

Development of an assessment instrument to
measure disability related distress in primary
school learners with vision impairment due to
uncorrected refractive error in rural areas of
KwaZulu-Natal Province, South Africa

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A thesis submitted to the College of Health Sciences, University of KwaZulu-Natal, Westville,
in fulfillment of the requirements of the Doctor of Philosophy in Optometry

Supervisors

Professor Kovin Naidoo

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A thesis submitted to the School of Optometry, Faculty of Health Science, University of KwaZulu-Natal, Westville Campus, for the Doctor of Philosophy (Optometry).

This is to certify that the contents of this thesis are the original research work of Mr. Ving Fai Chan.

As the candidate's supervisor, I have approved this thesis for submission.

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Signed:

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Date:

ABSTRACT

Background

With the increasing global emphasis on improving eye health in children, numerous efforts are being implemented to meet the eye care needs of the children. There is no instrument which can be used to measure the impact of the Disability Related Distress (DRD) on children with vision impairment (VI) due to uncorrected refractive error (URE).

Aim

The aim of the study was to develop an assessment instrument to measure DRD in Grade 1 to Grade 5 learners with VI due to URE in a rural and semi-rural setting.

Methods

This mixed-method study was conducted in 4 primary schools in Pinetown, KwaZulu Natal, Durban in 3 phases. Phase 1 involved twelve focus group discussions using semi-structured interviews to identify themes that formed the DRD items in the Instrument. A topic was qualified as an item if at least two participants made substantive comments on the topic in a single focus group and the topic was discussed by at least one child in two different groups. In Phase 2, we consulted ten experts to construct an instrument for pre-testing by considering relevance, relative importance, upsetting issues and wording of the items. Issues that had a mean score < 2 for relevance or importance were excluded. In Phase 3, we pre-tested the instrument to identify missing or redundant issues. An item was included in the final instrument if the mean score of relevance was > 1.5 ; prevalence ratio $> 30\%$ or prevalence of scores 3 or 4 $> 50\%$; range of rate of occurrence was > 2 points; no significant concerns expressed by Primary Subjects, Secondary Subjects and Tertiary Subjects, and compliance of less than 5% of the responses to the item in the debriefing session suggested that the issues were not related to VI due to URE.

Results

In Phase 1, thirteen children with normal vision and 63 children with VI due to URE consented to participate in the focus group discussions. Eleven themes were generated from the focus group discussions and included as items in the draft provisional list. In Phase 2, one item was excluded and the experts pointed out the need to give explanations to the children. The items included were from the domains of *Loss of Self Confidence* ($n=3$), *Loss of self-worth* ($n=3$), *Loss of interconnection/ interaction with community* ($n=2$), *Suspicion, humiliation and fight* ($n=1$) and *Discrimination* ($n=2$). In Phase 3, pre-testing was conducted on 120 children (Normal vision, NV: Mild vision impairment, MVI: Severe vision impairment, SVI: 60:30:30).

The rate of occurrence of the items showed an increasing trend, from NV to MVI and SVI. The average time needed for completing the questionnaire showed an increasing trend, from NV to MVI and SVI. All eleven items in the provisional list fulfilled the retention parameters.

Conclusion

The developed instrument is valid, appropriate and culturally sensitive to the rural population. Its administration is resource-friendly and efficient with straightforward analysis and interpretation of data. This makes it easy to communicate the finding to a wide range of stakeholders and decision makers.

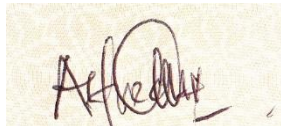
DECLARATION 1- PLAGIARISM

I, Ving Fai Chan, declare that

1. The research reported in this thesis, except where otherwise indicated, is my original work.
2. This thesis has not been submitted for any degree or examination at any other university.
3. This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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 - a. Their words have been re-written, but the general information attributed to them has been referenced.
 - b. Where their exact words have been used, then their writing has been placed in italics and inside quotation marks, and referenced.
5. This thesis does not contain text, graphics or tables copied from the Internet, unless specifically acknowledged, and the source being detailed in the thesis and in the references section.

A detail contribution to publications that form part and/or include research presented in this thesis is stated (include publications submitted, accepted, in press and published).

Signed

A handwritten signature in dark ink on a light-colored, textured background. The signature is cursive and appears to read 'Ving Fai Chan'.

15 October 2017

DEDICATION

This work is dedicated to God for His unfailing love towards me, giving me the wisdom to handle each obstacles that came my way.

This is also dedicated to my mother and late father parents and all my family for their love and support throughout my studies and every other day of my life as well as for teaching me many life skills that has contributed to my success.

And lastly, this work is dedicated to John Brock, an amazing man, without him, there will be no thesis. His support, perseverance, confidence, strength and optimism are what kept me going in completing the thesis.

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List of Abbreviations

BREC	Biomedical Research Ethics Committee
CRC	Convention on the Rights of Children
CRPD	Convention on the Rights of Persons with Disabilities
CVAQC	Cardiff Visual Ability Questionnaire for Children
CVFQ	Children's Visual Function Questionnaire
DRD	Disability related distress
IQ	Intelligent Quotient
IVI-C	Impact of Visual impairment of Children Questionnaire
LogMAR	Logarithm of Minimal Angle of Arc
LVP-FVQ	L. V. Prasad Functional Vision Questionnaire
LVQoL	Low Vision Quality of Life Questionnaire
MVI	Mild vision impairment
NFER	National Foundation of Education Research
NV	Normal vision
PedsQL	Pediatric Quality of Life Inventory
PS	Primary subjects
QoL	Quality of life
SAT	Scholastic Aptitude Test
SD	Standard deviation
SPPC	Self Perception Profile for Children
SS	Secondary subjects
SVI	Severe vision impairment
TS	Tertiary subjects
UNICEF	United Nations Children's Emergency Fund
VA	Visual Acuity

VI	Vision Impairment
VMI	Visual-Motor Integration
WHO	World Health Organization
WPPSI-R	Wechsler Preschool Primary Scale of Intelligence-Revised

Chapter One: Background

Introduction

Disability usually represents a complex relationship between health circumstances, environmental and personal factors.¹ It is not restricted to biological or social aspects.¹ Disability can occur in three dimensions:¹

- a. An impairment in body function or structure, such as uncorrected refractive error which can prevent someone from seeing clearly
- b. A limitation in activity, such as the inability to read or move around freely due to inability to see clearly
- c. A restriction in participation, such as exclusion from school or sporting activities due to inability to read or move around freely.

Some children have congenital disorders that lead to disability while others can have one or more disabilities because of a disease, injury or lack of nourishment.² There are children who have one disability while others may have more than one.²

The prevalence of people living with disability accounts for approximately 1/6 of the world's population (>1 billion people worldwide) .² However, this figure may be higher as vision impairment due to refractive error has been a late entry into the World Health Organisation (WHO) numbers. There are 624 million people who are blind or vision impaired because of lack of spectacles.^{3,4} There is currently no reliable information regarding the number of children with disabilities. This might be due to differences in definition; or due to the wide range of methodologies and instruments used. However, the United Nations International Children's Emergency Fund (UNICEF) reported that 72 million children (the majority of whom (57%) are girls) in developing countries are not attending primary school education, even though they are of school-going age.⁵ This situation may be in part related to disabilities since children with disabilities have a lower chance of enrolling at school and their ongoing attendance and progression in schools are lower compared to those without disabilities.² In many developing countries, there are few schools catering for children with disabilities. Even if there are schools providing educational opportunities for children with disabilities, they are mostly in urban settings.

According to the South Africa Census 2011,⁶ the national disability prevalence rate was estimated at 7.5%, and is more prevalent among females than males (8.3% and 6.5% respectively). The statistics showed that disability is positively correlated with age; more than half (53,2%) of persons aged 85 years and older reported having a disability and the results further show slightly higher rates in the 5–9-year-old age group (10.8%).

Globally, the prevalence of children living with poor vision is high, with 12 million vision impaired children and 1.4 million blind children.⁷ Estimates suggest that almost 500 000 children a year become blind.⁸ Blinding conditions are associated with child mortality, with up to 60% of children in developing countries dying within two years of becoming blind.⁸

In South Africa,⁶ noticeable age differences exist among those persons who experience difficulty in seeing, and those who do not. The proportion of persons who have vision impairment increases as age increases (from 51% at age 5–9 years to 97% at age 85+ years), which is an indication that the ageing process has a profound negative impact on the prevalence of vision impairment. However the impact of vision impairment on the children is significant as well. For example, children with severe difficulties in functioning are the most marginalized, with children from the Coloured population being most affected in terms of access to primary education. The white population group has the lowest proportion of children not attending school. Non-attendance is prevalent among children with severe difficulty in functioning, particularly children with severe communication and walking difficulties; an indication that children with disabilities were the most disadvantaged in terms of access to primary education.⁹

Child Eye Health issues however are not confined to childhood blindness and eye diseases; but they also include refractive error and low vision,¹⁰ which can be corrected if identified early. A systematic review and meta-analysis performed by Flaxman et al.¹¹ found that there were about 116 million people living with moderate to severe vision impairment (MSVI) due to distance URE in 2015. Furthermore, 7.42 million people (out of a total of 36.0 million blind) were blind due to distance URE. In addition, myopia is shown to be the primary cause of distance vision impairment due to URE with approximately 80% of the total myopia cases among children in Asia can be found in East Asia (35% of the world's myopic children population).¹² The number of people of all ages living with myopia is speculated to reach 2.5 billion in year 2020.¹³

Context

Impact of vision disability in children

If a child lives with blindness, it is also likely that the child and his or her family members are affected in one way or another. This encompasses educational, employment, personal and social aspects.¹⁴ The negative effects of blindness on education and future employment are significant in children.¹⁰ Research has also found that worldwide, the percentage of blind children who go to school is as low as 10 per cent.⁵

There are very limited published studies which looked at the impact of vision disability on school learners in terms of daily living, mental health, distress and learning. One such study is a population census in Canada, which reported that 13.7% of Canada's population has some form of physical limitation.¹⁵ However, Provincial and Federal legislation ensures that children with disabilities receive the best treatment and education possible, along with their able bodied peers.¹⁶ It is essential that parents and teachers are aware of the developmental effect of disability so that timely and appropriate interventions are designed and administered.¹⁶

A more recent study by Chadha and Subramaniam¹⁷ looked at the impact of visual impairment (VI) on quality of life among 3-16 year-old children. Quality of life (QoL) in this study was determined using the Low Vision Quality of Life Questionnaire (LVQOL). It was found that visually impaired children had significantly worse QoL than normal sighted children, resulting in a decrease of 35.6% in QoL score.¹⁷

Problem Statement

With the increasing global emphasis on improving eye health in children, numerous efforts are being made to meet the eye care needs of the children. To date, the main means to measure the impact of these efforts are quantitative outputs, that is number of children identified as having a vision problem, number of children who were referred for further eye management, number of children who were managed. Currently, there is no instrument which can be used to measure the impact on the DRD of children following their vision management. Assumptions are often made by eye health programme implementers that after the management of the condition, the children will lead a better life, psychologically and socially.

Limitations of existing questionnaires that measure vision impairment related issues in children

Numerous questionnaires exist for determining the impact of vision impairment in the general population. In our literature review, we found four questionnaires developed to determine the effect of vision impairment in children¹⁸⁻²¹ They are the Cardiff Visual Ability Questionnaire for Children (CVAQC),¹⁸ Children's Visual Function Questionnaire (CVFQ),¹⁹ the LV Prasad-Functional Vision Questionnaire (LVP-FVQ)²⁰ and Impact of Visual impairment of Children Questionnaire (IVI-C)²¹ and the Low Vision Quality of Life Questionnaire (LVQoL).²²

All these questionnaires measure vision-related concepts, which are either vision ability, vision related QoL or vision function. None of the questionnaires are aimed at determining the disability related distress (DRD) in children with vision impairment due to uncorrected refractive error.

Each of these was developed with certain objectives. The Cardiff Visual Ability Questionnaire for Children (CVAQC) was developed using self-reported visual ability from a sample of children with normal vision and children with vision impairment from the age of 5 to 18 years of age through focus group discussion. However, it is targeted to children in developed countries and is therefore not applicable to the developing world context due to the heterogeneity of the social and cultural context in developing countries.¹⁸

The Impact of Visual impairment of Children (IVI-C) Questionnaire was developed for Australian children from self-reported and proxy reported vision related quality of life (QoL). The sample was children from 8 to 18 years old. It is also targeted to children in developed countries.¹²

The Children's Visual Function (CVF-Q) Questionnaire is an instrument to measure vision-related QoL and was developed from literature review, physicians' clinical experiences, proxy experiences on children from birth to 7 years old.¹⁹ Since the age range does not cover all the ages or grades relevant to the present study, the instrument is not applicable to our targeted population.

LV Prasad-Functional Vision Questionnaire (LVP-FVQ) targets children 8 to 18 years old, living in developing countries. The instrument was developed using literature review and focus group discussions with children with vision impairment, the children's parents and support providers. It has been validated,²⁰ but is limited to visual functions only.

The Low Vision Quality of Life Questionnaire (LVQoL) was developed for assessing the effect of low vision intervention. It was developed by reviewing the existing vision related questionnaires by a panel of low vision rehabilitation professionals and patients. However, the LVQoL Questionnaire is only applicable in a clinical setting, and not at community level.²² All of these measures have limitations regarding their use in children with vision impairment and therefore the aim of this study was to develop such an instrument which could be used in children with vision impairment. A DRD assessment instrument for children with vision impairment due to uncorrected refractive error will help to directly determine the impact on the psychosocial well-being of those children following their vision management programmes. Table 1 summarizes the features of the questionnaires.

Table 1: Summary of features of questionnaire measuring vision related issues in children

Description	CVAQC	IVI-C	LVP-FVQ	CVFQ	LVQoL
Age range (years)	5-18	8-18	8-18	Up to 7	Unspecified
Basis of development	Focus Group with children (VI and normally sighted)	Focus group with VI children, parents, teachers and support providers	Literature review and focus group with VI children, parents and support providers	Clinical experience and literature review	Review of existing vision related questionnaires
Population the questionnaire was developed for	Children in developed countries	Children in Australia/ developed countries	Children in developing countries	General	Low vision patients
Self-reported/proxy	Self-reported	Both	Self-reported	Proxy	Review by low vision rehabilitation professionals and patients
Concept being measured	Visual ability	Vision related QoL	Visual function	Vision related QoL	Low vision specific strategy and management in clinical setting

Furthermore, for the monitoring of eye health programme effectiveness, the instrument can be used to quantify the success or progress of the interventions that aim at providing refractive correction to children. The information collected allows better communication in demonstrating the impact of eye care interventions to all stakeholders. This is vital for public relations, motivation to eye health programme implementers, and also serves as evidence and provides a basis to secure investment from current and future funders.

Hypotheses

This study has two components, namely a qualitative and quantitative component. The qualitative component is exploratory in nature which has no hypothesis to be tested. The outcomes of the qualitative component are to identify relevant issues and items for the Instrument.

The quantitative component is for the development of the Instrument, which is not comparative in nature. Statistical analyses were conducted to make sure the elements of the Instrument will be a good fit to produce a valid and reliable instrument.

The null hypotheses of the study were:

- a. There is no significant difference in the trend in the overall rates of occurrence of the DRD issues among children with normal vision, mild vision impairment and severe vision impairment.
- b. There is no significant difference in the overall mean rates of occurrence of the DRD issues among children with normal vision, mild vision impairment and severe vision impairment across different ages.
- c. There is no significant difference in the trend in the overall mean scores of relevance of the DRD issues among children with mild vision impairment and severe vision impairment.
- d. There is no significant difference in the overall mean scores of relevance of the DRD issues among children with mild vision impairment and severe vision impairment across different ages.

Aims and objectives

Aims and methods of this study are based on international guidelines for developing patient-reported outcomes.

Aim

To develop an instrument aimed at measuring disability related distress (DRD) in school learners who are visually impaired due to uncorrected refractive error.

Specific objectives of the study

To explore the disability related distress caused by vision impairment due to uncorrected refractive error in learners from Grade 1 to Grade 5

To develop a draft assessment instrument to measure disability related distress caused by vision impairment due to uncorrected refractive error in learners from Grade 1 to Grade 5

To pre-test the draft assessment instrument to assess:

- Occurrence among children Grade 1 to Grade 5 of the disability related distress items caused by vision impairment due to uncorrected refractive error
- Relative relevance among children Grade 1 to Grade 5 of the disability related distress items caused by vision impairment due to uncorrected refractive error
- Whether learners were confused or felt upset with the disability related distress items in the assessment instrument

To develop a final assessment instrument to measure disability related distress caused by vision impairment due to uncorrected refractive error in learners from Grade 1 to Grade 5

Chapter Two: Literature review

Disability related distress (DRD)

According to Carstens and Moberg,²³ National Research Council²⁴ and Moberg,²⁵ distress is defined as “an aversive, negative state in which coping and adaptation processes fail to return an organism to physiological and/or psychological homeostasis”. In this context, the disability researched is vision impairment due to uncorrected refractive error. Hence, DRD is defined as the negative stress experienced by the individual with vision impairment due to uncorrected refractive error.

DRD has an effect on the relationship between psychological and social processes.²⁶ Psychological processes are internal which include thoughts, feelings, motivations and perceptions. Social processes are external and include social networks, community, family and environment.²⁷ Our feelings interact with the environment around us.

Disability, such as vision impairment, can harm the individual and the community due to but not limited to:²⁸

- loss of “self-confidence”;
- loss of “self-worth”;
- a loss of “interconnection”;
- “suspicion, humiliation or fight”;
- “discrimination”

Vision is vital for children’s and adolescents’ education and learning, as 80% of learning happens through sight.^{29,30} Reduced educational achievement,³¹ leisure activities²⁹ and social life³² were reported to be negative outcomes of vision loss early in life.

When students progress in school, vision demands also increase greatly because of a higher workload and the font size of their text books and work books becomes smaller. Children with vision impairment will need to exert more effort in reading their school work.

People living with vision impairment can have disadvantages in their social life such as having fewer friends compared to those with normal vision,²¹ fewer opportunities to interact with others and fewer chances to develop interactive abilities.³³ We still do not fully know to what extent

vision impairment will negatively impact on a child even though there are various detrimental impacts on them. However, responses and perceptions on the distress faced by the children is best gathered from the children themselves, and then the people they interacted with.

Khadka et. al¹⁸ conducted a study to look at the “educational, social and leisure activities and issues” among visually impaired school children and adolescents compared to children with normal vision. Thirteen focus group discussions were conducted and these groups were separated according to age, sex, vision status, and urban and non-urban schooling. The study recruited 81 study subjects aged 5-18 years old to participate in the focus group discussions. There were 22 visually impaired boys and 12 visually impaired girls (n=34); and 47 normally sighted participants. There were 121 daily living activities which have great impact on children and adolescents that were discussed in the focus groups discussions. Six themes were identified from the study, which were:

- a. Visually impaired and normal sighted children had common interests
- b. Visually impaired children and adolescents had difficulties with some specific activities
- c. Visually impaired children and adolescents faced challenges in using low vision devices
- d. Occasionally, presence of the teacher aides could cause reliance by the visually impaired children and adolescents and sometimes discrimination towards them
- e. Over protection by parents towards the visually impaired children and adolescents can limit their children’s independence
- f. Both visually impaired children and adolescents would like to be self-reliant.

In another study which aimed to demonstrate the effects of vision impairment among young people quantitatively using the PedsQL Generic Core Scales., 1249 adolescents from the age 11 years old to 18 years old and 948 parents were recruited (the Singapore Cohort study).³⁴ The PedsQL Generic Core Scales is an instrument that measure health related quality of life among children with chronic and acute health conditions.³⁵ It has four scales (physical, emotional, social and school functioning) with a total of 23 items.³⁵ It was reported that the visually impaired but healthy adolescents have a significantly lower total health scores, psychosocial health scores and school functioning scores, compared to those with normal vision.³⁴

Impact of refractive error in children

Methodology of literature review on the impact of refractive error in children

The literature review was limited to studies that investigated the impact of refractive errors and refractive correction on children (5 to 18 years old). The review focused on the following outcome measures:

- Self-esteem and wellbeing
- Quality of life
- Educational aspects
- Social and psychological aspects

The articles search period was limited from year 1994 to 2015 and limited to English for feasibility reasons. Searches were conducted in databases for health and education literature. These were Medline, EMBASE, Global Health, Web of Science, ERIC. Randomized-controlled studies, cohort studies, case-control studies, cross sectional studies, intervention studies and qualitative studies were included in the review. The search strategy is shown in Figure 1.

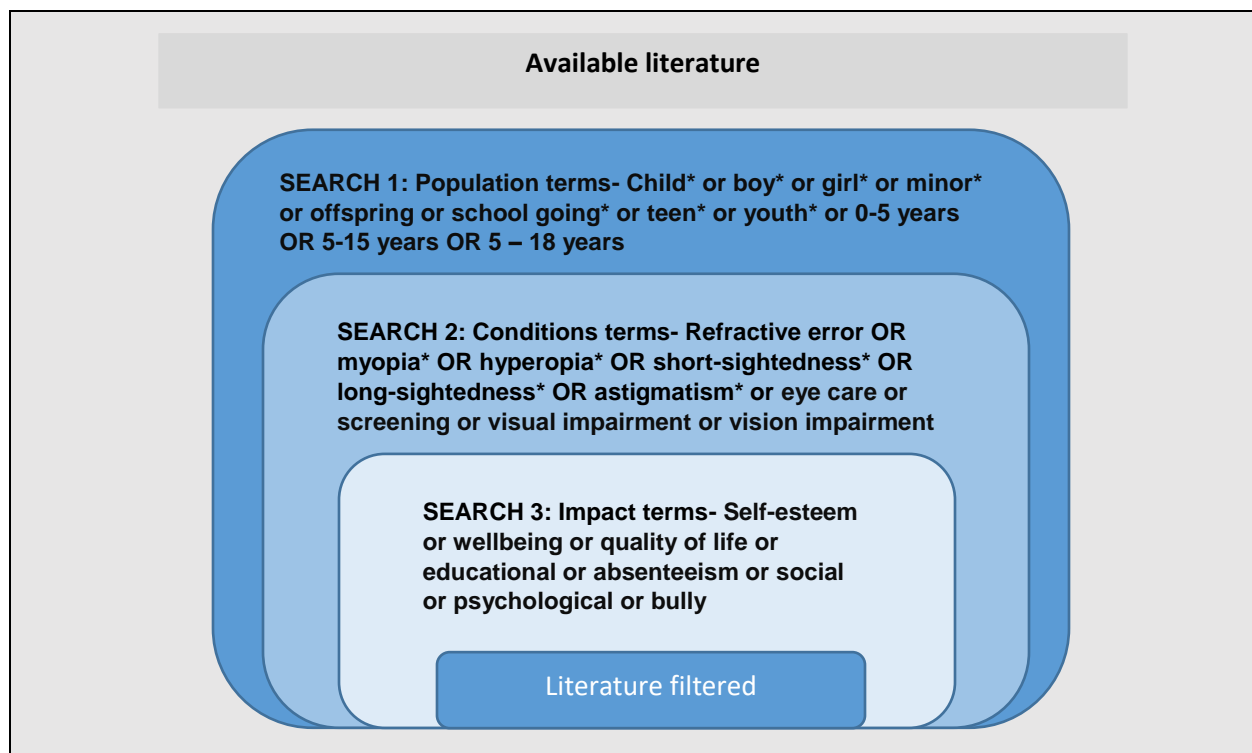


Figure 1: Search strategy for literature

Abstracts of the studies were first assessed and their relevance determined. Full texts of relevant studies were then assessed. A data extraction sheet was used to systematically extract relevant information from published articles. This includes:

- Author(s)
- Year of Publication
- Country and study setting
- Title of paper
- Purpose
- Study Design
- Type of Study
- Sample Size, sampling methodology and sample
- Outcome Measures
- Results

Full data extraction of literature is shown in Appendix 1.

Impact of refractive error on self-esteem among children

Diaz et. al.³⁶ evaluated the self-perceived self-esteem of 469 myopic children (6 to 11 years old) using the Self Perception Profile for Children (SPPC) questionnaire, and looked at the association between self-esteem and specific ocular or demographic characteristics. The children were recruited from four different colleges of optometry in Houston, Philadelphia, Birmingham and Boston. It was found that children with visual symptoms (score < 10) perceived themselves better than their counterparts in all domains of measurement (scholastic competence, social acceptance, physical appearance, behavioural conduct and global self-worth), except their athletic competence.

Impact of the refractive correction among children with refractive error

In 1997, Terry et. al.³⁷ conducted a randomized-controlled-trial to identify the changes in self-concepts among 125 children who were 10-13 years old after prescribing them with contact lenses instead of their usual habitual spectacles. At the end of the 3-year study, it was observed that self-concept measures between the contact lens wearing group and glasses wearing group did not change significantly. However, it was found that self-concept measures were significantly higher

in boys than girls at the end of the study. It was also observed that the children's self-concept of their appearance and popularity increases more over time than their self-concept of anxiety . However, their self-concept of behaviour, intelligence, and happiness did not change significantly after their contact lens wear.

Impact of refractive error on educational outcomes among children

Several studies³⁸⁻⁴⁵ were conducted to assess the impact of refractive error on educational outcomes among children. These studies concluded that refractive error has an impact on school achievement.

A randomised-controlled trial by Roch-Levecq et. al.³⁸ assessed the cognitive abilities of 70 children with refractive error. Visual-Motor Integration (VMI) score and Wechsler Preschool Primary Scale of Intelligence-Revised (WPPSI-R) performance were collected at baseline and the follow up period was six weeks following optical correction. The children were recruited from those sequentially seen at the mobile eye clinic in San Diego. At baseline pre-correction, children with refractive error scored significantly lower VMI score and WPPSI-R performance scales. During follow-up, the refractive error group increased significantly on VMI performance compared to those without refractive error.

Ma et. al.⁴⁶ conducted a clustered randomized control trial of 252 primary school which included 3052 children in China to determine if providing free glasses to children improved their spectacle wear and academic performance. The outcome measure for academic performance was math test scores. By allocating free glasses to children, they found improvement on math test scores compared to parental education even though the observed differences between the three groups were smaller than expected.

Williams et. al.⁴⁰ conducted a cross-sectional study among a cohort of 101 primary school children in Rhondda Cynon Taff, Wales to investigate the progress of educational attainment among children with normal vision and among children with defective vision. It was found that there was no association between anisometropia and the National Foundation of Education Research (NFER) score for the fogging test referral group ($r = 0.05$). Those who were hyperopic $<+3D$ achieved higher NFER and Scholastic Aptitude Test (SAT) scores while hyperopic children $>+3D$ provided

the lowest scores. The authors concluded that children with different refractive error were proficient in different tasks.

Rosner and Rosner⁴¹ conducted a cross sectional study among 782 children from 1st to 5th Grade in suburban and middle class schools in United States of America (USA) to determine the amount of hyperopia that can negatively affect academic performance. The outcome measure was test scores. It was found that significantly lower test scores were achieved among children with hyperopia exceeding +1.25D ($p=0.014$). The authors concluded that hyperopia among children may have a negative effect on school achievement.

Hannum et. al.⁴² conducted an analysis on 18817 children from two data sets in rural Gansu, China, to investigate the association between vision correction and educational performance, which included standard achievement tests and failure rate. The results showed that spectacle wear had a positive effect on mathematics and literacy tests and by correcting refractive error among children, failure rate was lower.

Shashidhar et. al.⁴³ conducted a cross sectional study among 1230 children 13 to 18 years old from corporate and private schools in Bangalore. They determined the health factors affecting scholastic performances of adolescents and found a decrease by 4.219 times in scholastic performance among students who have refractive error. Of all conditions, refractive error showed significant effect with scholastic performance.

Shankar et. al.⁴⁴ assessed the relationship between refractive error, particularly hyperopia, and emergent literacy and visual cognitive skills among 4 to 7 years old children ($n=41$) in a cross sectional study in Canada. Despite a small sample size, there was a correlation between moderate levels of hyperopia and a decrease in emergent literacy skills.

Saw et. al.⁴⁵ assessed the association between myopia and school performance among 10 to 12 years old Singaporean children. This was a cross-sectional study conducted among 740 children. It was found that among children who have myopia, children in the highest quartile in their scores had higher Intelligence Quotient (IQ) scores compared to those in the lowest quartile.

Chapter Three: Conceptual framework

Stages of psychosocial development

There are several psychologists⁴⁷⁻⁴⁹ who described development as a series of stages. A stage refers to a duration in development in which people show specific behaviour patterns and form particular capabilities. These theories share three common assumptions:⁵⁰

1. People go through stages in a typical order, with each stage building on capabilities developed in the preceding stage.
2. Stages are associated with age.
3. Development is intermittent, with qualitatively different capabilities evolving in each stage.

“Stages of psychosocial development” was used as the conceptual framework. The study explored both integration of the visually impaired children and the environment as cognitive development and physical exploration are inter-related. However, in this particular study we will use Erikson’s theory of psychosocial development because of the shortcomings of Piaget’s theory and Kohlberg’s theory.

Piaget’s Theory of Cognitive Development describes the children’s thinking at different ages of their lives. Children are seen to be active and have the innate ability to motivate and learn by themselves. Piaget’s theory, like Erikson’s, also hypothesized that children go through four stages of cognitive development with each stage building on the previous stage.⁴⁸ The four stages are sensorimotor (Birth to 2 years old), preoperational (2 to 7 years old), concrete operational (7 to 12 years old) and formal operational (12 years onward).⁴⁸ However, recent studies have shown that Piaget’s theory greatly underestimated children’s capabilities.⁵¹⁻⁵⁴

A study by Matthews⁵³ found that children as young as six to 11 years old were able to describe their environment and home area using structured stimuli. They could even recall most details from their journey home from school by “free recall mapping” technique. This is different from Piaget’s view that children at this age have three main weaknesses, which are centration, irreversibility, and egocentrism.⁴⁸ These weaknesses hinder the children’s ability to conserve information.⁴⁸ Furthermore, Hargreaves and Davies⁵² argued that because the ability of a child to

process information improves with age, the pre-operational stage of cognitive development of Piaget's theory might not have accurately described the children's cognitive ability. Metz⁵¹ also expressed concern that the complexity of children's cognitive development may have critical implications on designing children science curricula.

On the other hand, Kohlberg's theory reasoned that people often show the reasoning characteristic of several different levels simultaneously.⁵⁵⁻⁵⁷ Kohlberg's theory of moral development has 3 levels, which are the pre-conventional morality level, conventional morality and post-conventional level. At the pre-conventional level, often in children nine years old and younger, Kohlberg deduced that the moral code of children of these ages are solely shaped on the standards of the adults and the binding of the rules. When a child transitions into the conventional level, the child starts to internalise but not question the moral standards of the adult. And finally, the child transitions into the post-conventional level when the child is able to make judgement based on their own moral principles.

However, Kohlberg's theory has its own limitations. For instance, in one situation, a person might reason as if he is at a conventional stage, and in another situation, he might use reasoning typical of a post-conventional stage. Kohlberg's theory of moral development favours cultures that value individualism.⁵⁶ In other cultures, highly moral people may base their reasoning on communal values rather than abstract ethical principles. Table 2 summarizes the shortcomings of Piaget's and Kohlberg's theory.

Table 2: Shortcomings of Piaget's Theory of Cognitive Development and Kohlberg's Theory of Moral Development

Piaget's theory	Kohlberg's theory
Underestimated children's capabilities.	Several different levels of development can happen simultaneously.
Children simultaneously develop skills which makes the idea of stages seem less viable.	Moral development favours cultures that value individualism.
Ignored cultural influences.	The theory has cultural biasness

Erikson's theory of psychosocial development speaks to a process of personality development, where personality is said to develop in pre-set steps.⁴⁷ Erikson's task or crisis states that the "society encourages challenges that arise at predetermined times". Every stage has a task which

must be accomplished for a good outcome and it serves as a foundation before proceeding to the next stage. Erikson focuses on socialization, culture and history; with completion of each task relying on the child's relationship with his/her culture and that is a lifelong development. Table 3 summarizes the life stages and development tasks according to Erikson's theory of psychosocial development.

Impact of disability on psychosocial development

According to Erikson's Theory of Psychosocial Development,⁴⁷ a typical primary school-going child aged from 6 to 12 years old should have developed psychosocial skills such as building friendships, ability to learn skills, ability to make self-evaluation and participating in team play. However, having a disability such as vision impairment can disrupt this development of these psychosocial skills. For example, a visually impaired child may require help to access and interact with a stimulating surrounding, where a child with normal vision may not. A visually impaired child will need motivation to participate in social activities and acquire the skills through a participatory approach.⁵⁸ This can be achieved with the use of special devices by the child and special attentions given by the caregivers. Disability may further impact on the development of children in terms of their experience, emotions, attachment self-concept and development tasks.

Table 3 summarises the life stages and development tasks according to Erikson's theory of psychosocial development.

Experience

Vocabulary is acquired through environment and experiences.⁵⁹ The environment is where the opportunities are for learning, but the presence of physical limitations of a disability will deny those opportunities. Experience that is provided by the environment is needed for normal functioning of an individual. Since these experiences are interrelated, disability can have detrimental effects on both the child's environment and the caregivers. Research has also found that the divorce and abandonment rate is higher among parents of children with disabilities compared to parents of children without disabilities.⁶⁰

Table 3: Summary of life stages and development tasks according to Erikson's theory of psychosocial development

Life stage	Psychosocial crisis	Positive outcome	Definition	Developmental Task
Birth to 18m	Trust vs mistrust	Trust in people and environment	Enduring belief that one can attain one's deep and essential wishes	Social attachment Maturation of sensory, perceptual and motor function Primitive causality
18m to 3 yrs	Autonomy vs shame and doubt	Pride in self Assertion of will	Determination to exercise and self-control	Locomotion Fantasy play Language development Self-control
3yrs to 6 yrs	Initiative vs guilt	Able to initiate activities and enjoy learning	Courage to imagine and pursue valued goals	Sex-role identification Early moral development Self esteem Group play Egocentrism
6yrs to 12 yrs	Industry vs inferiority	Acquire skills for and develop competence in work Enjoy achievement	Free exercise of skills and intelligence in comparison of tasks	Friendship Skill learning Self-evaluation Team play
12yrs to 18yr	Group identity vs alienation	A strong group identity Ready to plan for the future	Ability to freely pledge and sustain loyalty to others	Physical maturation Emotional development Membership in peer group Sexual relationship

Emotions and Disability

There will be instances where caregivers respond differently to a disabled child compared to a normal child. This distortion of emotions may be due to a delay in development of expression of emotions in children with a disability. The child may feel rejected.⁵⁹ This has been shown in studies looking at children with disabilities where the children have presented weaker expression of emotions.^{61,62}

Attachment and Disability

Attachment is an important process of emotional bonding between mother and child.⁶² Ashburn and Schuster⁶² emphasize that bonding is very critical in building the child's identity and feelings of security. The successful bonding process is the foundation of the child's ability to be independent of his/her mother when the time comes. Hence, it is important for both the child and the parents. Sometimes the reaction from the child with disabilities can be mistaken as rejection by the parents and the parents will need to learn the skills to react normally to this behaviour. This also applies to the children themselves as reactions from parents can also be misinterpreted as rejection by the child.

Self-concept

A successful development in mastery and skills will lead to development of social self, followed by cognitive and physical and personal self.⁵⁹ If the child with a disability has less interaction with his/her surroundings or feels rejected by their peers and caregiver, it may negatively affect the development of self-concept. Teachers and parents will need to give full support in developing the interaction skills of the child with a disability to enable the child's development of self-concept.

Relationship of Disability to Developmental Tasks

Disability disrupts the normal growth and development of the child. This includes psychological, cognitive and physical development.⁶³ Disability can make the child become anxious and feel helpless over his/her life. This further contributes to a lack of enthusiasm for involving themselves in gaining new experiences. Even though there is no known direct association between disability and mental development, the inability to interact with the environment can have detrimental effects on the development of cognitive skills.⁶⁴ Tasks which must be acquired at each level may be

interrupted by the presence of a disability. Hence, the child will be affected because they have not mastered certain tasks.

Chapter Four: Methodology

Methodology development

While reviewing the literature on developing an assessment instrument, the process could be summarised into six main steps. There include but are not limited to:

- a. Determining the items that need to be included in the instrument through content validation
- b. Composing the wording in the draft instrument
- c. Designing a layout for the instrument
- d. Pretesting the instrument
- e. Making final adjustments of the instrument

Determining the items that needed to be included in the instrument through content validation

The first step in developing an assessment instrument is understanding the specific area that needs to be assessed, followed by what information is needed to be included in the instrument. This exercise is essential to ensure that the instrument measures what it is intended to assess. Howitt et al.⁶⁵ suggest that the best approach is to gather information using a qualitative approach, especially in a new area of study. This is the most effective way to explore the area of study and deciding the items that needs to be included in the instrument.

In understanding a new issue such as disability-related distress, focus group discussions provide an exploratory approach and are effective to understand new insight.^{66,67} Morgan⁶⁸ suggests that focus groups should be drawn from a specific population which then can be used to compare the other groups' reactions to the same concepts. Another advantage of using focus group discussion is that the focus group members can assist in providing language that is appropriate and acceptable to their population. Morgan⁶⁸ further suggests that the themes derived from focus group discussions are appropriate for generating and refining items in the instrument.

In order to gather information on the children's perceptions, emotional state and experiences, focus groups and interviews are the standard methods recommended.⁶⁹ These qualitative methods are considered as efficient and effective, where interviewees share their experiences and with their peers' ideas, more themes can be constructed. From these themes, new theories can be developed and the topic of interest can be better understood.^{69,70} Focus group discussions have also been

employed to successfully understand health issues among children and adolescents.⁷¹⁻⁷⁴ This is also the preferred method to construct the provisional items for several questionnaires which looked at the effects of vision impairment on the subjects' vision functions.^{18,21}

Polit and Beck⁷⁵ described content validity as the measure of how relevant, comprehensive and appropriate items related to the construct of interest are. According to Burns and Grove,⁷⁶ content validity can be determined at two stages: development stage and judgment stage. At the development stage, content validity is highest when items are derived from a sample that is drawn from a representative population. At judgmental stage, content validity is best examined using a panel of experts from relevant fields. They are then required to provide their feedback based on their judgement, focusing on whether the items are relevant and whether they are important.⁷⁷ The aim of this exercise is to ensure that the instrument covers what needs to be measured and omit irrelevant items that may divert the instrument from the initial objective.

Composing the wording in the draft instrument

One of the main downfalls in instrument development is the usage of complicated words or jargon that must be avoided.⁷⁸ If there is a need to include complicated words or jargon in the instrument, then explanations must be given to avoid confusion. Stone⁷⁸ also highlighted that precision is essential and this can be achieved by keeping only one idea in one item. The use of words that can lead to bias in responding should not be used.

Designing a layout for the instrument

Boynton and Greenhalgh,⁷⁹ pointed out that researchers do not spend sufficient time on making sure the physical presentation of the instrument is appropriate. The presentation includes font size, colour and the sequence of the items presented in the instrument. Studies have shown that an instrument with a poor layout can yield low response rates.

Stone⁷⁸ outlined the need to include an introduction section in the instrument to explain the purpose of the study to the participants. The sequence of the items should start from items which are neutral in nature, followed by more sensitive items. The visual aspects such as print, font types and size must be legible. If coding is used, care must be placed in making sure the coding is comprehensible, appropriate and unambiguous.⁷⁸

Pretesting the instrument

Pretesting the questionnaire ensures the instrument is able to measure what it claims to measure, or what is referred to as a valid and reliable instrument. Validation of the instrument is usually performed in a group of samples drawn from the target population of interest. The first criterion to be assessed is how relevant each of the items in the instrument are to the target population.⁷⁸ The higher the relevance the respondents placed on the item, the more likely the item will be retained in the instrument.⁸⁰ The inclusion of a control group is also a way to determine whether the instrument is measuring what it intends to measure and sometimes termed as face validity.⁸¹

The second criterion to be assessed is the frequency or the rate of occurrence of each item among the respondents. The more frequent the respondent experiences the items included in the instrument, the higher the probability the item is to be retained in the instrument.⁸⁰ The frequency or rate of occurrence is usually associated with the severity of the condition. The more severe the condition, the higher the frequency or rate of occurrence of certain items in the instrument. The understanding of the rate of occurrence between the different levels of the disability (from normal to severe disability) can also indicate whether the instrument covers the range of diversity of the measurement.⁸¹ This is to avoid ceiling effect.⁸¹

Two other validations mentioned in the literature are concurrent and criterion validity.⁸¹ Concurrent validity is a measure to comparing the developed instrument with another instrument which is administered at the same time while criterion validity looks at how much the outcomes of the developed instrument corresponds to the standard instrument.⁸¹ Both of these validations were not included in the methodology because there was no “gold standard” in measuring disability related distress at present.

Study design

This study has two components:

- a. Qualitative component to understand DRD of vision impairment due to uncorrected refractive error in primary school learners and determine a provisional item list for an assessment Instrument
- b. Quantitative component that is used to determine retention of items in the final assessment Instrument

Sites of research

This study was conducted in four public schools in the education district of Pinetown, eThekweni Metro Municipality, province of KwaZulu Natal, South Africa. The list of eligible schools, obtained from the Department of Education, was categorized according to the socio-economic status, area and language of instruction.

Sampling, sample size and enrolment

The methodology section was discussed separately for Phase 1, Phase 2 and Phase 3 in order to ensure flow of content and ease of understanding by the reader.

- Phase 1 was the process to identify the themes that form the items in the provisional list.
- Phase 2 was the process to determine the content validity of the provisional list
- Phase 3 was pre-testing to determine which items were to be retained in the final instrument

In Phase 1, a total of twelve focus groups were planned. The groups were primarily divided on the basis of vision status: normal vision or vision impaired (in accordance to the WHO Refractive Error Working Group Recommendations, WHO REWG).⁸² The WHO REWG⁸² recommended that the level of significance of vision impairment should be at 6/12. At this level of vision impairment, the child can notice the decrease in vision and be given full refraction and correction. Correcting the child's vision at this level of vision impairment is to improve spectacle usage and spectacle wear compliance among children.

Four mixed gender group discussions and eight single gender group discussions with children aged 5–12 years old were conducted. We ensured that the groups were relatively small to enable the moderator to manage “turn taking” without the use of visual cues. Attempts were made to assign

participants who knew each other to their respective groups so that they felt comfortable to participate in the discussion.

Our subjects in Phase 1 included:

- (i) School-going children with vision impairment due to uncorrected refractive errors (Primary subjects, PS)
- (ii) School-going children with no vision impairment (Secondary subjects, SS)

Four to eight subjects were interviewed from each age group in Primary Subjects (PS) and Secondary Subjects (SS). We ensured that the age and gender distribution of recruited participants reflected the target population (Male:Female ratio of 48% to 52%).

In Phase 2, we recruited a multi-disciplinary panel of experts, which included expertise in refractive error, child psychiatry and psychology, low vision and rehabilitation, special education and public health. This was to ensure a robust mix of feedback on appropriateness of content and breadth of coverage on the provisional list was obtained. We included ten health professionals as Tertiary Subjects (TS), who were:

- Ophthalmologists, n=2
- Optometrists, n=2
- Psychiatrist, n=1
- Psychologist, n=1
- Rehabilitative/occupational therapist, n=1
- Low vision specialist, n=1
- Special educationist, n=1
- Public health specialist, n=1

In Phase 3, a sample matrix was drawn up to include all relevant subject groups. Each cell of the sample matrix contained at least 5 to 10 participants. Table 4 shows the sampling matrix of subjects included in Phase 3.

Selection criteria

The study participants in Phase 1 and Phase 3 were learners from Grade 1 to Grade 5 (age 5 years to 12 years old). They were learners who had normal vision and children with vision impairment

due to uncorrected refractive error. Learners who have vision impairment due to other causes and children with co-morbidities were excluded. Learners with learning difficulties were excluded after consulting the class teachers.

In Phase 2, health care professionals with at least 5 years of clinical experience working with children with vision impairment due to uncorrected refractive error were included.

Recruitment of focus groups

Head teachers and class teachers were contacted to recruit children aged 5 – 12 years old. Short interviews were conducted with class teachers to ensure the child had no other learning disabilities (such as dyslexia) which could confound the study.

First, the recruitment of participants was done by an optometrist to identify children with and without vision impairment due to uncorrected refractive error. The following steps⁸³ were followed:

- a) LogMAR tumbling E chart (Precision Vision, Villa Park, Illinois) was placed at 4 meters from the child. Vision was screened monocularly. Letters on line 6/12 and 6/24 were isolated.
- b) The vision was then screened at 6/12.
- c) If a child passed 6/12, a +2.00DS lens was placed in front of the right eye, and the vision was re-screened at 6/24. If the child passed 6/24, s/he was categorised as having refractive error.

If the child failed 6/24, s/he had no refractive error.

If the child failed 6/12, a pinhole was put in front of the right eye, and the right eye's VA was re-screened at 6/12.

If the child passed 6/12, the child was categorised as having refractive error.

If the child failed 6/12, ophthalmoscopy was performed on the child to determine any ocular morbidities of the eye. Children who found to have ocular morbidities other than refractive error were referred to the eye clinic for further management

- d) Step a) to c) for was repeated for the left eye.

A child was considered passing vision at 6/12 or 6/24 line if the child was able to correctly identify 4 or more letters out of five letters while s/he was considered failing vision at 6/12 or 6/24 line if s/he was able to correctly identify three or less letters out of five letters.

The children did not need any prior experience of focus group discussion to take part in this study. A research information pack and consent forms together with a formal request letter were sent to the parents of the eligible learners. Consent to participate in the screening was first obtained from the parents. For the children who were eligible to participate in the research, informed consent was obtained from their parents or legal guardians and assent was further obtained from the children.

Methods

Phase 1: Generation of disability related distress issues

We aimed to compile an exhaustive list of relevant disability-related distress (DRD) issues that covered the domains of interest. The following criteria were used to determine the inclusion of issues into the instrument:

- a) Relevance: the extent to which school-going children have experienced issues on the list including problems, limitations and positive experiences;
- b) Breadth of coverage: to ensure that all DRD issues were included

In considering the information gathered from interviews, the responses of PS and SS were given highest priority.⁸⁴ Primary subjects and SS interviews were the most important steps identified by Rothman et al. to ensure that high content validity was achieved and demonstrated.⁸⁵ DRD measures were derived in a learner-centred way, to ensure greatest content validity and reliability.

Interviews with Primary Subjects (PS) and Secondary Subjects (SS)

Qualitative or semi-structured interviews were employed to ensure content validity as per the Food and Drugs Administration guidelines.⁸⁴ PS and SS were recruited from 2 types of schools (rural and semirural).

a. Interview technique

In semi-structured interviews, the PS and SS described their experiences and provided information freely. Both groups of subjects were encouraged to comment on the issues and to score each issue

for relevance to themselves. All interviews were recorded for later analysis. The question route used to conduct the focus groups with PS and SS is shown in Annex 1.

b. Breadth of coverage

All information provided by the PS and SS was transcribed for later analysis. This method ensured accuracy of wording as used by subjects and reduced any bias that could result from the selective noting of subjects' comments.

During the open or semi-structured interview, the subjects were encouraged to consider all issues which they believed to be relevant to vision impairment due to uncorrected refractive error. A constant review of accumulating data ensured the interviews continued until no new issues were raised.

c. Review of provisional list of issues

From the responses gathered, we constructed a provisional list of DRD issues, which was then given to approximately nine subjects, followed by a debriefing interview to determine what the various issues meant to the subjects, the extent to which subjects have experienced the problems, limitations, or positive experiences to check for any significant omissions ("debriefing") (Annex 2).

This was to refine items and avoid ambiguity in the final list. The debriefing interviews were conducted individually. Subjects were encouraged to explain their responses to each item as they read through the items ("think aloud" technique). After completion of the item list, a structured interview was used to explore additional issues on the lists provided, or by the subject's own experiences.

Phase 2: Construction of the draft instrument

Interviews with tertiary subjects (TS)

Tertiary subjects (TS) were recruited from health professionals with a variety of expertise, and years of experience of both sexes. The provisional list of issues and the core instrument were presented to TS, for feedback on appropriateness of content and breadth of coverage. The question route used to conduct the focus groups with TS is shown in Annex 3. When interviewing subjects about

DRD issues, TS were asked to rate issues for relevance and for relative importance. If an issue was common, it was retained as an item.

To avoid ambiguity when interpreting responses, the TS were asked to consider each issue and to score its relevance a on a scale of 1 to 4, with:

- 1 being not relevant
- 2 being little relevant
- 3 being quite relevant and
- 4 being very relevant

To determine relative importance, TS were asked to rank each item for importance on a 5-point scale of issues which they perceived to trouble the PS most (or cause the greatest problems/ nuisance/ distress).⁸⁶ Subjects were also asked to identify issues which they thought should definitely be included or definitely excluded.

Furthermore, the TS were asked to examine the wording of the items to see if the items needed to be re-worded. If the TS suggested that these items to be reworded, the reasons for rewording and their suggestions were recorded.

Constructions of provisional item list

The statements were constructed in a clear, brief and unambiguous manner. Conditional questions were broken into their component parts,^{87,88} for example

1. Do you have a problem seeing the blackboard? (yes/no).
2. If yes, how much have you been troubled by this?

All statements were negatively worded and the scale relating to functioning scored was in a positive direction.^{86,89} Differences in the orientation of items (negative versus positive) avoided possible confusion and biased responses. PS and SSs' attentions were drawn to these differences by highlighting or underlining keywords and/or phrases. Items of similar orientation were grouped together in the item list.⁹⁰⁻⁹²

Phase 3: Pre-testing

The aim of pre-testing was to identify and solve potential problems in interview administration (such as the phrasing of questions, the sequence of questions) and to identify missing or redundant issues. The pre-testing questionnaire is shown in Annex 4.

The pre-testing consists of:

1. Administration of the provisional item list

Provisional item list was administered to school-going children with normal vision and children with vision impairment due to uncorrected refractive error to obtain a response score for each item, together with rating of relevance and importance. The responses were considered in the final analysis of items. In addition, each item of the new item list was rated by each subject for “importance” and “relevance” to that individual. Importance and relevance were ranked from the most to the least important or relevant items.

2. The structured interview

Structured interviews were conducted with each subject after their completion of the entire instrument, which consisted of the core instrument and a debriefing questionnaire to ensure completeness and acceptability of the items in the list. The interviewee was directed to each item separately and invited to further comment about:

- The particular experience to which the item refers (for example, is this experience related to vision impairment due to uncorrected refractive error?);
- The wording of the item itself (for example, was the item difficult to respond to? Was the item annoying, confusing or upsetting?)

These general questions were supplemented by the further probing of selected items that are expected to cause some difficulty or items that appeared to be troublesome during the interview.

The pre-testing interviews were completed with two questions directed to the entire questionnaire.

- Were there questions that you found irrelevant?
- Can you think of additional issues that are relevant for you but are not included in this questionnaire?

3. Analysis and retention of items

Any difficulties arising in the wording of items were corrected. Each item was considered for retention according to comments made by participants. Items viewed as irrelevant by a substantial number of subjects were considered for rejection.

Data analyses

Data management

Data recording forms collected were stored in a locked cabinet in the office and only the principal investigator had access. The quantitative data captured in the recording form were checked for their completeness and consistencies on the examining site. The data were captured on a day-to-day basis. Research data will be retained for a period of 5 years after the project ends. At the end of the data storage period (5 years), all data will be destroyed thoroughly and completely to make sure data cannot be extracted or re-constructed.

Interview transcripts

Each interview was transcribed verbatim. Transcripts were comprehensively reviewed and coded to highlight the views and perceptions of the children. Words and phrases (codes) obtained from the transcripts were used to link similar statements between focus groups. A database was created consisting of text with its associated codes. We organized and extracted portions of text linked by common codes. We then displayed the systematic relationships between coded texts. Using the search function in Excel, it was then possible to locate related ideas across the entire focus groups data by bringing together strands of data. This process allowed us to explore the data and conceptualize the findings.

Children with normal vision were included in the focus group discussions as they served as controls. Only topics that were mentioned by the primary subjects (children with vision impairment) but not the children with normal vision were considered as an item in the provisional list.

Two criteria were used to qualify any topic as an item. The first criterion was that at least two participants had to make substantive comments on the topic in a single focus group. This required

that they did more than just agree with each other, but that they elaborated on the topic on the basis of their experience.

The second selection criterion was that the topic was discussed by at least one child in two different groups. Both criteria had to be satisfied before the topic was regarded as an item. Redundant items identified were reviewed once again by the principal investigator before they were omitted as items.

Generation of provisional list of issues

The list of DRD issues raised by PS and SS in Phase 1, together with the responses of the TS, were reviewed by the principal investigator. Decisions to exclude issues raised during interviews were based on the following features:⁹³

- Redundancy, either because of overlap with the core questionnaire or because of the generation of multiple closely related issues
- Upsetting, issues which were potentially distressing were excluded, if no acceptable alternative wording could be found
- Lack of relevance, if an issue was raised by only one subject and was scored very low for relevance by the health care professionals it was excluded

If one or more PS, SS or TS mentioned an issue, it was included, provided that the rationale was plausible. Since the number of PS and SS interviewed was large (>30) and the list of issues was scored by learners and the experts, issues that had a low mean score (mean score < 2) for relevance or importance were excluded.⁸⁰

Generation of the final instrument

To reduce the provisional list to a shorter list of items the feedback of the PS and SS was given the greatest weight in the selection of items. In Phase 3, some selection measures were applied to remove unnecessary items, balanced against the need to produce a list that adequately covered all the DRD concerns of the learners. Comments provided by PS and SS were taken into consideration.

The relevance and importance ratings provided by PS were considered before review of the other responses and items which failed to score adequately were excluded.

- Relevance: The item was retained if >60% scored 3 or 4 “quite relevant and very relevant”
- Problems (e.g., symptoms) that relatively few PS described
- Abilities that relatively few PS were limited in
- Parameters of each item to be considered included the mean score and the number of PS reporting the item (score 2, 3 or 4) divided by the total number that completed the item (prevalence ratio). A full range of responses was important. Items that had limited variance were excluded.

The following cut-off points were used for selection of items for retention in the final list (after consideration of importance and relevance as noted above):

1. Mean score > 1.5
2. Prevalence ratio >30% or prevalence of scores 3 or 4 >50%
3. Range > 2 points
4. No significant concerns expressed by PS, SS and TS (e.g. item is upsetting, ambiguous)
5. Compliance: less than 5% of the responses to the item in the debriefing session suggested that the issues were not related to vision impairment due to uncorrected refractive error^{80,94–96}

The trend of overall rate of occurrence among children with normal vision, mild vision impairment and severe vision impairment across the different age groups was assessed employing the linear trend test. The overall rate of occurrence among children with normal vision, mild vision impairment and severe vision impairment was tested with ANOVA tests (means of three groups).

The trend of overall rate of relevance among children with mild vision impairment and severe vision impairment across the different age groups was assessed employing the linear trend test. The overall rate of relevance among children with mild vision impairment and severe vision impairment was tested with the z-test (means of two groups).

Ethics considerations

Potential risks or discomfort

The study posed no physical, social, economic and legal risk. We anticipated minimal psychological risks where participants could feel uneasy, sad or emotionally distressed while answering questions regarding quality of life and, barriers and challenges experienced due to their disability related distress.

To further protect the participants against psychological risks, they were reminded of their right to withdraw from the research or limit their participation if they became uncomfortable. Counselling and psychological support was made available for participants who experienced distress. This proved to be unnecessary as they were no reported cases of psychological distress as a result of the interview process. All participants were thoroughly debriefed after research sessions were completed.

The study did not involve use of drugs or invasive clinical procedures. It posed no drug-related or physical discomfort. Ethics approvals were obtained from the Human and Social Science Ethics Committee (HSSEC), University KwaZulu Natal (Annex 5) and Ethics Committee, Department of Education (Annex 6).

Permission to conduct the study was sought from the school principals. The process included:

- a. Engaged gatekeeper (Department of Education) prior to project commencement to obtain its permission to conduct the study.
- b. Letters were sent to the school principals indicating the intention of the study (Annex 7).
- c. Each principal was briefed on the aim and the process of the study, enabling them to successfully canvass support from the teachers, parents and learners.

A copy of the information document in layman language was given to the participants' parents prior to the study (Annex 8). Informed consent was sought from parents after explaining the aims, potential risks and discomfort of the study to the subjects (Annex 9). Subjects' participations were voluntary and they reserved the right to withdraw from the study at any stage.

Since the study involved children, certain measures were taken to protect the autonomy of the learners and to prevent social stigmatization and/or secondary victimization of learners. They were:

a. Helping the parents and learners in making reasoned judgment

Full autonomy requires that the parents and learners be able to understand that the learners will only be asked to share the experience of their daily lives. We gave the eligible learners, parents and teachers a briefing session so that any queries were answered. This helped them to make reasoned judgments about the effect their participation would have on them, and made a decision to participate. Most of all, emphasis was made that their decision would be free from coercive influence.

b. Informed consent process

In the informed consent obtainment process, we provided the learners, parents and teachers with full disclosure that the study was explorative in nature, that the psychological risks were minimal, and that the interviews would be conducted by trained social scientists. The social scientists would be able to answer the learners' concerns in the debriefing session. We also gave the learners and parents an extended opportunity to ask questions before they decided whether or not to participate.

c. Other measure

If any serious unanticipated risks manifested, we were prepared to stop the study and report to the Humanities and Social Studies Ethics Committee. A dedicated psychologist was on standby if a child needed counselling thereafter. We also protected the subjects' privacy and confidentiality by preventing the disclosure of, or unauthorized access to, data that could be linked to a child's identity.

An information document (Annex 10) was given to learners over 6 years old or learners who could read to obtain their assent to participate in the study. (Annex 11).

Privacy and confidentiality

We minimized the need to collect and maintain identifiable information about the participants. The only demographic information that was recorded were age and grade. Data were collected anonymously or the identifiers were removed and destroyed as soon as possible. If there was any identifiable data, these were encrypted. Fact sheets containing identifiers (for example, names and addresses) from survey instruments containing data after receiving from study participants were removed.

Interviews were conducted in a classroom far away from the crowd. In the event of face-to-face interview, it was conducted without the presence of a third party. We linked individual participants with their responses and assigned each participant a study ID prior to collecting data. On a separate document, each participant's name along with their unique study ID (e.g., 001) was recorded and stored separately from data documents.

Principals were contacted to recruit eligible children for the study. No further advertising (notices or other media) was used to ensure confidentiality of the children's vision status. Vision screening was performed for all students. Study participants were made aware of their vision status and the causes of vision impairment, if any. Learners presenting with vision impairment as a result of refractive error were referred to the nearest eye care facility for further investigation and intervention.

Research feedback was given in the form of briefing session after each focus group discussion and interview. During the briefing session, participants were encouraged to ask any questions and raise concerns about their anonymity in the study, and the interviewers explained in detail that their names would be excluded from the results analysis.

Chapter five: Results

Phase 1

Demographic profiles of children interviewed in Phase 1

In Phase 1, vision screening was conducted on children in 4 primary schools (2 rural and 2 semi-rural). Of the 7,693 children screened, 439 (5.7%) children failed. Of those, 122 (27.8%) children were found to have vision impairment (visual acuity less than 6/12), of which 68 (55.7%) children had uncorrected refractive error, and 41 (44.3%) of them were of other ocular morbidities (such as amblyopia, corneal scar and posterior segment morbidities).

The 68 children found to have vision impairment due to uncorrected refractive error were asked to participate in the focus group discussions, but five children refused to participate. Hence, 63 children with vision impairment due to uncorrected refractive error (thereafter referred to as primary subjects) and 13 children with normal vision (thereafter referred to as secondary subjects) were included in our sample to participate in the focus group discussion, with 36 (47%) boys and 40 (53%) girls. The breakdown of the number of children is shown in Table 5.

We further categorized the primary subjects into mild vision impairment (visual acuity $<6/12$ but $\geq 6/60$, thereafter referred to as MVI) and severe vision impairment (visual acuity $<6/60$, thereafter referred to as SVI). There were 35 children with MVI and 28 children with SVI in our sample.

Table 4: Demography profile of children interviewed in Phase 1

Group Number	Gender, Number of children		Vision status, Number of children			Grade, Number of children				
	Male	Female	NV	MVI	SVI	I	II	III	IV	V
1	3	4	1	5	1	3	4	0	0	0
2	3	3	0	2	4	0	4	2	0	0
3	4	3	2	2	3	0	1	2	2	2
4	2	5	3	3	1	0	0	1	2	4
5	5	0	0	3	2	5	0	0	0	0
6	6	0	2	4	0	1	5	0	0	0
7	0	6	2	1	3	0	1	4	1	0
8	0	7	0	2	5	0	0	1	6	0
9	8	0	1	3	4	0	0	0	0	8
10	0	4	0	2	2	0	0	3	1	0
11	0	8	0	5	3	0	3	5	0	0
12	5	0	2	3	0	0	0	0	3	2
Total	36	40	13	35	28	9	18	18	15	16

Note 1: NV= Normal vision; MVI= Mild vision impairment; SVI= Severe vision impairment

Disability-related distress identified from focus group discussions

Loss of self-confidence

Theme 1: I feel sad that I cannot participate with friends in games/fun because I cannot see well.

The respondents expressed their sadness by saying that they “do not feel nice” or “feel sad” when they cannot participate with their peers in activities because they do not have clear vision. This was particularly articulated in both focus groups in Grade 5. These activities happened in both in- and outside of school, which included sports activities in school (games) and after school playground activities (fun). The loss of confidence was shown when they believed that “I cannot see well enough”.

As one member said:

“I don’t feel nice because I want to have fun with my friends in the playground but I cannot see well enough”.

(Group members nodding their heads in unison showing agreement with what was said.)

Moderate Vision Impairment, Grade 5

The distress was also felt because of the lack of participation. Their loss of confidence was further demonstrated by the respondents in that they perceived that they are as good as their peers, but the fact that their vision is reduced has caused them to reduce their participation time in these activities. This was stressed by another group member, saying that:

“I cannot see as well as them (their friends) but I think I am good too, especially in soccer. I do feel sad sometimes. I have one-and-a-half hour of PE and I just play for half an hour.”

(Group members giggling)

Severe Vision Impairment, Grade 5

Theme 2: I feel unhappy that I have to stop playing games because I cannot see clearly.

Unlike Theme 1, where the affected children were unable to participate in the activities, there were also children who expressed that they once took part in the activities, but stopped because their vision deteriorated. This was reflected in their reduced ability to perform the activity over time and eventually ceasing to participate when it became too difficult. A participant expressed:

“I have to stop playing soccer. I cannot see the people and the ball. I fell down a lot. When I kick the ball, I kick air. I don’t feel happy because I bought my sport equipment and they are expensive. But I can’t play with my friends.”

Severe Vision Impairment, Grade 5

In another group, the same was felt where he “don’t feel good”, and the loss of confidence was again shown when he “see his friend in the pool, I don’t feel good”. And in some cases, the respondents also experienced injury when taking part in these activities and were regarded as “clumsy”.

“Yes. I don’t play often. I used to swim but because I cannot see clearly, especially under water, I stopped swimming. I think I will swim very well if I can see better. When I see my friends in the pool, I don’t feel good.”

Moderate Vision Impairment, Grade 5

“I stopped playing jumping castle because I cannot see where I am jumping and I hurt myself when the other children become rough. I cried but my mother said I am just clumsy.”

Moderate Vision Impairment, Grade 3

Theme 3: I feel dependent that I need assistance from my teacher/parents/siblings because I cannot see clearly.

The last themes elicited from the domain of loss of confidence was “dependence”. The respondents found that their lack of/reduced ability to do certain tasks because of reduced vision necessitated them seeking assistance from other people, including parents, peers, siblings and teachers. This was particularly experienced by the younger respondents.

Two groups from Grade 1 said:

“My parents will need to help me because I cannot read from the book. The words are very small. They will help to read it out to me so that I can copy. Sometimes my sister helps me too. But ... (I’m) too slow.”

Another group member followed:

“I asked (my) sister most of the time, but she is also struggling with her own writing (examination).

Moderate Vision Impairment, Grade 1

Another member from Grade 1 said the following:

“(When) I cannot read from the blackboard, I will copy from my friend. I also ask help from my teacher. But there are many friends in the classroom. I have to wait until the teacher is free. Sometimes I feel shy to ask my teacher.

Severe vision impairment, Grade 1

Loss of self-worth

Theme 1: I feel I am not as good as my friends because I cannot see as clearly as them.

The loss of self-worth was evident among the respondents when they tried to compare their skills with their peers, whom the respondents perceived to be on par with in terms of their skills. The respondents reported that they feel “not as good as my friends” or “I cannot see as clear as (my friends)”.

Many respondents spoke of similar experiences with two respondents saying:

“I read and write stories and poems but I feel very intimidated because I can’t see as well as them. They are more clever because they can see better than me.”

Moderate Vision Impairment, Grade 5

“(Looking down at the floor)... Sometimes my parents stop me from playing because I cannot see as clear as my friends and they are worried that I will hurt myself.”

Moderate Vision Impairment, Grade 3

Theme 2: I feel lonely that I cannot play with my friends because they can see better than me.

The inability to participate in activities and games with their friends due to their reduced vision had evidently made the respondents feel lonely by saying they were either “uncomfortable, isolated and lonely” or “I’m alone”.

The loss of self-worth can be seen when they expressed that “I am not as good (as their friends)”. Frustration was observed in the respondents who had to give up on playing with their friends despite their desire to participate.

One female respondent said:

“Sometimes if it’s too hot, my eyesight becomes worse. I cannot see and I cannot play hockey with my friends. I feel very uncomfortable, isolated and lonely. I really want to play with my friends but I am just not as good. I cannot see the ball.”

(Other group members laughing)

Moderate Vision Impairment, Grade 5

“Many times I find it difficult to see my friends, especially it’s too sunny. I gave up after a while and I’m alone.”

Severe Vision Impairment, Grade 4

Theme 3: I feel jealous that my friends do better than me because I cannot see clearly.

The respondents also expressed feelings of being jealous, grumpy and envious of their peers who out-perform them because of better vision. For example, respondents from Grade 5 and Grade 4 said that:

“I fail my exams all the time. I am passionate and hardworking. I also exercise and play sports. But my friends are all doing better even though they are not as hardworking as me. I am jealous. I am as good as them!”

Severe Vision Impairment, Grade 5

“I want to compete with my friends. I feel envious that they always do better because they can read faster than me. They can run faster. They see better. But my teachers give me assistance. But I feel like I am also at the same level with my classmates.

Severe Vision Impairment, Grade 4

The respondents felt so as a result of comparison with their peers on their actual ability to carry out the same activities, or it was caused by the fact that they were “not chosen” to perform certain activities. Respondents also mentioned that:

“I am grumpy and envious because they see well, they are always chosen by the teachers to do class activities.”

Severe Vision Impairment, Grade 5

“I cannot pay full attention in whatever I am doing. I feel jealous of _____ because he is always doing so well. I think it’s my small eyes.

(Another member pulling his eyes up to demonstrate the inability to see clearly while other members started giggling)

Moderate Vision Impairment, Grade 1

Loss of interconnection/interaction with community

Theme 1: I do not go for outside school activities with my friends as much as I wish because I cannot see very well.

There were a considerable number of respondents who experienced inability to participate in activities outside of school, such as “going out with their friends”. The loss of interaction was shown when the respondents felt that they were a burden because they had to be “taken care of” and their friends “have to let me win”. For example:

“I don’t go out with them (my friends). They feel they have to wait for/ take care of me/ I’m slow.”

Severe Vision Impairment, Grade 1

“I’m not invited because they have to let me win.”

Severe Vision Impairment, Grade 2

Theme 2: I do not go to family/friends parties because I cannot see very well.

The respondents expressed that they were unable to participate in parties, organized by friends, family or relatives. Due to their reduced vision, they were asked not to take part in these parties so that they were not injured in the process or “get lost” in unfamiliar places. Their participation in parties was also limited as the respondents were dependent on a chauffeur, such as an older brother.

A respondent from Grade 5 said that:

“I like visiting friends and relatives. We walk to their places sometimes. But because I cannot see clearly, my mother does not allow me to go alone, unless my brother goes with me. But he is older. He is in Grade 12. He needs to study. So I stay at home until he is free.”

Moderate Vision Impairment, Grade 5

And another respondent also said that:

“I rarely go out to family gatherings. I am slow. I always get lost. I am not sure but I think it’s because I cannot see clearly and I cannot recognise the road.”

Severe Vision Impairment, Grade 5

Suspicion, humiliation and fight

Theme 1: I am excluded from games because I cannot see clearly.

While the respondents did not report obvious suspicion and physical abuse (fight) from their friends and the community, they did experience humiliation in the form of “exclusion”. Some experienced “exclusion” because they were seen as a burden to the bigger group as they “made them lose in the competition”. Some respondents also have lost interest in the activities they were participating in or intended to participate in.

Respondents said that:

“They exclude me from the team because I cannot see clearly. I make them lose in the competition.”

Moderate Vision Impairment, Grade 5

“Sometimes they ask me to sit aside in the playground. I don’t want to do it anymore.”

Severe Vision Impairment, Grade 2

Theme 2: I am called names because I cannot see very well.

One of the humiliations felt by the respondents was being given nicknames. This was reported by most of (7 out of 10) the focus groups. The nicknames given to them because of their vision impairment included:

- “Four eyes” (Moderate Vision Impairment, Grade 4)
- “Mancane”, which means small (Moderate Vision Impairment, Grade 4)
- “Mehlo ekati”, which means cat eyes (Moderate vision Impairment, Grade 3)
- “Shota”, which means short (Severe Vision Impairment, Grade 2)

Some experienced being ridiculed by being “laughed at”, such as:

“They laughed at me. They say I am small eyes.”

Moderate Vision Impairment, Grade 2

Discrimination

Theme 1: I felt left out that I am asked not to participate because I cannot see clearly.

The respondents particularly felt “left out” and “ignored” when asked to “sit on one side” as a result of their reduced ability to perform certain tasks caused by their reduced vision. A respondent mentioned that they have “the right to play too”, indicating some degree of discrimination being felt in those circumstances.

“Sometimes, I felt left out when playing because I cannot see clearly. But I have the right to play too! They just ignored me.

Moderate Vision Impairment, Grade 3

“I don’t like it when my class teacher asks me to sit at one side because I cannot see the blackboard clearly. They beat me sometimes. Because I am slow in reading and copying. I cannot see clearly and (cannot) read fast.”

Moderate Vision Impairment, Grade 2

Theme 2: I feel sad that I am asked not to participate because I cannot see clearly.

Similarly, the respondents’ inability to read or play certain sports, such as “cannot read the notes” or “I cannot catch the ball” due to their reduced vision made them “sad and cried” or “felt very bad”. This feeling was felt from being told “not able to join” and “not chosen”.

“I want to sing in the choir. I was told that I am not able to join because I cannot read the notes from the blackboard. I was very sad and I cried. I tried again the next year.”

Moderate Vision Impairment, Grade 4

“(I) went for sports day but never get chosen for soccer team. My brother plays school team. But I am always not chosen. They say I cannot catch the ball. I know I’m short but I also cannot see the ball. I felt really bad and I told my mum. She said try other sports but I like soccer.

Severe Vision Impairment, Grade 3

Theme generation table is shown in Appendix 2.

Generation of draft provisional list

Using the responses from the subjects, a draft provisional list was developed, with the aim of determining its content validity. The items included in the draft provisional list were:

1. I feel sad that I cannot participate with friends in games/fun because I cannot see well.

2. I feel unhappy that I have to stop playing games because I cannot see clearly.

3. I feel dependent because I need assistance from my teacher/parents/siblings because I cannot see clearly.

4. I feel that I am not as good as my friends because I cannot see as clearly as them.

5. I feel lonely as I cannot play with my friends because they can see better than me.

6. I feel jealous that my friends do better than me because I cannot see clearly.

7. I do not go for outside school activities with my friends as much as I wish because I cannot see very well.

8. I do not go to family/friends' parties because I cannot see very well.

9. I feel excluded from games because I cannot see clearly.

10. I feel left out when I am asked not to participate because I cannot see clearly.

11. I feel sad that I am asked not to participate because I cannot see clearly.

Phase 2

Demographic profiles of panel of experts

To determine the content validity of the draft provisional list, a panel of experts was included as the tertiary subjects. Their experience managing children with vision impairment or disability ranged from 5 to 18 years. The detailed demographic breakdown shown in Table 6.

Table 5: Demography of tertiary subjects in Phase 2

Demography	Number (%)
Field of expertise	
Low vision and rehabilitation	2 (20)
Paediatric ophthalmology	2 (20)
Paediatric optometry	2 (20)
Psychiatry and psychology	2 (20)
Special education	1 (10)
Public health	1 (10)
Years of practice (years)	
5-7	3 (30)
8-10	4 (40)
>10	3 (30)
Sex	
Male	3 (30)
Female	7 (70)
Total	10

Rate of relevance of the provisional list by the tertiary subjects

The rating of relevance of the items in the provisional list were consistent for Item 1 and 2, where all tertiary subjects rated them as very relevant (rating 4). Furthermore, there were no respondents who rated Item 2, 3, 4, 5, 7, 8, 9 and 11 as not relevant (rating=1) and little relevant (rating=2).

However, Item 6 was rated as not relevant by three respondents and little relevance by four respondents. The detailed breakdown of responses is shown Table 7.

Table 6: Rate of relevance of the provisional list by the tertiary subjects

Provisional list	Rate of relevance, number of respondents			
	1	2	3	4
1. I feel SAD that I cannot participate with friends in games/fun because I cannot see well.	0	0	0	10
2. I am UNHAPPY that I have to stop playing games because I cannot see clearly.	0	0	0	10
3. I feel DEPENDENT that I need assistance from my teacher/parents/siblings because I cannot see clearly.	0	0	3	7
4. I feel I AM NOT AS GOOD AS MY FRIENDS because I cannot see as clear as them.	0	0	3	7
5. I feel LONELY that I cannot play with my friends because they can see better than me.	0	0	3	7
6. I feel JEALOUS of my friends that they do better than me because I cannot see clearly.	3	4	3	0
7. I do not go for outside school activities with my friends as much as I wish because I cannot see very well.	0	0	4	6
8. I do not go to family/friends parties because I cannot see very well.	0	0	5	5
9. I feel EXCLUDED from games because I cannot see clearly.	0	0	2	8
10. I feel LEFT OUT that I am asked not to participate because I cannot see clearly.	1	2	3	4
11. I feel SAD that I am asked not to participate because I cannot see clearly.	0	0	4	6

Ranking of importance of the provisional list by the tertiary subjects

In ranking the importance, the respondents were first asked to select five items which they felt were the most important items to be included in the Instrument. They were then asked to rank the chosen items from 1 to 5 (one being most important and 5 being least important of the five items). The respondents were then asked to indicate which items they felt should be excluded, with their justifications.

In terms of ranking of importance, there were no clear trends in the responses from the tertiary subjects. However, there were six subjects who responded that Item 6 should be excluded because jealousy was a “subjective” feeling and is an “upsetting” issue. The detailed breakdown of rating of importance is shown in Table 8.

Table 7: Ranking of importance of the provisional list by the tertiary subjects

Provisional list	Rank of importance, number of respondents					
	1	2	3	4	5	Excluded
1. I feel SAD that I cannot participate with friends in games/fun because I cannot see well.	3	1	1	0	2	0
2. I am UNHAPPY that I have to stop playing games because I cannot see clearly.	0	3	0	0	2	1
3. I feel DEPENDENT that I need assistance from my teacher/ parents/ siblings because I cannot see clearly.	2	0	2	0	1	0
4. I feel I AM NOT AS GOOD AS MY FRIENDS because I cannot see as clear as them.	3	0	0	2	2	0
5. I feel LONELY that I cannot play with my friends because they can see better than me.	0	0	2	2	1	0
6. I feel JEALOUS of my friends that they do better than me because I cannot see clearly.	0	0	0	0	0	6
7. I do not go for outside school activities with my friends as much as I wish because I cannot see very well.	0	1	2	1	1	0
8. I do not go to family/friends parties because I cannot see very well.	0	2	1	1	0	1
9. I feel EXCLUDED from games because I cannot see clearly.	0	0	2	1	0	0
10. I feel LEFT OUT that I am asked not to participate because I cannot see clearly.	2	0	0	1	1	1
11. I feel SAD that I am asked not to participate because I cannot see clearly.	0	1	0	2	0	0

Wording and wording suggestions

When asked about the wording of the items, tertiary subjects gave a range of suggestions. One crucial point made by the majority of tertiary subjects was the need to give explanations to the children because the terms used in the provisional list are very “technical” (n=6) and “may be difficult to be understood” (n=4).

Queries and suggestions that were raised by tertiary subjects are shown verbatim as follows:

- a. What does “cannot participate” mean?
- b. What constitutes “games or fun” and “school activities”?
- c. What is the difference between “cannot participate”, “not asked to participate” and “stopped playing”?
- d. Is “cannot do things on my own” better than “dependent”?
- e. Does the child understand the meaning of “lonely”, “helpless” and “excluded”?
- f. Maybe you should define “excluded” and “unsafe” might be a better word.
- g. Some examples will be helpful.

Suggestions were also given by the professionals on the inclusion of the concepts of “helplessness” and unsafe”. After collating the suggestions from the tertiary subjects, a linguistic expert was engaged to refine the items in the provisional list. Detailed wording suggestions are shown in Table 9.

Table 8: Wording suggestions by tertiary subjects

Item number	Wording suggestions
1	<p>I feel sad that I cannot see well.</p> <p>I feel sad that I cannot play games with my friends because I cannot see well</p>
2	<p>I feel unhappy when I cannot play games with my friends because I cannot see clearly</p> <p>I feel unhappy that I have to stop doing certain activities because I cannot see clearly. (Give examples of activities)</p> <p>I feel sad that I cannot play games with my friends because I cannot see clearly</p>
3	<p>I feel sad that I cannot do things on my own because I cannot see clearly</p> <p>I feel sad that I have to ask for help to do things because I cannot see clearly</p> <p>I do not like asking for help from others because I cannot see clearly</p>
4	<p>I feel I am not as good as my friends because I cannot see clearly like them</p>
5	<p>I feel lonely that I cannot play with my friends because I cannot see clearly.</p> <p>I feel lonely that I cannot participate in activities with friends because they can see better than me. (Give examples of activities)</p>
6	<p>I feel jealous that my friends do better than me because they can see better than me.</p>
7	<p>I do not join my friends for outdoor activities/fun because I cannot see clearly.</p> <p>I do not go out with my friends for outdoor activities/fun because I cannot see clearly.</p>
8	<p>I do not go to parties because I cannot see clearly.</p> <p>I do not go to family activities as much as I wish because I cannot see very well.</p> <p>I do not go for gatherings because I cannot see very well.</p>
9	<p>I feel excluded from participating in activities when I am asked to leave because I cannot see clearly.</p> <p>I feel excluded for not participating in activities because I cannot see clearly</p>
10	<p>I feel left out when I cannot participate because I cannot see clearly</p>
11	<p>No suggestions given.</p>

The Instrument for pre-testing is shown below in Figure 2.

Part 1- Introduction

- I. This is a list of feelings that the child **might or might not have** depending on how well s/he can see clearly.
- II. The questions should be directed to the child to indicate how often s/he has experienced the following feelings.
- III. If s/he has never experienced that particular feeling, mark X in box 1.
- IV. If s/he responded that s/he has experienced that particular feeling, you will need to determine how often does s/he experienced them.
 - a. If it is sometime, mark X in box 2.
 - b. If it is most of the time, mark X in box 3.
 - c. If it is all the time, mark X in box 4.

Part 2- Basic information of the child

Name: _____ Class: _____

Age: _____ Date: _____

Unique Study Number: _____

- Vision Screening: ① Pass
 ② Fail- cannot see 6/12 but can see 6/60
 ③ Fail- cannot see 6/60

Part 3- Questionnaire

1. I feel **SAD** that I cannot participate with friends in games/fun because I cannot see well. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Cannot participate means the child **wants to** take part **but is unable** to do so.

Games or fun can be **sports, recreational activities** in the playground or/and entertainment/video games at home.

2. I am **SAD** that I have to stop playing games because I cannot see clearly. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Stop playing means the child **once played** the games but **discontinued** playing.

Games can be **sports, recreational activities** in the playground or/and entertainment/video games at home.

3. I am **SAD** that I cannot do things on my own because I cannot see clearly. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Cannot do things on my own means the child **needs assistance** from other person/s to carry out certain activities.

4. I feel I am **NOT AS GOOD AS MY FRIENDS** because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

5. I feel **LONELY** that I cannot play with my friends because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Lonely means feeling isolated because of having few or no friends.

6. I do not join my friends for outdoor activities/fun because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

7. I do not go to parties because I cannot see very well.

- ① Never ② Sometimes ③ Most of the time ④ All the time

8. I feel **EXCLUDED** because I am asked not to participate in school activities because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Excluded means feeling denied because of prohibition to take part in school activities.

School activities can be sports, classroom activities or extracurricular activities within school compound. Activities may include reading, painting, singing, poetry, etc).

Asked not to participate means an active request to not take part in certain activities.

9. I feel **SAD** that I am **asked not to participate** in out-of-school activities because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Outside school activities can be sports beyond school compound, or extracurricular activities such as activities in the playground or at the child's or peer's house compound.

10. I feel **HELPLESS** that I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Helpless mean feeling incapable, weak or powerless to carry out tasks, activities or responsibility.

11. I feel **UNSAFE** because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Unsafe means a feeling of insecurity that harm may occur to the child.

Figure 2: Instrument for pre-testing

Phase 3

Demographic profiles of the sample

Pretesting was conducted on 120 children. Of those, 60 children (60/120=50%) had normal vision, with an almost equal male to female ratio (53.3%:46.7%). We aimed to include 12 children in each grade. However, we found more Grade 1 children (n=14, 23.3%) and less Grade IV children (n=10, 16.7%) in the sample. The majority of our sample were 6 years old (n=17, 28.3%) followed by 8 years old (n=13, 21.7%) and 10 years old (n=12, 20.0%).

The median age of the study subjects were 8 years old (Inter-quartile range, IQR 6 – 10) for children with normal vision, 9 years old (IQR 8 – 10) for children with mild vision impairment and 9 years old (IQR 8 – 9) for children with severe vision impairment. The boxplots are shown in Figure 3.

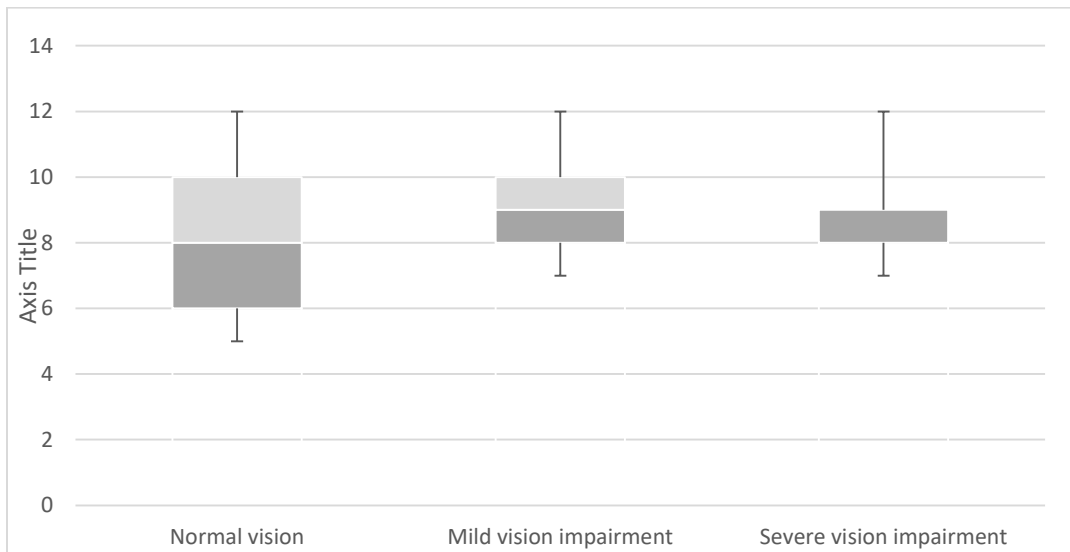


Figure 3: Age and vision status in the subjects (n=120)

There were 60 children who were identified to have vision impairment. Thirty of them had mild vision impairment including 13 boys and 17 girls. The majority of those were from Grade III (n=9, 30%) and 8 years old (n=8, 26.7%). Thirty children had severe vision impairment with the highest number from Grade II and Grade III (both n=8, 26.7%), and 8 and 9 years old (both n=8, 26.7%). The detailed breakdown is shown in Table 10.

Table 9: Demography profile of respondents in Phase 3, (n=120)

	Normal vision N‡ (%*)	Mild vision impairment N (%)	Severe vision impairment N (%)
Sex			
Male	32 (53.3)	13 (43.3)	14 (47.7)
Female	28 (46.7)	17 (56.7)	16 (52.3)
Grade			
I	14 (23.3)	3 (10.0)	6 (20.0)
II	12 (20.0)	5 (16.7)	8 (26.7)
III	12 (20.0)	9 (30.0)	8 (26.7)
IV	10 (16.7)	7 (23.3)	4 (13.3)
V	12 (20.0)	6 (20.0)	4 (13.3)
Age			
6	17 (28.3)	3 (10)	2 (6.6)
7	2 (3.3)	2 (6.6)	2 (6.6)
8	13 (21.7)	5 (16.7)	8 (26.7)
9	9 (15.0)	8 (26.7)	8 (26.7)
10	12 (20.0)	6 (20.0)	3 (10.0)
11	4 (6.7)	5 (16.7)	4 (13.4)
12	3 (5.0)	1 (3.3)	3 (10.0)
Total	60	30	30

Note 2: ‡N=number; %*=percentage

Rating of occurrence among children with normal vision

The rate of occurrence of the items among the children with normal vision was low, ranging from 1.00 to 1.18. From Table 11, one can observe that among the children with normal vision (n=60), none rated any of the disability-related-distress items as 3 (most of the time) or 4 (all the time). Almost all reported that they never experienced any of the distress presented. Item 1 stands out as having the highest number of children (n=11, 18.3%) rating it as 2 (sometimes).

Table 10: Rate of occurrence of each item in provisional list for children with normal vision (n=60)

Item no	Rate of occurrence				Average rate, Score (SD†)
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)	
1	49 (81.7)	11 (18.3)	0 (0)	0 (0)	1.18 (0.39)
2	53 (88.3)	7 (11.7)	0 (0)	0 (0)	1.12 (0.32)
3	56 (93.3)	4 (6.7)	0 (0)	0 (0)	1.07 (0.25)
4	58 (96.7)	2 (3.3)	0 (0)	0 (0)	1.03 (0.18)
5	59 (98.3)	1 (1.7)	0 (0)	0 (0)	1.02 (0.13)
6	55 (91.7)	5 (8.3)	0 (0)	0 (0)	1.08 (0.28)
7	58 (96.7)	2 (3.3)	0 (0)	0 (0)	1.03 (0.18)
8	58 (96.7)	2 (3.3)	0 (0)	0 (0)	1.03 (0.18)
9	58 (96.7)	2 (3.3)	0 (0)	0 (0)	1.03 (0.18)
10	60 (100)	0 (0)	0 (0)	0 (0)	1.00 (0)
11	59 (98.3)	1 (1.7)	0 (0)	0 (0)	1.02 (0.13)

Note 3: ‡ N= Number of respondents, * %= percentage, † SD= Standard deviation

The average time needed for answering the questionnaire was 3.39 minutes (Standard Deviation, SD 0.78 minutes). There were no children who reported needing further assistance in answering the questionnaire. However, there were three children who found the questions confusing and one child who found the questions upsetting. The reason stated was that they did not understand why they were asked these questions when they have no eye problems.

Rate of occurrence among children with mild vision impairment

Among children with mild vision impairment, there was a spread in the ratings of the disability related distress items, with the average rate of occurrence ranging from 2.17 to 2.43. Most children (50.0% to 73.4%) reported having experienced the distresses sometimes. However, 20% to 40% of children reported having experienced the distresses most of the time. The detailed breakdown is shown in Table 12.

Table 11: Rate of occurrence of each item in provisional list for children with mild vision impairment (n=30)

Item no	Rate of occurrence				Average rate, Score (SD†)
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)	
1	2 (6.7)	21 (70)	7 (23.3)	0 (0)	2.17 (0.53)
2	2 (6.7)	20 (66.7)	7 (23.3)	1 (3.3)	2.23 (0.63)
3	1 (3.3)	22 (73.4)	7 (23.3)	0 (0)	2.20 (0.48)
4	1 (3.3)	21 (70.0)	8 (26.7)	0 (0)	2.23 (0.50)
5	2 (6.7)	17 (56.7)	11 (36.6)	0 (0)	2.30 (0.60)
6	5 (16.7)	15 (50.0)	9 (30.0)	1 (3.3)	2.20 (0.76)
7	2 (6.7)	18 (60.0)	9 (30.0)	1 (3.3)	2.30 (0.65)
8	2 (6.7)	15 (50.0)	12 (40.0)	1 (3.3)	2.40 (0.68)
9	1 (3.3)	17 (56.7)	10 (33.3)	2 (6.7)	2.43 (0.68)
10	3 (10.0)	17 (56.7)	9 (30.0)	1 (3.3)	2.27 (0.69)
11	3 (10.0)	19 (63.3)	6 (20.0)	2 (6.7)	2.23 (0.73)

Note 4: ‡ N= Number of respondents, * %= percentage, † SD= Standard deviation

The average time needed for answering the questionnaire was 4.37 minutes (SD 0.92 minutes). No children reported that the questions were confusing or upsetting.

Rate of occurrence among children with severe vision impairment

The average of occurrence among the children with severe vision impairment was high, ranging from 3.27 to 3.70. Most rated the items as 3 (20.0% - 56.7%) or 4 (36.7% - 76.7%) while none reported ever having experienced the distresses. The detailed breakdown is shown in Table 13.

Table 12: Rate of occurrence of each item in provisional list for children with severe vision impairment (n=30)

Item no	Rate of occurrence				Average rate, Score (SD†)
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)	
1	0 (0)	3 (10.0)	16 (53.3)	11 (36.7)	3.27 (0.64)
2	0 (0)	2 (6.6)	17 (56.7)	11 (36.7)	3.30 (0.60)
3	0 (0)	3 (10.0)	12 (40.0)	15 (50.0)	3.40 (0.68)
4	0 (0)	1 (3.3)	11 (36.7)	18 (60.0)	3.57 (0.57)
5	0 (0)	3 (10.0)	12 (40.0)	15 (50.0)	3.47 (0.57)
6	0 (0)	1 (3.3)	7 (23.4)	22 (73.3)	3.70 (0.54)
7	0 (0)	0 (0)	13 (43.3)	17 (56.7)	3.57 (0.50)
8	0 (0)	2 (6.6)	11 (36.7)	17 (56.7)	3.57 (0.57)
9	0 (0)	1 (3.3)	8 (26.7)	21 (70.0)	3.67 (0.55)
10	0 (0)	1 (3.3)	7 (23.4)	22 (73.3)	3.70 (0.53)
11	0 (0)	1 (3.3)	6 (20.0)	23 (76.7)	3.73 (0.52)

Note 5: ‡ N= Number of respondents, * %= percentage, † SD= Standard deviation

The average time needed for answering the questionnaire was 5.37 minutes (SD 1.94 minutes). There were no children who reported that the questions were confusing or upsetting.

Figure 4 shows that there was no significant trend in the overall rate of occurrence of the DRD issues across different ages within the different vision status groups (NV, Linear trend test, $p=0.98$, MVI, Linear trend test, 0.87 and SVI, Linear trend test, $p=0.84$). However, the overall mean rate of occurrence of the DRD issues among the children increases when their vision decreases (ANOVA, $p=0.001$).

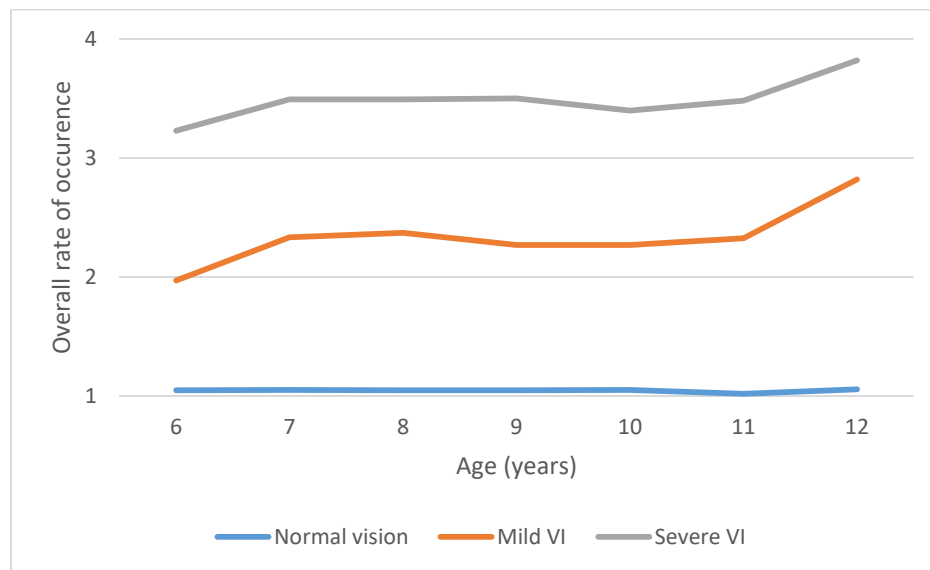


Figure 4: Overall rate of occurrence among children across different ages (n=120)

Rate of occurrence among primary subjects

Table 14 shows ratings of all 60 primary subjects (children with mild and severe vision impairment) combined for analysis. Most children (55.0% - 58.0%) reported having either experienced the distress sometimes, most of the time or all the time. The prevalence ratio for rating 3 and 4 ranges from 56.7% to 68.3% and prevalence ratio for rating 2, 3 and 4 ranged from 91.7% to 98.5%.

Table 13: Rate of occurrence of each item on the provisional list for all primary subjects (n=60)

Item no	Rate of occurrence				Prevalence ratio [†]	Prevalence ratio 2, 3 and 4
	1 N [‡] (%*)	2 N (%)	3 N (%)	4 N (%)	3 and 4 N (%)	and 4 N (%)
1	2 (3.3)	24 (40.0)	23 (31.7)	11 (18.3)	34 (56.7)	58 (96.7)
2	2 (3.3)	22 (36.7)	24 (40.0)	12 (20.0)	36 (60.0)	58 (96.7)
3	1 (1.7)	25 (41.7)	19 (31.7)	15 (25.0)	34 (56.7)	59 (98.3)
4	1 (1.7)	22 (36.7)	19 (31.7)	18 (30.0)	37 (61.7)	59 (98.3)
5	2 (3.3)	20 (33.3)	23 (38.7)	15 (25.0)	38 (63.3)	58 (96.7)
6	5 (8.3)	16 (26.7)	16 (26.7)	23 (38.7)	39 (65.0)	55 (91.7)
7	2 (3.3)	18 (30.0)	22 (36.7)	18 (30.0)	40 (66.7)	58 (96.7)
8	2 (3.3)	17 (28.3)	23 (38.7)	18 (30.0)	41 (68.3)	58 (96.7)
9	1 (1.7)	18 (30.0)	18 (30.0)	23 (38.7)	41 (68.3)	59 (98.3)
10	3 (5.0)	18 (30.0)	16 (26.7)	23 (38.7)	39 (65.0)	57 (95.0)
11	3 (5.0)	20 (33.3)	12 (20.0)	25 (41.7)	37 (61.7)	57 (95.0)

Note 6: [‡] N= Number of respondents, * %= percentage, [†] Prevalence ratio = rate of occurrence

Rate of relevance among children with mild vision impairment

Table 15 reflects the spread in the ratings of relevance of the disability related distress items among children with mild vision impairment (n=30). Most children reported that the items were of little relevance (rating number 2) or quite relevant (rating number 3). There were 43.3% to 66.7% of the children who rated that the items were of little relevance, while 23.4% to 43.3% rated the items quite relevant.

Table 14: Rate of relevance of each item on the provisional list for children with mild vision impairment (n=30)

Item no	Rate of relevance			
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)
1	2 (6.6)	16 (53.3)	8 (26.7)	4 (13.4)
2	2 (6.6)	20 (66.7)	7 (23.4)	1 (3.3)
3	1 (3.3)	18 (60.0)	10 (33.4)	1 (3.3)
4	2 (6.6)	15 (50.0)	11 (36.8)	2 (6.6)
5	0 (0)	15 (50.0)	12 (40.0)	3 (10.0)
6	0 (0)	15 (50.0)	12 (40.0)	3 (10.0)
7	1 (3.4)	13 (43.3)	13 (43.3)	3 (10.0)
8	1 (3.4)	13 (43.3)	13 (43.3)	3 (10.0)
9	3 (10.0)	13 (43.3)	13 (43.3)	1 (3.4)
10	4 (13.3)	14 (46.7)	9 (30.0)	3 (10.0)
11	3 (10.0)	16 (53.3)	8 (26.7)	3 (10.0)

Note 7: ‡ N= Number of respondents, * %= percentage, † SD= Standard deviation

Rate of relevance among children with severe vision impairment

Table 16 shows that there were no children with severe vision impairment who rated the items as not relevant. The majority of children rated the items quite relevant or very relevant. In this group, 23.4% to 63.3% of the children rated the items as quite relevant and 23.4% to 73.3% rated the items as very relevant.

Table 15: Rate of relevance of each item on the provisional list for children with severe vision impairment (n=30)

Item no	Rate of relevance			
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)
1	0 (0)	1 (3.3)	22 (73.3)	7 (23.4)
2	0 (0)	3 (10.0)	17 (56.6)	10 (33.4)
3	0 (0)	1 (3.3)	19 (63.3)	10 (33.4)
4	0 (0)	1 (3.3)	10 (33.4)	19 (63.3)
5	0 (0)	1 (3.3)	13 (43.4)	16 (53.3)
6	0 (0)	0 (0)	11 (36.7)	19 (63.3)
7	0 (0)	2 (6.7)	9 (30.0)	19 (63.3)
8	0 (0)	1 (3.3)	7 (23.4)	22 (73.3)
9	0 (0)	0 (0)	8 (26.7)	22 (73.3)
10	0 (0)	0 (0)	8 (26.7)	22 (73.3)
11	0 (0)	0 (0)	8 (26.7)	22 (73.3)

Note 8: ‡ N= Number of respondents, * %= percentage, † SD= Standard deviation

Rate of relevance among primary subjects

When all 60 primary subjects (children with mild and severe vision impairment) were combined for analysis, it was found that between 35 (58.3%) to 45 (75.0%) children rated the items as quite relevant or very relevant. This is shown in Table 17.

Table 16: Rate of relevance of each item on the provisional list for all primary subjects (children with mild and severe vision impairment, n=60)

Item no	Rate of relevance				Rate of relevance of 3 and 4 N (%)
	1 N‡ (%*)	2 N (%)	3 N (%)	4 N (%)	
1	2 (3.3)	17 (28.3)	30 (50.0)	11 (18.3)	41 (68.3)
2	2 (3.3)	23 (38.3)	24 (40.0)	11 (18.3)	35 (58.3)
3	1 (1.6)	19 (31.7)	29 (48.3)	11 (18.3)	40 (66.7)
4	2 (3.3)	16 (26.7)	21 (35.0)	21 (35.0)	42 (70.0)
5	0 (0)	16 (26.7)	25 (41.7)	19 (31.7)	44 (73.3)
6	0 (0)	15 (25%)	23 (38.3)	22 (36.7)	45 (75.0)
7	1 (1.6)	15 (25%)	22 (36.7)	22 (36.7)	44 (73.3)
8	1 (1.6)	14 (23.3)	20 (33.3)	25 (41.7)	45 (75.0)
9	3 (5.0)	13 (21.7)	21 (35.0)	23 (38.3)	44 (73.3)
10	4 (6.7)	14 (23.3)	17 (28.3)	25 (41.7)	42 (70.0)
11	3 (5.0)	16 (26.7)	16 (26.7)	25 (41.7)	41 (68.3)

Note 9: ‡ N= Number of respondents, * %= percentage

Table 18 reflects the mean scores for the items' rate of relevance fell between 2.23 (SD 0.82) and 2.60 (SD 0.68) for mild vision impairment and between 3.20 (SD 0.49) and 3.70 (SD 0.47) for severe vision impairment. When combined, both mild vision impairment and severe vision impairment (n=60), the mean scores for rate of relevance was between 2.75 (SD 0.64) and 3.14 (SD 0.64).

Table 18: Mean scores of rate of relevance for children with mild vision Impairment (n=30) and severe vision impairment (n=30) and all primary subjects (n=60)

Item no	Mean scores of rate of relevance, Score (SD†)		
	Mild vision impairment	Severe vision impairment	All primary subjects
1	2.47 (0.82)	3.20 (0.49)	2.84 (0.66)
2	2.23 (0.63)	3.27 (0.64)	2.75 (0.64)
3	2.37 (0.62)	3.40 (0.57)	2.89 (0.60)
4	2.43 (0.73)	3.70 (0.53)	3.07 (0.63)
5	2.57 (0.77)	3.43 (0.57)	3.00 (0.67)
6	2.60 (0.68)	3.63 (0.50)	3.12 (0.66)
7	2.60 (0.72)	3.50 (0.63)	3.05 (0.68)
8	2.60 (0.72)	3.67 (0.55)	3.14 (0.64)
9	2.40 (0.72)	3.70 (0.47)	3.05 (0.60)
10	2.37 (0.85)	3.70 (0.47)	3.04 (0.66)
11	2.37 (0.81)	3.70 (0.47)	3.04 (0.64)

Note 10: †SD= standard deviation

Error! Reference source not found. shows that there was no significant difference in the mean score of relevance of the DRD issues across different ages within the vision status groups (Children with MVI, Linear trend test, $p=0.78$ and SVI, Linear trend test, $p=0.88$). However, the overall mean scores of relevance of the DRD issues among the children with severe vision impairment was significantly higher than the children with mild vision impairment (z-test, $p=0.02$).

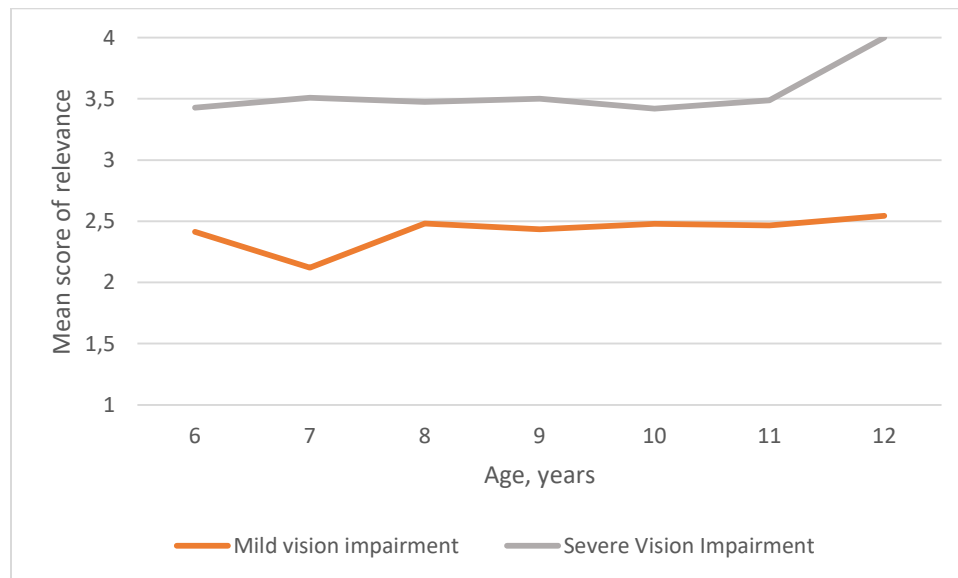


Figure 5: Mean score of relevance among children of mild vision impairment (n=30) and severe vision impairment (n=30) across different ages

Retention of items in the final assessment Instrument

As previously detailed, pre-set item retention parameters were used to decide whether each item was to be included into the final Instrument. The parameters were:

- Mean score of relevance > 1.5
- Prevalence ratio >30% or prevalence of scores 3 or 4 >50%
- Range > 2 points
- No significant concerns expressed by learners and experts (e.g. item is upsetting, ambiguous)
- Compliance - less than 5% of the responses to the item in the debriefing session suggested that the issues were not related to vision impairment due to uncorrected refractive error

All eleven items in the provisional list fulfill the retention parameters. They were all included in the final instrument. The results were summarized in Table 19 and the final instrument is shown in Figure 6.

Table 17: Retention of items in the final assessment instrument

Item	Retention parameters					Does it comply to vision impairment due to uncorrected refractive error? (Yes/No)	Retain (Yes/No)
	Was score of relevance more than 1.5? (Yes/No)	Was prevalence ratio for score 3 or 4 more than 50%? (Yes/No)	Was range of importance more than 2 points? (Yes/No)	Were there significant concerns? (Yes/No)	Does it comply to vision impairment due to uncorrected refractive error? (Yes/No)		
1	Yes	Yes	Yes	No	Yes	Yes	
2	Yes	Yes	Yes	No	Yes	Yes	
3	Yes	Yes	Yes	No	Yes	Yes	
4	Yes	Yes	Yes	No	Yes	Yes	
5	Yes	Yes	Yes	No	Yes	Yes	
6	Yes	Yes	Yes	No	Yes	Yes	
7	Yes	Yes	Yes	No	Yes	Yes	
8	Yes	Yes	Yes	No	Yes	Yes	
9	Yes	Yes	Yes	No	Yes	Yes	
10	Yes	Yes	Yes	No	Yes	Yes	
11	Yes	Yes	Yes	No	Yes	Yes	

Part 1- Introduction

- I. The purpose of completing this questionnaire is to determine the disability related distress among school children with vision impairment due to uncorrected refractive error.
- II. This is a list of feelings that the child **might or might not have** depending on how well s/he can see clearly.
- III. The questions should be directed to the child to indicate how often s/he has experienced the following feelings.
- IV. If s/he has never experienced that particular feeling, mark X in box 1.
- V. If s/he responded that s/he has experienced that particular feeling, you will need to determine how often does s/he experienced them.
 - a. If it is sometime, mark X in box 2.
 - b. If it is most of the time, mark X in box 3.
 - c. If it is all the time, mark X in box 4.

Part 2- Basic information of the child

Name: _____ Grade: _____

Age: _____ Date: _____

- Vision Screening:
- ① Pass
 - ② Fail- cannot see 6/12 but can see 6/60
 - ③ Fail- cannot see 6/60

Part 3- Questionnaire

1. I feel **SAD** that I cannot participate with friends in games/fun because I cannot see well. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Cannot participate means the child **wants to** take part **but is unable** to do so.

Games or fun can be **sports, recreational activities** in the playground or/and entertainment/video games at home.

2. I am **SAD** that I have to stop playing games because I cannot see clearly. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Stop playing means the child **once played** the games but **discontinued** playing.

Games can be **sports, recreational activities** in the playground or/and entertainment/video games at home.

3. I am **SAD** that I cannot do things on my own because I cannot see clearly. (Mark one)

- ① Never ② Sometimes ③ Most of the time ④ All the time

Cannot do things on my own means the child **needs assistance** from other person/s to carry out certain activities.

4. I feel I am **NOT AS GOOD AS MY FRIENDS** because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

5. I feel **LONELY** that I cannot play with my friends because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Lonely means feeling isolated because of having few or no friends.

6. I do not join my friends for outdoor activities/fun because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

7. I do not go to parties because I cannot see very well.

- ① Never ② Sometimes ③ Most of the time ④ All the time

8. I feel **EXCLUDED** because I am asked not to participate in school activities because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Excluded means feeling denied because of prohibition to take part in school activities.

School activities can be sports, classroom activities or extracurricular activities within school compound. Activities may include reading, painting, singing, poetry, etc).

Asked not to participate means an active request to not take part in certain activities.

9. I feel **SAD** that I am **asked not to participate** in out-of-school activities because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Outside school activities can be sports beyond school compound, or extracurricular activities such as activities in the playground or at the child's or peer's house compound.

10. I feel **HELPLESS** that I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Helpless means feeling incapable, weak or powerless to carry out tasks, activities or responsibility.

11. I feel **UNSAFE** because I cannot see clearly.

- ① Never ② Sometimes ③ Most of the time ④ All the time

Unsafe means a feeling of insecurity that harm may occur to the child.

Figure 6: Final assessment Instrument to measure disability related distress among primary school learners with vision impairment with uncorrected refractive error

Chapter six: Discussion

The study aimed to develop an instrument that measures disability related distress (DRD) in visually impaired school learners due to uncorrected refractive error. In Phase 1, eleven themes were generated from the focus group discussions and included as items in the draft provisional list. Subsequently, one item was excluded from the draft provisional list after it was reviewed by a panel of ten experts in Phase 2. One item was recommended by the experts and was added to the provisional list. In Phase 3, pre-testing found an increasing trend of the rate of occurrence of the items from NV to MVI and SVI. The average time needed for answering the questionnaire increased from NV to MVI and SVI. Finally, all eleven items in the provisional list fulfilled the retention parameters.

Phase 1

Vision plays a critical role in a child's life in both their developmental and their educational learning.¹⁰ The inability to see clearly can cause a delay in achieving developmental milestones, such as effective communication and social skills acquisition. The delay in developing these life skills, which are extremely essential for participation in group activities (such as games) can consequently cause the children with vision impairment to lag behind their peers, in both curricular and extra-curricular activities.⁹⁷ Miller,⁹⁸ while trying to analyse and adapt teaching techniques according to the social skills development for children with visual impairment, found that the lack of social skills and social activities among children with vision impairment is exceptionally detrimental because these are closely linked to self-concept and self-esteem and can negatively impact the overall well-being of the child. He further emphasized that social skills lead on to social learning which has its foundation in good learning and task development skills that many children with vision impairment have not developed.⁹⁸

One important and preferred method of developmental learning is through games/fun because it involves exploration, organization and synthesis of information while interacting with other children. When children are unable to do so due to their inability to see clearly, they feel discouraged and this physical limitation impacts negatively on their curiosity to learn and explore.⁹⁹ Seligman,¹⁰⁰ in an animal study, described this as "learned helplessness" and the exhibition of passive and helpless behavior can be expressed simply as "unhappiness" by children.

Our study showed that the children with vision impairment stopped playing games as they found effective participation extremely difficult.

In many cases, children with vision impairment in the classroom had not been identified prior to our study, and hence their educational needs were not being met. For example, the ability to read and copy from the chalkboard was greatly reduced and the children placed great reliance on their friends sitting next to them. Our finding is in agreement with Margalit's study,¹⁰¹ which compared the leisure activities of 51 cerebral palsied children to normal controls. The study found that children with cerebral palsy were also more dependent on others. While the nature of disability between the current study and Margalit's study is different, there seemed to be a similarity in their feeling of dependence. This feeling of dependence, as described by Kitchin,¹⁰² can be a distress that is internalized by people with disability. The sense of dependency can also lead to marginalization.^{102,103,104}

While some children expressed their need for more assistance from their teachers, Watson et. al.¹⁰⁵ warned that assistance should be given cautiously because any such assistance may emphasize that children with disabilities need "extra help" and thus portray the children to be "different" from their peers. This can further create academic identities among the children. One of the subjects in our study reported that she was labeled as a "bad student" because she was not good in English.

Furthermore, environmental factors, such as lack of facilities, limitation of play space and lack of physical assistance¹⁰⁶⁻¹⁰⁸ may also discourage children with vision impairment from participating in games that they used to play. In mainstream public schools, infrastructure is designed according to the needs of "average" children. Children with disabilities may face restrictions in these physical environments and find themselves unable to integrate into the schooling community.¹⁰⁹

The feeling of "not as good as my friend" was described as an internalized representation and interestingly, was observed by Holt¹¹⁰ among children with learning disabilities.¹¹⁰ The study by Holt¹¹⁰ was undertaken to understand what "disabled" children's experiences are and how they performed while going to mainstream schools in England. The study found that the children see themselves as "not good" at many subjects taught in schools. Holt¹¹⁰ argued that this may be due to the learning expectations of adults towards the children. This demonstrated that to improve classroom participation of children with vision impairment, interventions have to be implemented

beyond the four walls of the education institution and include the parents, family, the community and the society.

Another important observation in our study was that children were age-organized into different grades. While it is common practice in school environments with high student-teacher ratios to have some form of group organization to meet societal expectation, children with vision impairment, or any disability, may not have the same level of competency as children with normal vision even if they are of the same age.

The subjects in our study experienced the feeling of loneliness due to their inability to participate in activities with friends. Feeling lonely has been described as a “children factor” that is caused by lack of confidence in social activities such as playing with friends, or feeling awkward or self-consciousness among the children with vision impairment.^{111,112} This in turn can cause friendlessness and limited empathic abilities (the ability to share feelings together) because the child’s emotional, behavioural and social spheres become affected.¹¹³⁻¹¹⁶ Loneliness can be a threat to a child’s development as supportive relationships are critical for developing social relationships, and help the child to participate in daily activities.¹¹⁶⁻¹¹⁸

The feeling of jealousy was experienced by a few subjects who expressed that this was due to the frequent “punishments” they got from teachers because they were “slower” than their peers. This was seen as a “hidden rule”¹¹⁹ to reward those who perform according to expectations and penalize them if they perform below the set standards. When observing their peers being praised by teachers for academic achievement, and thus reaffirming their peers’ identity as being a success,¹²⁰ the primary subjects felt a sense of inferiority.

The primary subjects in the study experienced exclusion and stigmatization in the school environment, especially in group activities. Their interaction with children with normal vision became challenging when there was an obvious difference in their ability to perform in group activities requiring good vision. Children with vision impairment were seen as a burden to their team and blamed as the reason for a team’s under-performance. They were often excluded from their team to avoid the team failing in group activities. This phenomenon was also observed by Baker and Donnelly,¹²¹ and Davis and Watson.¹²² In Baker and Donnelly’s study,¹²¹ they observed that children with fragile X syndrome were prevented from participating in activities which their “normal” friends could. Davis and Watson¹²² further questioned whether this “supposed

integration” actually works if the adults do not observe and listen to the opinions of the children with disabilities when designing educational framework and policies.

Dear et. al.,¹²³ in their meta-analysis of 44 hierarchy studies, also observed that children with learning disabilities are usually more excluded from children’s cultures.¹²³ The failure to participate in leisure and recreational activities such as games, becomes a predictor to lower life satisfaction and well-being in their adult life^{124,125} because they are restricted in their ability to develop social, intellectual, emotional and communication skills.

In our study, the primary subjects were often given derogatory nicknames in their schools. This was also recognised by Law and Dunn¹⁰⁹ who described that disabilities restricted the children to their constrained environment, causing them to be unable to participate in community activities, thus preventing them from integrating socially.¹⁰⁹ This was often caused by negative community attitudes towards children with disability.^{126–130}

As mentioned previously, children with vision impairment were often asked not to participate in group activities. Brown and Gordon¹³¹ perceived this as society’s distorted reaction towards disability. In their study documenting daily activities of children with disabilities and those with no disabilities in the United States, they found that children with disabilities spent more time engaging in dependent and quiet activities compared to socially engaging activities. The feeling of being “left out” may further make the children feel more handicapped because they are prevented from accumulating experience from these group activities. Their inability to participate in group activities prohibits them from acquiring a broad range of life skills, feeling incompetent and self-determination becomes weak. This was also described by Fraser¹³² who further argued that in order to overcome the impact of disabilities, intervention should target the contributing factors and not the impairment only. The inability of the children with disability to participate in meaningful activities decreases their quality of life.^{133–135}

Phase 2

To examine the content validity of the provisional list in the judgment stage, ten experts from various fields were asked to objectively determine the relevance and importance of each item towards the construct of the assessment instrument. A panel size of five to ten experts is recommended,⁷⁶ because it was deemed unnecessary to have more than ten.¹³⁶

Of the eleven items identified from the focus group discussions, only one item was rated less than two (little or not relevant) by the majority of the panel (n=7). This item was “I felt jealous of my friends that they do better than me because I cannot see clearly”. The panel recommended that the item be excluded from the Instrument as they found the feeling of jealousy a very subjective feeling which may not be easily understood by children. Furthermore, the panel also felt that this is a potentially upsetting issue which may have a negative psychological impact on the children. This item was thus omitted in the provisional list. EORTC⁸⁰ and McGorry¹³⁷ stressed that upsetting and sensitive issues can have severe implications on study conclusions. McGorry,¹³⁷ in her study to measure survey translations in a Hispanic population, found that wordings that are culturally and linguistically inappropriate can cause measurement errors.

We also observed no clear trend in terms of importance as ranked by the experts. This might be because the experts were from different fields of expertise and thus be assessing the items from different perspective. For example, a psychologist may rank psychological issues higher than a public health specialist, who might place more emphasis on sociological aspects. While it is important to have a diverse opinions from a group experts, Baker et. al. argued that it is choosing the right “experts” that increases the reliability of the instrument.¹³⁸

The experts commented that there is a need to include explanation for terms used in the provisional list because this can improve understanding of the questions and clarity for both the interviewer and interviewee. The aim was to ensure no ambiguity in the interpretation of DRD issues included in the provisional list. Schaeffer et. al., in providing fundamentals in survey designs, stressed the importance of giving clear and simple explanations to improve comprehension of the reader towards what needs to be done, and thus increase both reliability and validity of an instrument.¹³⁹

Examples of ambiguity raised by the experts were the difference between “cannot participate”, “not asked to participate” and “stopped participating”; “games or fun” and “outdoor activities”. Ambiguity is a topic discussed in depth by Schaeffer et. al.,¹³⁹ where they warned against the using of complex and confusing words, making the questions difficult to understand. We then consulted the linguist who clarified the subtle differences between these terms, and advised that explanations of the terms should be included in the Instrument.

Additionally, the panel expressed concerns regarding the use of comparative nouns such as “better than me” as they felt that comparing ability with others is a subjective concept which may be

interpreted very differently from individual to individual. The panel suggested replacing phrases such as “cannot see clearly” with “cannot see very well”.

Phrases describing feelings of being “left out” or “sad” were perceived to have very similar meanings and the panel queried whether the children could actually differentiate the subtle difference between the two. However, the linguist explained that

“there is subtle difference, yes, but I do not recommend using them interchangeably because one speaks of exclusion while the other speaks about feeling. By using them interchangeably you reduce the validity of your Instrument. I would recommend giving descriptions for the phrases”.

Linguist

While it is important to avoid using jargon and technical terms,^{139,140} the linguist stressed that using simple phrases to explain certain complicated terms “even if it means using more words” is important in obtaining accurate responses from the children. This ensures that we are measuring what we intended to measure. One example was using “cannot do things on my own” rather than the word “dependent” to avoid any misunderstanding by the children.

The panel also advised broadening the range of activities so that the items are not restricted to particular activities, but rather capture the nature of the activities. For example in Item 8, the panel advised that the word “parties” be changed to “gatherings and family activities”.

Best efforts were made to employ the exact words used by the subjects. Amendments were made cautiously in order to retain the children’s meaning of the DRD issues they raised as clearly as possible.

All the items were negatively phrased with a positive scale throughout the questionnaire. We chose this question pattern as it has been shown to reduce carelessness in responding and cognitive fatigue (exhaustion of the mind due to prolonged processing of the items),¹⁴¹ improve internal consistencies,¹⁴² avoid method factor (variability among the respondents)¹⁴³ and eliminate “noise” or measurement bias.¹⁴⁴

Phase 3

A critically important feature of the study was ensuring a heterogeneous sample in the pretesting. Thus the sample was purposively selected to include children from different age groups and a balance in number of children of each gender, with three levels of vision status (normal vision, mild vision impairment and severe vision impairment). This ensured that the responses covered the diversity of demography and enabled us to identify any trends in our findings. This sample selection also ensured that the final instrument can be used across demographics in future researches.

The average time to complete the questionnaire for both primary subjects (mild and severe vision impairment) and secondary subjects (normal vision) was relatively short. A positive trend was observed where the average time to complete the questionnaire increased from children with normal vision to children with mild vision impairment and severe vision impairment (3.4 minutes, 4.4 minutes and 5.4 minutes respectively). We believe that this was because the provisional list was obtained from the themes derived from the interviews with the children, thus making it easy for children to understand the questions in the assessment Instrument. Burns and Grove observed that if the domains of construct were determined directly from the representative population of interests through qualitative methods such as focus group discussions, “a clear picture of limitations, dimensions and components of the subject can be reached”.⁷⁶ This may also suggest a high content validity at instrument development stage.

Furthermore, the inclusion of standardized explanations assisted the children’s understanding of the items, making it easier to complete the instrument. This is exceptionally important as potential future respondents will be children from different backgrounds, age groups, comprehension ability and severity of vision impairment. Standardized explanations can help improve clarity, avoid ambiguity and ensure simplicity of the items so not to cause any misclassification. Van Sonderen et al. highlighted the need to avoid invalid responses caused by acquiescence, inattention or confusion by using careful wording.¹⁴⁵

We recognized that children may have a short attention span and therefore a tendency to rush through the instrument without fully considering each item. We therefore endeavor to keep the instrument short and simple. We wanted to avoid the possibility of the children responding to the

first item and assuming the same pattern for subsequent items.¹⁴⁶ Furthermore, the simple wording of the items reduce confusion and the possibility of over- or under-interpretation of the items.¹⁴⁷

There were no children who expressed that the statements were confusing or upsetting. As has been found in many studies, we might be underestimating the children's coping mechanisms for issues the professionals perceived as sensitive.

Due to queries from respondents with normal vision who were confused about the reasons they were required to answer these questions even though they felt no distress, we added a paragraph in the introduction to the Instrument explaining that this is a list of feelings that the child **might** or **might not** have depending on how well s/he can see. This is to avoid confusing and discouraging the child from participating in the assessment. Additionally, in cases where the Instrument is to be used in studies with a control group/s involved, such as a case control study or randomized controlled trial, this will help to reduce non-participation due to confusion.

Almost all children with normal vision reported that they have not experienced the distresses posed in the instrument. This was a critical finding because the normal vision children served as a benchmark (control) to validate that the cause of the distress experienced by the children in the case groups was solely related to vision impairment.

The majority of the children with mild vision impairment reported that they experienced the distresses "sometimes" and "most of the time", while children with severe vision impairment reported they experienced the distresses "all the time". This clear linear trend between the rate of occurrence and level of vision impairment indicates that the Instrument has a high floor effect and thus is highly sensitive in measuring the children's level of distress. The high sensitivity of the Instrument serves two purposes. Firstly, it can be used to compare DRD levels at a specific point in time among children with different vision status. Secondly, it is potentially an instrument to measure the change in DRD levels following vision management.

In the absence of a similar instrument that can measure DRD issues among children with vision impairment due to refractive errors, this new instrument is complementary to the existing instruments which assess the impact of vision impairment on vision functions in children. The new instrument will help to provide a comprehensive analysis of the direct impact of vision impairment due to refractive errors on the psychosocial well-being of the children. This can further help to

quantify the success or progress of the intervention that aims at providing refractive correction to children.

Limitations of the study

The development of the instrument focused on disability related distress of a specific eye condition - refractive error. Hence, the process of the development began with vision screening to identify children with vision impairment due to uncorrected refractive error. This process has confined the applicability of the developed Instrument to a particular condition and limits its use for other conditions. However, the rationale of developing a disease-specific Instrument is the unique nature of refractive error. It can be easily detected, treatment is cost-effective and non-invasive and often, the result is immediate. Many school eye health programmes specifically target uncorrected refractive error to understand prevalence, its impact on children and address associated service delivery needs. This instrument can be a useful adjunct in such situations.

The instrument used in this study was culture-specific. The study population is black South African, semi-rural and rural children. Thus, the items identified may not be generalizable to a bigger population. However, it would be interesting to investigate whether the new instrument exhibits different psychometric characteristics in a population that is demographically and culturally different to the sample.

The sample used in the process of themes identification and validation excluded the teachers and parents. The subjects of the study were school going children and a panel of experts. The items were identified through in-depth interviews with the school-going children and re-assessed by a panel of experts. Thus, we may have over-looked some issues that could have been observed by teachers and parents and which may not have been reported by the children and the panel. However, the instrument will be administered to school going children. We made an assumption that school going children may not relate to issues identified by parents and teachers, thus the inclusion of these issues would reduce the ceiling and floor effect of the Instrument.

The developed instrument is meant to be administered by trained personnel and not self-administered. Therefore, we have not tested the reliability and validity of the Instrument if the Instrument is for self-administration because the sample consisted of children who were very young. They might not comprehend the items in the instrument if the items are not explained them.

Furthermore, we have not tested the inter-observer variability as we had only one interviewer administering the instrument.

Recommendations

Raising awareness

There is a need to raise awareness among teachers and train them to identify children with vision problems by observing the children's behavior and academic performance in school. The children spend almost 8-10 hours daily in school. This high teacher-student contact time makes it effective and efficient for the teachers to identify the children with problems. The teachers can then inform the parents of the children if there is a possibility of a vision-related problem and the need for an eye examination.

Furthermore, the teachers should be sensitized on the nature of refractive error and the difficulty and the distress children with vision impairment faced in and outside of school. This creates realistic expectations for the teachers and the children. Teachers should also be equipped with the skills to manage children with vision impairment effectively, without making those children feel marginalized. Early detection makes it easier to plan appropriate interventions for children with vision impairment as physical and psychosocial needs are different to normal vision children.

Teachers may also need to look out for discrimination experienced by children with vision impairment as these children may need a certain amount of protection. The Convention on the Rights of Children (CRC) and The Convention on the Rights of Persons with Disabilities (CRPD), however, pointed out that these protections should be based on making sure the rights of the children with disabilities are realized and not on ensuring that all children should be treated equal.^{148,149} This is referred to as "reasonable accommodation".¹⁴⁹

The social model of disability highlighted that it was not the physical impairment that posed the barriers to the person with disability, but the community, the society and the environment.¹⁵⁰ It is normal that parents and the community have certain expectations and aspirations for their children. The discovery that the child has vision impairment can be seen as the parents' and community's hopes being destroyed. Hence, efforts should be directed at educating the family and community members on vision impairment and ensure that they do not overlook the child's potential and

inherent abilities. For example, the parents or teacher may see that the child struggles with science and mathematics because of their vision impairment but overlook the child's gift for art.

Awareness should also be raised among children with normal vision that having an impairment is only one characteristic of a person and that everyone has strengths, weaknesses and challenges. Children should also understand that children with disabilities also want to have friends, be respected and included, and that children with disabilities can do many of the things a child with normal vision can, but they may need assistance and takes a little longer.

Vision screening

Vision screening should be conducted before a child enrolls in school so that any child with vision problems can be detected as early as possible. Vision management can then be given timeously. Conditions such as refractive error are easy to detect and management is cost-effective, but if left undetected and untreated, can have a lifelong negative impact on children.

Vision screening has to be conducted periodically because the severity of refractive error progresses over time and develops most rapidly in adolescent years. Under-corrected refractive error also presents a serious problem because its effect is the same as uncorrected refractive error. Early and organized detection will ensure children are diagnosed and corrected, thus reducing the possibility of the children being teased by their peers and improve the inability to participate in activities with their peers.

Inclusive education

As inclusive education is pursued to achieve the global goal of universal access to education, a situational analysis should be conducted in South Africa to assess the existing support structure available to children with disability, including children with vision impairment. This includes sufficient proportion of budget spent on disability welfare, human resources, infrastructure, curriculum and the capacity of teachers.

One should also understand that inclusive education has long term effects, which include better participation in society, improved career opportunities and greater social and economic securities. It was shown in Bangladesh, that the loss of income from lack of schooling and work is as high as USD 1.2 billion each year (1.7% of GDP).²

It has also been shown that not only there is no significant difference in the cost of inclusive education and special education, the academic achievement in inclusive schools is higher.¹⁵¹ The United Nations Educational, Scientific and Cultural Organization (UNESCO) emphasizes that enrolling children with disabilities in a mainstream schools without giving the necessary support is not inclusive education.¹⁵¹ It needs commitment from all parties within and outside the school to achieve effective inclusive education.¹⁵¹

Usage of the instrument

We recommend that the instrument should be administered essentially by well-trained health care personnel. These personnel can be nurses, community health workers or eye care personnel. The ability of the personnel to understand the aims of the assessment and the instructions on the administration of the instrument is crucial because a badly administered instrument will receive invalid responses in the target population. Furthermore, recognizing that nurses, community healthcare workers and eye care personnel may not always have the necessary interview skills, as many function within a clinical paradigm, the personnel should receive training prior to the assessment being conducted.

We also recommend that the instrument is tested on its inter-observer variability and repeatability in different modes of administration in future studies. This is a pre-requisite for the instrument to be used in a different sample, or if it is to be administered by more than one person.

The instrument should only be administered individually to primary school children, age 6 to 12 years old, from a rural background. The instrument is not recommended for the assessment of older children and urban children as their social engagement may be different and urban children may present different activity patterns which were not captured in the instrument. Furthermore, this instrument should only be used to assess DRD issues among children with vision impairment due to uncorrected refractive error because the instrument is refractive error specific.

We also recommend the instrument be administered after a child is diagnosed with refractive error but prior to spectacle wear to collect baseline DRD ratings. The assessment should then be repeated after vision management is given to children with refractive error. Since it is not our objective to determine the time needed for the vision management to take effect on the DRD status of a child, it will be the clinician's judgement to decide on the time and interval of the repetition of the DRD

assessment. However we recommend that reasonable time be allocated for the child to adapt and benefit from the spectacle correction. Furthermore, we recommend that the instrument is tested in prospective studies to assess the time and interval for detecting changes in DRD pre- and post-vision management.

We do not recommend changing of the wording or the order of the items because these changes might affect a change to the measure. If such change is needed, the instrument should be pre-tested and specified as such in the research methodology. Furthermore, the researchers may need to consider the format of the instrument to suit their objectives, because the children's responses may change depending on how the specific items appear in the instrument. It is therefore our recommendation not to change the wording and the item order, to ensure the comparability of DRD status across studies. However, changes can be made if our study is repeated in a different cultural setting and differences in responses are elicited that suggest that changes are needed.

When analyzing the DRD ratings, comparisons can be made item-by-item, pre- and post-intervention. This can help the clinician to track the changes for the specific items. Comparisons can also be made using an average on the overall ratings to determine the overall changes in the DRD status of a child pre- and post-intervention.

Chapter 7: Conclusion

The burden of disability, blindness and vision impairment in children is high,^{2,3} and a 2004 study by Kempen et al.¹³ predicted an exponential increase in the prevalence of shortsightedness among children. Thus, we can expect the incidence of vision impairment due to uncorrected refractive error to continue rising.

In response to the great burden of vision impairment due to uncorrected refractive error among children, and its negative impact on them, their community and society at large, significant efforts are in place to deliver comprehensive child eye health interventions. However, the measurement of the effectiveness of these interventions is not comprehensive.

Currently, outcome indicators are confined to numbers of children reached in the programmes, scholastic performance (test scores and Intelligence Quotient) and vision function-related quality of life. There is no existing Instrument to measure the distress experienced by visually impaired children due to uncorrected refractive error in rural areas.

This assessment Instrument, to measure disability related distress in rural primary school learners with vision impairment due to uncorrected refractive error, complements the existing measurements of the effectiveness of eye health interventions. The strengths of this Instrument include:

- a. It is valid, appropriate and culturally sensitive to the rural population, where many child eye health interventions are implemented.
- b. It is resource-friendly, in that it does not require specialised personnel to administer it. Well-trained primary healthcare personnel can adequately conduct the assessment.
- c. The administration of the Instrument is not time-consuming, making it easy to collect large amounts of data efficiently.
- d. Analysis and interpretation of the data is straightforward, making it easy to communicate the finding to a wide range of stakeholders and decision makers.

From a programmatic perspective, the advantages of comprehensive measurement of the effectiveness of these interventions are multifold. Firstly, comprehensive measurement of the

impact of the interventions takes into account the psychological, social and emotional well-being of the children, thus providing a more holistic view.

Meaningful comparisons can be made with other competing critical health issues, such as HIV/AIDS, malnutrition and tuberculosis. Effectiveness of health interventions which are more holistically measured enable more powerful communications with practitioners in related disciplines such as social science, child psychology, education and public health.

Children have to be treated as whole human beings. Focusing only on eye and vision function, without taking into consideration the psychological, social and emotional well-being of the children, makes it challenging to integrate child eye health with child health. Such integration requires multidisciplinary approach and by measuring the disability related distress of the children with vision impairment due to uncorrected refractive error, we are completing the picture. This strengthens our advocacy efforts to secure funding, and prioritize child eye health issues among competing health issues.

Dissemination

Research findings will be published and made available to eye health professionals through seminars and professional meetings and presentations at local, regional and international conferences.

Publications about the following key areas are anticipated:

Publications	Journal	Timeline
Disability related distress among primary school learners with vision impairment due to uncorrected refractive error	International Eye / Public Health	6-8 months after completion of thesis
Development of questionnaire to measure DRD among primary school learners with vision impairment due to uncorrected refractive error	International Eye / Public Health	6-8 months after completion of thesis
Case studies	International Eye / Public Health	6-8 months after completion of thesis

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Appendices

Appendix 1: Data extraction of literature

Authors	Publication year	Country and study settings	Title	Purpose	Study Design	Type of Study	Sample Size	Sampling	Outcome Measures	Results
Roch-Levecq et al.	2008	USA, mobile eye clinic of University of California, San Diego and the San Diego Unified School District	Ametropia, Preschoolers' Cognitive Abilities and Effects of Spectacle Correction	To determine the relevance for clinical practice in the care of preschool children by assessing the cognitive abilities of ametropic children	Longitudinal control study; baseline and six weeks follow up	RCT	70	Participants were recruited from children sequentially seen on the	VMI, WPPSI-R scores	At baseline before optical correction, children with ametropia scored significantly lower on the VMI (P=0.005) and WPPSI-R performance scales (P=0.01). After six weeks of correction, ametropic group significantly improved on VMI performance compared to emmetropes (P=0.02).
Ma et al	2014	China, primary schools	Effect of providing free glasses on children's educational	To determine if education promoting the wearing of glasses aimed at school	Clustered Randomized control trial: 252 primary schools	RCT	3052	Sample size of 252 school with a minimum of 10 students ;	Glasses wear	The provision of both free glasses and vouchers increased the wearing of glasses compared with controls, as measured by both observed and self-

			outcomes in China: cluster randomized control trial	children will improve children's glasses wear and improve their academic performance.				84 schools allocated to the free glasses group; 84 allocated to the voucher group; 84 were allocated to the control group		reported wear. In full multiple model, baseline score, allocation to the free glasses group (p=0.04), younger age, and residence in Shaanxi remained associated with the end-line score.
Williams et al.	2005	Wales, community paediatric service in Rhondda Cynon Taff	Hyperopia and educational attainment in a primary school cohort	To report on the efficiency of the school vision screening program in Rhondda Cynon Taff in respect of undiagnosed hyperopia, and investigate educational progress in children with normal and	Cross sectional - present study comes from a cohort of 2400 children	Cross section	101	Community paediatric service in Rhondda Cynon Taff; ages 7-8 years	NFER scores	There was no correlation between anisometropia and NFER score for the fogging test referral group (r = 0.05). The higher NFER and SAT scores were provided by the < +3D group while the lowest scores were provided by the more strongly hyperopic.

				defective sight.						
Rosner J, Roser J	1997	USA, suburban middle class school district.	The relationship between moderate hyperopia and academic achievement: how much plus is enough?	To address how much hyperopia is significant i.e., given an asymptomatic school aged hyperopic child, what is the minimum amount of refractive error that would justify lens application	Children underwent static retinoscopy and scores were obtained from the Iowa Test of Basic Skills	Cross section	782	1000 children were selected at random by school personnel from 1st to 5th grade classroom in four schools in a suburban middle class school district.	Iowa Test of Basic Skills scores	Significantly lower achievement test scores among hyperopic children with a RE exceeding 1.25D (p = 0.014). When emmetropes are removed from the study, the difference between myopes and hyperopes is significant (p=0.017)
Dias L, et al, The COMET Group	2002	USA, four colleges of optometry: Houston, Philadelphia, Birmingham, Boston,	The relationship between self-esteem of myopic children and ocular and demographic characteristics	To evaluate how a group of myopic children view themselves in various self-esteem domains and whether any specific ocular or demographic characteristics	Baseline data for children already enrolled in the COMET study was obtained, and children completed the Self Perception	Qualitative	469	Children were selected from the COMET Study (multi center clinical trial) - from 4 different college of optometry	Self esteem	Less symptomatic children (score < 10) evaluated themselves more positively in all areas (p < 0.05). Except athletic competence. Age at myopia diagnosis and length of time since diagnosis were significantly associated with self-esteem in only one domain (behavioural

		health facility based,		are associated with self esteem	Profile for Children (SPPC)			sites in the US		conduct and physical appearance, respectively).
Terry R, et al	1997	USA, urban: central Indiana, public schools	Spectacles, Contact lenses, and children's self-concepts: a longitudinal study	To search for changes in children's self-concepts after the replacement of their spectacles with contact lenses	RCT	Longitudinal study	125	Coin toss procedure was used to assign participants randomly to the contact lens and spectacle groups	Self-concepts: total, behavioural, intelligence, appearance, anxiety, popularity, happiness	The contact lens group did not differ significantly from the spectacles group. The distribution of genders was disproportionate between the two groups. No significant interactions were obtained. The Appearance and Popularity scores tended to increase more over time than the Total and Anxiety scores, whereas the Behaviour, Intelligence, and Happiness scores held relatively constant.
Hannum et al	2008	China, Gansu (rural), school based	Poverty and Proximate Barriers to Learning: Vision Deficiencies, Vision Correction and Educational	To investigate whether vision correction matters for educational outcomes - performance on standardized achievement	Randomization; analysis of 2 data sets	Analyses of 2 data sets (one is RCT with controls)	18817	Randomization - some townships were given treatment and others served as controls	Educational outcomes	results attest to significant unmet need for vision correction

			Outcomes in rural Northwest China	tests and class failure						
Shashidhar et al	2009	India, Bangalore, corporation and private schools	Factors Affecting Scholastic Performances of Adolescents	To determine the health factors, social influences and study habits affecting scholastic performances of adolescents and to compare the above factors among adolescents of 2 categories of school-corporation and private	Cross sectional study done in May 2004 to November 2005	Cross sectional study	1230	Not explained	Scholastic performance	Scholastic performance decreased by 4.219 times if a student has refractive error, by 3.623 times, if no one helps a student in his studies at home, by 5.235 times if a student does not do his homework regularly, by 3.394 times if a student does not answer question bank papers, by 3.802 times if a student reads only before an examination
Shankar S et al	2007	Canada, Oxford county Public Board of Health, vision	Hyperopia and Emergent Literacy of young	to look at preschool and early school aged children to determine whether there were	Recruitment from vision screenings in Oxford	cross sectional	41	Patients were recruited from the vision screening component	Visual motor skills, visual perceptual skills, WRAT	No differences in performance in letter and word recognition, receptive vocabulary, and emergent orthography. No significant differences between the two groups assessed by

		screening	children: pilot study	differences between hyperopic and emmetropic children in their emergent literacy skills, as well as their visual cognitive skills	County, Canada			of a county wide health screening program operated by the Oxford County Public Board of health	standard scores, PPVT standard scores; VA crowding effects	VMI (p=0.92). Results indicate there are no differences between the two groups in visual cognitive abilities
Saw S et al	2004	Singapore, northeast and southeast Singapore, school based	IQ and the Association with Myopia in Children	to evaluate the association between intelligence and myopia	Data sourced from SCORM study	cross section	1204, males and females	Cross sectional study based on SCORM data; sampling methodology explained elsewhere	Intelligent quotient (IQ)	

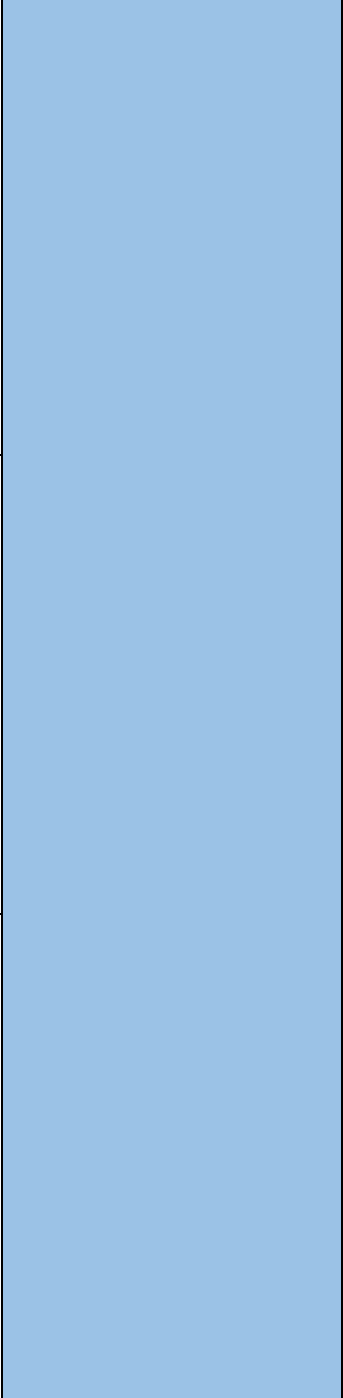
Appendix 2: Theme generation sheet

Meaning unit	Condensed meaning unit	Subcategory	Theme
<p>"I don't feel nice because I want to have fun with my friends in the playground but I cannot see well enough".</p>	<p>do not feel nice, I want to have fun</p>	<p>Loss of self-confidence</p>	<p>I feel sad that I cannot participate with friends in games/fun because I cannot see well.</p>
<p>"I cannot see as well as them (their friends) but I think I am good too, especially in soccer. I do feel sad sometimes. I have one-and-a-half hour of PE and I just play for half an hour."</p>	<p>feel sad, I am good too</p>		
<p>"I have to stop playing soccer. I cannot see the people and the ball. I fell down a lot. When I kick the ball, I kick air. I don't feel happy because I bought my sport equipment and they are expensive. But I can't play with my friends."</p>	<p>Stop playing, can't play with my friends</p>	<p>Loss of self-confidence</p>	<p>I feel unhappy that I have to stop playing games because I cannot see clearly.</p>
<p>"Yes. I don't play often. I used to swim but because I cannot see clearly, especially under water, I stopped swimming. I think I will swim very well if I can see better. When I see my friends in the pool, I don't feel good."</p>	<p>Used to swim, stopped swimming, I don't feel good</p>		

<p>“I stopped playing jumping castle because I cannot see where I am jumping and I hurt myself when the other children become rough. I cried but my mother said I am just clumsy.”</p>	<p>Stopped playing jumping castle, cired, I am just clumsy.</p>		
<p>“My parents will need to help me because I cannot read from the book. The words are very small. They will help to read it out to me so that I can copy. Sometimes my sister helps me too. But ... (I’m) too slow.”</p>	<p>need to help me, help to read out, sister helps, slow</p>	<p>Loss of self-confidence</p>	<p>I feel dependent because I need assistance from my teacher/parents/siblings because I cannot see clearly.</p>
<p>“I asked (my) sister most of the time, but she is also struggling with her own writing (examination).</p>	<p>asked my sister</p>		

<p>“(When) I cannot read from the blackboard, I will copy from my friend. I also ask help from my teacher. But there are many friends in the classroom. I have to wait until the teacher is free. Sometimes I feel shy to ask my teacher.</p>	<p>Copy from my friend, help from teacher, feel shy to ask</p>		
<p>“I read and write stories and poems but I feel very intimidated because I can’t see as well as them. They are more clever because they can see better than me.”</p>	<p>intimidated, more clever</p>	<p>Loss of self-worth</p>	<p>I feel that I am not as good as my friends because I cannot see as clearly as them.</p>
<p>“(Looking down at the floor)... Sometimes my parents stop me from playing because I cannot see as clear as my friends and they are worried that I will hurt myself.”</p>	<p>worried, hurt myself, looking down at the floor</p>		

<p>“Sometimes if it’s too hot, my eyesight becomes worse. I cannot see and I cannot play hockey with my friends. I feel very uncomfortable, isolated and lonely. I really want to play with my friends but I am just not as good. I cannot see the ball.” (Other group members laughing)</p>	<p>cannot play hocky with my friendds, uncomforatble, isolated and lonely, really want to play with my friends.</p>	<p>Loss of self-worth</p>	<p>I feel lonely as I cannot play with my friends because they can see better than me.</p>
<p>“Many times I find it difficult to see my friends, especially it’s too sunny. I gave up after a while and I’m alone.”</p>	<p>gave up, alone</p>		
<p>“I fail my exams all the time. I am passionate and hardworking. I also exercise and play sports. But my friends are all doing better even though they are not as hardworking as me. I am jealous. I am as good as them!</p>	<p>I also exercsie and play sport, tey are not as hardworking, jealous, as good as them</p>	<p>Loss of self-worth</p>	<p>I feel jealous that my friends do better than me because I cannot see clearly.</p>

<p>“I want to compete with my friends. I feel envious that they always do better because they can read faster than me. They can run faster. They see better. But my teachers give me assistance. But I feel like I am also at the same level with my classmates.</p>	<p>compete, envious, also at same level</p>		
<p>“I am grumpy and envious because they see well, they are always chosen by the teachers to do class activities.”</p>	<p>grumpy, envious, they are always chosen</p>		
<p>“I cannot pay full attention in whatever I am doing. I feel jealous of _____ because he is always doing so well. I think it’s my small eyes. (Another member pulling his eyes up to demonstrate the inability to see clearly while other members started giggling)</p>	<p>jealous, my small eyes</p>		

<p>"I don't go out with them (my friends). They feel they have to wait for/ take care of me/ I'm slow."</p>	<p>don't go out with them, wait for/ take care of me/ I'm slow</p>	<p>Loss of interconnection/interaction with community</p>	<p>I do not go for outside school activities with my friends as much as I wish because I cannot see very well.</p>
<p>"I'm not invited because they have to let me win."</p>	<p>Not invited, let me win</p>		
<p>"I like visiting friends and relatives. We walk to their places sometimes. But because I cannot see clearly, my mother does not allow me to go alone, unless my brother goes with me. But he is older. He is in Grade 12. He needs to study. So I stay at home until he is free."</p>	<p>Like visiting, does not allow me, go alone, brother goes with me, I stay at home</p>	<p>Loss of interconnection/interaction with community</p>	<p>I do not go to family/friends' parties because I cannot see very well.</p>
<p>"I rarely go out to family gatherings. I am slow. I always get lost. I am not sure but I think it's because I cannot see clearly and I cannot recognise the road."</p>	<p>rarely go out, family gatherings, slow, get lost, cannot recognise the road</p>		

<p>“They exclude me from the team because I cannot see clearly. I make them lose in the competition.”</p>	<p>exclude me, make them lose</p>	<p>Suspicion, humiliation and fight</p>	<p>I feel excluded from games because I cannot see clearly.</p>
<p>“Sometimes they ask me to sit aside in the playground. I don’t want to do it anymore.”</p>	<p>ask me to sit aside, don’t want to do it anymore</p>		
<p>“Sometimes, I felt left out when playing because I cannot see clearly. But I have the right to play too! They just ignored me.</p>	<p>have the right, ignored me</p>	<p>Discrimination</p>	<p>I feel left out when I am asked not to participate because I cannot see clearly.</p>
<p>“I don’t like it when my class teacher asks me to sit at one side because I cannot see the blackboard clearly. They beat me sometimes. Because I am slow in reading and copying. I cannot see clearly and (cannot) read fast.”</p>	<p>don't like it, sit at one side, beat me, slow</p>		

<p>“I want to sing in the choir. I was told that I am not able to join because I cannot read the notes from the blackboard. I was very sad and I cried. I tried again the next year.”</p>	<p>want to sing, told that I am not able, sad, cried</p>	<p>Discrimination</p>	
<p>“(I) went for sports day but never get chosen for soccer team. My brother plays school team. But I am always not chosen. They say I cannot catch the ball. I know I’m short but I also cannot see the ball. I felt really bad and I told my mum. She said try other sports but I like soccer.”</p>	<p>never chosen, not chosen, felt really bad</p>		<p>I feel sad that I am asked not to participate because I cannot see clearly.</p>

Annexures

Annex 1: Question route used to conduct the focus groups with Primary Subjects and Secondary Subjects (English and isiZulu version)

Introduction

We are asking for your help in designing a questionnaire which will be used to understand the experiences of primary school learners who cannot see very well because they need a pair of glasses. I would like to ask you a few things about your eye health. Can you tell me about the experiences you may have had because you cannot see very well?

Key questions	Probes
Can you please tell me what is/are the best thing/s you did in the last two weeks?	Can you tell me more about that? Can you think of any additional experiences?'
What do you really like/dislike doing at school?	Can you please tell me, what are the activities you like/dislike the most in your school or classroom? Why? How do you feel about it?
How often do you go out to meet your friends, visit relatives, social gatherings and partying?	What do you do with your friends or family in your free time/ for fun or during holidays? Can you tell me your hobbies? Do you find it difficult to see your friends in school or in playgrounds? Do you go shopping? How often? With whom? Do you go for social gatherings such as weddings or party?

	<p>Do you go to visit your friends and families in their houses?</p> <p>If you don't do them, is it anything to do with your vision? In what way? Can you give me an example? What makes you think this?</p>
<p>What are the games you play? How do you feel if you are unable to play these games?</p>	<p>Are there games you used to play but stopped? Why?</p> <p>Is it anything to do with your vision? In what way? Can you give me an example? What makes you think this?</p>
<p>Tell me something you would really like to do but are not able to? Is it due to poor vision? How do you feel about it?</p>	<p>Why? In what way? Can you give me an example? What makes you think this?</p>

There is a list of thoughts/ feelings related to primary school learners who cannot see very well because they need a pair of glasses may have. Please could you indicate which one in the list has been something which you have felt or thought about?

I feel	Angry		because I cannot see well
	Confused		
	Frustrated		
	Shameful/embarrassed		
	Sad		
	Stressed		

Relative importance of issues

I would like to ask you which of these problems, including the problems you have mentioned yourself troubled you most? Please look again at these lists and pick out five problems that caused you the greatest problem.

Items	Rate of importance
1.	
2.	
3.	
4.	
5.	
6.	
7.	

Isingeniso

Sicela usizo lwakho ukwakha uhla lwemibuzo oluzosetshenziswa ukuze kuqondwe okubhekene nabantwana besikole samabanga aphantsi abangakwazi ukubona kahle ngoba bedinga izibuko. Ngizothanda ukuthi izinto ezimbalwa mayelana nesimo sempilo samehlo akho. Ungangitshela mayelana nesimo obukade ubhekene nakho okungenzeka ukuthi ube naso ngenxa yokungaboni kahle?

Imibuzo esemqoka	Uphenyo
Ungangitshela ukuthi iyiphi/yiziphi izinto ezingcono ozenzile emasontweni amabili edlule?	Ungangitshela kabanzi ngalokho? Ungacabanga ngesipiliyoni esengeziwe?
Yini othanda ukuyenza esikoleni?	Ngicela ungitshela, imiphi imisebenzi oyithandayo ngokudlulele esikoleni sakho noma endlini yokufundela?
Ujwayele ukuphuma kangaki ukuyohlangana nabangani bakho, uvakashele izihlobo, kanye nasemicimbini?	Yini eniyenzayo nabangani noma nomndeni wakho ngesikhathi senu esingahlelwe lutho noma ngamaholidi? Ungangitshela ngezinto othanda ukuzilibazisa ngazo? Ingabe ukuthola kunzima ukubona abangani bakho esikoleni noma ezindaweni zokudlala? Ingabe uyaya ukuyothenga izimpahla esitolo? Kuba kangaki? Nobani? Ingabe uyaya emicimbini enjengemishado noma amaphathi? Ingabe uyaya ukuyovakashela abangani bakho kanye nemindeni emakhaya abo?

	Uma ungakwenzi, kungabe kunokwenza nokubona kwakho? Ngayiphi indlela? Unganginika isibonelo? Yini ekwenza ucabange lokhu?
Yimiphi imidlalo oyidlalayo?	Ikhona imidlalo obujwayele ukuyidlala kodwa osuyiyekile? Kungani? Kungabe kuphathelene nokubona kwakho? Ngayiphi indlela? Unganginika isibonelo? Yini ekwenza ucabange lokhu?
Ngitshele ngento ongathanda kakhulu ukuyenza kodwa ongakwazi ukuyenza? Ingabe kungenxa yokungaboni kahle?	Kungani? Ngayiphi indlela? Unganginika isibonelo? Yini ekwenza ucabange lokhu?

Kunohla lwemicabango noma imizwa ephathelene nabafundi bamazinga esikole aphantsi abangakwazi ukubona kahle ngenxa yokuthi kungenzeka ukuba badinga izibuko. Sicela usikhombise ikuphi kuloluhla okungaba ukuzwile noma ukucabangile?

Ngizizwa	Ngidiniwe		ngoba angikwazi ukubona kahle.
	Ngididekile		
	Ngikhungathekile		
	Ngiphoxekile		
	Ngiphathe kabi		
	Ngicindezelekile		

Annex 2: Debriefing (English and isiZulu version)

Subject Study no.						
--------------------------	--	--	--	--	--	--

Date of interview								
--------------------------	--	--	--	--	--	--	--	--

1. How long did it take to complete the questionnaire?

--

Minutes

2. Would you like any help to complete the questionnaire?

<input type="checkbox"/>	No	<input type="checkbox"/>	Yes
--------------------------	----	--------------------------	-----

If so, what kind of help?

--

3. Were there questions that you find confusing or difficult to answer?

<input type="checkbox"/>	No	<input type="checkbox"/>	Yes
--------------------------	----	--------------------------	-----

If yes, which ones?

4. Were there questions that you found upsetting?

<input type="checkbox"/>	No	<input type="checkbox"/>	Yes
--------------------------	----	--------------------------	-----

If yes, which ones?

Thank you!

Inombolo yesihloko sesifundo							
-------------------------------------	--	--	--	--	--	--	--

Usuku lwe interview								
----------------------------	--	--	--	--	--	--	--	--

1. Kuthathe isikhathi esingakanani ukuqeda uhla lwemibuzo?

	Imizuzu
--	----------------

2. Ungathanda ukuthola usizo ukuphendula uhla lwemibuzo?

	Cha		Yebo
--	-----	--	------

Uma kunjalo, iluphi uhlobo losizo?

--

3. Ingabe ikhona imibuzo oyithole idida noma inzima ukuyiphendula?

	Cha		Yebo
--	-----	--	------

Uma uthi Yebo, imiphi?

4. Ikhona imibuzo oyithole ikucasula?

	Cha		Yebo
--	-----	--	------

Uma uthi Yebo, imiphi?

Siyabonga!

Annex 3: Question route used to conduct the focus groups with Tertiary Subjects (English and isiZulu version)

Introduction

We are asking for your help in designing a questionnaire which will be used to understand the experiences of primary school learners who cannot see very well because of uncorrected refractive error.

Place list with issues before the health professional:-

Here you can see a list with issues relevant to primary school learners who cannot see very well because of uncorrected refractive error. Could you please indicate for each issue separately the extent to which you find it relevant for this group?

Response categories range from (1) not relevant to (4) very relevant.

“Relevance” refers to the frequency with which a specific complaint occurs and if it “occurs”, the trouble it may cause. Thus the more frequently a complaint occurs and the more trouble it causes, the more relevant it will be for the primary school learners who cannot see very well because of uncorrected refractive error.

After completion:

Could you please tell me for each issue for which you circled 1 (not relevant) or 2 (a little relevant) why you consider it not or only a little relevant?

This is a list of thoughts and/or feelings which patients with cancer may experience. Could you please go through the list and, for each one, tell me whether you think it is something your patients have ever considered?

Relative importance

The list of issues we have identified from the learners is too long to be administered to the students. Therefore a subset of issues must be chosen.

Please could you mark those items that, in your opinion, affect the disabled-related distress of these learners most profoundly and that we should definitely include in the final questionnaire? You

may choose a 5 issues that you consider to be most relevant and that you think should definitely be included. If there are items that you think should definitely be excluded please mark these also and say why you think they are not a priority.

Ukubaluleka okuhlobene kwezimo

Ngizothanda ukukubuza ukuthi yizipha kulezizinkinga, kuhlanganisa nezinkinga ozibalule wena ukuthi zikuhluphe kakhulu? Ngicela ubheke futhi kuloluhla bese ukhetha izinkinga ezinhlanu ezikubangele inking enkulu.

Sicela usizo lwakho ukwakha uhla lwemibuzo oluzosetshenziswa ukuze kuqondwe okubhekene nabantwana besikole samabanga aphantsi abangakwazi ukubona kahle ngoba okungalungisiwe.

Beka uhla lwalezizimo ngaphambi kowezipilo oqeqeshiwe:-

Lapha ubona uhla lwezimo eziphathelene nabafundi bamazinga aphantsi abangakwazi ukubona kahle ngenxa yokuthi yokungalungiswa nokubona kwabo. Ungabonisa odabeni ngalunye ngokuhlukana izinga lapho uthola kunokufana kuleliqembu? **Iziphendulo ngezigaba kusuka ku – (1)ezingafanele (4) ezifanele kakhulu.**

“Ukubaluleka” kubhekisa ukwenzeka kaningi kwesikhalazo esithile okuthi uma “senzeka” , kungabe sekwenzeka inkinga. Yize uma kulokhu kuqhubeka ukukhalaza kanjalo nenkinga iya ngokwanda, kuya ngokwanda kubantwana abafunda amazing aphantsi abangaboni kahle ngenxa yenkinga yokubona engalungisiwe.

Emuva kokuthi sekuqediwe:

Ngicela ungitshela mayelana nodaba ngalunye koluzungeze 1 (okungafanele) noma 2 (okufanele kancane) kungani ucabangela ukuthi akufanele noma kufanele kancane?

Lolu uhla lwemicabango noma imizwa iziguli ezinesifo somdlavuza ezingabhekana nakho. Ngicela ufunde uhla bese, kulowo nalowo, ungitshela noma ucabanga ukuthi into le iziguli zakho esezike zayicabangela?

Ukubaluleka

Uhla lwezimo esizitholile kubafundi lude kakhulu ukuthi singaluphathisa abafundi.

Ngakho kufanele kukhethwe izimo ezimbalwa.

Ngicela ubalule lezo zinto ngokomqondo wakho, ezinomthelela ekukhubazekeni okuhlobene nokucindezeleka kwalezizingane ngendlela ejulile kakhulu naleyo okumele nakanjani siyibale kuhla lwemibuzo lokugcina?

Kungenzeka ukhethhe okuhlanu okubona kuyikhona okufanele kakhulu futhi ucabanga ukuthi nakanjani kumele kufakwe. Uma kunezinto obona ukuthi akufanele zifakwe ngicela ufake uphawu kuzo ngokunjalo bese usho ukuthi kungani ucabanga ukuthi azizi kuqala.

Annex 4: Pre-test (English and isiZulu version)

I see that you have (particular problem) to some degree.

- Is this correct?
- Can you tell me about this problem?
- Do you think that this problem is related to (disease or treatment)?
- Did you have difficulty in replying to this question?
- Did you find this question annoying?
- Did you find this question confusing?
- Did you find this question upsetting?
- How would you have asked this question?

I see that you did not have this problem.

- a. Is this correct?
- b. Have you ever experienced this problem before last week?
If not, go to question (e)
- c. If yes, do you think that had something to do with your disease (or treatment)?
If not, go to question (e)
- d. If yes, can you tell me about this problem?
- e. Did you have difficulty in replying to this question?
- g. Did you find this question confusing?
- h. Did you find this question upsetting?
- i. How would you have asked this question?
- j. Did you find this question annoying?

Interview directed to the entire provisional list

If provisional list contain a large number of items (e.g., over 20), the time involved in questioning about each individual item would be prohibitive. In those cases the questions will be directed towards the entire module. For example:

- Were there questions that you found difficult to answer?
- Were there questions that you found annoying?
- Were there questions that you found confusing?

- Were there questions that you found upsetting?
- Were there questions that you found intrusive?
- Do you have other comments about these questions?

Ngiyabona ukuthi unaleninga ngezinga elithile

- Kungaba kunjalo?
- Ungangitshela ngaleninga?
- Ucabanga ukuthi lenkinga ihlobene (nesifo noma nemishanguzo) ?
- Ingabe kukhona ubunzima obe nabo ukuphendula lombuzo?
- Ingabe uthole lombuzo ukucasula?
- Ingabe uthole lombuzo ukudida?
- Ingabe uthole lombuzo ukudina?
- Ubungawubuza kanjani lombuzo?

Ngiyabona ukuthi awubananga nayo lenkinga.

- a. Kungabe kunjalo?
- b. Uke wabhekana nalenkinga ngaphambi kwesonto eledlule?
Uma akunjalo, dlulela kumbuzo (e)
- c. Uma kunjalo, ucabanga ukuthi kuhlange nesifo onaso (noma imishanguzo oyithathayo)?
Uma kungenjalo, dlulela kumbuzo (e)
- d. Uma kunjalo, ungangitshela ngaleninga?
- e. Ingabe kukhona ubunzima obe nabo ukuphendula lombuzo?
- g. Ingabe uthole lombuzo ukudida?
- h. Ingabe uthole lombuzo ukucasula?
- i. Ubungawubuza kanjani lombuzo?
- j. Ingabe uthole lombuzo ukudina?

I-Interview eqondiswe ohlwini lonke lwesikhashana

Uma uhlu lwesikhashana luqukethe isibalo esikhulu sezinto (njengo, ngaphezulu kuka 20), If provisional list contain a large number of items (e.g., over 20), isithathi esihlangene nokubuzwa mayelana nephuzu ngalinye siyakuvimbeleka. Esimweni esinjengaleso imibuzo iyobe seyiqondiswa kwisigaba sonke. Njengalokhu:

- Ibikhona imibuzo oyithole kunzima ukuyiphendula?
- Ibikhona imibuzo oyithole ikucasula?
 - Ibikhona imibuzo oyithole ikudida?

- Ibikhona imibuzo oyithole ikudina?
- Ibikhona imibuzo oyithole ikuphazamisa?
- Ingabe kukhona ukuphawula onakho ngalemibuzo?

Annex 5: Ethics approval certificate from Humanities and Social Science Study Ethics Committee



19 January 2016

Mr Ving Fai Chan 214585370
School of Optometry
Westville Campus

Dear Mr Chan

Protocol reference number: HSS/1061/015D

Project Title: Development of an assessment instrument to measure disability related distress in primary school learners with vision impairment due to uncorrected refractive error

Full Approval – Full Committee Reviewed Protocol

In response to your application received 31 July 2015, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Sheruka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

Cc Supervisor: Professor K Naidoo and Professor S Singer
Cc Academic Leader Research: Prof Mershen Pillay
Cc School Administrator: Ms P Nene

Humanities & Social Sciences Research Ethics Committee

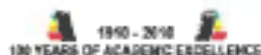
Dr Sheruka Singh (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 3087/3050/4557 Facsimile: +27 (0) 31 260 4809 Email: vinbapo@ukzn.ac.za / svr@ukzn.ac.za / ms@ukzn.ac.za

Website: www.ukzn.ac.za



King's Campus

Edgewood

Howard College

Medical School

Pietermaritzburg

Westville

Annex 6: Approval letter from Department of Education



education

Department:
Education
PROVINCE OF KWAZULU-NATAL

Enquiries: Nomangoli Ngubane

Tel: 033 392 1004

Ref:2/14/8/555

Mr VF Chan
172 Umbilo Road
DURBAN
4000

Dear Mr Chan

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: "DEVELOPMENT OF AN ASSESSMENT INSTRUMENT TO MEASURE DISABILITY-RELATED-DISTRESS IN PRIMARY SCHOOL LEARNERS WITH VISION IMPAIRMENT DUE TO UNCORRECTED REFRACTIVE ERROR", in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 20 October 2015 to 31 November 2016.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Miss Connie Kehologile at the contact numbers below.
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Office of the HOD, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education.

See list attached

Nkdsinathi S.P. Sishi, PhD
Head of Department: Education
Date: 19 October 2015

KWAZULU-NATAL DEPARTMENT OF EDUCATION

POSTAL: Private Bag X 9137, Pietermaritzburg, 3200, KwaZulu-Natal, Republic of South Africa ...dedicated to service and performance
PHYSICAL: 247 Burger Street, Anton Lembede House, Pietermaritzburg, 3201. Tel. 033 392 1004 beyond the call of duty
EMAIL ADDRESS: kehologile.connie@kzndoe.gov.za / Nomangoli.Ngubane@kzndoe.gov.za
CALL CENTRE: 0800 596 363; Fax: 033 392 1203 WEBSITE: www.kzndoe.gov.za

Annex 7: Letter sent to principals seeking permission to conduct study in the school

School Principal

12 April 2016

Subj: Permission to conduct Development of a assessment instrument to measure disability related distress among primary school learners with vision impairment due to uncorrected refractive error in schools in Pinetown District

1. Reduced vision in children has far reaching implications for the affected child and his/her family because it impacts negatively on educational and employment opportunities, while also limiting personal and social prospects. To address this problem. However, there is no instrument which can help to measure the negative impact of vision disability caused by vision impairment due to uncorrected refractive error among primary school learners.

3. The study will involve 60 to 120 school children (Grade 1-5). Depending on the size of the schools, we are planning to conduct the study in 4 - 5 schools. The schools should ideally be feasible logistically, and include both boys and girls from different ethnicities. A mix of urban and rural is not necessary for now but it would be a criterion in a bigger study in the future when the tool is validated.

4. The duration of the study is approximately 12 schooling days. We anticipate that the study shall start in the first week of November. In each school, it will take approximately 3 days and 7 hours per day. Each examination for a child will take approximately 10 minutes and interview will take 45 minutes to 1 hour. The research team will arrive in the school 7:30am to set up the rooms and endeavor to start the screening and interview at 8:00am. Our aim is to depart at 2:30pm.

5. The eye examination will be conducted by a qualified optometrist and the interview to be conducted by social scientist. There is minimal psychological risk whereby children may feel uncomfortable answering questions about their experience regarding vision impairment. The study does not involve any intervention hence there is no discomfort.

7. Ethics approval will be obtained from Humanities and Social Science Study (HSSS) Research Ethics Committee, University KwaZulu Natal. Permission will be sought from the custodians of the schools, which includes the schools' principals. A copy of the information document will be given to the students' parents/guardians prior to the study. Informed consent will be sought from parents/guardians after explaining the aims, potential risks and discomfort of the study to the subjects. Students also reserve the rights to withdraw from the study at any point of the study.

8. Students who are found to have uncorrected or under-corrected refractive error will be referred to the nearest eye care personnel for further check-up. The study will help to develop a world-first assessment instrument that is novel in gathering information on disability related distress among primary school learners with vision impairment due to uncorrected refractive error.

9. We are very grateful to the Department of Education, Pinetown District, for always supporting programs that contribute to the District and also to the Country. Do not hesitate to contact me if you are in need of further clarity. Also attached is a full protocol for your perusal.

Thanking you in advance.

Yours truly,

Ving Fai Chan
PhD. Candidate
University KwaZulu Natal

Permission

I _____ have been informed about the study entitled Development of an assessment instrument to measure disability related distress among primary school learners with vision impairment due to uncorrected refractive error by _____.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that allowing the school children's vision to be screened in this study.

If I have any further questions/concerns or queries related to the study I understand that I may contact Mr. Ying Fai Chan (School of Optometry, UKZN), the PhD candidate on 063 420 7202.

If I have any questions or concerns about the children's rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

Prof. Kavin Naidoo (School of Optometry, UKZN), the project supervisor on 083 777 4293

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000 KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557 - Fax: 27 31 2604609

Email: HSSREC@ukzn.ac.za

Additional consent, where applicable

Signature of Principal

Date

Signature of Witness

Date

Annex 8: Information sheet to parents

Study title : Development of an assessment instrument to measure disability related distress among primary school learners with vision impairment due to uncorrected refractive error

Greeting : Dear Participant

Introduction :

We, Prof. Kovin Naidoo and Mr. Ving Fai Chan, are doing a research to understand the negative effects of vision loss in school going children due to a lack of corrective spectacles and use the information to develop a Instrument. There are many children in the world who have vision impairment and sometime blindness due to eye problem. Vision disability can cause bad effects on school children in terms of daily living, mental health, distress and learning.

Invitation to participate : We are inviting you to participate in this research study.

What is involved in the study

By being part of this study, you agree to have your eyes examined to see if there is a need for glasses and to examine the health of your eyes. All tests to be used in the eye examination are not harmful to your eyes in any way. And if your child is eligible for the interview, you will also be contacted. They will be interviewed by experts and the interview will take about 45mins to 1 hour.

Risks: There are minimal psychological risks of being involved in the study.

Benefits : Receiving the knowledge of the quality of your eye sight.

Treatment: Will be referred to the nearest eye clinic is correction in the form of spectacles or contact lenses if required.

Reimbursements: There is no cost to be a participant in this study.

Confidentiality: Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. Organization that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee and the Medicines Control Council. Your participation in the study is completely voluntary and a refusal to participate will involve no penalty. You may discontinue your participation from the study at any time. All personal information will be kept confidential.

For further information please contact:

Prof. Kovin Naidoo
University of Kwazulu-Natal
Discipline of Optometry
Tel: (083) 777 4293
Mr. Ving Fai Chan
University of Kwazulu-Natal
Tel: (071) 413 1009

**Humanities and Social Sciences Research Ethics
Committee –**
**Administrator : Telephone : 031 260 4557 Fax :
(031) 260 2384**
e-mail: hssrechealthsciences@ukzn.ac.za
(for reporting of complaints / problems)

Annex 9: Consent form for parents (English and isiZulu version)

DISCIPLINE OF OPTOMETRY

CONSENT FORM

Research Study: Development of an assessment instrument to measure disability related distress among primary school learners with vision impairment due to uncorrected refractive error

Dear Sir/ Madam

There are many children in the world who have vision impairment and sometime blindness due to eye problem, which can be corrected with a pair of spectacles. Vision disability can cause bad effects on school children in terms of daily living, mental health, distress and learning.

The aim of this study is to determine how the vision impairment due to lacking a pair of corrective spectacles affects the school-going children. With that information, we will develop a Instrument to measure the effects of vision impairment due to lacking a pair of corrective spectacles affects children.

The study will involve a free eye test and interviews. During the free eye test for your child, s/he will be examined to see if there is a need for spectacle correction and any eye diseases. The eye test will help to see if your child is eligible for the study. None of the procedures to be performed will in no way harm your child's eye or vision. If there is a need for further management, we will refer him/her to the nearest eye specialist.

During the interview, we will have a social scientist to conduct the discussions and the discussions will be recorded on an Dictaphone. The interview will take only about 45 minutes to 1 hour. We will arrange a time with the teacher so that it will not affect your child study time.

Your child will not be identified in person but rather results of the group will be released. All the information will be discarded after 5 years. The results obtained from this study will be included in scientific publications. You have the right to withdraw your child from the study at any time. If s/he does not want to participate, s/he will not result in any form of disadvantage.

If you understand the information provided and voluntarily wish to participate in this study please sign your name below. This research is been done Ving Fai Chan (University of KwaZulu Natal, h/p: 0714131009), with permission from the Humanities and Social Sciences Research Ethics Committee, University KwaZulu Natal.

If you are in need of further clarification, you can contact Prof. Kovin Naidoo (School of Optometry, UKZN), the project supervisor on 083 777 4293.

Declaration form (to be kept by the researcher)

I, _____, (full name of parent/guardian) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent my child to participate in the research project.

I also consent that the discussions with my child to be audio-recorded.

I understand that I am at liberty to withdraw my child from the project at any time, should I so desire.

Parent/Guardian signature

Date

Interviewer's signature

Witness' signature

ISIYALO SAKWA-OPTOMETRY

IFOMU LEMVUME

Ucwaningo: Ukuthuthukiswa kwethuluzi lokuhlola ukuze kukalwe ukukhubazeka okuhlobene nokucindezeleka phakathi kwabafundi bamabanga aphansi abanenkinga yokubona ngenxa yokungaboni okungalungisiwe

Mnumzane/Nkosazane

Baningi abantwana emhlabeni abanenkinga yokubona kanjalo nokuvaleka ukubona ngenxa yenkinga yamehlo, okungenzeka ilungiseke ngezibuko. Ukukhubazeka ngokubona kungadala imiphumela emibi kubantwana besikole mayelana nempilo yansuku zonke, impilo yengqondo, ukucindezeleka kanye nokufunda.

Inhloso yalolucwaningo ukuthola ukuthi ukungaboni kahle ngenxa yokuntula kwezibuko kubaphazamisa kanjani abantwana abafundayo. Ngokuba nalolulwazi, sizothuthukisa ithuluzi ukuze sikale ukuthi ukungaboni kahle ngenxa yokuntula kwezibuko kubathinta kanjani abantwana.

Ucwaningo luzobandakanya ukuhlolwa kwamehlo mahhala kanye nezingxoxo. Ngesikhathi sokuhlolwa mahhala kwengane yakho, uzobe esexilongwa ukubona ukuthi sikhona yini isidingo sezibuko kanye nanoma isiphi isifo samehlo. Ukuhlola amehlo kuzosiza ukubona ukuthi umntwana wakho ukulungele yini ukuba kulona ucwaningo. Akukho kwinqubo ezokwenziwa okuzolimaza amehlo noma ukubona komntwana wakho. Uma kunesidingo sokubhekwa okwengeziwe, sizobe sesimdlulisela kudokotela oseduze obhekelela amehlo ngokukhethekile.

Ngesikhathi sezingxoxo, sizoba nososayensi wezenhlalo zomphakathi ozoqhuba izingxoxo kanti izingxoxo zizoqosha kwisiqophamazwi. Izingxoxo zizothatha imizuzu engamashumi amane nanhlano kuya kwihora. Sizohlela isikhathi nothisha ukuze kungaphazamiseki isikhathi somntwana sokufunda.

Angeke ivezwe imininingwane yengane yakho kodwa kuzokhishwa imiphumela yeqoqo. Lonke ulwazi luyolahlwa emuva kweminyaka emihlanu. Imiphumela eyotholakala kulesisifundo izohlanganiswa kushicilelo lwezesayensi. Unelungelo lokuhoxisa umntwana wakho kulesisifundo noma ngabe kunini. Uma engafuni ukubamba iqhaza, ngeke kuholele ekutheni angazuzi lutho.

Uma uluqonda ulwazi olunikeziwe futhi uzithandela ukubamba iqhaza kulesisifundo sicela usayine igama lakho ngezansi. Lolucwaningo lwenziwa uVing Fai Chan (University of KwaZulu Natal, h/p: 0714131009), ngemvume evela kwiKomidi lenkambo elungileyo yocwaningo yezoluntu nesayensi yenhlalo yomphakathi, Enyuvesi ya-KwaZulu Natal.

Uma udinga ukucaciselwa okwengeziwe, ungathintana noSolwazi Kovin Naidoo (School of Optometry, UKZN), ongumqondisi ku 083 777 4293.

Mina, _____, (Igama lomzali/umbheki)
ngiyafunga ukuthi ngiyaqonda okuqukethwe kulombhalo kanye nohlobo locwaningo lwaloluhlelo,
futhi ngiyavuma ukuthi ingane yami ibambe iqhaza kulolucwaningo lwaloluhlelo.

Futhi ngiyavuma ukuba izingxoxo nomntwana wami ziqoshwe.

Ngiyaqonda ukuthi nginenkululeko yokuhoxisa umntwana wami kuloluhlelo noma ngabe inini,
uma ngifisa kanjalo.

Kusayina umzali/umbheki

Usuku

Kusayina obuza imibuzo

Kusayina ufakazi

Annex 10: Information sheet for primary subjects and secondary subjects



What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

Important things to know...

You get to decide if you want to take part.

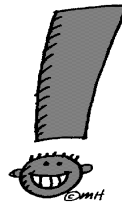
You can say 'No' or you can say 'Yes'.

No one will be upset if you say 'No'.

If you say 'Yes', you can always say 'No' later.

You can say 'No' at anytime.

We would still take good care of you no matter what you decide.



Why are we doing this research?

We are doing this research to find out more about, if you have any eye problem needing glasses and how does that affect your daily life.



What would happen if I join this research?

If you decide to be in the research, we would ask you to do the following:

Reading a letter chart: A person on the research team would point you some letters on the letter chart. Then you would say your answers out loud

Interview: We will discuss with you on how not having a glasses affects you. It will take about 45 minutes to 1 hour.



Could bad things happen if I join this research?

Some of the questions might be hard to answer. We will try to make sure that no bad things happen.

You can say ‘no’ to what we ask you to do for the research at any time and we will stop.



Could the research help me?

We think being in this research may help you because if you need glasses to see clearly, we can know and ask you to see the eye doctor.

We do hope to learn something from this research. And someday we hope it will help other kids to know if they are also affected by eye problem without a pair of glasses.



What else should I know about this research?

If you don’t want to be in the study, you don’t have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell the research doctors.

You can ask questions any time. You can talk to Prof. Kovin Naidoo (083) 777 4293 and Mr. Ving Fai Chan (071) 413 1009 . Ask us any questions you have. Take the time you need to make your choice.



Luyini ucwaningo?

Ucwaningo lususiza ukufunda izinto ezintsha. Singahlola imiqondo emisha. Siqala ngokubuza umbuzo. Sibe sesizama ukuthola impendulo. Leliphepha likhuluma ngocwaningo kanjalo nesinqumo ozosithatha sokuthi ube yingxenye kulo. Sifuna usibuze noma yimuphi umbuzo onawo. Ungabuza imibuzo noma ingasiphi isikhathi.

Izinto okubalulekile ukuba uzazi...

Uthola ukunquma uma ufuna ukuba yingxenye.

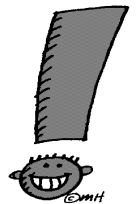
Ungasho ukuthi 'Cha' noma uthi 'Yebo'.

Akekho ozodumala uma uthi 'Cha'.

Uma uthi 'Yebo', ungabuye uthi 'Cha' ngokuhamba kwesikhathi.

Ungasho uthi 'Cha' noma ngabe inini.

Sizoqhubeka sikunakekele noma ngabe ikuphi okukhethayo.



Kungabe silwenzelani lolucwaningo?

Silwenza ukuze sithole ukuthi kungabe unayo yini inkinga yamehlo edinga ukuba uthole izibuko nokuthi kungabe ikuthinta kanjani empilweni yakho yansuku zonke.



Yini ezokwenzeka uma ngijoyina lolucwaningo?

Uma ukhetha ukuba kulolucwaningo, sizokucela ukuba wenze lokhu okulandelayo:

Ufunde okubhalwe kwishadi lamagama: Umuntu wethimba lwalolu cwaningo uzokhomba izinhlamvu ezikwishadi. Uzobe ususholo izimpendulo zakho phezulu.

Sizoxoxa nawe ngokuthi ukungabi nezibuko kukuthinta kanjani. Kuzothatha imizuzu engamashumi amane nanhlanu kuya kwi-hora.



Kukhona okubi okungenzeka uma ngijoyina lolucwaningo?

Eminye yemibuzo ingaba lukhuni ukuyiphendula. Sizozama ukuqinisekisa ukuthi azikho izinto ezimbi ezikwehlelayo. Ungasho ukuthi ‘Cha’ kulokho esicela ukuthi ukwenze kulolucwaningo noma ngabe inini sizobe sesima.



Kungenzeka lungisize ucwaningo?

Sicabanga ukuthi ukuba khona kwakho kulolucwaningo kungakusiza ngoba uma udinga izibuko ukuze ubone kahle, sizokwazi bese sikucela ukuthi ubonane nodokotela wamehlo. Siyethemba ukuthi kukhona esizokufunda kulolucwaningo futhi siyethemba ukuthi ngelinye ilanga kuyosiza ezinye izingane ukwazi ukuthi kuzithinta kanjani uma zinenkinga yamehlo ngaphandle kokuba nezibuko.



Kungabe ikuphi okunye okumele ngikwazi ngalolucwaningo?

Uma ungafuni ukuba kulolucwaningo, awuphoqiwe. Kulungile futhi uma uvuma bese ubuye ushintshe umqondo wakho ngesinye isikhathi. Ungayeka noma ngabe inini ukuba kulolucwaningo. Uma ufuna ukuyeka, yazisa udokotela wakulolu cwaningo.

Ugabuza imibuzo noma ngabe inini. Ungakhuluma noSolwazi Kovin Naidoo (083) 777 4293 noma uMnumzane Ving Fai Chan (071) 413 1009. Sibuze noma ngabe imuphi umbuzo onawo. Thatha isikhathi osidingayo ukwenza isinqumo sakho.

Annex 11: Assent form for primary subjects and secondary subjects (English and isiZulu version)



What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

Important things to know...

You get to decide if you want to take part.

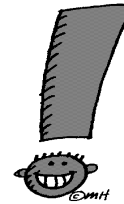
You can say 'No' or you can say 'Yes'.

No one will be upset if you say 'No'.

If you say 'Yes', you can always say 'No' later.

You can say 'No' at anytime.

We would still take good care of you no matter what you decide.



Why are we doing this research?

We are doing this research to find out more about, if you have any eye problem needing glasses and how does that affect your daily life.



What would happen if I join this research?

If you decide to be in the research, we would ask you to do the following:

Reading a letter chart: A person on the research team would point you some letters on the letter chart. Then you would say your answers out loud

Interview: We will discuss with you on how not having a glasses affects you. It will take about 45 minutes to 1 hour.



Could bad things happen if I join this research?

Some of the questions might be hard to answer. We will try to make sure that no bad things happen.

You can say ‘no’ to what we ask you to do for the research at any time and we will stop.



Could the research help me?

We think being in this research may help you because if you need glasses to see clearly, we can know and ask you to see the eye doctor.

We do hope to learn something from this research. And someday we hope it will help other kids to know if they are also affected by eye problem without a pair of glasses.



What else should I know about this research?

If you don’t want to be in the study, you don’t have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell the research doctors.

You can ask questions any time. You can talk to Prof. Kovin Naidoo (083) 777 4293 and Mr. Ving Fai Chan (071) 413 1009 . Ask us any questions you have. Take the time you need to make your choice.



Is there anything else?

If you want to be in the research after we talk, please write your name below. We will write our name too. This shows we talked about the research and that you want to take part.

Name of Participant _____

(To be written by child/adolescent)

Printed Name of Researcher _____

Signature of Researcher _____

Date

Time



Luyini ucwaningo?

Ucwaningo lususiza ukufunda izinto ezintsha. Singahlola imiqondo emisha. Siqala ngokubuza umbuzo. Sibe sesizama ukuthola impendulo. Leliphepha likhuluma ngocwaningo kanjalo nesinqumo ozosithatha sokuthi ube yingxenye kulo. Sifuna usibuze noma yimuphi umbuzo onawo. Ungabuza imibuzo noma ingasiphi isikhathi.

Izinto okubalulekile ukuba uzazi...

Uthola ukunquma uma ufuna ukuba yingxenye.

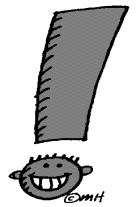
Ungasho ukuthi 'Cha' noma uthi 'Yebo'.

Akekho ozodumala uma uthi 'Cha'.

Uma uthi 'Yebo', ungabuye uthi 'Cha' ngokuhamba kwesikhathi.

Ungasho uthi 'Cha' noma ngabe inini.

Sizoqhubeka sikunakekele noma ngabe ikuphi okukhethayo.



Kungabe silwenzelani lolucwaningo?

Silwenza ukuze sithole ukuthi kungabe unayo yini inkinga yamehlo edinga ukuba uthole izibuko nokuthi kungabe ikuthinta kanjani empilweni yakho yansuku zonke.



Yini ezokwenzeka uma ngijoyina lolucwaningo?

Uma ukhetha ukuba kulolucwaningo, sizokucela ukuba wenze lokhu okulandelayo:

Ufunde okubhalwe kwishadi lamagama: Umuntu wethimba lwalolu cwaningo uzokhomba izinhlamvu ezikwishadi. Uzobe ususholo izimpendulo zakho phezulu.

Sizoxoxa nawe ngokuthi ukungabi nezibuko kukuthinta kanjani. Kuzothatha imizuzu engamashumi amane nanhlanu kuya kwi-hora.



Kukhona okubi okungenzeka uma ngijoyina lolucwaningo?

Eminye yemibuzo ingaba lukhuni ukuyiphendula. Sizozama ukuqinisekisa ukuthi azikho izinto ezimbi ezikwehlelayo. Ungasho ukuthi ‘Cha’ kulokho esicela ukuthi ukwenze kulolucwaningo noma ngabe inini sizobe sesima.



Kungenzeka lungisize ucwaningo?

Sicabanga ukuthi ukuba khona kwakho kulolucwaningo kungakusiza ngoba uma udinga izibuko ukuze ubone kahle, sizokwazi bese sikucela ukuthi ubonane nodokotela wamehlo. Siyethemba ukuthi kukhona esizokufunda kulolucwaningo futhi siyethemba ukuthi ngelinye ilanga kuyosiza ezinye izingane ukwazi ukuthi kuzithinta kanjani uma zinenkinga yamehlo ngaphandle kokuba nezibuko.



Kungabe ikuphi okunye okumele ngikwazi ngalolucwaningo?

Uma ungfuni ukuba kulolucwaningo, awuphoqiwe. Kulungile futhi uma uvuma bese ubuye ushintshe umqondo wakho ngesinye isikhathi. Ungayeka noma ngabe inini ukuba kulolucwaningo. Uma ufuna ukuyeka, yazisa udokotela wakulolu cwaningo.

Ugabuza imibuzo noma ngabe inini. Ungakhuluma noSolwazi Kovin Naidoo (083) 777 4293 noma uMnumzane Ving Fai Chan (071) 413 1009. Sibuze noma ngabe imuphi umbuzo onawo. Thatha isikhathi osidingayo ukwenza isinqumo sakho.

Kusayina umzali/umbheki

Usuku

Kusayina obuza imibuzo

Kusayina ufaka