Evaluating Health-Related Quality of Life (HRQoL) and Vision-Related Quality of Life (VRQoL) among Adult Populations with Low Vision in Trinidad.

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Abstract:

Objective: To investigate HRQoL and VRQoL in adults with Low Vision and compare results with healthy controls.

Methods: Participants diagnosed with Low Vision in Trinidad were contacted via telephone and a healthy control group was selected and enrolled in the study once consent was provided. They were required to answer questions from the Center for Disease Control Health Related Quality of Life Questionnaire (CDC-HRQoL-14) and the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ-25). The data was analyzed using Chi Square, Classical Test Theory and Rasch Analysis on SPSS.

Results: 60 participants' responses were analyzed (40 Low Vision, 20 healthy control). The control group findings indicate a higher mean number of mentally unhealthy days (6.60 ± 1.724) compared to the low vision group (1.73 ± 0.527). Conversely, the low vision group reported higher mean number of physically unhealthy days (6.10 ± 1.120) compared to the control group (1.20 ± 0.574). The NEI-VFQ-25 questionnaire was tested for its internal reliability and validity using Cronbach's α coefficients, and overall performance using Rasch Analysis. The control group evidently performed better at the NEI-VFQ-25 with a mean composite score of 97.05 ± 3.79, whereas the low vision group had a mean composite score of 50.43 ± 22.63.

Conclusion: The healthy control group demonstrated good general health, but poor mental health and the converse was observed for the low vision group. The analysis of the NEI-VFQ-25 showed the control group scoring higher than the low vision group.

Introduction:

Low vision should not be confused with blindness, but rather involves visual abilities that are less than what is normally required to efficiently perform essential daily activities(Ganesh et

al., 2013). This normally involves moderate to severe visual impairment (MSVI), which according to the World Health Organization (WHO), 2.2 billion people have a near or distance visual impairment (WHO, 2021). 1 billion of which are considered to have MSVI due to uncorrected refractive error(84 million, 8.84%), cataract(94 million, 9.4%), glaucoma(7.7 million, 0.77%), corneal opacities(4.2 million, 0.42%), diabetic retinopathy(3.9 million, 0.39%) (Bourne et al., 2017).

In the Bhaktapur district of Nepal, the average prevalence of low vision was found to be 52.9%. Based on presenting visual acuity, the prevalence of blindness was found to be 1.94% (Thapa et al., 2018). Comparatively, in the Sub-Saharan Africa, the average prevalence of blindness was found to be 7.3% while the prevalence of low vision was found to be 10.3% (Cherinet et al., 2018). Closer to Trinidad and Tobago, in the Caribbean, Barbados reported a 9-year incidence of 1.0% and 2.1% for blindness by the WHO and US criteria respectively(Hennis et al.,2009). There was also a reported low vision incidence of 6.0% by the WHO criteria and 9.0% by the US criteria (Hennis et al., 2009). In terms of geographical location, Trinidad and Tobago (T&T) is a twin island state in the Caribbean consisting of a population of approximately 1.3 million people of a variety of ethnicities; 35.4% East Indians, 34.2% Africans and 22.8% mixed races (Joshi et al, 2021; Ekemiri et al., 2022). While the WHO claims that 80% of blindness is preventable, visual impairment and vision loss remains a global issue. In Trinidad, the leading cause of blindness was discovered to be glaucoma (31.08%) and diabetic retinopathy(20.94%)(Braithwaite et al., 2017; Joshi et al., 2021)

Visual impairment can affect the way in which an individual is able to perform daily tasks and as such it is important to understand the QoL of low vision individuals, with the hope of providing better care. Vision related quality of life(VRQoL) refers to a person's satisfaction with their visual ability and how their vision impacts on their daily lives (Asaoka et al., 2011). Visual impairment has a significant impact on the individual with the impairment but also on their families, friends and society at large. There is a severe negative impact on the person's level of independence such as, impaired mobility, inability to provide for themselves and their family, depression and mental health issues, reduced employment opportunities and as a consequence, major economic pressures such as having to pay for medical expenses and other

necessities for survival (Welp et al, 2016). Mobility issues in social settings or unfamiliar territories may result in minor injuries from bumping into objects (Lange et al., 2021).

Figure 1: According to the WHO classification of visual impairment

Category	**Presenting distance visual acuity**	
	Worse than:	**Equal to or better than:**
0 Mild or no visual impairment		6/18 3/10 (0.3) 20/70
1 Moderate visual impairment	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
2 Severe visual impairment	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
3 Blindness	3/60 1/20 (0.05) 20/400	1/60* 1/50 (0.02) 5/300 (20/1200)
4 Blindness	1/60* 1/50 (0.02) 5/300 (20/1200)	Light perception
5 Blindness	No light perception	
9	Undetermined or unspecified	
	* or counts fingers (CF) at 1 metre.	

Additionally, research has shown that severe visual impairment is often accompanied by various systemic health conditions which may further impact an individual's quality of life from a health perspective, thereby compounding their VRQoL with their health-related quality of life (HRQoL) (Bener & Warid, 2008). Diabetes and hypertension can be seen as the leading systemic complications considered as major risk factors for the progression or worsening of

visual impairments (Bener & Warid, 2008). Wang et al concluded from their study that individuals with hypertension or diabetes for more than 10 years were linked to more severe visual impairments, especially diabetic retinopathy. However, it was also proposed that intensive control of blood glucose levels were found to reduce the risk of diabetic retinopathy in patients with diabetes (Wang et al., 2016).

As such, individuals with visual impairment compounded with health related complications, evidently encounter a range of functional problems in their daily life leading to a reduced overall quality of life. Therefore, a comprehensive assessment allows for an overview of how severely such individuals are impacted, from their subjective perspective (Yibekal et al., 2020). The Centre for Disease Control (CDC) HRQoL-14 questionnaire and the National Eye Institute (NEI) Visual Function Questionnaire (VFQ-25) were the two questionnaires used in this research to gather data surrounding the extent to which an individual's quality of life may be affected by both their vision and/or their health status. From 1993 to 2001, more than 1.2 million adults responded to the CDC's HRQoL-14 questionnaire(Moriarty et al., 2003). Similarly, numerous articles have proven the NEI's VFQ-25 questionnaire to be reliable and valid for assessing quality of life in a range of visual problems(Kovac et al., 2015; Revicki et al., 2010) proving both questionnaires credible and reliable.

The visual impairment burden of T&T is a serious problem especially for those with systemic complications such as diabetes, as research has shown that there appears to be poor management, compliance and monitoring of diabetic treatment in this country, with only 44.7% of diagnosed diabetics having their blood sugar levels under control (Joshi et al, 2021). If this burden is not taken seriously, there may be a direct impact on the individual's productivity and employment opportunities as a result of potential mental health problems such as depression and anxiety (Welp et al, 2016).

As such, by our research we hope to further understand the link and impact of VRQoL and HRQoL by the use of the globally acceptable and trusted HRQoL-14 and NEI-VFQ-25 questionnaires, on Trinidadian adults with low vision diagnosed with: Advanced Glaucoma, Age-Related Macular Degeneration, Diabetic Retinopathy and Retinitis Pigmentosa, and compare findings with that of a healthy control group.

Relevance to Public Health/Significance of Study:

This study aims to investigate and understand how MSVI together with general health problems affect the lives of individuals with low vision, as opposed to those without any visual impairment. It would additionally contribute to existing literature in the field of Optometry since new research findings centred upon QoL would be provided for a certain geographical location, Trinidad. It is expected that our research findings would be useful to further studies as information regarding HRQoL and VRQoL which may arise from our study may be new and not currently available. The UWI Optometry Clinic as well as The Faculty of Medical Sciences may also benefit by the findings of this study because of the anticipated statistical information that would be obtained as well as new information regarding the correlation between QoL and low vision individuals as compared with healthy individuals. Further studies within the faculty may even be built upon this foundation by exploring larger population samples within the country over a period of years and gauging progression and/or improvements in the HRQoL and VRQoL of individuals with low vision by the use of the CDC-HRQoL-14 and NEI-VFQ-25 questionnaires which are proven globally, as effective tools to determine improvements or lack thereof in QoL. By conducting this study, it is our hope and intention to educate the Optometry community in Trinidad at a public health level based on our findings to promote more effective management services to individuals with low vision who experience a reduced QoL.

Literature Review:

In both developing and developed countries, low vision is regarded as a worldwide health problem (Tegegn et al., 2020). Research has shown that visual impairment can lead to a variety of restrictions in many aspects of daily life causing reductions in QoL and severely impacting social and functional activities together with one's physical and emotional well-being (Adigun et al., 2014a). Therefore, it is imperative that eye care professionals focused on low vision rehabilitation and intervention use patient information regarding their QoL, specifically the impact of visual impairment on their daily activities and its role in influencing

symptoms of depression, to improve the level of professional care required to treat with these low vision patients(Kempen et al., 2012).

Prevalence of Visual Impairment (VI) and associated ocular conditions.

According to two Ethiopian studies, the prevalence and associated factors of low vision can vary from country to country depending on several elements such as socio-economic differences, genetics and ethnical variations, quality of health care systems and the availability of eye care professionals and rehabilitative organizations (Cherinet et al., 2018; Assefa et al., 2020). Similar findings are conveyed from a study in China, which indicated that inequalities in socioeconomic development, eye care program accessibility and blindness prevention awareness may be responsible for differences in statistical prevalence of low vision across different parts of China (Sun et al., 2021). Sun et al also found that age was a major attributing element, and that cataract, uncorrected refractive error, glaucoma, and AMD were the main causes of low vision whilst cataract, glaucoma, retinitis pigmentosa and AMD were among the leading causes of blindness. Moreover, a Russian study conducted within the same period, concluded similar findings with older ages being a major factor (Bikbov et al., 2021).

Risk factors and associations of VI with poor health.

Evidently, there have been studies confirming links between MSVI and certain common medical conditions such as diabetes and hypertension, moreover, the significance of controlling and managing these conditions to reduce the chances of further complications to the eye and overall health(Liu et al., 2020; Seid et al., 2022). A 2008 study from Doha, Qatar found that the prevalence of low vision was high especially in women with major risk factors being Type 2 Diabetes and hypertension(Bener & Warid, 2008). Similarly, a study done in Eastern Taiwan recognized a much higher trend in prevalence of visual impairment among individuals with a history of hypertension and diabetes for more than ten years and recognized that patients with diabetic retinopathy were more inclined to progress further into a decreased visual state compared to those without (Wang et al., 2016). Additionally, an Urban Southeast Asian population study also concluded that at-risk groups such as the elderly, those with lower levels of education, and those with medical conditions as diabetes and hypertension, were independently associated with visual impairment (Chong et al., 2009).

Impact of Visual Impairment on Quality of Life.

In order to comprehensively understand patient concerns, challenges and obstacles as it relates to their visual impairment, particular attention must be paid to the effectiveness of questions asked and questionnaires used as this would directly influence the patient's response. Furthermore, and in accordance with visual factors, eye care professionals involved in low vision rehabilitation need to also focus on nonvisual factors that may affect QoL, specifically those factors surrounding physical and mental well-being(Hernandez Trillo & Dickinson, 2012). According to a study conducted in Italy, the use of the NEI-VFQ-25 questionnaire was validated as a means of assessing improvements or lack thereof, in patients diagnosed with POAG over a period of time. The findings of the study demonstrated an increase in scores with respect to VRQoL over a one-year period and although the reason for the increase in scores is uncertain, the researchers have based their reasoning on patients' psychological adaptation and understanding of their visual impairment (Riva et al., 2019).
As it relates to practical challenges encountered by visually impaired individuals, Lange et al in 2021 narrowed down various activities that were considered to be normal daily tasks. The major themes explored with patients and their respective challenges included activity limitations, reading, driving, social function, emotional well-being, and mobility. Under each of these six themes, visually impaired individuals experienced some level of difficulty or challenge. Participants expressed concerns over dangers linked to driving and the lack of independence associated due to limitations in social function and work. Additionally, all participants experienced difficulty reading and described feelings of anger, frustration and embarrassment from bumping into obstacles due to their visual impairment and expressed concern over safe mobility (Lange et al., 2021). Likewise, an Ethiopian study confirmed that more than half their sample population experienced a poor QoL. The study also found that participants over seventy-five years old were more likely to have a poor VRQoL compared to those less than forty-five years old. (Yibekal et al., 2020).

Numerous research centered on low vision or visual impairment and its implications on QoL (Chong et al., 2009; Khorrami-Nejad et al., 2016; Wang et al., 2016; Yibekal et al., 2020) have concluded variations of the same findings and made recommendations for improving the rehabilitation and intervention efforts which includes improving eye care accessibility and

availability, targeted interventions of at-risk groups and greater awareness through eye and health campaigns, to name a few.

Aim/purpose of study: To investigate HRQoL and VRQoL in adults with Low Vision and compare results with healthy controls. This was done by conducting research using two questionnaires, namely, the CDC-HRQoL-4 and the NEI-VFQ-25 on both low vision patients and healthy control patients.

Objectives of study:

i. To assess the VRQoL in adults with low vision and compare to a healthy control.
ii. To evaluate the HRQoL in adults with low vision and to compare with a healthy control.

Research Questions:

1. How does the visual impairment of the patient hamper or disrupt their daily activities and livelihood, and to what extent?
2. What are the differences between adults with low vision and healthy controls regarding general HRQoL and VRQoL?

Hypothesis: It is expected that individuals with Low vision would complain of having a poorer QoL than that of the healthy controls in this study.

Ethical Approval/Considerations:

Permission was granted by the UWI Optometry Unit to conduct research on this topic. A research proposal was submitted to the UWI Ethics Committee, reference number CREC-SA.1175/. Research procedures were performed in accordance with the World Medical Association's (WMA) Declaration of Helsinki.

Patient files were accessed via the UWI Optometry Clinic after permission was granted. There were no recorded names during the period for which this research was conducted and names

were not used when analysing data. As such, when statistical information is being shared via presentations to discuss our findings, patient names would not be mentioned as there would be no record of such.

Since this study was conducted via telephone interview, there was no risk involved. Patients were asked to give verbal consent over the telephone before any questions about their vision or health were asked of them.

Methodology: The research conducted was concerned with evaluating QoL among adult populations with low vision individuals in Trinidad. It was hoped that based on data collected from this study, a true image of the quality of life of these persons would be ascertained and as such, suggestions or improvements can be made to the relevant institutions that can help such as the Government of Trinidad and Tobago. This particular section of the research project deals with what were the data collection methods that were deemed most suitable and why. Additionally it will evaluate who was chosen to participate and what made them suitable. This section will also concentrate on how the data was analysed, methods or steps taken to ensure confidentiality of participants and finally the validity and reliability of the research conducted.

Study setting:

The setting of this study took place in Couva, more specifically The UWI Optometry clinic located in the Couva Children's Hospital multi-training facility. The area of Couva is located in the western-central part of Trinidad. With respect to the history of this place, it is known as one of the oldest villages that produced sugar and in fact is what this town became well-known for. Initially Couva was nothing more than a settlement just north of what was known as the Couva river and within close proximity was the Exchange estate. The population of Couva increased after a railway was made as well as the discovery of oil which explains why today Couva is a huge industrial area.

Couva is located southward of the city's capital Port-of Spain. Port-of-Spain is known to be very busy as not only are many companies located there, but it holds many popular spots for people to gather. Historically Port of Spain was home to wetlands and mangroves whereby indigenous people would dock their canoes. It became the city's capital was seen fit as it had

the means for a port and the exchange of goods. Eastward of Couva is Presyal. Presyal is a small community known for its love of cricket. Westerly of Couva is Waterloo road and Carli Bay, both which are just off the Gulf of Paria's coast. Waterloo is famous for the attraction known as the temple in the sea. Lastly, north of Couva is to the north of San Fernando. It is the second largest city in Trinidad. It is known for the San Fernando hill which was first spotted by the Amerindians. It eventually housed the estate which surpassed sugar production in the country and then later became a home to the oil industry. It is now one of the busiest areas of Trinidad to exist with all its businesses, schools and other places of livelihoods.

Study Design:

This study utilizes a quantitative approach amongst a control and experimental low vision group whereby two organized questionnaires were implemented. The questionnaires were firstly shared amongst peers who were not a part of the research population participants, to ensure they were deemed appropriate. The first questionnaire assessed health related quality of life , more specifically age and gender, general health and limitations, physical and mental health, the impact of health status on activities, and symptoms experienced with respect to health.

The second questionnaire assessed vision related quality of life more specifically, general health, general vision, ocular pain, ability to do near and far activities, ability to function socially, mental health, role difficulty, dependency, driving, colour vision and peripheral vision.

Study Population:

This study was aimed at adults between the ages of 18-85 years, who had ocular disease as well as those free of ocular disease. The study was inclusive of all genders, ethnicities and races. Participants were engaged to do the surveys via face to face interactions and telephone calls. Each participant was educated about the survey before, to ensure they were comfortable participating as well as to obtain their consent. Consent was given by each participant.

The candidates for this research were chosen based on having one of the following diseases : diabetic retinopathy, retinitis pigmentosa, glaucoma and macular degeneration, for the

experimental low vision group and candidates for the control group were chosen based on being free of ocular disease or who were deemed healthy.

Study Sample

The sample size was determined using EPITOOLS (Ausvet software company) sample size calculator created by the company Ausvet for a case-control study. The utility calculated the sample size required for a case-control study, with specified levels of confidence and power and case and control groups of equal size. Inputs are based on previous studies the expected proportion exposed (0.1) in the controls, the assumed odds ratio (10),and the desired level of confidence (0.95) and power for the detection (0.8) of a significant difference between the two groups.

Inclusion/Exclusion Criteria

The Inclusion criteria was as follows : Participants must be able to provide valid and informed consent to the surveys carried out. Adults with low vision caused by diabetic retinopathy, retinitis pigmentosa, glaucoma , macular degeneration and aged 18 to 85 would be accepted and finally any adult aged 18 to 85 with healthy eyes, that is, free of ocular disease or any impairment would be used as the control group of the research.

The exclusion criteria was as follows : Any participant aged under 18 would not be accepted or able to participate, persons with corneal defects such as keratoconus or any other anterior surface eye disease would not be an accepted candidate and finally persons with Alzheimer's disease, dementia or any other complication which hinders their ability to recall any past experience, would not be allowed to participate.

Data Collection

The data was collected using two (2) questionnaires. The first questionnaire was the VRQoL questionnaire and the second was the HRQoL. The questionnaires were conducted both face to face and via telephone calls.

Participants:

The participants were given consent forms or asked to give consent to the surveys before taking it. This was done face to face and via the telephone. The participants were inclusive of low vision persons and persons without any visual impairment.

Health Related quality of life:

The CDC-HRQoL-14 questionnaire is a questionnaire on general HRQoL. Since interviews were conducted via telephone, participants provided oral responses which were recorded by the student researcher.

Vision related quality of life:

The NEI VFQ-25 questionnaire is a questionnaire to determine the overall visual status as well as quality of life based on that visual status of an individual based on their answers of this questionnaire. It contains various subscales such as general health, general vision status, eye pain, distance and near activities ,ability to function socially, mental health, difficulty carrying out roles, dependency on others, driving, colour vision and peripheral vision. Since interviews were conducted via telephone, participants provided oral responses which were recorded by the student researcher.

Data Analysis:

Statistical Analysis: The data generated from this study was analysed using the IBM Statistical Package for Social Sciences (SPSS) Version 28 for Mac. Means, standard error means, frequencies were calculated for descriptive purposes for the CDC-HRQoL-14 questionnaire. P-values <0.05 were considered statistically significant and 95% confidence intervals were used for the main findings when statistically possible. Tabulated results indicate such values for the total sample size, and for both control and low vision groups individually, to allow for comparisons to be made. Responses for questions which warranted a “number of days out of 30 days” response were categorized into <15 days was considered good and >15 days which was considered poor. The NEI-VFQ-25 questionnaire subscale scores were generated and analysed using the Classical Test Theory (CTT) which expressed mean $\pm$ SE mean scores for both groups, and the questionnaire was tested for its internal reliability and validity using

Cronbach's α. Rasch Analysis was also applied for the NEI-VFQ-25 to express and analyze the performance of respondents.

Data Protection:

All data collected from each participant, confidentiality was maintained such that the data was anonymous and a codebook was used and a database was created. This database can only be viewed by the principal investigator and co-investigators when necessary. The database is to be maintained on a password protected computer, in which the principal investigator oversees.

To ensure each participant is well protected and anonymity is preserved, no personal identifiers such as their name or address was recorded. Instead, the data was codified such that the first letter of their first name , the first letter of their mother's and father's first names and their date of birth was used. An example is Lily Smith, their mother's first name begins with D and their father's first name begins with J and Lily's date of birth is 19/04/1998 hence the code would look like LAD19041998. After five years, it is expected all codes are shredded and destroyed to further erase any trace and ensure the protection and confidentiality of the participant.

Results:

Gender and Age Distribution:

A total of 60 adult individuals were enrolled in this study; 24 males (40%) and 36 females (60%). Their ages ranged from 21 to 84 years with a mean age of 50.72 $\pm$ 21.01 years. 20 participants (33.3%) with a mean age of 28.95 $\pm$ 9.78 years were used as the healthy control group and the remaining 40 participants (66.7%) and mean age of 61.60 $\pm$ 16.03 years were adults diagnosed with low vision. ***(Table 1.0)***

Table 1.0: Gender and Age Distribution:

Variables	Total Population (n=60)	Control Group (n=20)	Low Vision Group (n=40)
	Frequency(%)	Frequency(%)	Frequency(%)
Gender			
Male	24 (40%)	7 (35.0%)	17 (42.5%)
Female	36 (60%)	13 (65.0%)	23 (57.5%)
Age			
21-30	17 (28.3%)	15 (75.0%)	2 (5.0%)
31-40	6 (10.0%)	1 (5.0%)	5 (12.5%)
41-50	5 (8.3%)	3 (15.0%)	2 (5.0%)
51-60	9 (15.0%)	1 (5.0%)	8 (20.0%)
61-70	14 (23.3%)	0	14 (35.0%)
71-80	3 (5.0%)	0	3 (7.5%)
81-84	6 (10.0%)	0	6 (15.0%)

Note: n: number of individuals within sample; Frequency: measure of occurrences; %: percentage

Table 1.1: Mean $\pm$ SE Mean Ages

	Total Population (n=60)	Control Group (n=20)	Experimental Low Vision Group (n=40)
Mean $\pm$ SE Mean Age	50.72 $\pm$ 2.713	28.95 $\pm$ 2.187	61.60 $\pm$ 2.534

Table 1.1: General Health and health limitations:

The findings indicate that the majority of participants in both Control (90%, n=18) and Low Vision (52.5%, n=21) groups had what they considered to be a good to excellent overall health. Additionally because of the nature of their physical and mental health conditions, the majority of participants in both groups experienced poor physical and mental health for less than 15 days out of a period of 30 days. 82.5% of the low vision group (n=33) expressed unhealthy days for <15 days out of 30 days while 80% of the control group (n=16) reported the same. Thus, the findings illustrate that the majority of individuals from both groups did not experience unhealthy days for >15 days. ***(Table 2.0)***

Table 2.0: Healthy days and activity limitations:
Healthy Days Core Module:

	Experimental Label			P value
	Control (n=20)	Low Vision (n=40)	Total (n=60)	
	Frequency (%)	Frequency (%)	Frequency (%)	
General Health				0.003
Good to Excellent	18 (90.0%)	21 (52.5%)	39 (65.0%)	
Fair to Poor	2 (10.0%)	19 (47.5%)	21 (35.0%)	
Poor Physical health in the last 30 days:				0.066
< 15 days	20 (100%)	36 (90.0%)	56 (93.3%)	
> 15 days	0	4 (10.0%)	4(6.7%)	
Poor Mental health in the last 30 days:				0.016
< 15 days	17 (85.0%)	40 (100%)	57 (95.0%)	
> 15 days	3 (15.0%)	0	3 (5.0%)	
Limitations in activities due to poor physical and mental health for:				0.471
< 15 days	20 (100%)	37 (92.5%)	57 (95.0%)	
> 15 days	0	3 (7.5%)	3 (5.0%)	
Total Unhealthy days				0.201
0 – 15 days	16 (80.0%)	33 (82.5%)	49 (81.7%)	
16 – 30 days	4 (20.0%)	7 (17.5%)	11 (18.3%)	

Total unhealthy days were recorded by the sum of unhealthy physical days and unhealthy mental days. The control group findings indicate a higher mean number of unhealthy mental days (6.60 ± 1.724) compared to the low vision group (1.73 ± 0.527). Conversely, the low vision group reported higher mean number of unhealthy physical days (6.10 ± 1.120) as compared to the control group (1.20 ± 0.574). The mean number of total unhealthy days were similar for both groups. ***(Table 2.1)***

Table 2.1: Mean number days for Healthy Core Days Module

	Experimental Label		P Value
	Control n=20 (33.3%) (Mean $\pm$ S.E. mean)	Low Vision n=40 (66.7%) (Mean $\pm$ S.E. mean)	
Number of unhealthy physical days	1.20 ± 0.574	6.10 ± 1.120	0.066

Number of unhealthy mental days	6.60 ± 1.724	1.73 ± 0.527	0.016
Total Unhealthy days	7.80 ± 1.945	7.83 ± 1.343	0.201
Number of activity limitation days	2.45 ± 0.749	3.58 ± 1.009	0.471

Note: S.E. mean: Standard Error mean

Health problems/impairments and its influence on activity limitations:

The majority of the control group reported no major health problems or impairments (60%, n=12) while the majority of the low vision group were limited in their daily activities by at least one of the major health impairments on the CDC-HRQoL-4 questionnaire (85%, n=34), the most prominent impairment apart from eye/vision problem (100%, n=40), being diabetes (52.5%, n= 21). ***(Table 2.2)***

Table 2.2: Activity Limitations Module:

	Control (n=20)	**Low Vision (n=40)**	**Total (n=60)**	**P Value**
Participant limited by impairment?				< 0.001
Yes	4 (20.0%)	34 (85%)	38 (63.3%)	
No	16 (80.0%)	6 (15%)	22 (36.7)	
Major health problem/impairment:				< 0.001
None	12 (60.0%)	0	12 (20.0%)	
Diabetes	0	21 (52.5%)	21 (35.0%)	
Hypertension	0	15 (37.5%)	15 (25.0%)	
Eye/Vision problem	0	40 (100%)	40 (66.7%)	
Arthritis/Rheumatism	1 (5.0%)	6 (15.0%)	7 (11.7%)	
Depression/anxiety	4 (20%)	1 (2.5%)	5 (8.3%)	
Heart problem	1 (5.0%)	2 (5.0%)	3 (5.0%)	
Stroke	0	1 (2.5%)	1 (1.7%)	
Back/neck problem	2 (10.0%)	0	2 (3.3%)	
Hearing problem	0	1 (2.5%)	1 (1.7%)	
Fractures/bone injury	0	1 (2.5%)	1 (1.7%)	
Walking problem	0	1 (2.5%)	1 (1.7%)	
Other	0	1 (2.5%)	1 (1.7%)	
Period of health problem/impairment				< 0.001
Days	4 (20.0%)	-	4 (6.7%)	
Months	-	-	-	
Years	4 (20.0%)	40 (100%)	44 (73.3%)	
N/A	12 (60.0%)	-	12 (20.0%)	

Healthy days Symptoms:

The majority of both control and low vision groups reported less than 15 days where they experienced painful, sad and anxiety ridden days. Findings also indicate the majority of the control group(65%, n=13) and low vision group (97.5%, n=39) had less than 15 days without sleep. 60% of the control group (n=12) and 60% of the low vision group (n=25) spent 15 days or more, full of energy. ***(Table 3.0)***

Between both groups, the low vision group had a higher mean number of painful days (4.22 ± 0.874) whereas the control group had a higher mean number of sad days (4.00 ± 1.100), worried days (6.85 ± 1.688) and days without sleep (12.15 ± 2.587). ***(Table 3.1)***

Table 3.0: **Healthy Days Symptoms Module:**

	Experimental Label			**P value**
	Control (n=20)	Low Vision (n=40)	Total (n=60)	
	Frequency (%)	Frequency (%)	Frequency (%)	
Number of painful days				0.111
<15	19 (95.0%)	39 (97.5%)	58 (96.7%)	
>15	1 (5.0%)	1 (2.5%)	2 (3.3%)	
Number of sad days				0.135
<15	20 (100%)	40 (100%)	60 (100%)	
>15	0	0	0	
Number of days spent worried/anxious				0.041
<15	18 (90.0%)	40 (100%)	58 (96.7%)	
>15	2 (10.0%)	0	2 (3.3%)	
Number of days without sleep				0.014
<15	13 (65.0%)	39 (97.5%)	52 (86.7%)	
>15	7 (35.0%)	1 (2.5%)	8 (13.3%)	
Number of days full of energy				0.252
<15	8 (40.0%)	15 (40.0%)	23 (38.3%)	
>15	12 (60.0%)	25 (60.0%)	37 (61.7%)	

Table 3.1: Mean number of days for Healthy Days Symptoms Module

	Experimental Label		**P Value**
	Control n=20 (33.3%) (Mean ± S.E. Mean)	Low Vision n=40 (66.7%) (Mean ± S.E. Mean)	
Number of painful days	1.95 ± 1.509	4.22 ± 0.874	0.111
Number of sad days	4.00 ± 1.100	2.20 ± 0.576	0.135
Number of days spent worried/anxious	6.85 ± 1.688	1.73 ± 0.497	0.041
Number of days without sleep	12.15 ± 2.597	5.30 ± 0.982	0.014
Number of days full of energy	18.85 ± 2.302	19.08 ± 1.479	0.252

Vision Related Quality of Life

Classical Test Theory:

The NEI-VFQ-25 questionnaire was tested for its internal reliability and validity using Cronbach's α coefficients. Subscales demonstrated an overall good reliability based on the obtained Cronbach's α coefficient values. Additionally, based on mean subscale scores,

evidently the healthy control group performed better at the NEI-VFQ-25 questionnaire, with higher subscale scores, than the low vision group. ***(Table 4)***

Table 4: Mean Scores and reliability and validity analysis of the NEI-VFQ-25 Questionnaire.

Index (item number of subscale)	Score (Mean ± SD)		Cronbach's α
	Control (n=20)	Low Vision (n=40)	
NEI-VFQ-25 Composite Score	97.05 ± 3.79	50.43 ± 22.63	0.83
General Health (1)	68.75 ± 24.16	40.63 ± 25.12	N/A
General Vision (1)	88.00 ± 11.97	37.50 ± 15.15	N/A
Ocular Pain (2)	90.63 ± 8.95	65.31 ± 15.88	0.80
Near Activities (3)	98.34 ± 4.36	41.66 ± 22.09	0.96
Distance Activities (3)	97.50 ± 5.48	43.75 ± 20.83	0.87
Social Functioning (2)	98.75 ± 5.59	65.31 ± 25.71	0.74
Mental health (4)	94.38 ± 5.33	54.32 ± 18.21	0.55
Role Difficulties (2)	100 ± 0.0	31.25 ± 20.22	0.99
Dependency (3)	100 ± 0.0	46.67 ± 26.54	0.95
Driving (3)	100 ± 0.0	38.33 ± 33.83	0.78
Colour Vision (1)	100 ± 0.0	80.00 ± 24.81	N/A
Peripheral Vision (1)	100 ± 0.0	50.63 ± 25.63	N/A

Note: SD: Standard Deviation
N/A= Not applicable (statistics need two or more items to compute Cronbach's α)

Rasch Analysis:
Rasch Analysis was used as a method to express and analyze the performance of respondents. Particularly, infit and outfit values were developed to further understand the potential of the NEI-VFQ-25 questionnaire and its productivity for measurement. ***(Table 5)***

Table 5: Fit Statistics of the NEI-VFQ-25 using Rasch Analysis:

NEI-VFQ-25 Item	Item Mean	Measure	SE Measure	Infit	Outfit
General Health	2.45	0.00677	0.168	0.339	0.351
General Vision	2.18	0.18701	0.179	0.508	0.498
Worry about eyesight	2.05	0.28786	0.188	0.528	0.596
Pain around eyes	1.82	0.48197	0.208	0.352	0.404
Reading normal newsprint	1.82	0.48197	2.08	1.145	1.173
Seeing well up close	1.77	0.52631	0.213	0.859	0.730
Finding objects on crowded shelf	1.41	1.01486	0.294	0.895	0.727
Reading street signs	1.86	0.43978	0.203	0.742	0.846

Going downstairs at night	1.55	0.79350	0.253	0.685	0.602
Seeing objects off to the side	1.23	1.48298	0.405	0.467	0.377
Seeing how people react	1.50	0.86017	0.264	0.968	1.198
Matching clothes	1.09	2.27235	0.671	0.756	0.546
Visiting others	1.27	1.33482	0.366	2.842	1.343
Going out to movies/plays	1.55	0.79350	0.253	2.356	1.600
Driving during daytime	1.18	1.66839	0.458	0.531	0.398
Driving during night-time	1.73	0.57309	0.219	0.797	0.972
Driving in difficult conditions	1.77	0.52631	0.213	0.578	0.759
Accomplish less	4.36	-1.25771	0.225	1.575	1.935
Limited endurance	4.32	-1.20874	0.218	1.694	2.108
Amount of time in pain	4.64	-1.64508	0.291	1.016	1.033
Stay home most of the time	4.73	-1.83682	0.330	0.608	0.835
Frustrated	4.59	-1.56488	0.276	1.213	1.659
No control	4.41	-1.30995	0.232	1.579	1.999
Rely too much on other's words	4.50	-1.42659	0.251	1.797	3.402
Need much help from others	4.64	-1.64508	0.291	1.120	1.577
Embarrassment	4.73	-1.83682	0.330	0.608	0.835

Box Plots:

Box and whisker plots were developed based on mean subscale scores, for subscales with two or more item numbers on the NEI-VFQ-25 questionnaire. Findings from the control group (Figure 2) indicate close proximity of scores among the participants, as can be seen from the majority of scores being the maximum '100', with few outliers for near activities, distance activities and social functioning. A wider range of responses and differences in scores can be identified for the Low Vision group (Figure 2).

Figure 2: Box Plot for the control group

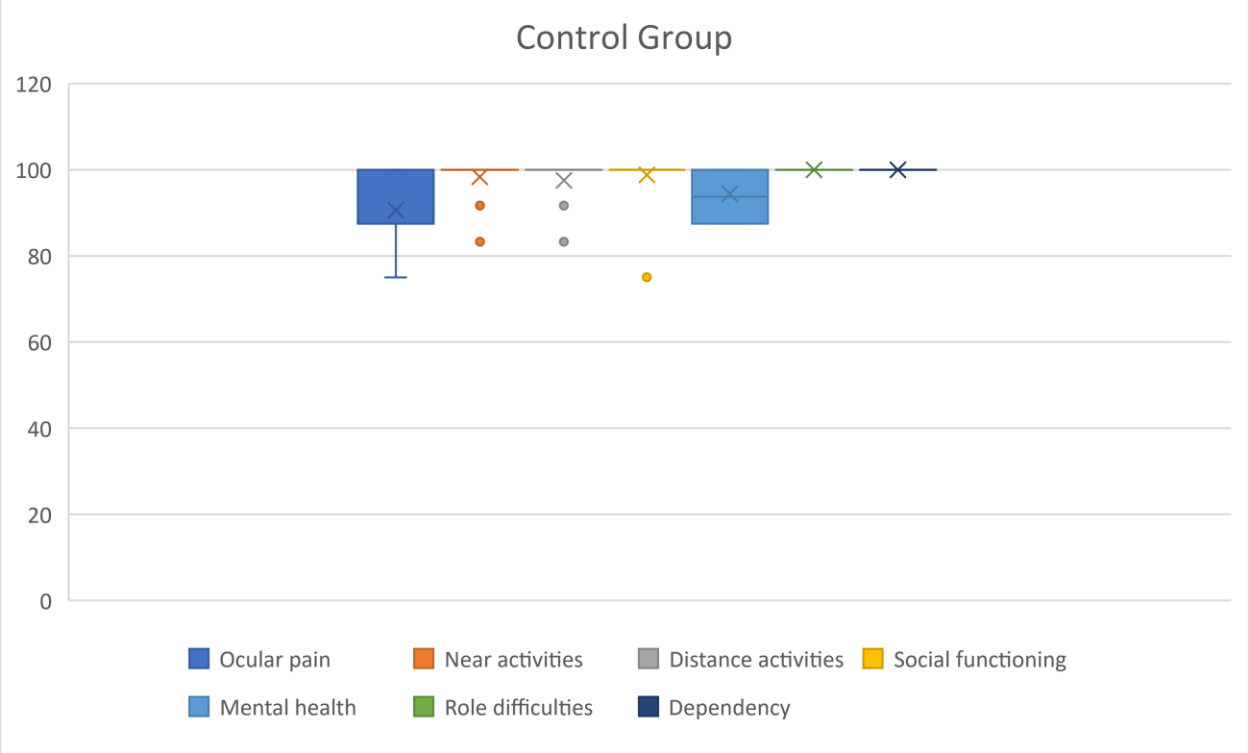


Figure 3: Box Plot for the Low Vision group

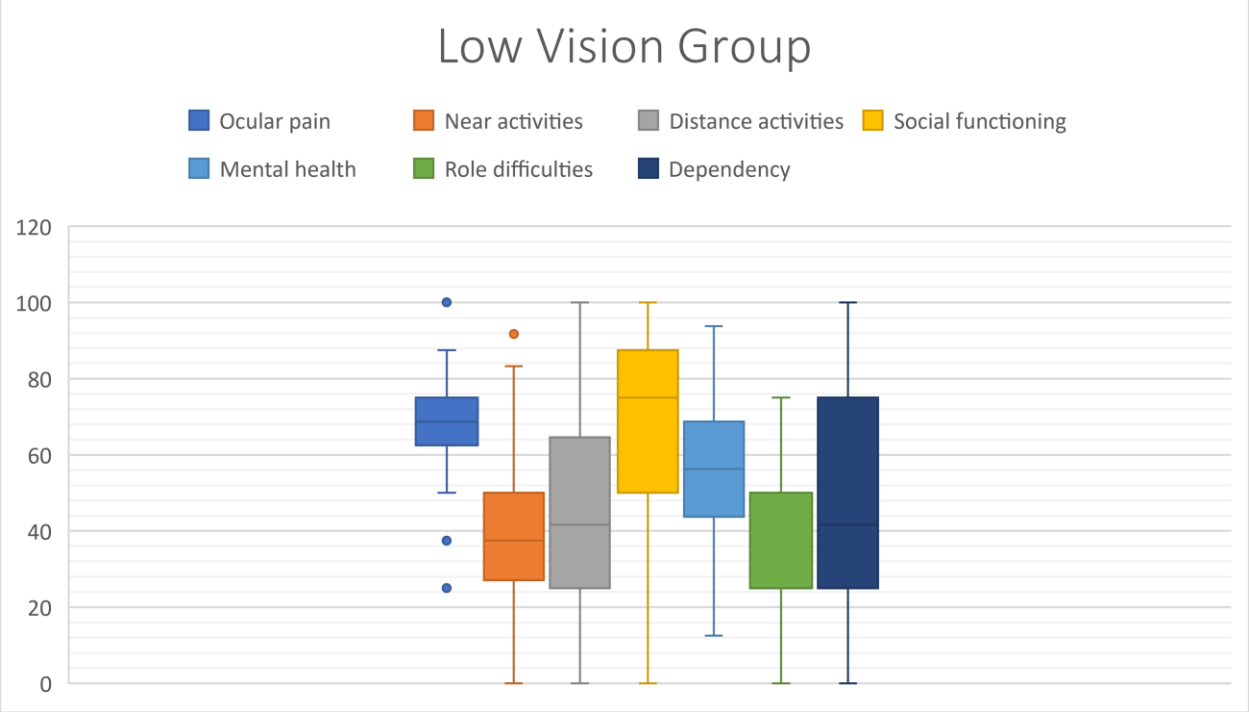
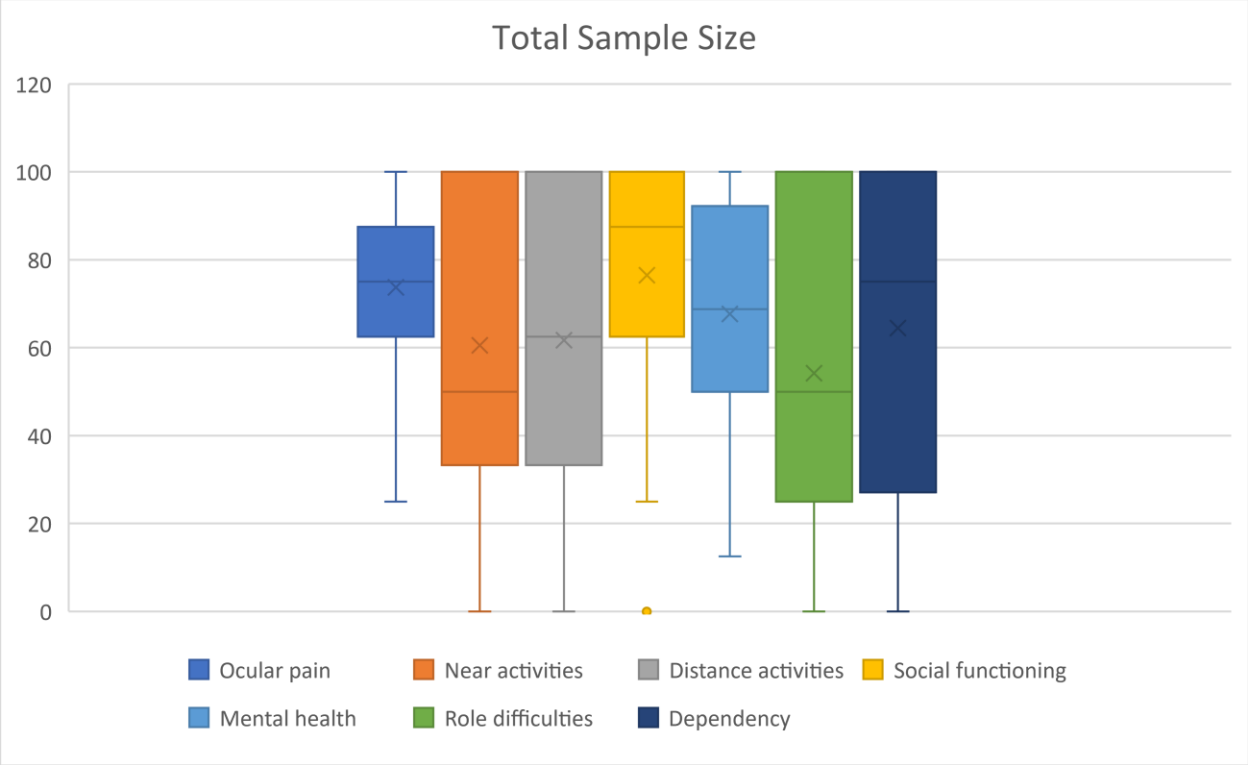


Figure 4: Box plot for the total sample size.



Discussion:

In this study, although both the healthy control and low vision individuals scored similarly in the HRQoL subscales, the low vision individuals still had a worse score. Likewise, the VRQoL highlighted that based on the subscales, the low vision individuals performed much worse than that of the control.

In order to accurately assess or discuss the findings of this study, social demographics must first be considered. Social demographics in this case would include age and gender. The sociodemographic characteristics of this particular study is such that it comprised both male and female participants, that is, 60% female participants and 40% male participants. With respect to age, the healthy control group was chosen to be a younger population than that of the experimental low vision group, starting from the age of 18 to about 45 years. The experimental low vision group was expected to be from about 40 to 85 years due to the fact

that low vision has been proven to be more prevalent in older adults. The difference in distribution of age between the two groups was intentionally done to be able to compare and assess more accurately.

In contrast, a study done by (Gyllencreutz et al,2021), the demographics were varied such that they presented more males than females with 56.6% males and 43.3% females, however the gender did not seem to have much of an effect as the results were synonymous or similar with that of this study regardless of having no male participants. Similarly, in a study done in Spain, the majority of participants were now male and the ages were very varied as any participants over 18 were deemed acceptable. This particular study deemed that gender in fact has an impact on the diabetic retinopathy and hence an immediate impact on quality of life. (Roberts-Martinez Aguirre,2022)

In this study various ocular diseases were encountered such as diabetic retinopathy, macular degeneration, retinitis pigmentosa and glaucoma. However not all ocular diseases have an equal impact on the vision and health related quality of life on a person such that some ocular diseases may have a greater impact on either one. Based on findings diabetic retinopathy seemed to be the most prevalent ocular disease at 52.5% presenting. Diabetic retinopathy can affect one's quality both visually and in terms of health. Persons with diabetic retinopathy reported trouble reading, depression or anxiety, issues seeing in the dark and limitations on their ability to do daily activities. This can be supported by Cyrus et al, whereby their study stated "diabetic retinopathy imposes limitations on patients in three ways :physical, social and emotional." The article also states that as a person's retinopathy increases, their health related quality of life decreases thereby further supporting the statement diabetic retinopathy affects health related quality of life the most and vision related quality of life the least.(Cyrus et al 2017)

This study utilized the HRQoL questionnaire. to assess health related quality of life and the NEI-VFQ 25 to assess vision related quality of life, both to quantify and assess the data obtained. With respect to health related quality of life other questionnaires do exist such as the simplified coping style questionnaire (SCSQ),the perceived social support scale (PSSS) and the general self-efficacy scale (GSES). While each of these questionnaires may have been useful in pinpointing specific areas of health related quality of life such as how supported they feel or how well they

are able to maintain their independence however not every aspect of their quality of life with respect to health is assessed quite like the HRQoL questionnaire does.

According to a study done by Jankovic et al it was concluded that the HRQoL questionnaire and its scales showed good reliability, and is a good reliable instrument to determine a patient's health related quality of life. (Jankovic et al 2021)Similarly, the Centre for disease control or the CDC uses this questionnaire to assess or determine if one has healthy days or a healthy quality of life and states that many institutions use it as well. It is stated that it can be used to "identify health disparities, track population trends and build broad coalitions around a measure of population health compatible with the World Health's Organization definition of health" (CDC,2018)

As it stands the NEI-VFQ 25 is one of the most widely and commonly used instruments to assess a person's vision related quality of life. There are very few others to exist for example the AS-20 or the ASQE but they both deal with quality of life strictly in persons with strabismus and amblyopia so as such it would not have been applicable in this study.

Many studies support the use of the NEI-VFQ 25 and it has been assessed many times and concluded as useful. This can be seen by Dennis et al whereby it states "The NEI-VFQ 25 demonstrated good reliability and construct validity as a measure of vision related functioning outcomes in patients with AMD" (Dennis et al 2010). Another study by Owen et al concluded that the NEI-VFQ 25 is a useful tool to measure visual challenges and can be used in research with elderly people of significant vision impairment. (Owen et al 2006)

In contrast however Marella et al agrees that while it a good tool, they concluded that based on their findings the NEI-VFQ 25 is "not psychometrically optimal for assessing overall vision-related functioning or sub traits in a low vision population" , it was further expressed that in order to make it optimal that further studies are need to evaluate the sensitivity of the scales. (Marella et al 2010)

The HRQoL looks at the participants' mental and physical health as well as any limitations encountered. With respect to general health, these findings indicate that the control group scored better than the experimental low vision group.

The HQRoL further used a bracket to compare the two groups, the bracket worked such that if one's total unhealthy days both mental and physically when added were less than 15 then it is considered good however if when added it amounts to more than 15 days then it is considered bad. Looking at table 2, it actually shows that the experimental low vision group scored better with respect to mental health days such that this group did not record more than 15 days. In contrast, the control group scored better in physical health such that no more than 15 days were recorded indicating a good bracket.

Mean findings of the control group were higher with respect to unhealthy mental health days and the mean findings of unhealthy physical health days were higher in the experimental low vision group.

These findings in this study can be further justified or supported by that of those seen in the study by ,Gyllencreutz et al it was shown that the adults with FASD scored better psychosocially than that of the healthy control and adults with FASD scored lower or worse with respect to physical health than that of the healthy control. (Gyllencreutz et al 2021)

Another article that supports these results is that of Robert-Martinze-Aguierre et al, where by it compared those diabetics with better or corrected visual acuities versus those with lower VAs. The results showed that those who had better VAs had worse mental health days but better physical health days than those with low visual acuities. (Robert-Martinez Aguierre,2022)

This is known as the activities limitation module. A minority of the control group indicated yes while a significant amount of the experimental control population indicated yes, showing that the experimental group is in fact more limited in the activities they can do.

Gyllencreutz et al. evaluated if the persons with FASD are limited in what they can do. Likewise to this study, the participants with FASD scored worse on the subscales and were in fact limited in what they were able to do, while the healthy control was limited in the least bit if any and were able to carry out their tasks easily and free of dependency or limitation due to health.

In the study shown by Robert-Martinez-Aguierre et al, while there were some limitations shown, it varied to this study such that even though those with better VAs were less limited, they still had restrictions to what they were able to do unlike those in the aforementioned studies whereby those participants were almost completely unlimited. Hence showing a contrast

between this study and the one conducted. The discrepancy or difference could possibly lie in that this study used adults who were disease free while this study used all adults who were diabetics or had diabetic retinopathy, just at different stages hence the varying in results.(Robert-Martinez et al,2022)

Another module of the HQRoL is healthy days symptoms. This seeks to determine any days where one is filled with fear or anxiety or experiences sleeplessness or even the days where they feel full of life. Table 3 shows that the vast majority of the experimental group experienced less than 15 painful days and similarly the control group experienced this as well. Similarly most of the experimental low vision group recorded less than 15 anxious days. However while the control group was close as the majority had less than 15 worried days, a small amount recorded more than 15 days worried indicating they fall into the “bad” bracket. With respect to the number of days without sleep, a noted difference between both groups were observed, with the bracketing favouring those of the experimental low vision group. Another question was how many days were full of energy, both groups had an equal answer of the same amount, both populations recording less than 15 days and an equal amount of both populations answering more than 15 days.

Robert-Martinez et al 2022 did not discuss factors such as anxiety and lack of sleep such as was done in this study however it, he did highlight that to further assess accurately the health related quality of life, factors such as this or emotional wellbeing needs to be a wide set variable for further studies on this topic.

Gyllencreutz et al 2021 however did discuss this but rather classified it as socioemotional and it showed that the results were in conjunction with that of this study whereby the scores on the subscale were similar for both experimental and control however over the control scored better than the experimental.

Table 3.1 highlights the mean number of healthy days symptoms. Overall it indicated that the experimental low vision group had a higher mean of painful days and days of full energy while the control group had a higher mean in sad days, anxious days and number of days without sleep.

The VQRoL looks at how well the person's vision is and how well they can use their vision to carry out daily tasks or if they do require help. To assess this, the NEI-VFQ-25 was used. Based on the analysis, it was found the control group scored better on the subscales than the experimental low vision group. Looking at table 4, different subscales, the control group scored better than the low vision group in each subscale as well as in the overall SPSS analysis. Each subscale had a specific number of questions. To ensure the NEI-VFQ-25 was a proper assessment, it was tested for validity and reliability using Cronbach's alpha coefficients. Cronbach's alpha tests internal consistency of the questionnaire and for most of the subscales it scored good, reliable and consistent. More than or equal to 0.9 is considered excellent and less than or equal to 0.6 is equal to poor reliability Majority of the subscales fell between 0.9 to 0.8 and one or two weighing at 0.7. The subscale that had the lowest rating for Cronbach's alpha was mental health which rated at 0.55 and this would be the only subscale of questionable nature. Hence the reliability and validity of the NEI-VFR-25 can be deemed of sound nature.

Another aspect to be examined was how well and productive were the responses of the participants. To do this a Rasch analysis was performed. A Rasch analysis assesses the performance of the total performance of the questionnaire. The Rasch analysis scoring algorithm is done in two stages. Stage 1 looks at the scale to sample targeting, thresholds for item response, item fit statistic, stability and reliability and stage two deals with a revision of the scoring structure. The two domains that exist out of this are activity limitation and socio-emotional functioning, To understand this, the values of the infit and outfit are crucial factors. Outfits and infits reading between 0.5-1.5 are indicative of a productive measure. In this Rasch analysis conducted as seen in table 5, the infits range from 0.3-2.8 however within that range the majority of infits are observed to be well within the range with the exception of the subscales general health, seeing objects to the side, visiting others and going to the movies are the only ones above or below the scale. Similarly for outfits it ranges from 0.3-3.4. Again the majority of outfits are well within range besides the subscales general health ,pain around eyes, seeing objects to the side , daytime driving, limited endurance and rely too much on others which are below or above the scale. Overall the infits and outfits indicate productive measurement.

Lastly to further evaluate the subscales, more specifically the subscales with two or more items, box and whisker plots were done to illustrate the results. Figure 1 represents the control group

and almost all the participant's answers were similar as seen in the majority being recorded at the 100 mark. However outliers were noticed in categories such as near activities and social functioning. Figure 2 is representative of the experimental low vision group. There were varied responses and hence a varied range, outliers in ocular pain and near activities were noted. Lastly figure 3 shows the box whisker plot for the entire sample size. It shows a wide range in responses and only outliers in social functioning.

Others who have conducted research similar to this particular research study have had almost the same results, using vision related or quality of life questionnaires. A study conducted by Adigun et al showed that upon having respondents answer a vision related quality of life questionnaire highlighted that participants without major impairments responded better to visual demands as well as quality of life versus those who had major visual impairments. Similarly some participants even though majorly impaired visually, were able to score well in quality of life despite scoring badly in visual demands(Adigun et al., 2014)

Likewise in a study conducted by Yibekal et al, the same questionnaire was used as in this study and the outcome showed that 49.2% of participants had poor visual related quality of life, but they found contributing factors were living in a rural area, old age and extreme duration of having long term impairment(Yibekal et al., 2020)

While the findings of the aforementioned studies were in likelihood of this research, i.e. similar statistics and methods, the results itself showed that this study had more significant better mental health days and some subscales were comparable or even better than that of the constant group however overall, the low vision patients still scored worse.

While both groups scored similarly in the HRQoL, the control, mental health wise performed poorly however overall the experimental low vision group performed worse on the questionnaire. Similarly for the VRQoL, based on the findings from the analyses done, the experimental control group performed significantly worse than the control group.

This study is of great significance as it shows the need for better aid and education throughout the general public, governments and family and friends of those with low vision as more help can improve their health related quality of life and by extension their vision related quality of life.

Hence it can be concluded that overall the experimental low vision group has a worse health and vision related quality of life.

Limitations of Methodology:

Possible limitations that may have been encountered are discussed as such :

Recall bias such that when participants were asked about their previous experiences, they may not be able to recall accurately and hence the answer given could affect the results. This was possible because the data being collected was via a questionnaire and hence that determines their lifestyle rather than a physical element that can be recorded or seen in real time.

Cause and effect may have been another limitation such that just because the person deemed low vision it does not mean they would automatically have a poor quality of life overall, as low vision does not necessarily cause a low quality of life despite it being a risk factor for having a chance of having a lower quality of life.

Since patient information was retrieved from 'Low Vision' files at the UWI Optometry clinic and interviews were conducted via telephone to gather data, patients up to date Visual Acuities were not known.

The last limitation would be sampling bias such that it is a specific environment and hence the population or those volunteering to participate especially the control group, may not be accurately representative of that of the actual general population.

Conclusions:

The healthy control group proved to be in better physical health than that of the experimental low vision group. The experiment low vision group proved to be in better mental health than that of the healthy control group. The healthy control group scored better overall in both the health and vision related questionnaires showing overall the healthy control group had a better quality of life than that of the experimental low vision group.

It can be concluded that based on the study the low vision adult population seen had a worse vision and health related quality of life than that of the healthy individuals.

Recommendations: Our findings indicate that adults with low vision in Trinidad have tend to have a poorer QoL in terms of both their overall health and their vision, as compared to younger and healthier adults. Also based on our findings, the younger, healthier control group has a poorer mental health as compared to the low vision group. In moving forward, this study can be as the foundation for further research in the medical field into the causes and impact of poor mental health among young individuals and propose solutions to reducing the development of mental health problems. In the field of Optometry, we would expect to encourage eye care professionals in Trinidad, Tobago and by extension the Caribbean, to pay particular attention to individuals with low vision and help to promote the importance of frequent eye examinations to detect potential abnormalities as early as possible. In doing so, the condition can be better managed and the chances of regaining and/or maintaining the individual's visual status would be greater. The Optometry community should be engaged in more stringent discussions about the growing crisis of vision loss and communicate to the relevant health agencies and authorities to offer better access to eye care for the vulnerable within the population.

Next Steps: It is our hope that the findings generated from this study can influence the way eye care professionals in Trinidad treat with and manage patients with low vision. Additionally, we hope that the research conducted in this study can be used as the foundation for further research in the field to gather more data, perhaps on a larger scale. By doing so, Optometrists can better understand how the quality of life of individuals with low vision is affected and would take the necessary steps to promote better patient management and care.

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Appendices:

CDC-HRQoL-14 Questionnaire:

ASSESSMENT	HEALTH-RELATED QUALITY OF LIFE

The Centers for Disease Control and Prevention Health-Related Quality-of-Life 14-Item Measure (CDC HRQOL-14)is an interview scale that is used extensively in survey research studies. It is also used in clinical practice. Good predictive and construct validity has been demonstrated in clinic populations. A description of the scale, along with scoring and interpretive considerations is excerpted below.[1]

The standard 4-item set of Healthy Days core questions (CDC HRQOL-4) has been in the State-based Behavioral Risk Factor Surveillance System (BRFSS) since 1993 (see BRFSS Web site **http://www.cdc.gov/brfss**). Since 2000, the CDC HRQOL-4 has been in the National Health and Nutrition Examination Survey (NHANES) for persons aged 12 and older. Since 2003, the CDC HRQOL-4 has been in the Medicare Health Outcome Survey (HOS)—a NCQA HEDIS measure. Standard Activity Limitation and Healthy Days Symptoms modules have also been available since January 1995. When used together, these measures comprise the full CDC HRQOL-14 Measure.

How is the summary index of unhealthy days calculated?

Unhealthy days are an estimate of the overall number of days during the previous 30 days when the respondent felt that either his or her physical or mental health was not good. To obtain this estimate, responses to questions 2 and 3 are combined to calculate a summary index of overall unhealthy days, with a logical maximum of 30 unhealthy days. For example, a person who reports four physically unhealthy days and two mentally unhealthy days is assigned a value of six unhealthy days, and someone who reports 30 physically unhealthy days and 30 mentally unhealthy days is assigned the maximum of 30 unhealthy days.

Healthy days are the positive complementary form of unhealthy days. Healthy days estimates the number of recent days when a person's physical and mental health was good (or better) and is calculated by subtracting the number of unhealthy days from 30 days. The method for estimating unhealthy days is supported by the actual pattern of survey responses to two individual questions. The majority of individuals report substantially different numbers of physically unhealthy days versus mentally unhealthy days; for example, in the 1998 Behavioral Risk Factor Surveillance System (BRFSS), 67.8% of the 68 619 adults who reported any unhealthy days, reported only physically unhealthy days or mentally unhealthy days, while 4.5% reported equal numbers for each measure.

Additional evidence indicates that other reported days do not overlap; for example, 10.5% of the 256 persons who reported both 15 physically unhealthy days and 15 mentally unhealthy days also reported more than 15 days of recent activity limitation due to poor physical or mental health. An alternative calculation method that assumed a maximum amount of overlap in the two responses (eg, a person who reports 4 physically unhealthy days and 2 mentally unhealthy days is assigned a value of 4 unhealthy days) was not as plausible from the overall response pattern. Furthermore, this latter method resulted in only a 0.4-day overall mean difference in unhealthy days compared with the recommended method and showed similar demographic patterns and subgroup differences with aggregated population data.

Frequent mental distress is defined as having 14 or more mentally unhealthy days as measured by [question 3].

CDC HRQOL–14

Healthy Days Core Module

1. Would you say that in general your health is:

	Please read.		**Do not read these responses.**	
	a. Excellent	1	Don't know/Not sure	7
	b. Very good	2	Refused	9
	c. Good	3		
	d. Fair	4		
or	e. Poor	5		

2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

a. Number of Days	_ _	Don't know/Not sure	7 7
b. None	8 8	Refused	9 9

3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

a. Number of Days	_ _	Don't know/Not sure	7 7
b. None	8 8	Refused	9 9

If both Q2 AND Q3 = <None>, skip next question.

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

a. Number of Days	_ _	Don't know/Not sure	7 7
b. None	8 8	Refused	9 9

- - - - - CONTINUED ON NEXT PAGE - - - - -

[1]Information about the CDC HRQOL-14 is available at http://www.cdc.gov/hrqol. A Spanish language version is available at http://www.cdc.gov/hrqol/spanish.htm.Note: To use the response codes for statistical analyses, see http://www.cdc.gov/hrqol/syntax.htm for instructions (eg, for use with SPSS, SAS, and SUDAAN).

NEI-VFQ-25 Questionnaire:

PB/SA

National Eye Institute Visual Functioning Questionnaire - 25 (VFQ-25)

version 2000

(SELF-ADMINISTERED FORMAT)

January 2000

6. The user of the NEI VFQ-25 - July 1996 will provide a credit line when printing and distributing this document orin publications of results or analyses based on this instrument acknowledging that it was developed at RAND underthe sponsorship of the National Eye Institute.

7. No further written permission is needed for use of this NEI VFQ-25 - July 1996.

7/29/96

The following is a survey with statements about problems which involve your vision or feelings that you have about your vision condition. After each question please choose the response that best describes your situation.

Please answer all the questions as if you were wearing your glasses or contact lenses (if any).

Please take as much time as you need to answer each question. All your answers are confidential. In order for this survey to improve our knowledge about vision problems and how they affect your quality of life, your answers must be as accurate as possible. Remember, if you wear glasses or contact lenses, please answer all of the following questions as though you were wearing them.

INSTRUCTIONS:

iii. In general we would like to have people try to complete these forms on their own. If you find that you need assistance, please feel free to ask the project staff and they will assist you.

iv. Please answer every question (unless you are asked to skip questions because they don't apply to you).

v. Answer the questions by circling the appropriate number.

vi. If you are unsure of how to answer a question, please give the best answer you can and make a comment in the left margin.

vii. Please complete the questionnaire before leaving the center and give it to a member of the project staff. Do not take it home.

viii. If you have any questions, please feel free to ask a member of the project staff, and they will be glad to help you.

STATEMENT OF CONFIDENTIALITY:

All information that would permit identification of any person who completed this questionnaire will be regarded as strictly confidential. Such information will be used only for the purposes of this study and will not be disclosed or released for any other purposes without prior consent, except as required by law.

Visual Functioning Questionnaire - 25

PART 1 - GENERAL HEALTH AND VISION

- **In general, would you say your overall health is:**

(Circle One)

Excellent 1
Very Good 2
Good 3
Fair 4
Poor 5

- **At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very poor or are you completely blind?**

(Circle One)

Excellent 1
Good 2
Fair 3
Poor 4
Very Poor 5
Completely Blind 6

- **How much of the time do you <u>worry</u> about your eyesight?**

(Circle One)

None of the time 1
A little of the time 2
Some of the time 3
Most of the time 4
All of the time? 5

- **How much <u>pain or discomfort</u> have you had <u>in and around your eyes</u> (for example, burning, itching, or aching)? Would you say it is:**

(Circle One)

None 1
Mild 2
Moderate 3
Severe, or 4
Very severe? 5

PART 2 - DIFFICULTY WITH ACTIVITIES

The next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity.

- **How much difficulty do you have <u>reading ordinary print in newspapers</u>? Would you say you have:**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **How much difficulty do you have doing work or hobbies that require you to <u>see well up close</u>, such as cooking, sewing, fixing things around the house, or using hand tools? Would you say:**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>finding something on a crowded shelf</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **How much difficulty do you have <u>reading street signs or the names of stores</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>going down steps, stairs, or curbs in dim light or at night</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>noticing objects off to the side while you are walking along</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>seeing how people react to things</u> you say?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>picking out and matching your own clothes</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>visiting with people in their homes, at parties, or in restaurants</u> ?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Because of your eyesight, how much difficulty do you have <u>going outto see movies, plays, or sports events</u>?**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

- **Are you <u>currently driving</u>, at least once in a while?**

(Circle One)

Yes ..... 1 *Skip To Q 15c*

No..... 2

15a. IF NO: Have you <u>never</u> driven a car or have you <u>given updriving</u>?

(Circle One)

Never drove ..... 1 *Skip To Part 3, Q 17*

Gave up 2

15b. IF YOU GAVE UP DRIVING: Was that <u>mainly because of your</u> <u>eyesight</u>, <u>mainly for some other reason</u>, or because of <u>both youreyesight and other reasons</u>?

(Circle One)

Mainly eyesight	**1**	*Skip To Part 3, Q 17*
Mainly other reasons	**2**	*Skip To Part 3, Q 17*
Both eyesight and other reasons ...	**3**	*Skip To Part 3, Q 17*

15c. IF CURRENTLY DRIVING: How much difficulty do you have <u>driving during the daytime in familiar places</u>? Would you sayyou have:

(Circle One)

No difficulty at all..... 1
A little difficulty..... 2
Moderate difficulty 3
Extreme difficulty..... 4

- **How much difficulty do you have <u>driving at night</u>? Would you say you have:**

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Have you stopped doing this because of your eyesight 5
Have you stopped doing this for other reasons or are you not interested in doing this 6

16A. How much difficulty do you have <u>driving in difficult conditions, such as in bad weather, during rush hour, on the freeway, or in city traffic</u>?Would you say you have:

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Have you stopped doing this because of your eyesight 5
Have you stopped doing this for other reasons or are you not interested in doing this 6

PART 3: RESPONSES TO VISION PROBLEMS

The next questions are about how things you do may be affected by your vision. For each one, please circle the number to indicate whether for youthe statement is true for you all, most, some, a little, or none of the time.

(Circle One On Each Line)

READ CATEGORIES:	**All of the time**	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
17. Do you accomplish less than you would like because of your vision?	**1**	**2**	**3**	**4**	**5**
18. Are you limited in how long you can work or do other activities because of your vision?	**1**	**2**	**3**	**4**	**5**
19. How much does pain or discomfort in or around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to be doing? Would you say:	**1**	**2**	**3**	**4**	**5**

For each of the following statements, please circle the number to indicatewhether for you the statement is definitely true, mostly true, mostly false, or definitely false for you or you are not sure.

(Circle One On Each Line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
20. I stay home most of the time because of my eyesight.....	**1**	**2**	**3**	**4**	**5**
21. I feel frustrated a lot of the time because of my eyesight.	**1**	**2**	**3**	**4**	**5**
22. I have much less control over what I do, because of my eyesight.	**1**	**2**	**3**	**4**	**5**
23. Because of my eyesight, I have to rely too much on what other people tell me. .	**1**	**2**	**3**	**4**	**5**
24. I need a lot of help from others because of my eyesight.....	**1**	**2**	**3**	**4**	**5**
25. I worry about doing thingsthat will embarrass myself or others, because of my eyesight.....	**1**	**2**	**3**	**4**	**5**

Appendix of Optional Additional Questions

SUBSCALE: GENERAL HEALTH

A1. How would you rate your overall health, on a scale where zero is asbad as death and 10 is best possible health?

(Circle One)

0	1	2	3	4	5	6	7	8	9	10
Worst										**Best**

SUBSCALE: GENERAL VISION

A2. How would you rate your eyesight now (with glasses or contact lens on, if you wear them), on a scale of from 0 to 10, where zero means theworst possible eyesight, as bad or worse than being blind, and 10 means the best possible eyesight?

(Circle One)

0	1	2	3	4	5	6	7	8	9	10
Worst										**Best**

SUBSCALE: NEAR VISION

A3. Wearing glasses, how much difficulty do you have reading the smallprint in a telephone book, on a medicine bottle, or on legal forms?
Would you say:

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

A4. Because of your eyesight, how much difficulty do you have figuringout whether bills you receive are accurate?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

A5. Because of your eyesight, how much difficulty do you have doingthings like shaving, styling your hair, or putting on makeup?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

SUBSCALE: DISTANCE VISION

A6. Because of your eyesight, how much difficulty do you haverecognizing people you know from across a room?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

A7. Because of your eyesight, how much difficulty do you have taking partin active sports or other outdoor activities that you enjoy (like golf, bowling, jogging, or walking)?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

A8. Because of your eyesight, how much difficulty do you have seeing andenjoying programs on TV?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not interested in doing this 6

SUBSCALE: SOCIAL FUNCTION

A9. Because of your eyesight, how much difficulty do you haveentertaining friends and family in your home?

(Circle One)

No difficulty at all 1
A little difficulty 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
Stopped doing this for other reasons or not

interested in doing this 6

SUBSCALE: DRIVING

A10. [This item, "driving in difficult conditions", has been included as partof the base set of 25 items as item 16a.]

SUBSCALE: ROLE LIMITATIONS

A11. The next questions are about things you may do because of your vision. For each item, please circle the number to indicate whether foryou this is true for you all, most, some, a little, or none of the time.

(Circle One On Each Line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Do you have more help from others because of your vision?	**1**	**2**	**3**	**4**	**5**
b. Are you limited in the kinds of things you can do because of your vision?	**1**	**2**	**3**	**4**	**5**

SUBSCALES: WELL-BEING/DISTRESS (#A12) and DEPENDENCY (#A13)

The next questions are about how you deal with your vision. For each statement, please circle the number to indicate whether for you it is definitely true, mostly true, mostly false, or definitely false for you or youdon't know.

(Circle One On Each Line)

	Definitely True	**Mostly True**	**Not Sure**	**Mostly False**	**Definitely False**
A12. I am often irritable because of my eyesight.....	1	2	3	4	5
A13. I don't go out of my homealone, because of my eyesight.....	1	2	3	4	5

Research Consent Form:

UNIVERSITY OF THE WEST INDIES, ST. AUGUSTINE
FACULTY OF MEDICAL SCIENCES
OPTOMETRY UNIT
COUVA HOSPITAL AND MULTI-TRAINING FACILITY

CONSENT FORM FOR PARTICIPANTS OF RESEARCH PROJECT

Please read this consent form carefully before you decide to participate in the study. Any questions you may have would be answered by the researchers or project supervisor.

Study title: Evaluating Health-Related Quality of Life (HRQoL) and Vision-Related Quality of Life (VRQoL) among adult populations with low vision in Trinidad.

Purpose of the study: To investigate health related quality of life (HRQoL) and vision related quality of life (VRQoL) in adults with Low Vision and compare results with healthy controls.

Procedure: Participants should be adults aged 18-85 with low vision and/or adults aged 18-85 with healthy eyes i.e. no major visual impairment or anterior surface eye disease (control group). All participants may be required to complete both a vison related quality of life (VRQoL) questionnaire and a general health related quality of life (HRQoL) questionnaire.

Potential risks of participating: There are no risks of participation in this study as procedures are non-invasive and interviews would be conducted via telephone.

Potential benefits of participating: Participants would contribute significantly to the furthering of our educational endeavours as well as be a part of a study that would be beneficial to further research and to the society at large, since further education would be provided for people to be aware of low vision and how it may affect quality of life. Some participants with low vision may benefit from free optical aids if they require it, and if it proves to be useful to them to make their lives more comfortable if they choose to visit the UWI Optometry Clinic.

Compensation: Participants are not entitled to any compensation for their participation in this study.

Confidentiality: Your identity and other personal information disclosed to us would be kept strictly confidential, to the extent provided by the law. Your name would not be used in any report or presentation.

Voluntary participation: Your participation is completely voluntary and there is no penalty if you choose not to participate.

Withdrawal from the study: You reserve the right to withdraw yourself from this study at any time without any consequences.

Contact information for questions or concerns: If you have any questions or concerns about this study you may contact any of the following:

UWI Optometry Clinic: # -------
Research Supervisor: #-------

AGREEMENT:
I have read this consent form carefully and I understand all of the above information. I have received a copy of this description. I voluntarily give my consent and I agree to participate in this procedure regarding this research project.

(Please sign directly below)

Participant: _____ Date: _____

Student Researchers: _____ Date: _____

_____ Date: _____

Research Supervisor: _____ Date: _____