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Quality of Life of Visually Impaired Adolescents in Metro Manila

INTRODUCTION

According to the World Health Organization (WHO), quality of life (QOL) is “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns.”¹ The Occupational Therapy (OT) Practice Framework defines quality of life as “a person’s dynamic appraisal of his or her life satisfactions (perceptions of progress towards one’s goals), selfconcept (the composite of beliefs and feelings about oneself), health and functioning (including health status, self-care capabilities, role competence) and the socioeconomic factors (e.g. vocation, education income)”.² It is one type of outcome, which may be focused on during the process of occupational therapy.²⁽⁴⁾ By measuring QOL, progress (or non-progress) may be seen and goals and interventions may be prioritized. Testa, M & Simonson, D. referred to quality of life as perceptions of health because the researchers considered it as a domain of health that is influenced by the person’s experiences, beliefs, expectations, and perceptions.³

Visual impairment (VI) is defined by New York State Dept. of Health (NYSDOH) as “the loss of some aspect of vision that reduces an individual’s ability to see” caused by either the damage in the eye itself or the visual nervous system”.⁴ In the Philippines, there are 942,098 people estimated to be afflicted with visual impairment, as of the year 2005.⁵ Visual impairment is a particular interest to researchers since it is closely associated with having decreased functioning, social exclusion, high risk for poor social and emotional adaptation as vision plays an important role in the mobility, socialization and functioning. Therapists may employ a multimodal oriented approach in management for optimal performance in self care, IADL, education, play and work. With this in mind,

there is a need to determine how QOL is affected by visual impairment.

Visual impairment present at birth has a more significant effect on individual development than the one that occurs later after birth. Among the limitations imposed by visual impairment, three important points are 1) mobility restriction, 2) limited understanding of physical environment, and 3) delayed communication.⁶

Mobility is restricted because of the child's inability to visualize the environment with its potential dangers. Another factor that may contribute to this is lack of familiarity in places other than home. This may be addressed by adapting the environment, giving the client chance to explore the rooms by touch or other sensory channels or using assistive devices such as a sonic guide, etc.⁶⁽⁴⁾ Sensory deprivation may result from the restriction of mobility. Due to late development of ear-hand coordination, there is also an associated delay in motor development. Communication is also delayed because the individual cannot read body language or gestures and does not see the physical cueing that accompanies speech.⁷ Visual impairment is associated with a twofold risk of decreased functioning on functional status.⁸ There is strong evidence that limited function in ADLs and IADLs relates to visual impairment as seen in several studies.^{5(4),6(4),7(5),9}

Persons with visual impairment had lower QOL score as evidenced in the previous studies mentioned. According to the International Classification of Functioning, Disability and Health (ICIDH) Disability Framework (Figure 1), the person's health condition affects three interrelated aspects in person's life: body functions and structures, activity and participation. The condition (visual impairment) therefore may affect the function which can limit functional ability (due to loss of vision, there may be restricted mobility), which may in turn, may affect participation in activities in self care, education, school, etc.¹⁰

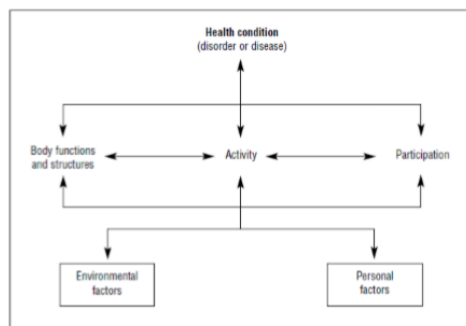


Figure 1: Interactions between the components of the *International Classification of Functioning, Disability and Health* (WHO, 2001)

There is a relevant relationship between VI and QOL across different age groups. According to one study, it was seen that children with VI aged 3-16 had significantly lower QOL scores than the comparison group, based on the Low Vision Quality of Life Questionnaire.¹¹ According to another study, the impairment of vision is associated with a significant decrement in diverse areas of quality of life in the elderly sample, and those who have problems with near vision were more likely than those of distant vision to affect quality of life.¹² Furthermore, in one study made by Polack et al (2010), the vision-related QOL scale was used to describe the relationship between VI and cataract. The findings of the study show that there is a worsening vision-related QOL associated with cataract vision loss, and the poorer generic health-related QOL among cases compared to controls indicated an impact of visual impairment on perceived health and well-being, beyond vision-specific experience.¹³

Adolescence is a stage of transition, from being children to being adults. In this stage, relationships deepen, autonomy in decision-making grows, and intellectual pursuits and social belonging are sought. Adolescents are characterized by increasing ability for mastery over complex challenges of academic, interpersonal, and emotional tasks, while searching for new interests, talents, and social identities.¹⁴

Visually-handicapped adolescents exhibited deficits on verbal components of social skill due to secondary issues of exclusion, perceived inferiority, miscommunication & environmental challenges at home, and especially at school.^{6(4),15,16} Social exclusion from activities that need sight give visually impaired individuals lesser opportunity to socialize.⁶⁽⁴⁾ Individuals with disabilities may have been considered as inferior even by their parents and this may affect their self concept as they mature 17. With decreased social interaction with individuals the same age, there is a big possibility of impedance of social skills development. Another issue is miscommunication such as not being able to give appropriate verbal or nonverbal feedback.¹⁵⁽⁶⁾ Also, visually impaired adolescents received limited inputs making them less aware of their surrounding and giving them access to less consistent experiences.¹⁵⁽⁶⁾

It was viewed that life satisfaction was considered to be predicted by the “objective

health” and the person’s negative affect.¹⁸ Thus, if people can find a way to perceive health positively, the adverse impact of illness or disability on life satisfaction can be lessened.¹⁸ (6) The study showed that persons with disabilities have lower QOL than those without. This is supported by the study of Edwards, where it was seen that adolescents with disabilities are at greater risk for psychosocial maladjustment than adolescents without disabilities.¹⁷⁽⁶⁾ Depression and low self rating scales of the QOL scores were major determinants of physical and mental health. ^{18(6),19} Due to these determinants it could be inferred that lack of motivation and other depressive symptoms may in turn impede the person to participate in occupation.¹⁸⁽⁶⁾

Life satisfaction with social support and network size was shown to have a positive effect on well being.¹⁹⁽⁶⁾ The role of parents, families, and peers is significant in the formation of identity of the adolescent thus affecting adolescent’s quality of life. A study suggests that visually impaired individuals have lesser friends and have deficits in social skills, thus there might be a possibility of having its negative effect on the well being of the person ¹⁶ (6). Having a disability increases risk of being bullied.²⁰

Many of the adolescents with VI may have secondary mental conditions. They are prone to depression as they are usually isolated, stigmatized. ^{15(6),17(6)} Having secondary conditions further limits the channels of learning, and impairs normal socialization.²⁰

As for the cognitive aspect of the visually impaired adolescent, learning media assessment should be done to be able to wisely plan the learning strategies.⁴⁽⁴⁾ In the Philippines, learning through Braille is offered in, but are not limited to, the following schools: Resources for the Blind for early intervention (2-5 y/o), Philippine National School for the Blind which offers elementary to high school education, and other public schools (such as Commonwealth Elementary School) which offer special education classes for students with disabilities, including visual impairment. However, few textbooks have a Braille version and it is only taught by the qualified teachers who mastered the Braille code. At present, all blind students are taught both Filipino Braille and English Braille which has long been used as a medium of instruction in schools.²¹ Majority of visually impaired students are now found in mainstreamed classes scattered throughout the country. ²¹⁽⁷⁾

Alternative methods of teaching can still be done and there are still important things to learn besides increasing literacy such as teaching effective ways to ambulate and orient body to the place. Social skills may be learned through social skills training and multimodal approach of special education, sensory integration, behavior modification and cognitive rehabilitation. ^{17(6),22} Republic Act No. 7277 (Magna Carta for Disabled Persons) provides the persons with disability (PWD) with their rights and privileges which aims at increasing social participation and increasing education opportunity of children and adolescents with disabilities.²³

Table 1. WHOQOL-BREF Domains

DOMAIN	FACETS	Item#
1. Physical Health	1. Activities of Daily Living	17
	2. Dependence on Meds	4
	3. Energy and Fatigue	10
	4. Mobility	15
	5. Pain and Discomfort	3
	6. Sleep and Rest	16
	7. Work and Capacity	18
2. Psychological Well-Being	1. Bodily Image and Appearance	11
	2. Negative Feelings	26
	3. Positive Feelings	5
	4. Self-Esteem	19
	5. Spirituality/Religion/Personal Beliefs	6
	6. Thinking, Learning, Memory, Concentration	7
3. Social Relationships	1. Personal Relationships	20
	2. Social Support	22
	3. Sexual Activity	21
4. Environment	1. Financial Resources	12
	2. Freedoms, physical safety and security	8
	3. Health and social care: accessibility and quality	24
	4. Home environment	23
	5. Opportunities for acquiring new info and skills	13
	6. Participation in Recreation/Leisure	14
	7. Physical Environment	9
	8. Transport	25

The World Health Organization – Quality of Life Brief Version (WHOQOL-BREF) questionnaire and its manual is free, is accessible in the WHO website and is already translated in >19 languages including Filipino language. It was developed to provide a short form quality of life assessment that looks at domain level profiles. The WHOQOL – BREF contains a total of 26 questions based on the 24 facets contained within 4 domains. The facets contained within each domain are listed in table 1. In addition, two questions regarding the person’s overall QOL and general health were also included. ²¹ In order to avail a copy of the WHOQOL-BREF Filipino version, permission of its use was submitted to the Multi-Country Studies Health Statistics and Informatics (HSI) arm of the World Health Organization.

WHOQOL-BREF has good to excellent psychometric properties of reliability and performs well in preliminary tests of validity ^{1,24,25}. It also has good cultural adaptations as the 23 different versions had showed good internal consistency (p-value<0.01) as well as good

content, construct and predictive validity (p values<0.05). Psychological domain had best predictive validity while social relations domain had best content validity. Also, inter-rater reliability had also shown excellent, ^{25,26} content validity for the revised social domain. Also, the instrument showed good internal consistency (Cronbach's $\alpha=0.87$; p-value<0.01) as well as good content, construct and predictive validity (pvalues<0.05) implicating that the revised tool was still reliable and valid even for an adolescent population.¹

In one local study conducted by Gomez (2010), WHOQOL-BREF (English and Filipino version) was used to measure the QOL of the parents of Filipino children with special needs (CWSN). The WHOQOL – BREF that was used in the study had 4 dimensions: physical, psychological, social and spiritual. The physical dimension was defined as an individual's perception of well being. The psychological dimension was defined as involving the human needs such as enjoyment, leisure, emotions sense of purposefulness and control over his life. Social dimension was defined as involving roles and relationships, financial burden, burden on the family, affection and sexuality. Meanwhile, the spiritual dimension was derived from other studies and was found out to be synonymous to uncertainty, meaning of illness and suffering and the purposes of life and transcendence. These dimensions were analyzed and used as determinants of the quality of life. The researcher also used interview as a data gathering tool, which was shown to be useful in understanding several themes (e.g., parental QOL level of care, and "sink and swim" or adaptation to the child's condition), and in knowing the variables which may affect the QOL (e.g., the parent's educational attainment, child's age, severity of condition) as it provided a broader insight on the perception of the parents to their QOL. ¹⁶ Limited studies have yet been used to prove the reliability and validity of the WHO QOL BREF FIL but this previous study had shown that QOL scores gathered through the WHO QOL BREF FIL was proven to have an effect on the performance and many determinants was shown to have an effect on the QOL scores such as age, gender, education, siblings, severity of illness.²⁷

There is a lack of information regarding the QOL of the VI and yet no clearer role of OT in the life of the VI specifically the adolescent population. Previous studies in the Philippines dwelt mostly on the older adult population who had acquired VI as they aged. The study

aimed to describe the QOL of visually impaired adolescents through the 4 domains of QOL (physical, social, psychological and environment).



Figure 2. Conceptual Framework

Quality of life affects a person’s performance in different areas occupation such as Activities of Daily Living, Instrumental Activities of Daily Living, Education, Play, Work, Leisure and Social Participation. In the article “Measuring Quality of Life in a Reformed Health System” by Anthony F. Lehman, the concept of quality of life encompasses what a person is capable of doing, his or her access to resources and opportunities to use these abilities to pursue interests, and sense of well-being. It has specific 4 specific domains that determine a person’s QOL and they are the: physical, psychological, environment and social. With the concrete QOL scores on these 4 dimensions, the OT can ponder on the perceived affected areas of the condition and may therefore help them focus on an important occupational area for the individual.

Illustrated in the framework is the relationship of a person’s occupational performance and his or her quality of life. A person with a poor QOL may have limited participation in if not all, some of the areas of occupation. A person afflicted by a condition such as visual impairment is said to have a lower QOL score. 28 Past studies have shown high correlation between impairment and low vision and the QOL domain specifically emotional and functional. Furthermore, it is said that a person with disability like visual impairment, has a decreased efficient participation in different areas of occupation.

VARIABLES AND OPERATIONAL DEFINITION

Visual impairment – Refers to total and partial blindness that may be congenital or acquired. Partial blindness or near total blindness means that the visual acuity is less than 20/1000 while the total blindness means no light perception.

Quality of life – Refers to the individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. This is subdivided into 4 dimensions: physical, social, psychological and environment.

Adolescent – Refers to 12 to 21 years old male or female with visual impairment with no other secondary physical, mental and psychological condition or complication. *Function* – Refers to Occupational Performance in different areas such as: ADL, IADL, education, work, social participation, leisure, play.

Occupation – meaningful and purposeful activity that a person engages to

ADL – Refers to Activities of Daily Living which enables basic survival and well being

IADL – Refers to Instrumental Activities of the Daily Living that includes care of other, care of pets, financial management and home management

Work – Refers to activities needed for engaging in remunerative employment or volunteer activities including school performance.

Social Relationships – refers to the relationships with friends and other personal relationships (to God, to family).

Leisure – Refers to nonobligatory activity that is intrinsically motivated and engaged in during discretionary time and that is not committed to other occupation. This facet is included in domain 4 – Environment.

Physical Health – This domain describes the health of an individual based on energy, physical pain, dependence on medical treatment, mobility, sleep satisfaction and ADL and work satisfaction.

Psychological Well-Being – This domain discusses psychological and mental aspect of the individual was based on the Acceptance of bodily Image and appearance, negative and positive feelings towards self, self esteem, spirituality/religion/personal beliefs, and concentration.

Self esteem – was described as satisfaction with self.

Social Relationships – This domain discusses the social aspect of the person based on their satisfaction with sexual relationship, personal relationship such with family, God, friends, and satisfaction from support of a friend both material and emotional.

Environment – This is domain discusses the external factors that surrounds the person specifically including health and safety of physical environment; financial support; availability of new information; opportunity for leisure activity and satisfaction with home conditions, health services, and ability to transport.

Questionnaire – Refers to the WHOQOL-BREF questionnaire that will be modified to construct primarily to gather data from the sample population but this will be read out.

METHODS

RESEARCH DESIGN

The study employed a descriptive approach since this study aimed to describe the impact of visual impairment in the quality of life of the chosen population. This was done describing the quality of life of the visually impaired adolescent based on the results gathered from the WHOQOL-BREF questionnaire, which contains questions regarding the 4 domains of QOL (physical, environmental, social relationships and psychological) and questions regarding overall QOL and health satisfaction. Results were analyzed based on the scoring specified in the WHOQOL-BREF User Manual. The results were discussed in relation to the responses of selected participants in the semi-structured interview.

SAMPLE POPULATION

The sample population consisted of 36 participants, consisting of students from the Philippine National School for the Blind (PNSB), Ramon Magsaysay High School (RMHS) Silahis Center and adolescents from Parent Advocates for the Visually Impaired Children (PAVIC), a parent organization that develops and implements programs for the visually impaired children in coordination with government and other NGOs. Purposive sampling technique was used to recruit the sample population which implied that the participant first had to qualify the inclusion criteria (refer to table 1) in order to participate in the study. For the ethical consideration, please refer to table 2.

Table 2. Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion Criteria
<ul style="list-style-type: none"> • male or female • acquired or congenital VI • aged 12 – 21 ^[29,30,31] • currently residing in Metro Manila • Filipino citizen • Can understand verbal Filipino or English • has partial blindness (20/1000) or total blindness 	<ul style="list-style-type: none"> • Visually impaired with cognitive and psychological problems such as, but not limited to, mental retardation, autism, global developmental delay, and ADHD • Visually impaired who had comorbid hearing impairment and speech deficit.

Table 3. Ethical Considerations

Ethical Considerations
<ul style="list-style-type: none"> • Consent forms will be given to parents of participants who are still a minor (<18 y/o). The researchers shall read the consent form to them. A copy of the consent form shall also be provided to the parents of the participants. The consent will be in Tagalog and English and the participant will be given choice between the two. • The WHOQOL questionnaire will be given only to the participants who qualified the inclusion criteria. • Letter of Permission addressed to the Superintendent Division of City School Manila (for Ramon Magsaysay High School) will be given. • Letter of Permission will be given to the administrators of the selected institutions, such as the Philippine School for the Blind and Parent Advocates for the Visually Impaired Children (PAVIC) before the implementation of the study.

IMPLEMENTATION

Phase 1: Acquiring Permission and Recruitment of Participants

Letters of permission for the implementation of the study were sent to the administrators of PNSB and RMHS, the superintendent of the Divisions of City Schools in Manila, and to PAVIC. A letter of permission to use the WHOQOL-BREF FIL was also sent to the WHO. After having acquired their permission, consent letters were given to the participants and to their parents or caregivers. After the consent forms were signed, the participants underwent the test implementation during their vacant time.

Phase 2: Data Collection

A. Handing out of Questionnaires

The following procedures were done in answering the WHOQOL-BREF (English and Filipino Versions): Questions were verbally asked to each participant by the researcher. The participants were asked to respond only within the given choices, with their responses based on their experiences or feelings that occurred to him or her for the past 2 weeks. The participants were given a maximum time of 20-30 minutes to finish the questionnaire. The time for implementation was during the dismissal of the students. Students were called one by one by the staff of the school. The staff, who was informed of the inclusion criteria prior to the interview, was the one who chose the participants.

B. Interview Proper

For the interview proper, selected participants were asked to be interviewed within the school grounds on the next testing day. With their confirmation, they were interviewed face to face using the guide questions (Appendix VI).

Phase 3: Analysis of Results

After collating and tallying survey forms, the results were analyzed based on the scoring included in the WHO-QOL User Manual. The results were used to describe the participants' QOL. The responses of the interviewees were transcribed and they were related to the results from the questionnaire.

SCORING

Four domain scores can be derived from the WHOQOL-BREF. There are also 2 items that are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The scores from the four domains denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction wherein higher scores denote higher quality of life. The mean score of items within each domain is used to calculate the domain score. Mean domain scores were transformed based on the 0-100 scale included in the User Manual in order to make them comparable with the scores used in the WHOQOL-100.

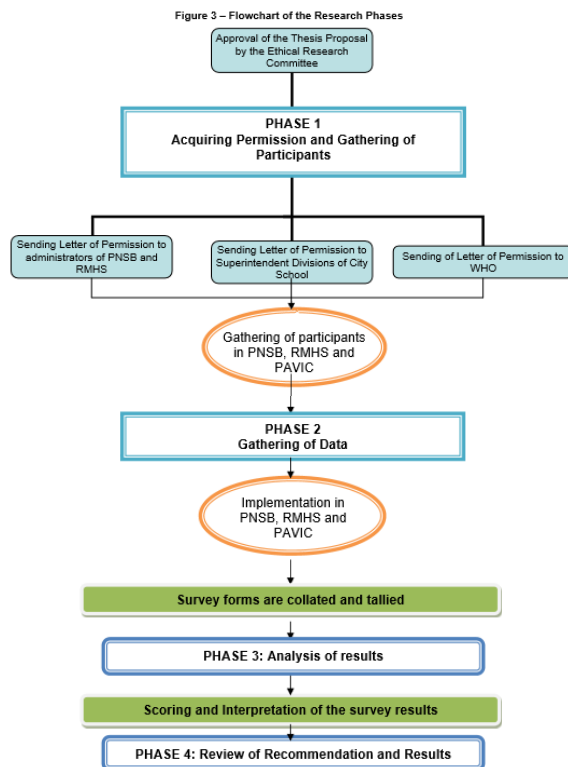
Where an item is missing within a facet, the mean of other items in the facet is substituted. Where more than two items are missing from the facet, the facet score should not be calculated.

For the Physical, Psychological and Social Relationships domains, where one facet score is missing, the mean of the other facet scores may be substituted. For the Environment domain, up to two missing facet scores may be substituted with the mean of the other facet scores.

STATISTICAL ANALYSIS

The results were encoded and analyzed using Microsoft Excel and Epi Info™, a data

collection, management, analysis, visualization and reporting software for healthcare professionals, available for download on the Epi Info™ website (wwwn.cdc.gov/epiinfo/). The mean, mode, and median of the transformed domain scores were obtained.



WHO-QOL BREF Questionnaire and a semi-structured interview were conducted. A total of 36 visually impaired adolescent and among the 36 students, 7 of them participated in the interview.

EXTENT OF BLINDNESS	Frequency	Percent
PB	18	50.00%
TB	18	50.00%
Total	36	100.00%

Table 4. Frequency of Extent of Blindness

Table 4 shows the Frequency of Extent of Blindness of the VI adolescents. Fifty percent (50%;18/36) are partially blind/with light perception and another fifty percent (50%; 18/36) are totally blind /without light perception. The age group was fairly distributed throughout the range of 11-21 years old with a mean age of 16 years old. Fifty five percent (55.56%; 20/36) are male participants and forty-four percent (44.44%, 17/36) are female participants.

The diagnosis of the participants included congenital blindness, glaucoma, cataract,

glaucoma with cataract, retina blastoma, tumor , congenital retinal detachment, acquired due to measles, overexposure to incubator light, assault. Eleven (11) out of thirty-eight (36) had unknown diagnosis due to lack of knowledge of the participant. As for the grade level, participants were almost evenly distributed from Grade 1 to High school (4th year). Refer to table 5.

GRADE LEVEL	Frequency
2ND YR HS	5
1ST YEAR HS	4
GRADE 6	4
2HS	3
NA	3
3HS	2
3RD YEAR HS	2
4TH YEAR HS	2
GRADE 1	2
GRADE 2	2
GRADE 3	2
GRADE 4	2
1HS	1
4HS	1
GRADE 5	1
Total	36

Table 5. Grade Level Frequency

As for the version of the questionnaire, one (1) participant used WHO QOL BREF English version and other 35 preferred the WHO QOL BREF Filipino. The institution included were Ramon Magsaysay Highschool (with 2 participants), Philippine School for the Blind (24 participants) and PAVIC (10 participants). Among the participants, only 2 are not students and another 2 participants are receiving SPED services. The remaining participants are in mainstream education.

Table 6: Mean of the transformed quality of life scores (N=36)

Domain	Physical mean	Psychological Mean	Social mean	Environmental	Overall QOL
	71.83	73	54.36	66.277	3.4777

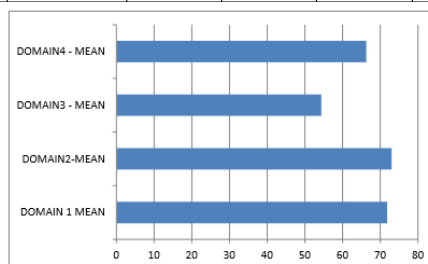


Figure 4. Comparison of Means of the Transformed Domain Scores

Each raw domain scores gathered from each respondent were transformed based on the table of scores with a scale of (0-100) supplied in the WHOQOL-BREF manual. The mean of the transformed scores were then gathered. The results showed that the mean for Domain 2, containing the facets for Psychological health, and Domain 1, containing the physical health facets, had the highest domain out of the 4 Domains. Meanwhile, Domain 4, containing the environmental facets, had the third greatest mean. Domain 3, containing

the facets of social relationships, showed the least mean value. The domain scores may range from 0-100 scale. The mean QOL score of the participants is 3.477 which means neither poor nor good to good. Refer to Table 6 and Figure 4.

DISCUSSION

In rating their quality of life, most of the participants answered (3) which is interpreted as 'neither poor nor good'. During the interview, one of the participants said that she has low self-esteem, brought about by people's negative comments regarding their condition. On the other hand, another participant said that he feels more fortunate than other people without impairment because he thinks that he appreciates life more than sighted individual do. Visual impairment is associated with significant decrement in diverse areas of quality of life. In the related literature, it was evident that persons with visual impairment have lower QOL scores compared to the current study's participants who rated their quality of life as average. The quality of life is further investigated through its domains.

In, domain 2(Psychological Health) the average of the transformed scores showed that it is one that had the highest score alongside Domain 1 (Physical Health). Physical Health consists of physical pain, dependence on medical treatment, energy, mobility, sleep and ADL satisfaction, and work performance. In the physical pain facet, majority of the participants answered (4) which is interpreted as "they have "a little" feeling that this prevents them from doing what they need to do". In the dependence on treatment, the majority of the participants answered (4) which is interpreted as "they have "a little" feeling that they need medical treatment to function in their daily life". In the energy and fatigue facet, most of the participants scored (4) which means is interpreted as "they "mostly" have enough energy for everyday life".

In the mobility facet, most of the participants answered (3), which is means that the ability to get around is neither poor nor good. In one of the interview, they pointed out that performance of the IADL tasks (such as household chores) are greatly affected by mobility since they cannot check the environment visually, and perform safely and efficiently tasks rather they have to use tactile sense or ask the other person to check the environment. In