended to analyze the psychosocial and economic condition of the study participants following the occurrence of their vision problem, all respondents were asked to present their respective opinion about the impact of their vision problem on their psychosocial and economic condition in terms of the new situation they faced.

In their response all respondents unanimously confirmed that their vision problem adversely affected their psychosocial and living condition. They further reported that following the occurrence of their vision problem they became exclusively dependent up on their families due to the loss of their own income. A total of 9 respondents corroborated that their vision problem forced them to stop their work and lose their own income.

With regard to their social interaction and interpersonal relationship, 9 study participants affirmed that they could not continue their healthy and reciprocal social contacts with others due to the existing negative attitude of people towards disability in general.

They further explained the situation that most of them had faced systematic rejection and sometimes open discrimination to participate in community based institutions such as Ikub, Idir etc. Some of them also reported that they isolated themselves from the participation of the services of this community-based institutions being frustrated by the adverse effect of their vision problem and the negative attitude of people to disability. The remaining two interviewees, however, argued that they have never experienced difficulty in their social and interpersonal interaction with their counterparts due to their vision problem.

Respondent 11 briefly elaborated how she experienced such social stigma and the challenges related to her livelihood as follows:

It is painful to me that I have lost my friends shortly after the occurrence of my visual problem. I understand that most of people with visual impairment face the same problem. The society may force you to blench and lose self-esteem and self-confidence. As a result, I was not confident to participate in different social activities such as mourning, wedding and ritual ceremonies. For instance, usually the bride and the groom will send me a single card of invitation to participate in their wedding ceremony without considering my special need to have assistance for my mobility. Hence, in such situation I will ask the bride and the groom apology for my failure to come and participate in their wedding ceremony. Lack of opportunities which had particular relevance for the improvement of my living condition also affected my psychological makeup which left un-healing scar in my life.

The other question presented for the participants of the study was related to the situation whether they encountered challenges from their respective families or not. Most of the respondents confirmed that the problem they faced from their families in reference to their vision problem that appeared at their late age was insignificant. However, 2 interviewees reported that they did get divorce shortly after the occurrence of their vision problem due to the reason that their spouses were not found in a position to accept their blindness genuinely and wholeheartedly.

The other question presented to be administered by the respondents was whether they were able to continue their occupational engagement following the occurrence of their vision problem, and if not what they did to overcome the challenges they encountered and perpetuate their life career independently.

Most of them confirmed that they were aware of the fact that they could not continue their former occupational engagement due to their visual impairment. Accordingly, most of the respondents used/applied the change of their profession and or academic qualification as a strategy for option to meet the requirements of the existing labor market of Ethiopia that relatively accommodate the special needs of jobs seekers with visual impairment. For instance, one of the interviewees, (R3) who was an accountant by his profession before the occurrence of his vision problem joined Addis Ababa University, Law School and finally, earned First Degree in Law and Governance with an intention to change his professional engagement. Unfortunately, he is still looking for job opportunity.

The other respondent, (R11) who was working as public relation personnel before the occurrence of her vision problem also reported that she succeeded in earning BA in social Work and she has continued her effort to promote her academic qualification being engaged in study of the same discipline at MA level. Alongside with her academic promotion performance, she succeeded in securing a job being an executive director of one of local NGOs working on visual impairment.

In the other aspect of the explanation of the study participants about the overall impact of late blindness, 10 interviewees did believe that the adverse effect of late blindness was exclusively serious for women with late blindness compared with their counterparts. These informants justified their argument saying that women with late blindness are exposed to different forms of harassments mostly sexual abuses directed even from their relatives at home which is commonly known as domestic violence.

In this respect, R (1) reported further information based on her past experience as follows that gave a showcase evidence for the argument.

Once up on a time, while I was travelling from school to my home using a Bajaj, one of the passengers gave me greetings that paved the way to introduce each other. Since we have exchanged telephone address we were able to meet after school in the upcoming days. Gradually, our ongoing friendship and intimacy enabled us to trust each other and finally fall in love. Meanwhile, not only his love but also his kind care and assistance made a difference in my life and even kindled the glimmer of hope for my future life. It was in this situation that I got pregnant as a result of our engagement in sexual relationship. Unfortunately, he suddenly disappeared when he was informed about my pregnancy. The situation was highly disappointing and painful to me. My brother, who closely followed up and understood my frustration, tried to kill him. But he could not find out his whereabouts. Assuming the adverse effect of my pregnancy particularly my inability to take care of my child due to lack of my own income, I was planning to go to the hospital for abortion. However, my mother encouraged me to give birth and she promised me to take care of my child.

It was in this tense and discouraging situation that I gave birth to a child. Even though my mother promised me to take care of my child, the situation was not as simple as I expected. I have suffered a lot in taking care of my child and I was condemned by the society believing that women with visual impairment are not competent to take care of a child due to their vision problem and also their poor economic status who are entitled to be dependent upon others, and the one they deserve compassion.

Likewise, I have been suffering from lack of appropriate and accommodative service in my study too. I could not succeed in getting genuine friends who have concern and understanding about my special educational needs.

On the other hand, one of the interviewees argued the issue in different ways. He did believe that the impact of vision problem is severe in affecting the life of men with late blindness as he described hereunder.

I cordially wish disability not be occurred on any one. I did believe that disability in general will have adverse impact on the life of men rather than their counterparts. When she became aware of my blindness, my girlfriend aged 18 disappeared not meet me forever. I was well informed that she left Addis for Holland. Hence, what I believe is that what happen to me may happen to other men.

## 4.1.4. Kinds of Coping Mechanisms Applied to Mitigate the Psychosocial Problems of Adults with Late Blindness

As a thematic issue of the topic signifies, all participants of the study were asked the question whether they had the opportunity to access interventions related to coping mechanisms which have particular significance to mitigate the psychosocial problems of adults with late blindness. In their response, all participants of the study unanimously confirmed that in addition to their respective personal endeavors, they have received institution and family-based special support that would enable them to cope with multiple psychosocial and economic problems they encountered following the occurrence of their vision problem. A total of 8 interviewees explained the mechanisms that they applied to mitigate the adverse effect of their vision problem and cope with the new situation. These include:

- Deploy themselves in different works intensively;
- Engage themselves in collaborative works with others;
- Invest their time in intensive study; and
- Use successful blind people in their academic performance as role models for their study.

One of these respondents reported that he was highly committed to his study so that he succeeded in joining Addis Ababa University to continue his study at higher education level. He furthermore noted that the then chairperson of Ethiopian National Association of the Blind who is a renowned professional in law was his role model to be actively engaged in his study and promote his academic qualification.

However, the remaining 3 respondents acknowledged that they did nothing to cope with the new situation withstanding the psychosocial problems they encountered as a result of their vision problem. They further admitted that their personal initiative in this respect was insignificant.

With regard to the availability of institution-based rehabilitation interventions, all participants of the study as members of AHCB participated in different Rehabilitation services of the center made available for people with late blindness. As per the information declared by the interviewees, the following components of rehabilitative interventions of the center were the most important ones that enabled them to cope with the new situation:

- Counseling service (Individual, Group, Psychosocial);

- Adaptive learning mechanisms;
- Social empowerment;
- Braille literacy and numeracy Skill;
- orientation and mobility Skill; and
- Adaptive ICT (Basic computer skill using talking screen reader/software).

Based on the onset of their impairment, all participants of the study were asked the question whether adults with late blindness have special needs emanated from their late visual impairment. A total of 7 respondents did believe that adults with late blindness have special needs related to both the type and onset of their impairment. They argued that adults with late blindness are highly in need of counseling service coupled with other adaptive skills such as orientation and mobility, braille reading and writing and adaptive ICT to cope with the new situation triggered by the occurrence of their vision problem at their late age and then lead their independent life. They further argued that the fact that they need information prepared in tactile and audio format also justifies the reality that people with late blindness have special needs to be known and properly addressed. In addition, the use of white cane as assistive appliance was also mentioned by the interviewees as another example of special needs of people with late blindness.

However, the remaining 4 respondents argued and did believe that even though their vision problem may affect the overall situation of their life and consequently they may need support and or special attention from their families, people with late blindness have no special need that makes their need different from the others.

Regardless of the scar of the adverse effect of their vision problem, all participants of the study unanimously acknowledged the irreplaceable role and support of their families for people with late blindness to cope with their psychosocial and economic challenges.

### 4.1.5. The Aspiration of Adults with Late Blindness on their Future Life

As per the central theme of this section of the study, all respondents were asked to explain their opinion how they aspire about their future life in terms of the new situation they encountered. Of the total of interviewees, 9 respondents reported that their late blindness obliged them to change their mind about their future life career. One of these study participants further explained the situation that she was actively engaged in intensive endeavor to leave the country with her boyfriend for abroad seeking better life and educational opportunity. However, she confirmed

that she could not succeed in achieving her aspiration due to the reason that she lost both her sight and the boyfriend too. She furthermore explained her future plan saying "currently I am living with my mother being dependent upon her income. However, I strongly wish to lead my independent life as soon as possible." Most of the respondents did believe that if they are able to generate their own income and have better economic status, there will be positive possibility to change their life with a capacity to lead their independent living. Hence, these respondents attribute the improvement of their economic status as a premise to aspire their future life positively with other social successes. For instance, the respondents who lost their marriage due to vision problem were asked what they have been planning regarding their future life in terms of their need to establish their own family. All except one interviewee expressed their own interest that they are delighted to get married once again. However, as stated above one of the interviewees explained his interest in a different way. He justified his opinion saying "I have no interest to get married with another girl. Rather, I still prefer to get my former wife back. Hence, I am planning to ask her to come back home when I will be able to secure a better job and regular income as a prerequisite to lead my independent life."

Finally, all participants of the study were asked to suggest what should be done on the way forward regarding the overall improvement of the life of persons with late blindness and who should be responsible to bring the required change in this respect in the context of Ethiopia. In their response, most of the respondents suggested the following recommendations to be taken into account with a view to making meaningful difference in the life of people with late blindness.

- Sensitize the awareness of the society about the issue of disability in general and the specific needs of people with late blindness in particular.
- Build the capacity of regular teachers and upgrade the knowledge and skills of special needs education teachers how to teach and support people with late blindness.
- Make the infrastructure mainly the transportation system and road facilities accessible for the mobility of people with visual impairment.
- Provide opportunities for people with late blindness to be deployed in various occupations based on their proclivity.
- Enable people with late blindness to access education, vocational and other skills trainings.

- Make available adaptive educational materials and assistive devices/appliances for people with late blindness prepared in tactile and audio formats with a view to enabling them to access information independently.
- Promote multi-sectorial collaboration to address the basic and specific needs of people with late blindness.
- Enhance the role of media in educating people about the special needs of people with late blindness and creating positive attitude within local communities about disability in general.
- Establish rehabilitation centers throughout the nation targeting persons with visual impairment and their special needs.

To sum up, the participants of the study concurred that the multi-sectorial collaborative engagement including government and non-government stakeholders such as Ministry of Labor and Social Affairs, Ministry of Education and Ministry of Health on the part of the government and Addis Hiwot Center for the Blind, Ethiopian Association of the Blind and other concerned NGOs representing Non State Actors should play a leading role in the national and local efforts underway with an objective to making difference in the life of people with late blindness.

#### 4.2. Case Stories

The following cases stories are prepared with an intention to present additional and concrete information/evidence for the thematic issues discussed in relation to the lived experience of adults with late blindness.

#### **4.2.1** Case Story One

Teka Mekonnen, aged 62 was born in south Wello Wereilu town. He joined leilt Yeshiemebet primary school at the age of 6 where he completed his primary school study. Following the completion of his primary education, he moved to Dessie to continue his study at W/ro Sihen Secondary and Preparatory School. Unfortunately, he could not succeed in scoring the result of the National Exam that would entitle him to join Higher Education. Hence, he travelled to Dire-Dawa and then persistently engaged in hunting of job. Finally, he succeeded in getting opportunity to be employed in Dire-Dawa Textile factory. Alongside with his engagement in the textile production of the factory, Teka Mekonnen used the educational opportunity given by the

factory for the workers who meet the requirement of the grant of the factory allocated for the promotion of academic qualification of the workers. As a result, Teka Mekonnen earned Diploma in Accounting being actively engaged and effective in his study. In this situation, he served the factory for 10 years.

Thereafter he moved to Addis in search of a job in accounting. Finally, he was able to be hired in Ethiopian Fiber Factory as an accountant. Teka worked in this factory with different positions as junior accountant and then cost and budget officer for nine years until his retirement.

Teka Mekonnen reported that he got married in 1981E.C and he has three daughters. Regarding his vision problem, Teka Mekonnen explained that even though the occurrence of his sight problem traces back to his early age caused by measles that significantly affected the degree of vision acuity of his left eye, He lost his sight suddenly at his late age, (53) in 2003 E.C. Teka reported that he encountered divorce due to the betrayal of his wife fooling the loss of his sight. He further explained that shortly after he lost his vision, he looked for different hospitals and specialists to get cure for his vision problem. Even though he got surgery three times with an intention to curing his eye sight problem, all efforts of the physicians came to an end without success in restoring his sight. As Teka reported since his family had no such experience in the past within his relatives, his families were shocked and himself suffered a lot from the adverse effect of his vision problem.

Ultimately, Teka Mekonnen lost his vision, his wife and his job by pension simultaneously. He explained the situation with bitter feeling saying that "you can imagine how challenging and shocking the situation will be when you face multiple and formidable problems in a condition that the society does not give you a room of opportunity to withstand problems you encountered." Even though he received support from his family, Teka Mekonnen did believe that the situation was extremely disappointing to accept his blindness he further reported that the situation that he lost his social networking and his interpersonal interaction with his friends, neighbors and the like due to his visual impairment aggravated his frustration which continued to be incurable scar in his future life. As per his confirmation, he has suffered a lot economically due to the reason that it was difficult for him to lead his independent living by his pension which was meager and inadequate to meet his basic needs. Teka, further explained the situation saying that "this multiple challenges embittered my life, and finally I lost my self-esteem and

confidence. For many years shortly after the loss of my sight, grouching, grumbling, edginess and desperation became the typical manifestations of my behavior."

Regardless of this multifaceted crisis that Teka Mekonnen encountered owing to the loss of his vision at his late age, he succeeded in recovering and managing his emotion by the support of his family, the professional service of AHCB and above all his personal effort and commitment. As a result, he once again joined higher education with a view to changing his qualification so that he earned LLB from School of Law and Governance of Addis Ababa University. He shifted his profession from accounting to law believing that his new profession is more relevant and conducive to access job opportunity regardless of his blindness.

#### 4.2.2 Case Story Two

Abreham Alemu, aged 32 was born in Addis Ababa City Administration in one of the localities of the city known as Kzanchis. He was born in the hose-hold having two boys including him. His father died while he was 5 years old. He learned his primary school education from Grade 1 to Grade 8 in Libe Fana Primary School. Likewise, he learned his study of Secondary and Preparatory grade levels Schooling, from Grade9 to Grade 11 in Misrak Preparatory School. He reported that he could not continue his study and take the National Exam of Grade 12 due to severe financial constraint he encountered to pay school fee.

Even though he could not promote his academic performance, he engaged in electricity work using his ordinary knowledge and experience that he earned from others focusing on electricity installation and maintenance of electronic devices and machines such as: percolators, ovens, stoves, refrigerators etc. There is no doubt that his engagement in such occupation enabled him to generate his own income.

However, once up on a time while he was conducting maintenance on refrigerator, he faced sudden explosive of gas that suddenly injured his eyes. Immediately after the occurrence of the accident he was admitted to hospital for emergency treatment. Since the damage that occurred on his eyes was severe, the ophthalmologists repeatedly conducted surgery to restore his sight loses. Abraham further explained that the accident damaged not only his eyes but also his hands too. The medical treatment that he received in the hospital brought significant cure on his hand, but the ophthalmologists could not restore his sight. It was in this unexpected and sudden accident that he lost his sight while he was working hard to win his bread. He argued that he was forced to

move to privately owned hospital for further and better treatment believing that he was maltreated in the public hospital where he was admitted following the occurrence of the accident. In this hospital he once again got surgery on his right eye however, no progress on his vision problem was observed. Rather, the ophthalmologists detected diabetes in my blood that resulted in another head ache for Abraham. In his report, Abraham confirmed that there is no visually impaired person within his family and relatives too. Hence, the situation was shocking and strange for his family that his mother in particular suffered a lot and she diligently engaged in endless efforts to find out solutions for the eye sight problem of her son. As confirmed by Abraham, his reaction to the occurrence of his vision problem was unspeakable. Abraham reported that after he returned back home from the hospital, the situation for him was absolutely frustrating and devastating due to the reason that he started to face the new world with the new situation entangled with loss of sight. Hence, he confirmed that he tried to commute suicide believing that living in this world with vision loss is futile and meaningless. He lost his compassion, self-esteem, motivation, hope and aspiration on his future life.

Thanks to the priceless and consecutive rehabilitative support and encouragement of his friend with visual impairment who is a famous vocalist in Ethiopia he succeeded gradually in erasing the scar of his emotional disturbance that ultimately enabled him to accept his blindness and whatever the challenges he may face related to his blindness. Abraham acknowledged that he learned a lot and shared a number of valuable experiences from his friend with visual impairment that enabled him to withstand and gradually eliminate those psycho social and economic challenges he faced following the loss of his vision. He further explained that his economic problem is still severe challenge which needs a surgical solution. Abraham said that "I have continued to be engaged in my work being deployed in electric devices maintenance. But, it is impossible to generate the amount of income that I have earned before due to the reason that most of people do not have trust on my capacity related to my blindness. In addition, in my current situation, I am required to hire an assistant to be effective in my work that incurred extra expense.

In the course of the interview, Abraham severely complained that mobility problem due to visual impairment affected not only my social interaction but also my work due to the reason that the nature of my work requires to move from one place to another for providing installation and maintenance services at customer's residences. He did believe that peoples with late blindness

will miss direction compared with people with congenital blindness. The other problem that Abraham suffered and caused the painful destruction in his life was the fact that he lost his love partner due to his visual impairment. He reported that he fell in love with his girlfriend for more than 18 years.

Finally, Abraham confirmed that, presently he is getting relief from his emotional disturbance owing to the commendable professional and rehabilitative support of AHCB and the priceless support of his mother. Hence, he wishes to be a famous vocalist and get married once again.

### 4.3. Summary of the Major Findings

In this study the following thematic issues were thoroughly investigated regarding lived experience of adults with late blindness: common causes of late blindness and the first impression of families of adults with late blindness, the conditions how the study adults with late blindness reacted to the occurrence of their vision problem, the impact of vision problem of the study adults with late blindness on their psychosocial conditions, the kinds of coping mechanisms applied to mitigate the psychosocial problems of adults with late blindness and the aspiration of adults with late blindness on their future life.

The study showed that most of the study participants well about the cause of their vision problem. Accordingly, tumors, glaucoma, measles, fluid in the brain, retina problem, scar in the brain and accident have been reported by respondents as leading causes of their blindness that occurred suddenly at their late age. As per the report of the respondents, the reaction of their families towards their vision problem was shocking. Likewise, even though the level of their reaction was not the same, the finding of the study revealed that the response of all respondents towards the occurrence of their vision problem was unenthusiastic.

All respondents unanimously pinpointed confirmed that the occurrence of their vision problem adversely affected their psycho social and economic situation. Immediately after the occurrence of their vision problem, most of the respondents lost their jobs, marriage, stamina, self-esteem and motivation to perpetuate their future life career in which some of them were reduced to be dependent upon their families. Most of the study participants, did believe that their vision problem negatively affected their social networking and interpersonal interactions, and this challenge forced them to been engaged in isolation from the rest of the society. This psycho social problem, as reported by the respondents was accompanied by emotional disorder including

inferiority complex that totally blurred the aspiration of the study participants on their future life. In fact, as confirmed by the findings of the study, most of the study participants made strong efforts to overcome those multiple challenges they encountered using institution-based rehabilitation services, family support and their own personal initiatives. As a result, following this persistent and relentless struggle, most of the respondents succeeded in curing their psychosocial, emotional and economic problems that put the foundation for their future life and lead their independent living with passion accepting their blindness.

#### 4.4 Discussion

In this chapter, key findings of the study and the opinions of the authors of the study coupled with the relevant literatures reviewed in the course of the study are briefly presented. Five research questions were used as guiding issues to address the thematic areas crafted based on the objective of the study.

The questions focused: on the common causes of late blindness and the first impression of families of adults with late blindness in the context of the study, the conditions how the study adults with late blindness reacted to the occurrence of their vision problem, The impact of vision problem of the study adults with late blindness on their psychosocial conditions, kinds of coping mechanisms applied to mitigate the psychosocial problems of adults with late blindness and the aspiration of adults with late blindness on their future life.

### 4.4.1 The Common Causes of late Blindness and the First Impression of Families of Adults with Late Blindness in the Context of the Study

All respondents were asked to explain the causes of their blindness that occurred at their late age and their response to the occurrence of the problem. As confirmed by the result of the study, the main causes of vision problem of late blindness were tumor, glaucoma, measles, fluid in the brain, retina problem, scar in the brain and accident. The studies conducted by the Federal Ministry of Health of Ethiopia with the Consortium of Non-State Actors such as Light for the World, (2005-2006) pinpointed that among these ground factors for vision problem, Cataract and Trachoma have been reported as the leading causes of visual impairment in the context of Ethiopia. Waddell (1998) corroborated that globally cataract, corneal ulceration and glaucoma were reported as the leading causes of visual impairment.

As substantiated by the respondents unanimously, the response of their families to the loss of their sight was appalling believing that the consequence of the problem was devastating for the family as a whole. However most of families of adult's with late blindness made persistent effort to access medical treatment at the time and to accept the vision problem. Studies conducted on the issue under discussion noted that the response of families and even people who faced impairment was not the same towards the occurrence of disability on the members of their family.

In Accordance with the study conducted by Trachtenberg (1994) cited in Fisseha (2002) p.13 "the process of acceptance includes the denial and isolation, anger, bargaining (It is characterized by a search for cure), depression and acceptance". It is a natural fact that most of people with disabilities particularly people who encountered visual and other impairments at their late age are expected to pass through those stages stated above until they will be able to accept the problem.

As the result of the study further showed, most of the respondents disclosed that they lost their sight suddenly due to unknown reasons.

### **4.4.2** The Conditions How the Study Adults with Late Blindness Reacted to the Occurrence of their Vision Problem

The question was out brought to respondent adults with late blindness with a view to exploring the conditions how they reacted to the occurrence of their vision problem.

As confirmed by the finding of the study, all study participants unanimously acknowledged that they were highly frustrated and disappointed when they became blind at their late age. They further explained the situation that they felt bitter grief when they recognized the fact that they lost their sight. Yukihiko (2018) confirmed that acquired visual impairment evoked several psychological reactions, including shock, depression, grief, resentment, shame, self-derogation, a resigned attitude, feelings of inadequacy, and feelings of excessive guilt.

In addition, Smart (2001) stated that "there are six stages of adjustment to adventitious disability, 1) shock or initial impact, 2) defensive retreat or denial, 3) depression or mourning, 4) regression, 5) personal questioning or anger, and 6) integration and growth." He further elaborated this situation saying all of those stages will be experienced but not commonly. A person with disabilities can experience depression and other those six stages multiple times during adjustment to their problem.

Likewise, Sudhir, Ashok & Bhavna (2008) in conformity with the opinions of the authors referred above explained that some psychological problems associated with visual impairment will may occur like denial or non-acceptance of visual disability, anger or feeling of bitterness about experiencing a visual problem, feeling of inferiority in contrast to people who have no vision problem or feeling of low self-esteem, anxiety and depression.

The result shows that the respondent didn't accept immediately the vision problem that occurs at later age. They encounter different challenges and they suffered to accept the vision problem as it is. As they explained they used different mechanisms to accept the problem and also their families support them to accept the vision problem as it is.

### 4.4.3 The Impact of Vision Problem of the Study Adults with Late Blindness on their Psychosocial Conditions

In this section, the impact of visual impairment that occurred at late age of the respondents on their psychosocial condition was raised and discussed. As all study participants concurred, the vision problem adversely affected their psychosocial and living condition. They further confirmed that the occurrence of the vision problem forced them to be dependent on their families. Most of the participants of the study explained that they were forced to stop their work due to the reasons attributed to their vision problem.

The result further showed that their vision problem adversely affected their social networking and interpersonal interaction with others including friends, neighbors, work mates etc. Individuals who are blind or have low-vision will face the constant challenge of psychologically and socially adjusting to their disability (Rosa, 1993 cited in Schinazi, 2007). As explained by Sudhir, Ashok & Bhavna, (2008) Psychological problems associated with visual impairment may include: denial or non-acceptance of visual disability, resentment or feeling of bitterness about having become a victim of visual loss, feeling of inferiority in comparison to healthy people or feeling of low self-esteem, anxiety and depression. Impaired vision significantly reduces activities associated with participation in society and religion, mobility, recreational and daily living etc. Vision loss in later life contributes to limitations on physical activity, reduces independent mobility, causes vision impairment and your falls, imbalance, entails risks of hip fracture, mortality and underlines the need for community and/or family support.

As confirmed by the findings of the study, the participants of the study reported that they experienced systematic avoidance from social participation such as Ikub, Eder, wedding, mourning and the like due to the existing negative attitude of people towards disability in general entrenched in the society for the last many centuries. Alongside with this social problem, the result of the study clearly confirmed that most of the respondents faced challenges to continue their former occupation because of the occurrence of their vision loss. As Kef, (2006, p. 89) confirmed "having a visual impairment might present a risk to adults for reduced participation and social exclusion. Moreover, young adults with low vision experience more difficulties in social interaction, and making relationships".

It is obvious that the consequence of this crisis was that most of the participants of the study encountered severe economic problems. Economic burden will be experienced by adults with visual impairment for example; there are the direct costs, such as those of treatment, extra facilities for education, social security disability benefits, as well as the indirect costs associated with disability, such as an impeded personal development, lower income, reduced productivity of those who help or care for a visually impaired person (Smith and Smith, 1996).

Most of the respondents confirmed that they were aware of the fact that they could not continue their former occupational engagement due to their visual impairment. Accordingly, the greater number of the participants of the study took pragmatic measure to change their profession and or academic qualification as a strategy for option to meet the requirements of the existing labor market of Ethiopia that relatively accommodate the special needs of jobs seekers with visual impairment.

In order to protect work forces not to lose their occupation in the form of reduction due to their impairment or other conditions the Ethiopian government enacted Labor law that included specific provision for the issue under discussion. In view of this, Article 29 (3) of the Ethiopian labor law Proclamation No.1156/2019 declares that

Whenever a reduction of work force takes place according to Sub-Article (1) of Article 28, the employer in consultation with trade union or representative shall give for workers having skills and higher rate of productivity priority of being retained in their posts and, in the case of equal skill and rate of productivity, the workers to be affected first by the reduction shall be in the following order

- (A) Subject to the provisions of (b) (e) of this Sub-Article, those having the shortest length of service in the undertaking;
- (B) Those who have fewer dependents;
- (C) Those not covered under Sub-Article 3 (a) and (b) of this Article;
- (D) Those who are disabled by an employment injury in the undertaking;
- (E) Workers' representatives; and
- (F) Expectant mothers and mothers within four months post-natal.

In the other aspect of the study, the participants of the study argued that the overall impact of late blindness was exclusively serious for women with late blindness compared with their counterparts and they further mentioned that visual impairment adversely affect the future life of women rather than men. Yeo & Moore (2003), stated that the challenges of women with visual impairment can be described in terms of various psychological and social problems which are rooted in poverty, illiteracy, illness, violence, harassment, rape, unemployment and lack of legal protection.

## 4.4.4 Kinds of Coping Mechanisms Applied to Mitigate the Psychosocial Problems of Adults with Late Blindness

Regarding the relevant intervention need to be provided for people with late blindness, the result of the study revealed that most of the respondents received different family and institution based supports in addition to their personal coping strategies they applied.

As confirmed by the Findings of the study, most of participants took the following personal initiatives/coping mechanisms with an objective to coping with psychosocial problems they encountered as a result of their vision loss.

- Deploy themselves in different works intensively;
- Engage themselves in collaborative works with others;
- Invest their time in intensive study; and
- Use successful blind people in their academic performance as role models for their study.

Alongside with these personal and family support coping mechanism initiatives made by the respondents, most of the study participants witnessed the importance of institution-based

intervention they entertained from AHCB that enabled them to cope with the new situation emanated from the occurrence of their vision problem at their late age. These include the following.

- Counseling service (Individual, Group, Psychosocial);
- Adaptive learning mechanisms;
- Social empowerment;
- Braille literacy and numeracy Skill;
- orientation and mobility Skill; and
- Adaptive ICT (Basic computer skill using talking screen reader/software). Zelalem (2013), confirmed that Adaptive Technology and Equipment, Rehabilitative Trainings and Support are necessary and helpful to persons with visual impairment in the workplace and other places to cope the challenges that has been faced.

Furthermore, the result of the study demonstrated that based on the onset of their impairment, adult with late blindness has special needs which includes counseling services with adaptive skills trainings such as; orientation and mobility skills, adaptive ICT training (Jaws) and braille reading and writing skills to cope with the new situations and to live independent life. Agba (2007) states that Assistive technologies such as jaws for windows, screen readers which enable the visually impaired to make use of computers, the open book scanning software which enables the visually-impaired to read printed materials, Win Braille which helps in the translation of printed materials into Braille, among others have revolutionized the education of the visually impaired.

As pointed out by Birk et al., 2004; Reinhardt, Horowitz, Raykov, MacMillan, & Brennan, (2004) Vision rehabilitation services, such as clinical low vision services and mobility training, have generally been found to have beneficial effects on the functioning and well-being of people who are visually impaired (that is, those who are blind or have low vision).

### 4.4.5 The Aspiration of Adults with Late Blindness on their Future Life

The other issue dealt with the aspiration of adults with late blindness on their future life. Even though the participants were forced to change their future career plan because of the vision problem, most of the respondents did believe that if they are able to generate their own income

and have better economic status, there will be positive possibility to change their life with a capacity to lead their independent living.

As per the finding of the study the participant suggested on the issue what should be done and who should took the responsibility to bring the required change to overall improvement of the life of persons with late blindness. They unanimously suggested that adults with late blindness should be supported to access education, vocational anther skills trainings and make available adaptive educational materials and assistive devices/appliances for people with late blindness prepared in tactile and audio formats with a view to enabling them to access information independently. Agba (2007) states that Assistive technologies such as jaws for windows, screen readers which enable the visually impaired to make use of computers, the open book scanning software which enables the visually-impaired to read printed materials, Win Braille which helps in the translation of printed materials into Braille, among others have developed the education of the visually-impaired.

As confirmed by Birk et al., 2004; Reinhardt, Horowitz, Raykov, MacMillan, & Brennan, (2004) Vision rehabilitation services, such as clinical low vision services and mobility training, have generally been found to have helpful effects on the functioning and well-being of people who are visually impaired.

### **Chapter Five**

### **Conclusion and Recommendation**

#### 5.1 Conclusion

As per the core objective of the study, the lived experience of adults with late blindness was assessed categorizing the issue in six thematic areas as described hereunder:

- The common causes of late blindness and the first impression of families of adults with late blindness in the context of the study;
- The conditions how the study adults with late blindness reacted to the occurrence of their vision problem;
- ➤ The impact of vision problem of the study adults with late blindness on their psychosocial conditions;
- ➤ The kinds of coping mechanisms applied to mitigate the psychosocial problems of adults with late blindness; and
- The aspiration of adults with late blindness on their future life.

The result of the study showed that the main causes of the vision problems of the study participants were tumor, glaucoma, measles, fluid in the brain, retina problem, scar in the brain and accident were the ground reasons of their vision problem. Even though the reaction of families towards their vision problem was shocking, as confirmed by the finding of the study, most of the respondents reported that they received tremendous support to access medical treatment with an intention to restore their sight. This finding of the study implies that the contribution and support of families to people with late blindness in finding the medical solution for the new phenomena was vitally important.

Regarding the reaction of the participants of the study towards the occurrence of the vision problem at their late age, all respondents confirmed that they passed through different challenges related to their vision problem which affected their emotion and their future aspiration too.

They further admitted that the occurrence of their visual impairment significantly damaged and blurred their resilience and determination to accept their blindness. It is possible to infer that the occurrence of any kind of impairment at late age may be challenging to be accepted by the person who encountered the problem.

The finding of the study vividly disclosed the other reality that people who faced blindness at their late age are exposed to lose their former occupation, social networking and interpersonal interaction they established with others.

The finding of the study further confirmed that various forms of coping mechanisms were needed to address those psychosocial problems of people with late blindness with a view to enabling them to lead their independent life coping with the new situation. In this regard, the availability of institution-based rehabilitation service coupled with the family support was proved by the finding of the study as significant intervention to meet the special needs of people with late blindness. As a result, the finding of the study confirmed that the aspiration of the study participants who received such rehabilitation service on their future life has been significantly and positively changed hoping to lead their independent life with passion and success.

#### **5.2 Recommendation**

Based on the key findings of the study, the following recommendations are identified and suggested to provide valuable input about lived experience of adults with late blindness and related issues for concerned government and non-state actors including academic institutions who are engaged in supporting and giving services to adults with late blindness. It is believed that the findings of the research would enable researchers to identify the gap and conduct further study on the issue respectively to enrich the quality of the proposed recommendations.

- The relevant executive bodies of the government should give recognition and have concern on late blindness as one of diversity of impairments that may endanger the future life career of adults with late blindness through mainstreaming this unique issue in their respective service delivery.
- Ministry of Labor and Social Affairs, Ministry of Education, Ministry of Science and Higher Education, Ministry of Health and other relevant government institutions should contribute for the establishment and expansion of rehabilitation centers which provide specialized service pertinent to the special needs of adults with late blindness.
- The concerned government executive body, particularly the institutions working on
  justice should review the incumbent civil servant as well as labor proclamations to
  include provisions that ensure the work guarantee of people who faced visual and other
  impairments at their late age.

- The legislations international and national documents which are adapted and developed like the conventions on the right of persons with disabilities and the Ethiopian Constitution should be properly implemented to meet the needs of peoples with late blindness which is related to rights of people with disabilities on work.
- Special attention should be given for adults with late blindness to be engaged in selfemployment through receiving vocational and motivational skills trainings, and strategies should be developed to facilitate them to secure financial support or loan for their engagement.
- Appropriate attention should be given for late blindness to be included in the curriculum of special needs education department as specific learning outcome.
- Conduct further study on the overall situation of adult with late blindness and enhance the capacity of different non-governmental organizations who are working on peoples with late blindness to give appropriate services for people with late blindness.

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### **Appendixes**

### Appendix 1

### **Addis Ababa University**

College of Education and Behavioral studies

**Department of Special Needs Education** 

**Interview Guides for Key Informants** 

Date

### **Consent Letter**

My name is MihiretAyele. I am a post graduate student of special needs and inclusive education at Addis Ababa University. I am conducting the research for the requirement of master's degree, entitled "Lived experience of adults with late blindness from psycho-social perspective: the case of Addis Hiwot Center for the Blind".

The purpose of the interview is to access your insights and experiences about the specific needs, concern and challenges of adults with late blindness. It is believed that the finding of the study will contribute for the promotion of the special needs of adults with late blindness and give insight or information for concerned stakeholders about the status of psychosocial condition of adults with late blindness in the context of Ethiopia.

The interview is planned to be recorded on digital recorder based on your consent, and the interview session is intended to be not more than an hour. I acknowledge that there are some questions that may disturb you creating discomfort and austerity feeling. In this situation, I assure you that you are authorized to withdraw the interview without a sense of guilty.

I would like to assure you that your information will be kept confidential, and you are not required to write your name.

Thanks for your understanding and participation in the research.

Part C	One: Profile of the Interviewees
1.	Sex: Male Female
2.	Age
3.	Marital status
	- Married
	- Single
	- Divorced
	- Widowed
4.	Academic qualification
5.	Occupation
6.	Onset of the impairment
7.	Level of Severity of the impairment:
	- Total Blind
	- Low vision
8. Posi	ition/responsibility in the study center:
9.	Date of membership of the association:
Part T	Two: Questions related to lived experience of adults with late blindness
2.1.	Questions related to the common causes of late blindness and the first impression of
far	milies of adults with late blindness in the context of the study:-
2.1.1.	Have you been well informed about the cause of your vision problem?
2.1.2.	Have you tried to access medical service for your vision problem? If not, why? And if
	yes, what was the finding of your diagnosis and the treatment you received?
2.1.3.	What was your family's reaction to your blindness?
2.1.4.	Do you have information about the same vision problem that affected one of your family
	members or close relatives? If yes, please explain the situation briefly?
2.1.5.	How did you lose your sight? Was it a sudden/accidental phenomenon or a long-lasting
	impact of known vision problem or disease?

# 2.2. Questions presented to assess the conditions how the study adults with late blindness reacted to the occurrence of their vision problem:-

- 2.2.1. What was your first reaction when you realized that you have vision problem?
- 2.2.2. What is your current and overall response to your blindness?
- 2.2.3. Have you accepted your blindness? If not or yes, why and how? And when if applicable?
- 2.2.4. Have you experienced friendship or contact with persons with visual impairment before losing your sight? If yes, was your experience helpful to face your vision problem with tenacity?
- 2.2.5. How you will assess your situation or feeling to live in the two entirely different worlds being a sighted and blind person?

# 2.3. Questions presented to evaluate the impact of vision problem of the study adults with late blindness on their psychosocial conditions:-

- 2.3.1. What kinds of challenges did you experience, economic, social and emotional following the vision problem you faced?
- 2.3.2. Did you encounter challenges emanated from your family including marriage? If yes, please explain it briefly.
- 2.3.3. Have you faced problem in your occupation owing to your late blindness? If not or yes, please explain it briefly.
- 2.3.4. Do you believe that your vision problem does not affect the continuation of your engagement in your former occupation? If not or yes, why?
- 2.3.5. Have you faced systematic avoidance or open discrimination in the participation of community-based networking such as Idir, Ekub, and Holidays etc. related to your late blindness? If yes, please explain it briefly.
- 2.3.6. Do you believe that your economic status has been affected by the factors related to your late blindness? If yes, how?
- 2.3.7. Did you feel that you have been emotionally affected due to your late blindness? If yes, how and why?
- 2.3.8. Do you believe that late blindness has severe impact on the life of women with late blindness rather than their counterpart? If yes, why?

# 2.4. Questions presented to assess the kinds of coping mechanisms applied to mitigate the psychosocial problems of adults with late blindness:-

- 2.4.1. What personal effort you made to cope with the adverse effect of your vision problem and mitigate its impact in your current and future life career?
- 2.4.2. Have you received professional/specialized support or intervention to empower yourself and lead your own independent life? If yes, where (home-based, center-based and the combination of the two) and what kind of support service
- 2.4.3. If your answer is yes for the question No. 2.4.2, Do you believe that the type and quality of the service you received is adequate and compatible with your specific needs? Why?
- 2.4.4. Do you believe that adults with late blindness have specific/special needs emanated from the onset of the impairment? If yes, please elaborate them briefly.
- 2.4.5. What was the contribution of your family in maximizing your capacity and self-esteem to cope with your new situation?

# 2.5. Questions presented to evaluate the aspiration of adults with late blindness on their future life:-

- 2.5.1. Have you changed your aspiration and plan for your future life career following the loss of your vision? If not or yes, please explain it briefly.
- 2.5.2. If your answer is yes, for question No. 2.5.1, what is your vision for your future life?
- 2.5.3. Which life career is currently preferred to your future engagement? Why?
- 2.5.4. If you are not married, do you want to get married?
- 2.5.5. What do you suggest for the overall improvement of the life of persons with late blindness and who should be responsible to bring the required change in this respect in the context of Ethiopia?

### Appendix 2

### አዲስ አበባ ዩኒቨርስቲ የትምህርት እና ባህሪ ጥናት ኮሌጅ የልዩ ፍላታት እና አካቶ ትምህርት ክፍል

<u>የቃለ                                    </u>
ቀን
<u>የስምምነት ደብዳቤ</u>
ምህረት አየለ እባላለው። በአዲስ አበባ ዩኒቨርሲቲ በልዩ ፍላንት እና አካቶ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ። ከጊዜ በኋላ አይነ ስውርነት ያጋጠጣቸው ጎልማሶች በህይወት ውስጥ የሚያጋጥጣቸውን የስነ-ልበና ቸግሮች እና ችግሮቹን መቋቋሚያ መንገዶች በሚል ርእስ የአዲስ ህይወት ሴንተር ፎር ዘ ብላንድ አባላትን ተሞክሮ መነሻ በጣድረባ ለጣስተርስ ዲግሪ መመረቂያ ጣሟያ ጥናት በጣድረባ ላይ እንኛለሁ፡፡
የዚህ ቃለ መጠይቅ አላማ ከጊዜ በኋላ አይነስውርነት ያጋጠማቸው ጎልማሶች ሊያጋጥማቸው የሚቸልን ልዩ ፍላንትና ተግዳሮት እንዲሁም አሳሳቢ ጉዳዮችን በተመለከተ ያሎትን እይታና ልምድ ለማጤን ነው። የዚህ ጥናት ውጤት ከጊዜ በኋላ አይነስውርነት ያጋጠማቸው ጎልማሶች ያላቸውን ልዩ ፍላጎት ለማስተዋወቅ አስተዋፅአ ያደርጋል ተብሎ ይታመናል፡፡ በተጨማሪም ይህ ጥናት ለሚመለከታቸው አካላት ከጊዜ በኋላ አይነስውርነት ስላጋጠማቸው ጎልማሶች የስነ-ልቦና ችግሮች እና ማህበራዊ ሁኔታዎች ከኢትዮጵያ ተጨባጭ ሁኔታ አንጻር አስፈላጊ መረጃዎችንና ሙያዊ እውቀቶችን በማዳበር አስተዋፅኦ ያደርጋል ተብሎ ይታሰባል፡፡
ቃለ መጠይቁ በእርስዎ ስምምነት መሰረት በመቅረፀ ድምፅ ተቀድቶ ለጥናቱ ዘገባ የተገኘው መረጃ ዝግጁ እንዲሆን ታቅዷል፡፡ የውይይት ጊዜውም በአማካኝ ከአንድ ሰዓት እንዳይበል ጥታስቧል። በቃለ መጠይቁ ወቅት የተወሰኑ ጥያቄዎች ስሜትዎትን የሚነኩ ወይም የሚያደፌርሱ ሊሆኑ እንደሚችሉ ይገመታል፡፡ ስለሆነም ይህ ሁኔታ ሲያጋጥምዎ ያለምንም የጥፋተኝነት ስሜትና ይሉኝታ እንዲሁም መሸጣቀቅ ቃለ መጠይቁን ጣቋረጥ የሚችሉ መሆኑን አረጋግጣለሁ።
በተጨማሪም፣ ማንነትዎ የማይገለፅና የሚሰጡትም መረጃ በሚስጥር የሚያዝ መሆኑን እንዲሁም ጥናቱ እንደ ተጠናቀቀ በመቅረፀ ድምፅ የተቀዳው ቃለ መጠይቅ የሚሰረዝ መሆኑን ላረ <i>ጋ</i> ግጥልዎ እወዳለሁ። ስለሆነም ስምዎትን መፃፍ የማይጠበቅብዎት መሆኑን አሳስባለሁ፡፡ በቅንነት ስለተረዱኝና በጥናቱ ላይ በመሳተፍ አስተዋፅኦ በማድረግ ፍቀደኛ በመሆንዎ ከልብ አመሰግናለሁ፡፡
ክልፍ 1- የ <i>ቃ</i> ለ <i>መ</i> ጠይቁ ተሳታፊዎች ፐሮፋይል
1. ጾታ: ወንድ ሴት  2. እድሜ  3. የጋብቻ ሁኔታ - ያነባ/ች

	- ያላንባ/ቾ	
	- የተፋታ/ቸ	
	- ባለቤቱ/ቷየሞተበት/ባት	
4.	የትምህርት ደረጃ	
5.	የስራ ሁኔታ	
6.	የእይታ ችግሩ የተፈጠረበት ጊዜ	
7.	የዕይታ መጠን ሁኔታ	
	- ሙሉ ለሙሉ ማየት መሳን	
	- በከፊል ማየት መሳን	
8.	በማሪከሉ ያለው/ያላት የስራ ድርሻና ሃላፊነት	
9.	የማሪከሉ አባል የሆነበት/የሆነችበት ቀንና ዓመ	ተ-ምህረት

### ክፍል ሁለት፡-ከጊዜ በኋላ በተከሰተ ዓነስውርነት ዙርያ ያለ ተሞክሮን በተመለከተ የቀረቡ ጥያቄዎች

- 2.1. ከጥናቱ መሰረታዊ ሃሳብ አንፃር ከጊዜ በኋላ ለሚከሰት አይነስውርነት ዋንኛ መንስኤዎችንና ዓይነስውርነቱ ሲከሰትም የቤተሰብ አባላት ምላሽን በተመለከተ የቀረቡ ጥያቄዎች፡-
- 2.1.1. ስለአይን ሕመምህ/ሽ ምክንያት ተገቢውን መረጃ አባኝተሃልን/ሻልን?
- 2.1.2. ለደረሰብህ የአይንህ/ሽ ቸግር ህክምና ማግኘት ቸለህ/ሽ ነበርን? ካልሆነ ለምን? ህክምና የማግኘት እድል ከገጠመህ/ሽ ምን ዓይነት የህክምና አገልግሎት ማግኘት ቻልክ/ሽ?
- 2.1.3. ከጊዜ በኋላ ስለተከሰተው የኢይን ህመም የቤተሰብህ/ሽ ምላሽ በወቅቱ ምን ይመስል ነበር?
- 2.1.4. አንተ ያጋጠመህ/ሽ የዓይነስውርነት ዓይነት በሌላ የቤተሰብህ/ሽ አባል ላይ ስለመከሰቱም ሆነ ወይም አለመከሰቱ በቂ መረጃ አለህን/ሽኝ? መልስህ/ሽ አዎ ከሆነ ስለሁኔታው በዝርዝር አስረዳ/ጃ:፡
- 2.1.5. የዓይን ብርሃንን ያጣህበት/ሽበት ሂደት እንኤት ነበር? በድንንትና በድንንተኛ ህመም ወይስ ለረጅም ጊዜ በቆየ የዓይን ህመም ምክንያት?
- 2.2. በጥናቱ የተሳተፉና ከጊዜ በኋላ አይነስውርነት ያጋጠማቸው ሰዎች ላጋጠማቸው ዓይነስውርነት በወቅቱ የሰጡት ምላሽን በተመለከተ የቀረቡ ጥያቄዎች፡-
- 2.2.1. የዕይታ ቸግር እንዳለብህ/ሽ በተረዳህ/ሽ ጊዜ ለችግሩ የነበረህ ምላሽ ወይም ስሜት ምን ነበር?
- 2.2.2. በአሁን ወቅት ስለ አይነስውርነትህ/ሽ ያለህ ስሜትና ምላሽ ምን ይመስላል?
- 2.2.3. አይነስውርነትህን/ሽን በፅጋ ተቀብለህዋልን/ሽዋልን? መልስህ/ሽ ተቀብዬዋለሁ ወይም አልተቀበልኩትም ከሆነና ምላሽ ለመስጠት ፍቃደኛ ከሆንክ/ሽ፤ ለምንና መቼ?
- 2.2.4. አይነስውር ከመሆን ህ/ሽ በፊት ከሌሎች አይነስውራን ጋር የመገናፕትና ጓደኝነት ወይም ወዳጅነት መፍጠር ቸለህ/ሽ ነበርን? መልስህ/ሽ አዎ ከሆነ ይህ አጋጣሚ ከጊዜ በኋላ ከገጠመህ/ሽ አይነስውርነት ጋር በጽናት ለመቆም አስችሎኛል ብለህ/ሽ ታምናለህን/ሽን?

- 2.2.5. በሁለቱ የተለያዩ ዓለማት ውስጥ ማለትም አይነስውር ከመሆንህ/ስ በፊትና በኋላ የነበርክበትን/ሽበትንና አሁን ያለህበትን/ሽበትን ህይወት በንፅፅር እንዴት ትመለከታዋለህ/ሽ?
- 2.3. ከጊዜ በኋላ የተከሰተው የአይነስውርነት ችግር በጥናቱ ላይ የተሳተፉ ሰዎች ህይወት ላይ ተፅእኖ ማሳረፍ አለማሳረፉን ለማጤን የቀረቡ ጥያቄዎች፡-
- 2.3.1. ዓይነስውር ከሆንክ/ሽ በኋላ፣ ምን ዓይነት ኢኮኖሚያዊ፣ማህበራዊ እና ስነ-ልቦናዊ ተማዳሮት ገጠማህ/ሽ?
- 2.3.2. ከቤተሰብህም/ሽም ሆነ ከትዳር አጋርህ/ሽ ዙሪያ በዓይነስውርነትህ/ሽ ምክንያት ፌተና ገጥሞህ/ሽ ያውቀልን? መልሱ አዎ ከሆነ ስለ ሁኔታው በዝርዝር አስረዳ/ጃ።
- 2.3.3. ከጊዜ በኋላ በተከሰተ ዓይነስውርነትህ/ሽ ምክንያት ከስራህ/ስ *ጋ*ር በተያያዘ ቸግር *ነ*ተሞህ/ሽ ያው ቃልን? መልስህ/ሽ አል*ነጠመኝም ወይም ነ*ተሞናል ከሆነ ሁኔታውን በዝርዝር *ባለፅጭ*፡፡
- 2.3.4. ከጊዜ በኋላ የተከሰተው ዓይነስውርነትህ/ሽ ተሰማርተህበት የነበረውን ስራህን/ሽኝ ለመቀጠል ሳንካ ፈጥሮብኛል ብለህ/ሽ ታምናለህን/ታምኛለሽ? መልስህ/ሽ ፈጥሯል ወይም አልፈጠረም ከሆነ ምክንያቱን በዝርዝር ግለፅ፡፡
- 2.3.5. ከዓይነስውርነትህ/ስ *ጋ*ር በተያያዘ ከማህበረሰሰቡ *ጋ*ር ባለህ/ሽ ማህበራዊ ትስስር ወይም ቁርኝት ላይ ፈተና ገጥሞህ/ሽ ያውቃልን? መልስህ/ሽ አዎ ከሆነ ሁኔታውን በአጭሩ ባለፅ፡፡
- 2.3.6. አይነስውር ከመሆንህ/ሽ *ጋ*ር በተያያዘ የኑሮ ወይም የኢኮኖሚ አቅምህ/ሽ ላይ ቀውስ ተፈጥሮአል ብለህ/ሽ ታምናለህን/ታምኛለሽን? መልስ አዎ ከሆነ እንኤት?
- 2.3.7. ከጊዜ በኋላ በደረሰብህ/ሽ አይነስውርነት ምክንያት የስሜት መዛባት ወይም ቀውስ ደርሶብኛል ብለህ/ሽ ታምናለህን/ታመኛለሽን? መልስህ/ሽ አዎ ከሆነ እንዴትና ለምን?
- 2.3.8. ከጊዜ በኋላ የሚከሰት አይነስውርነት ከወንዶች ይልቅ በሴቶች ላይ የሚያስከትለው ፈተና ከፍ ያለነው ብለህ/ሽ ታምናለህን/ታምኛለሽን? መልስህ/ሽ አዎ ከሆነ ለምን?
- 2.4. ከጊዜ በኋላ በተከሰተ አይነስውርነት ምክንያት ሊከሰት የሚችል ስነልቦናዊ ችግርን ለመቀነስ ስለሚያስችሉ የመቋቋሚያ ስልቶች የተመለከቱ ጥያቄዎች:-
- 2.4.1. ከጊዜ በኋላ ያጋጠመህ ዓይነስውርነት ያስከተለውን ፈተና ለመቋቋም እንዲሁም በቀጣዩ ህይወትህ ላይ ሊያጠላ የሚችለውን ችግር ለመቀነስ በግለሰብ ደረጃ ምን ጥረት አደረግህ?
- 2.4.2. የግል ሕይወትህ/ሽን በራስህ/ሽ ጥረት ለመምራት የሚያስቸልና አቅም የፈጠረልህ/ሽ የባለሙያ ልዩ ድጋፍ አግኝተሃልን/ሻልን? መልሱ አዎ ከሆነ አገልግሎቱን ያገኘህበትን/ሽበትን ቦታ ወይም ተቋምና የአገልግሎቱን ወይም ድጋፉን ዓይነት ግለፅ/ጭ።
- 2.4.3. በተራ ቁጥር 2.4.2፣ ላይ ለተቀመጠው ጥያቄ መልስህ/ሽ አዎ ከሆነ ያገኘኸው/ሽው የድጋፍ ዓይነትና ጥራት በቂና ከልዩ ፍላንትህ/ሽ ጋር ተጣጣሚ ነው ብለህ/ሽ ታምናለህን/ታምኛለሽን? ለምን?
- 2.4.4. ከጊዜ በኋላ ዓይነስውርነት ያጋጠማቸው ጎልማሶች ዓይነስውርነታቸው ከተከሰተበት ጊዜ አንፃር ልዩ ፍላጎት አላቸው ብለህ/ሽ ታምናለህን? መልስህ/ሽ አዎ ከሆነ ስለ ሁኔታው በአጭሩ አብራራ/ሪ፡፡

- 2.4.5. ከዓይነስውርነትህ/ሽ *ጋ*ር ከተከሰተው አዲስ ሁኔታ *ጋ*ር ራስህ/ሽን ማጣጣም ትችል/ይ ዘንድ በራስ *መተጣመ*ን ላይ ያለህ/ሽን አቅም ለማሳደ*ባ* የቤተሰቦችህ/ሽ አስተዋፅኦ ምን ነበር?
- 2.5. ከጊዜ በኋላ አይነስውር የሆኑ ንልማሶች ስለ መፃይ ህይወታቸው ያላቸውን ዕይታ ለመገምገም ታስቦ የቀረቡ ጥያቄዎች፡-
- 2.5.2. በተራ ቁጥር 2.5.1፣ ላይ ለቀረበው ጥያቄ መልስህ/ሽ አዎ ከሆነ በመፃይ ህይወትህ/ሽ ላይ ያለህ/ሽ ርዕይ ምንድን ነው?
- 2.5.3. ከመፃይ ህይወትህ አንፃር በአሁኑ ወቅት በየትኛው የስራ ዓለም ላይ ብትሰማራ/ሪ ትመርጣለህ/ሽ? ለምን?
- 2.5.4. ትዳር ከሌለ ትዳር የመመስረት ፍላንት አለህን/ሽን?
- 2.5.5. በኢትዮጵያ ተጨባጭ ሁኔታ ከጊዜ በኋላ ዓይነስውር ስለሆኑ ጎልጣሶች መፃይ ህይወት መሻሻል ምን መደረባ አለበት ብለህ ታስባለህ/ሽ? ለሚፈለገው ለውጥ ሃላፊነቱን መውሰድ አለበት ብለህ/ሽ የምታምነው/ኝው አካል ጣነው?