

# Quality of Life and willingness to accept cataract surgery

A dissertation submitted in partial fulfilment for the degree of  
Master of Medicine (Ophthalmology),  
Faculty of Medicine, Department of Ophthalmology, University  
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by

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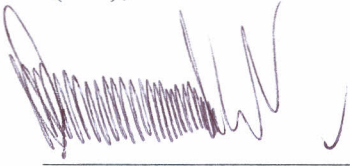
  
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## Abbreviations

CBM	- Christoffel Blind Mission
CI	- Confidence Interval
CSC	- Cataract Surgical Coverage
CSR	- Cataract Surgical Rate
IND-VFQ-33	- Indian Visual Function Assessment Questionnaire (33 items)
IOP	- Intra Ocular Pressure
KCCO	- Kilimanjaro Center for Community Ophthalmology
KDEC	- Kwale District Eye Centre
MoH	- Ministry of Health
NGO	- Non Governmental Organization
OR	- Odds ratio
QoL	- Quality of Life
SD	- Standard Deviation
SSI	- Sight Savers International
STD	- Standard
SVI	- Severe Visual Impairment
WHO	- World Health Organization
WHO/PBD	- World Health Organization- Programme for the Prevention of Blindness and Deafness
UV	- Ultra Violet
VA	- Visual Acuity
VI	- Visual Impairment
VFQ	- Visual Functioning Questionnaire
VRQoL	- Vision related Quality of Life

## Abstract

**Background:** Cataract is the major cause of blindness worldwide. Programmes like Vision 2020 make a great effort to eliminate avoidable blindness; but still acceptance and uptake of cataract surgical services remain low in developing countries. The barriers and factors that lead to refusal of cataract surgery are of great interest in contemporary applied research activities. There is growing recognition that measurement of a person's ability to perform daily activities which require vision is more meaningful than measurement of his distance visual acuity. Vision-related Quality of Life (VRQoL) Scales are a sensitive and useful tool to determine a patient's impairment in his daily life. So far little is known about the correlation between subjective perception of the visual impairment and the decision making processes towards cataract surgery.

**Aim:** The aim of the study was to determine whether the vision related Quality of Life scores differ among people who accept and those who refuse cataract surgery. Further objectives were to determine the socioeconomic variables influencing QoL scores and the decision to accept cataract surgery.

**Methods:** 144 people with visual impairment due to cataract were interviewed during outreach activities at Kwale District. 33 of them refused and 111 accepted free cataract surgery. The WHO Quality of Life questionnaire WHO/PBD VFQ-20 was used to determine the vision related Quality of Life; the socioeconomic variables were collected using structured questionnaires.

**Results:** There was a strong correlation between Visual Acuity and vision related QoL-scores, as expected. The second variable independently influencing QoL score was Literacy (Education). People with lower educational level had poorer QoL scores. Other sociodemographic factors like gender or marital status did not independently influence QoL scores. People with poor visual acuity were not more likely to accept surgery than people with better vision. The strongest predictor of acceptance was the QoL score. For every point decrease in QoL there was a 1.08 fold higher chance that surgery was accepted. The other factor that influenced acceptance independently was the gender. Males were 4,4 times more likely to accept than females.

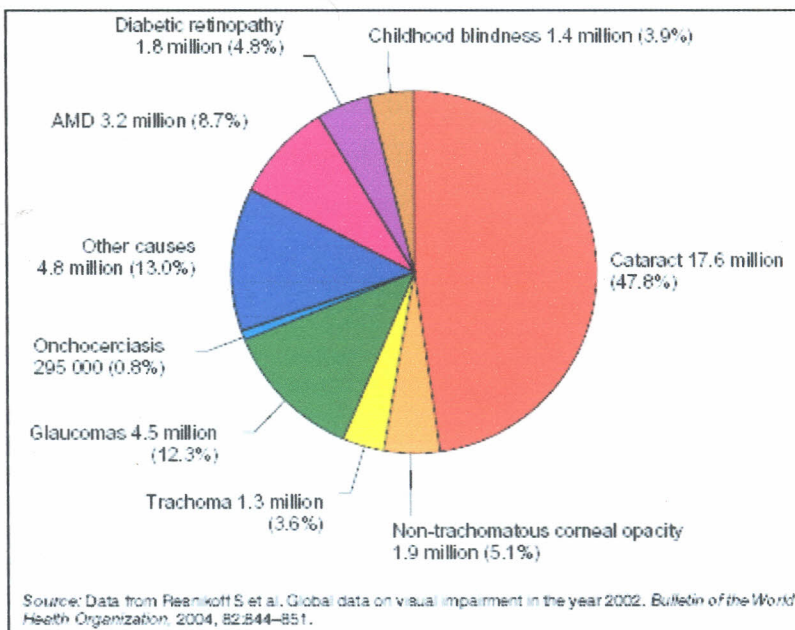
**Conclusion:** Visual acuity was not a predictor of someone's decision whether to accept or refuse free cataract surgery. The factors independently influencing acceptance were the QoL scores and being male. QoL scales are a useful tool to find out about someone's affection due to visual impairment and his potential willingness to accept free surgery.

# 1.0 Introduction and Literature Review

## 1.1 MAGNITUDE OF BLINDNESS

The World Health Organization (WHO) assumes that since 1972, when the first worldwide estimation of blindness took place, the magnitude of blindness has increased from 10-15 million people worldwide to around 37 million today<sup>1</sup>. According to the WHO, blindness is defined as a visual acuity of less than 3/60 in the better eye. Cataract is the leading cause of blindness worldwide. It is estimated to be responsible for around 17.6 million of the 37 million cases of blindness worldwide<sup>1</sup>. The prevalence of blindness in the world is estimated to be 0.7%, ranging from 0.3% for Europe to 1.4% in Sub-Saharan Africa<sup>2</sup>. Asia and Africa carry the largest burden of blindness<sup>3</sup>. The total number of blind people in sub-saharan Africa is estimated to be 6 million. Around 75% of the world blindness is preventable or treatable<sup>2</sup>. Apart from cataract other main causes of blindness that have been noted in several studies are trachoma and glaucoma<sup>4, 5, 6</sup>. In the industrialized countries blindness from cataract is comparatively rare. In these countries the rate of cataract surgery is high and operation is done when the visual acuity is better as compared to most of developing countries. In the western world age related macular degeneration (AMD) is now the leading cause of severe vision loss followed by glaucoma<sup>7</sup>.

**Figure 1: Year 2002 major causes of global blindness**





### 1.1.1 CATARACT BLINDNESS

Cataract is still the leading cause of low vision and blindness<sup>5</sup>; predominantly affecting the elderly. The prevalence of blinding cataract in the general population varies from one region to the other. It is estimated to be 0.5% for Africa, 0.3% for Asia, 0.15% in Central and South America, and less than 0.05% in Europe and Oceania. However, even within a region there may be considerable variation. The higher prevalence of blinding cataract in Africa is mainly due to the fact that in Africa the number of cataract surgeries done is considerably lower than in Asia and in developed countries<sup>1</sup>. On the other hand, lower life expectancy in developing countries leads to a lower lifetime risk of developing vision threatening cataracts compared to more developed countries<sup>7</sup>.

#### **Current studies from Africa:**

Recent studies reported a lower prevalence of blinding cataracts in sub-Saharan Africa than expected<sup>8</sup>. In Kenya, the last national survey was conducted in the early 1980s, the prevalence of blindness in the general population was estimated at 0.7%; cataract contributing to 42.0% of the total blindness in the country<sup>9</sup>. Recent, small scale studies done in two different regions of Kenya showed a prevalence of blindness in people aged >50 years to be 2.0% and 1.8% respectively<sup>10,11</sup>. Cataract was the main cause of blindness contributing 39.7% and 42.9% respectively. A third small scale population based blindness survey in Kibera slums revealed a prevalence of blindness in the general population of 0.6%. Cataract contributed to 37.5% of blindness<sup>12</sup>. It is still unclear whether those reports reflect the success of the national programme in control of avoidable blindness or whether the general VISION 2020 assumptions applied overestimate the burden of blindness.

### 1.2 CATARACT- PATHOGENESIS AND RISK FACTORS

Over 30% of the lens consists of proteins, the so-called crystallins. They are categorised into  $\alpha$ -,  $\beta$ - and  $\gamma$ -crystallin-groups, which themselves are divided into further crystallin subunits. The optical properties of the eye lens are determined by the physical and chemical stage of these crystallins. Throughout the ageing process they are subject to permanent oxidative stress which

leads to irreversible modifications. The human fetal lens protein pattern shows a more or less clear distribution of the individual components, lenses from older donors or cataractous lens show a wider spreading of protein spots and an increment of water insoluble protein<sup>13</sup>. These changes in the lens crystallins are primarily responsible for the reduction in transparency. Most scientists agree that the development of a senile cataract is a multifactorial process. Although many substances have been reported to increase cataract formation, the main risk factors for the development of senile cataracts are due to elevated levels of oxidative stress (smoking, UV B, high energy radiation etc.). Increased levels of antioxidants such as Vitamin A and C, and carotenoids may have a protective effect on the lens crystallins<sup>13</sup>. Studies have shown that certain crystallins have a protective effect (Chaperon effect) on posttranslational changes on the lens proteins, however most of these modifications during the ageing process are irreversible<sup>14</sup>. Ageing is therefore the most important contributor to cataract blindness. As mentioned above 17.6 million cases of blinding cataract are expected worldwide. It is estimated that by the year 2020, if no additional measures are implemented, world blindness will increase to 76 million. By 2020, the world will become older and more populated. People 65 years of age and above will increase from 7% to 9% of the population. Thus, cataract blindness at 2020 is estimated to reach 40 million<sup>15</sup>. A 16 year follow up survey of prevalence of blindness in Malawi, showed that the total aged population had doubled and that the number of blindness increased by 24%. Among the blind, more than 50% were above 70 years<sup>16</sup>. These and other studies support the fact that the aged population is growing and as the population becomes older, the burden of cataract blindness increases. Increasing age is a proxy for physiological and biochemical changes that occurs in an ageing human crystalline lens.

### 1.2.1 SEX

The prevalence of blindness worldwide is higher in females than in males. The overall odds (age-adjusted) of blind women to blind men is 1.43 (95% CI 1.33 – 1.53), ranging from 1.39 (95% CI 1.20 – 1.61) in Africa, to 1.41 (95% CI 1.29 – 1.54) in Asia, and 1.63 (95% CI 1.30 – 2.05) in industrialized countries<sup>17</sup>. Two major reason have been identified to explain this fact. First, women have a higher life expectancy than men and are therefore more affected by age-related diseases (cataract, AMD, etc) and secondly, women are, in particular in developing countries, less likely to seek for medical aid to restore reduced sight<sup>17</sup>.



### 1.2.2 LIGHT EXPOSURE

Various epidemiologic studies show associations between elevated risk of various forms of cataract and exposure to higher intensities of incident or reflected ultraviolet light or both. Nuclear cataract appears unrelated to risk for cataract in most studies. Geographic data provide some support for purported relationships between light exposure and cataract risk<sup>18</sup>. Persons living closer to the equator<sup>19</sup> and living at higher elevations appear to have an elevated risk of various forms of cataract<sup>20,21</sup>. Indeed, one of the strongest predictors of cataract surgery likelihood in a Medicare beneficiary is a person's latitude of residence. Although not a uniform observation,<sup>22,23</sup> these epidemiologic data have been corroborated or anticipated by exposure of squirrels to ultraviolet light *in vivo*<sup>24</sup> and in many experiments *in vitro*<sup>25-30</sup>.

### 1.2.3 HIGH-ENERGY RADIATION

Cataractogenesis is also clearly related to exposure to high-energy radiation. Taylor and associates showed a dose-response relationship between x-irradiation and risk for cataract in rats<sup>30</sup>. In a study with 99 patients, the 89 who received whole-body irradiation (10 g) had cataract develop in less than 4 years<sup>31</sup>. The 10 patients who were treated for aplastic anaemia and did not receive radiation treatment did not show evidence of cataractogenesis.

### 1.2.4 EXPOSURE TO HIGH LEVELS OF OXYGEN

Perhaps the clearest causal association between oxidative stress and cataract comes from experiences involving elevated levels of oxygen. Nuclear cataract was observed in patients treated with hyperbaric oxygen therapy,<sup>32</sup> and markedly elevated levels of mature cataract were observed in mice that survived exposure to 100% oxygen twice weekly for 3 hours<sup>33</sup>. A decline in glutathione (GSH) and an increase in glutathione disulfide (oxidative changes normally related to aging or cataract) also were noted.

### 1.2.5 SMOKING

Smoking and tobacco chewing appear to induce oxidative stress and have been associated with both diminished levels of antioxidants, ascorbate, and carotenoids<sup>34</sup> and with enhanced cataract at a younger age<sup>35-37</sup>.

### 1.3 CATARACT SURGICAL COVERAGE (CSC)

Cataract surgical coverage is an impact indicator which measures the proportion of cataract cases that have been operated on from the total number of cataract blind cases (or visually impaired cases) in a defined population at a particular point of time. Calculation of CSC can be done using the formula:  $(x + y) / (x + y + z) \times 100$  where x is individuals with unilateral pseudo/aphakia and visual impairment in the contralateral eye; y is individuals with bilateral pseudo/aphakia, regardless of acuity; and z is individuals with visual impairment or blindness in whom the principle cause was cataract (unilateral or bilateral).

In 1999 it was estimated that the total number of cataract surgeries done worldwide ranged from 8 – 10 million. Most of those operations were done in Europe and Asia and the least were done in Africa<sup>1</sup>. Cataract surgical coverage has been determined in a number of different settings. In many developing countries, despite the availability of cataract surgical services in most areas, utilisation of the services remains low. In a study done in Malawi, CSC was reported at only 14.8%<sup>16</sup>. In an Indian study, among identified cataract patients advised to attend a nearby eye camp (less than 5km from their village), only 7% attended the eye camp<sup>38</sup>. However, in nearby rural Maharashtra among cataract patients of 40 years of age and above, the coverage was 34%<sup>39</sup>. Even in relatively poor Nepal, among cataract patients of 40 years and above (found during population based eye screening), the coverage was reported as 46%<sup>40</sup>. Encouraging reports come from two recent Kenyan studies. Here CSC was reported to be 65.7% and 87.2% respectively<sup>10,11</sup>. In a study in Pakistan the CSC for individuals at 3/60, 6/60 and 6/18 cut-offs were 77%, 69% and 44%, respectively<sup>41</sup>. Review of cataract surgical coverage studies in developing countries found cataract surgical coverage to be 1.2 - 1.7 times higher in men than women. Overall, the odds ratio for having surgery for females as compared to males was 0.67 (95% CI 0.60 – 0.74). Women accounted 63% of cataract in these studies<sup>42</sup>. Australia and North America have the highest cataract surgical rate in the world of 5500<sup>1</sup>. In these countries, cataract surgery is done at earlier stage while the patient still has a better visual acuity as compared to developing countries. This might be due to advancement in techniques of cataract surgery such as phacoemulsification, higher expectations for a good sight as well as socioeconomic factors, such as a high eye-surgeons/population ratio and available insurance coverage.



### 1.3.1 GENDER AND CATARACT SURGICAL COVERAGE

Cataract surgical coverage is lower among females than males, particularly in developing countries, despite the fact that the burden of cataract blindness is higher among females. A study carried out in Malawi, showed an age adjusted prevalence of blindness in adults of 5.4%, where women had a 1.94:1 higher ratio compared to men, bilateral cataract blindness accounted 61.5% of total blindness, by which women accounted 60% of total cataract blindness<sup>16</sup>. Similarly another study done in Chikwawa District for the people of 50 years and above, women carried higher prevalence of blindness as compared to males (6.1% and 4.8% respectively), but women had a lower cataract surgical coverage<sup>43</sup>. A southern India study to determine sex inequalities and utilization of cataract surgical services found that women were less likely to be operated on for cataract (adjusted odd ratio 0.71, 95% CI 0.57 – 0.87) than men. In this study, the burden of cataract blindness in females was higher as compared to males ( $p < 0.001$ )<sup>44</sup>. This study was carried out in a district with extensive and long-term community based promotion activities. In developed countries there is less evidence for gender disparity in utilization of cataract surgery. A study done at Norrlands University Hospital in Sweden found that 66.2% of cataract surgeries were in women. Females responded to have more problems as compared to their counterpart males with the same visual acuities (approximately 59% for females, and approximately 44% for males)<sup>45</sup>. It has been suggested if cataract surgical services is provided equally for both men and women, cataract blindness will be reduced by a median of 12.5%<sup>42</sup>. The south Indian study suggested that if the surgical rate were equal for both sexes, there would be an additional 25.3% reduction in cataract blindness in India<sup>44</sup>. In contrast, encouraging results come from a recent Chinese study. After five years of access to free cataract testing and low-cost surgery programmes, elderly women were as likely as men to be willing to pay around 65 US-Dollar for cataract surgery and reversing gender differences present 5 years ago<sup>46</sup>.

### 1.4 BARRIERS TO CATARACT SURGERY

The barriers to cataract surgery are an area of ongoing research. Much effort has been directed to provide cataract surgical services in the developing world at an affordable cost and at accessible sites. Nevertheless, coverage of cataract surgical care remains low in Africa<sup>47</sup>. Several studies

have been carried out to determine factors that influence the low uptake of cataract surgery. The barriers differ depending on the location and availability of cataract surgical services. The barriers can be grouped in relation to the health system, the community and the individual. Health system barriers are the availability and accessibility of eye-hospitals, quality of surgery and costs of services among others. Community barriers include family dynamics, traditional beliefs etc. Another established method of grouping is under the headings of [a] awareness, [b] access and [c] acceptance.

Those related to access include cost of surgery, distance to surgery, lack of transport, poor outcome of surgery while those related to acceptance include need for assistance, fear of surgery, lack of perceived need and lack of decision making authority <sup>47</sup>.

## 1.5 HEALTH SYSTEM BARRIER

### 1.5.1 COST

Unlike in the countries of the developed world there is no functional health insurance system for the vast majority of people living in developing countries. Cost is one of the major barriers people face when getting sick. Concerning cataract surgery there are two main aspects of costs. The direct cost of surgery, which is the amount needed to be paid as hospital bill for cataract surgery and the indirect cost which involve the cost of transport to and from the hospital and the cost of food while at the hospital. We also consider a wage loss of the patient or involved relatives to be part of the indirect costs. However in many rural areas of Africa, the main source of income is from subsistent farming and wage losses can not accurately being determined. During times of planting or harvesting elderly people face problems to be accompanied by relatives. Studies show that the best time for them being brought to hospital is after harvesting <sup>8, 48</sup>. This time also coincidence with a higher chance of available cash resources. There is an ongoing debate about the advisability of charging people for health care services and in particular cataract surgery. It is common use by most of the eye-care provider to share costs with the patient. However, several centres offer free services in areas of great need <sup>49</sup>. Costs of cataract surgery as a main barrier remain a disputant research topic. Recent findings from Africa show that costs are often used as an excuse for refusal of surgery which will be unchallenged accepted by health workers <sup>50</sup>. Several others studies revealed that costs were not a main barrier and that even if sufficient resources were available uptake remained low <sup>8,51,52</sup>.



## 1.5.2 LOGISTICAL FACTORS

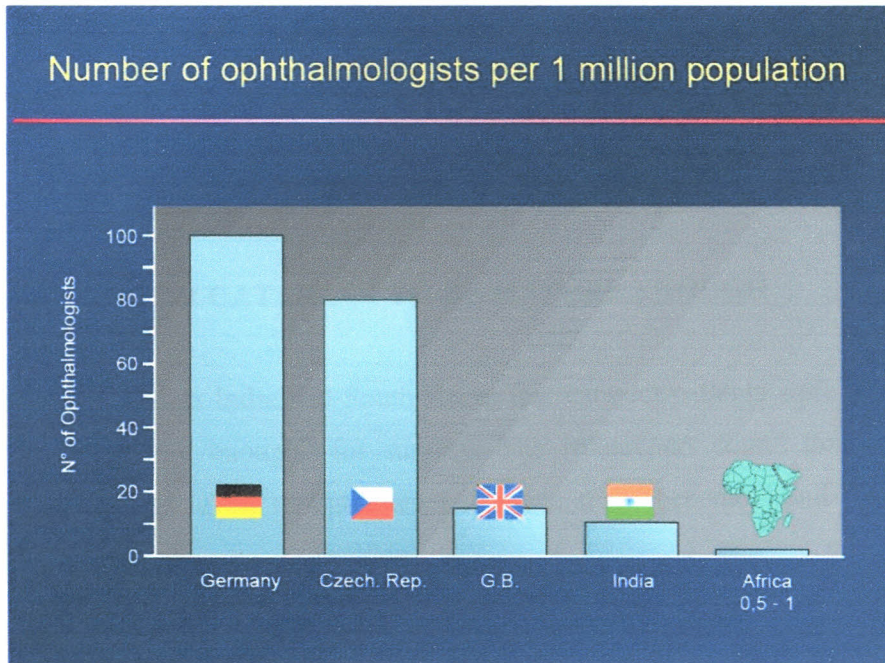
The distance towards the next eye care provider or the side of an outreach screening is an important predictors of peoples` attendance. In a study done in India, a multifactorial regression analysis showed that living closer than 3 km from the side of screening was associated with a 4.5 times higher probability of attendance<sup>38</sup>. Another study from Malawi showed that the farer a patient lives away from modern health care facilities the more cataract services were offered by traditional healers<sup>53</sup>.

Further logistic considerations include the need for an escort and availability of transport. In many settings there is an additional cost for transport for the caretaker; food and lodging for both the cataract patient and the caretaker is sometimes necessary. The caretaker has to leave his/her daily earning activities and there is the cost of lost wages. Among the elderly, especially among the elderly, sometimes there is no one who can provide such assistance.

## 1.5.3 EYE CARE PROVIDERS

Ophthalmologists are specialised doctors who have undergone many years of postgraduate training. Many of the eye care services they provide can not be paid for by the majority of patients in a rural environment of developing countries. It is therefore not surprising that most of the well-trained ophthalmologists have settled down in urban areas where they find a wealthier clientele and more adequate living conditions. In Africa, it is estimated that there is one eye doctor per million populations (see below diagram). The ratio in China and India is generally 10 per million populations, and in Europe and America it is 40-90 per million populations<sup>1</sup>. Unequal distribution of eye care providers might be the major factor for poor coverage of cataract surgical services especially in rural areas. In Ethiopia, where they had 58 ophthalmologists, 80% of them work in the capital leaving 20% to serve the rest of the country<sup>54</sup>. In Kenya it is a fact that more than half of all ophthalmologists live in major towns like Nairobi, Mombasa or Kisumu. Eye Care providers in rural area normally depend on funding from donors to cover for high quality services. Lack of enough trained eye care providers, especially ophthalmologists and cataract surgeons may also play a role.

**Figure 2: Ophthalmologists per million population**



#### **1.5.4 COST EFFECTIVENESS, QUALITY AND OUTCOME OF CATARACT SURGERY**

The cost-effectiveness of cataract surgery is related to short operation time, short length of stay in hospital, the potential for high volume (productivity), high success rates, and the low cost of consumables. However, when success rates are low, cost effectiveness is reduced<sup>55</sup>. Recent clinical trials<sup>56-58</sup> have demonstrated that cataract surgery can provide a good visual outcome (presenting visual acuity of 6/18 or better) in 90% or more of operated eyes. However, these trials usually exclude individuals with ocular co-morbidity, and are usually undertaken in tertiary institutions by highly trained surgeons. In contrast, population based surveys and rapid assessments conducted over the past decade, have shown that of all eyes operated for cataract, 21–53% had a presenting visual acuity of less than 6/60 (poor outcome)<sup>59-64</sup>. A significant cause of poor outcome is uncorrected aphakia due to loss or breakage of spectacles. But even in eyes receiving an intraocular lens (IOL) poor outcome is reported in 5–15%. Outcome data from population based surveys may not do justice to recent improvements in surgical techniques, but they may well reflect what the public perceives, influencing their expectations of regaining sight if they have surgery. However, only few studies have been carried out to assess the contribution



of fear of cataract surgery to poor surgical outcomes in Africa. In a Kenyan study, it was observed that monitoring of cataract surgical outcome could change surgeon attitudes regarding case selection. Better monitoring of cataract surgery outcomes yielded an improved outcome of the surgeries performed<sup>65</sup>. In many settings the visual outcome following surgery is sub-optimal but improved greatly with refraction.

### **1.5.5 WAITING FOR CATARACT TO BE MATURE ENOUGH**

It has been reported in India and South Korea that cataract patients were told to wait until the cataract was “mature enough” for surgery. The researchers found that most people never returned for surgery even though they had since then, become blind<sup>66</sup>. This advice may eventually increase the cataract backlog.

## **1.6 COMMUNITY BARRIERS**

### **1.6.1 SOCIAL SUPPORT & AGE**

Caretakers of the elderly may not view surgery as an important intervention<sup>8</sup>. They may not understand change in dependency following surgery. Some cataract patients believe that having cataract is a normal part of ageing and that nothing can be done to prevent it or cure it. Some cataract patients do not accept that a part of their body (the lens) should be removed (and buried) while they are still alive. In South Africa, 40% of respondents thought cataract was an intrinsic and irreversible part of ageing<sup>51</sup>.

Social support and aging, as a barrier, may be under-reported, because in most of studies the methods are not adequate to measure these perceptions. Qualitative data collection is likely to be more useful. For elderly patients some information may be missed if only collected on closed-ended interviews. Some cataract patients may have suffered from other illnesses, which prevent them to attend eye care services. In most instances such cataract patients are not included<sup>42</sup>. Difficulties associated with age may be explained by difficulties in finding an escort, long distances, and inadequate resources or social support.

## **1.6.2 TRADITIONAL MEDICINE**

Use of traditional medicine is recognized as a barrier for cataract surgery in some developing countries. Some cataract patients opt to seek treatment from traditional healers, as the traditional healers are their immediate health care providers<sup>53</sup>. Attending to traditional healers may increase the indirect costs (additional) for travelling to the eye care centre.

## **1.6.3 LACK OF AWARENESS**

Lack of awareness and poor knowledge of eye problems as well as lack of information about available eye care services contributes to the low uptake of cataract surgery. Lack of knowledge and awareness of eye problems negatively influences treatment-seeking behaviour. However, it should be recognized that even when awareness is pervasive, uptake could be very poor<sup>51</sup>.

## **1.7 INDIVIDUAL BARRIERS**

### **1.7.1 FEAR**

Fear is often given as the main reason for refusal of eye-surgery. In a study in India 40% of visually impaired people gave fear as the reason for not attending a nearby eye camp<sup>38</sup>.

In another Indian study, 10.5% of the respondents reported fear of the operation and its consequences<sup>66</sup>. In a qualitative study from South Africa 45% reported fear as the major barrier<sup>51</sup>. Eye-drops and spectacles were acceptable treatment option for all interviewed probates but surgery was considered as last resort. Some even thought they would die on the operating table<sup>27</sup>. On the other hand, fear of eye surgery shows a strong variation among different regions and societies. In a recent study done in Pakistan, fear was only mentioned by 1.4%<sup>41</sup>. Here costs were by far the most important barrier. In another study from Nigeria, where traditional couching has been performed for a long time, fear was also not among the main reasons given for poor surgery uptake<sup>67</sup>.

## **1.7.2 IGNORANCE**

Estimates from India are that about 50% of those blind from cataracts did not know they could be cured, and many did not know where they could get treatment <sup>68</sup>.

## **1.7.3 STOICISM**

Cataracts grow slowly. Gradual loss in vision is less noticeable than sudden loss. People adapt and manage despite poor vision and literally do not see the need for surgery <sup>38,69</sup>. For the majority of affected people surgery will become a more acceptable option as blindness from cataract worsens <sup>40</sup>. However, other studies suggest that for some people the chances to demand or accept surgery decline with increasing blindness from cataract <sup>8</sup>.

## **1.7.4 LITERACY**

Literacy may also play a role in eye care seeking behaviour; an Indian study showed that literate individuals (including women), were more likely to attend for cataract surgery as compared to the illiterate people <sup>44</sup>.

# **1.8 QUALITY OF LIFE SCALES**

## **1.8.1 VISUAL ACUITY**

Visual impairment is traditionally measured using visual acuity charts. These are relatively easy to use and provide an objective and reliable way to measure sight. However, visual acuity measures only a small part of visual function and does not in any way give a measure of subjective impairment.

The need for better measurements of visual function has long been recognized. Best corrected vision does not reflect the real-life situation and can over or underestimate the burden of visual impairment. Vision-related quality of life (VRQOL) scales are considered a more valid measure of the impact of poor vision on the individual, rather than visual acuity alone <sup>70</sup>.



### 1.8.2 VISION RELATED QUALITY OF LIFE ( VRQOL) SCALES

Several questionnaires have been developed which encompass subjective visual function<sup>12</sup>. These questionnaires ask the patient about the difficulties they may have when undertaking specific daily activities. The patient gives a 'difficulty rating' for each item. Response scales range from dichotomous ratings (agree- disagree) to category ratings (totally agree – partly agree and so on). Questions include level of difficulty, frequency of problems, level of agreement with a statement about problems, and level of disability. These scales are useful for populations in developing countries for several purposes—to guide referral from the field, to assist in defining blindness and visual disability more meaningfully (perhaps on a local level), to monitor the success of campaigns to reduce blindness and visual disability at the community level, and to promote the value of surgical intervention to policy makers and patients. Since 1980, more than a dozen such self-report visual function questionnaires have been developed.

Most studies investigating cataract and quality of life are from high-income countries and the questionnaires designed appropriately<sup>71</sup>. They are not appropriate for all populations, so several authors attempted to adjust Vision Function Assessment Questionnaires and Vision related Quality of Live Scales to the setup in developing countries<sup>72, 73</sup>. The first Visual function questionnaire used in sub-Saharan Africa and published in literature was created by van Dijk et al. and applied on a Malawian population<sup>74</sup>. The questionnaire contained 13 questions divided into 3 groups: Problems in near vision, problems in distance vision and problems in contrast sensitivity. The questionnaire did not include quality of life measures. It was found to be applicable for the study population and easy to use. Scores correspondent well with Visual Acuity measurements using Snellen Charts.

The WHO has emphasized time and time again on the need for more comprehensive forms of visual impairment measurements. It was noted that means for obtaining patient-reported assessments had received considerable development in recent years.

A visual function/quality of life questionnaire, developed specifically for the Madurai Intraocular Lens Study, had been administered in China, Hong Kong and Nepal<sup>75,76</sup>. A second, more general, visual functioning instrument (IND-VFQ-33) had been developed in India in a multi-institution effort that replicated the rigorous psychometric methodology used in developing the widely used NEI-VFQ-25<sup>72,73</sup>.

### **1.8.3 INDIAN VISION FUNCTION QUESTIONNAIRE (IND-VFQ-33)**

India is a low-income country accounting for nearly one quarter of the global burden of blindness. Because of low literacy levels and reading difficulties due to visual impairment, it was developed as an interview-administered questionnaire and attempts to measure the impact of visual disability on every day lives.

IND-VFQ-33 uses three areas: general functioning, psychosocial impact, and visual symptoms. It takes only an average of 20–25 minutes to complete, and is suitable for use in populations of mixed literacy levels. Subsequent studies done in India showed a high grade of test-retest reliability and validity <sup>72</sup>.

### **1.8.4 WHO/PBD VFQ-20**

This is a refinement of the original IND-VFQ-33 and is a 20-item visual functioning questionnaire. It addresses general vision, distance vision, near vision, color vision, role limitations, glare, light/dark adaptation, ocular pain/discomfort, social functioning, mental well-being, and dependency.

It can be used for other eye diseases as well as cataract. Polack et al. used this questionnaire in rural Nakuru, Kenya<sup>71</sup>. Test-retest validity was good and the results reproducible. They removed one question about impairment of bright light because they found it unsuitable for their study population. We used the WHO/PBD VFQ 20 for our study. All questions were applicable to our study population.

### **1.8.5 ASSOCIATION OF VISUAL ACUITY AND QOL-SCORES**

Several studies have shown that there is a strong association between commonly measured Visual Acuity and scores in QoL questionnaires <sup>71,74,77,78</sup>. A decrease in Visual Acuity will certainly be reflected back in poorer QoL scores. However, visual acuity alone, is a relatively limited measure of vision performance – Studies showed that it contributes only up to a fifth of the variation in total VRQoL scores <sup>79,80</sup>.

Other factors such as demographic variables (age, gender and socioeconomic status), binocular status, and difference in acuity between eyes have an important impact on VRQoL score variations. Measures of deprivation were not related to self reported vision function. Hence,

although visual acuity alone appears to be the most important determinant of the VRQoL score, it only gives a limited measure of visual performance.

## 1.9 KWALE DISTRICT

The study took place in Kwale District on the South Coast of Kenya. One of the poorest areas in the country, the population of about 600,000 mostly earns their living from subsistence farming or fishing. Kwale District Eye Centre (KDEC), a comprehensive eye centre with a strong community base, is the major eye care service provider for the District.

Potential cataract patients are identified through a network of field workers then screened in the field by a team from the Centre. Those requiring cataract surgery are offered free surgery and free transport. After surgery they are transported back to their home area. In 2004 10,389 patients were screened and treated. 1,180 people were recommended for cataract surgery, of whom 814 (68.9%) accepted.<sup>49</sup> This acceptance rate is high compared to other studies<sup>8,38</sup>.

Recent data from Kwale District Eye Centre showed even higher acceptance rates. Cost is not a major barrier to cataract surgery in Kwale District. Likewise factors such as lack of awareness and access are minor barrier because of the strong community-based project.

So why do people still refuse?

The setup with free cataract surgery services allowed us to focus on non cost related factors. The dominant factors here may be social and psychological, such as fear, or, more simply, acceptance that losing vision is a normal aging process



## 2.0 RATIONALE

Costs, both direct and indirect, are often cited as being the main barrier to cataract surgery. Many ophthalmic centers in sub-Saharan Africa therefore offer subsidized or even free surgery. This increase their acceptance rates significantly. At KDEC most cataract surgeries are performed free of charge to the patient. The Centre is charitable, supported both by Christoffel Blind Mission International (CBMI) and Sight Savers International (SSI) and, in addition, seeks donors from other sources to specifically sponsor cataract surgery.

On the other hand costs are often taken as an excuse by patients who don't want to undergo an operation. It is an excuse that is normally accepted unchallenged by health workers in the field<sup>50</sup>.

Further studies looked at other reasons<sup>8,38,47,48,52,52</sup> and found that acceptance was influenced by social factors such as traditional beliefs about the correlation between aging and blindness, fear, incapacity to make ones own decisions. Geneau et al. looked at the social and family dynamics behind the uptake of cataract surgery<sup>81</sup>. It seems that often the affected person is unable to make their own decision, relying on their closest relatives to do so for them. These factors constitute an area of ongoing research.

Little is known about the link between subjective perception of visual impairment and willingness to accept cataract surgery. We conducted this study believing that structured interviews including VRQOL scales will guide us better to the real causes of peoples' refusal to accept sight-restoring cataract surgery. We intended to find out about possible differences in QoL scores in people refusing surgery as compared to people accepting surgery.

### 3.0 JUSTIFICATION

There is lack of data on vision-related quality of life in Kenyans, especially with regard to the influence of subjective impairment on the decision-making processes for acceptance of cataract surgery.

There is need for better understanding on the correlation between perception of visual impairment due to cataract and the decision to accept sight-restoring cataract surgery.

Providers of cataract surgery make planning decisions based on studies regarding their services. Real costs of high quality cataract surgery can often not be paid by rural populations in developing countries. Subsidized or free cataract surgery requires donations from health-organizations (governmental or non-governmental) and/or private donors. Health care providers and donors need to know that the service is offered in a wise and helpful way, in accordance to their statues and believes and to the optimum benefit of the patient.



## 4.0 OBJECTIVES

The aim of the study was to determine factors associated with refusal to take up cataract surgery.

The main question in this context was:

*Do people who refuse cataract surgery have a different perception of their visual impairment than people who accept surgery?*

### 4.1 Primary Objective

The objective of the study was to determine whether, when measured with VRQOL questionnaire, the perception of an objective visual impairment (measured using standardized Visual Acuity charts) differed among people accepting and those refusing cataract surgery.

### 4.2 Null Hypothesis

The null hypothesis was that people who refuse to undergo sponsored cataract surgery do not differ in their perception of visual impairment from those accepting surgery hence the VRQOL scores, indicating subjective perception, will be equal in those refusing surgery and in those accepting surgery.

### 4.3 Alternative Hypothesis

The alternative hypothesis was that people who refuse surgery have different VRQOL scores (greater or less impairment) from than those accepting surgery.

### 4.4 Secondary Objectives

The study intended to quantify the correlation between the individual's perception of their visual impairment and their willingness to accept surgery. Other objectives were to determine the influence of age, sex, marital status, literacy and socioeconomic status on the QOL scores and on acceptance or refusal. We compared existing data from Kenya and other countries with our results.

## 5.0 METHODOLOGY

### 5.1 TYPE OF STUDY

The Study was designed as a qualitative population-based cross-sectional study. Two groups were compared. One consisted of visually impaired people who accepted cataract surgery. The other one consisted of visually impaired people who, despite their impairment, refused to undergo surgery. Standardized questionnaires were used to collect data on age, sex, level of education, literacy, marital status and socioeconomic status.

The Quality of Life Questionnaire WHO/PBD 20 Items (Appendix 2) was used to quantify the probate's perception of his/her visual impairment. The questionnaire was translated from English into Kiswahili then back again into English (different translators). It showed high consistency. The final translation is attached in the appendix (3). The interviews in the field were carried out by a local person who has not previously been involved with KDEC activities. She was fluent in the local languages with experience in research interviews. Intensive training in usage of the questionnaire and the necessary ophthalmic principles was done by the principal investigator and the medical director of KDEC. Whenever indicated, the questions were asked in local languages (Digo, etc.) by the interviewer. The ophthalmic examination of patients was conducted by one of the qualified ophthalmic nurses of the hospital and/or the principal investigator. Visual Acuity was measured for each eye independently using a Snellen Chart or more often an illiterate E-Chart. Visual Acuity was measured with available correction glasses worn during presentation. KDEC Community based workers supported the interviewer in the field. Most people in the study were functionally illiterate hence the questionnaire was explained to them and the items and possible answers read to them. The questionnaire was field tested before usage. All questions appeared suitable for our study population.

### 5.2 TARGET POPULATION AND IN-/EXCLUSION CRITERIA

The target population was all Kwale District inhabitants aged over 40 years with visual acuity less than or equal to 6/18 in one or both eyes, and referred for cataract surgery at KDEC. Inclusion criteria were: willingness to give consent, age over 40 years, visual acuity less than or equal to 6/18 in one or both eyes, and recommendation for cataract surgery.

Exclusion criteria were unwillingness to give consent, age less than 40 years, and other major ocular pathologies apart from cataract. This included e.g. glaucoma, trachoma, amblyopia or corneal opacities. Patients with mature cataracts and no fundal view, who were revealed postoperatively to have significant fundus and or optic nerve changes, were also being excluded.

### 5.3 STUDY PERIOD

The study period was five months from 1<sup>st</sup> November 2007 to 31<sup>st</sup> March 2008.

### 5.4 SAMPLE SIZE DETERMINATION

For the sample size calculation a small pilot study was conducted during outreach activities at Kwale District. Visually impaired people (VA between 6/36 and 2/60) were interviewed using the proposed WHO/PBD VFQ-20 questionnaire (n=25). Mean score was 50 points with a standard deviation of 7.05.

For further calculations Students t-Test was used. The required sample size to detect a difference of 10 % in the mean score at alpha=0.05 (two sided) and power 0.8 was calculated to 34 people per group. From internal data we know that the distribution of people accepting and people refusing is app. 2 to 1 (68.9% acceptance rate). For calculation of unequal group size the following approximation was used:

$$N' = [(c+1): 2c] \times N$$

With

$N'$  = new sample size number

$N$  = sample size number for equal group size

$C$  = controls per case

By putting  $C=2$  a total number of 26 people refusing and 68 people accepting surgery was required.

In total 144 people were interviewed. 33 of these refused, 111 accepted cataract surgery.



## 5.5 DATA COLLECTION

The following structured questionnaire was used:

### **WHO/PBD Visual Functioning Questionnaire (20 Items)**

For the bio data an exclusively designed form was used. Both are attached under Appendix at the end of this study.

### **The independent variables included:**

Age, sex, education, literacy, marital status and socioeconomic status. Presenting visual acuity with Snellen or illiterate E chart.

**The dependent variables included the vision related Quality of life scores of the patient.**

## 5.6 DATA MANAGEMENT AND EDITING

In the field the biospecific data and the Quality of Life data were recorded on paper forms. At KDEC the data was then transferred into an Excel file. This data entry was done twice at different times. Both data sheets were subsequently checked for alterations (by subtraction of values). Whenever there was an alteration found in one of the data sheets, the value was again checked with the original paper sheet and accordingly corrected.

### **5.6.1 DATA CONSISTENCY AND VALIDITY**

Through range checks, the data entry software ensures to a large extent that there were no inconsistencies or invalid data. However, the data, free of entry errors, was again checked for consistency.

### **5.6.2 DATA STORAGE**

At KDEC the data was stored on a hard disc and security copies were made weekly on a flash-disk. Also weekly the data was send through email to the principal investigator.

### **5.6.3 DATA ANALYSIS**

Qualitative data was analyzed and processed using SPSS version 15 statistical software. Statistical significance testing was carried out whenever appropriate and level of significance was taken at 5%. Regression analysis was carried out as needed, in particular to determine independent associated factors with acceptance/refusal and QoL score.

### **5.7 ANTICIPATED SOURCES OF BIAS**

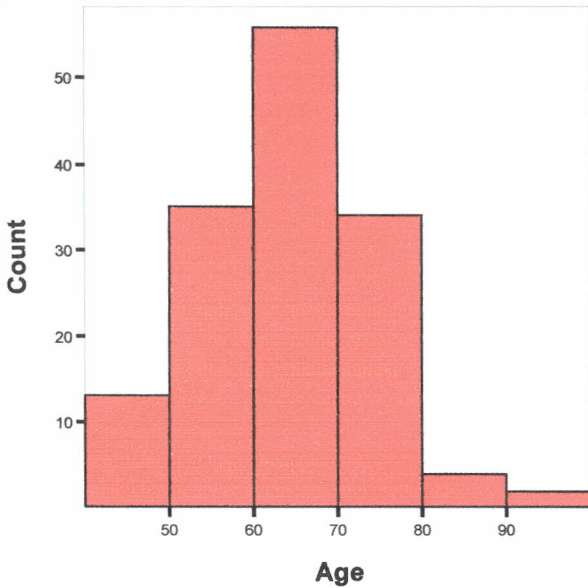
Translation from one language into another per se is a potential source of bias. We attempted to minimize translation bias by careful selection of the interviewer. The interviewer speaks all local languages as well as English fluently.

## **6.0 ETHICAL CONSIDERATION**

Ethical approval was obtained from the Ethical Committee of the Faculty of Medicine at the University of Nairobi, Kenya. Informed consent from subjects were enrolled and the Patient's data was kept confidential.

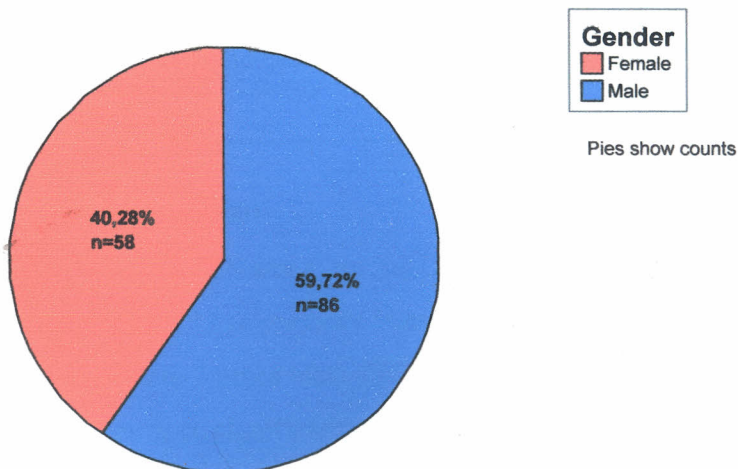
## 7.0 RESULTS

**Figure 3: Distribution of study population by age (n=144)**



The mean age of the study population was 66 years, the median 68 years and the mode 70 years. The minimum age was 41 years, the maximum age 98 years.

**Figure 4: Distribution of study population by sex (n=144)**



Males accounted for 59.7% of the study population, females for 40.3%.

**Table 1: Characteristics of the study population (n=144)**

Variable		Female	Male	OR (95% CI) or Students T-test (for continuous data)	p-value
		# (% within Gender) or Mean	# (% within Gender) or Mean		
Age		65.4	66.77	0.745	0.457
Marital Status	Unmarried or widowed	43 (74.1)	8 (9.3)	27.95 (10.95-71.22)	<b>&lt;0.001</b>
	married	15 (25.9)	78 (90.7)		
Educational Level	none	56 (96.6)	61 (70.9)	11.4 (2.60-50.68)	<b>&lt;0.001</b>
	Primary school or more	2 (3.4)	25 (29.1)		
Literacy	illiterate	54 (93.1)	57 (66.3)	6.87 (2.26-20.80)	<b>&lt;0.001</b>
	literate	4 (6.9)	29 (33.7)		
Previous Cat-OP	no	47 ( 81)	73 (84.9)	0.76 (0.315-1.84)	0.349
	yes	11 (19)	13 (15.1)		
Assets*	0	49 (84.5)	51 (59.3)	1.0	
	1 or 2	8 (13.8)	24 (27.9)	0.35 (0.14-0.85)	<b>0.03</b>
	3 or 4	1 (1.7)	11 (12.8)	0.09 (0.01-0.76)	<b>0.02</b>
Household Size	Small (1 to 3 persons)	12 ( 20.7)	8 (9.3)	2.35 (0.89-6.2)	0.13
	Bigger (4 or more)	44 (75.9)	69 (80.2)		
	Refused to answer	2 (3.4)	9 (10.5)		
Visual Acuity (WHO)	Normal	18 (31)	27 (31.4)	1.0	
	Visual Impairment	21 (36.2)	37 (43)	0.85 (0.38-1.9)	0.85
	SVI and Blindness	19 (32.8)	22 (25.6)	1.3 (0.55-3.05)	0.55
QoL scores		51.09	49.35	0.842	0.40

\*Anova: F:12.04 p-value: **0.001**

- Females are 28 times more likely to be unmarried compared to males
- Females are 11 times more likely to have no formal education compared to males
- Females are 7 times more likely to be illiterate
- Females have significantly fewer assets compared to males
- There was no difference between men and women in terms of previous cataract surgery, household size, visual acuity, and quality of life score



**Table 2: Characteristics of people who refuse or accept cataract surgery (n=144)**

Variable		Accepted # (% within Gender) or Mean	Refused # (% within Gender) or Mean	OR (95% CI) or Students T-test (for continuous data)	p-value
Age		66.33	65.82	0.24	0.811
Marital Status	married	79 (71.2)	14 (42.4)	3.35 (1.50-7.48)	<b>0.003</b>
	Unmarried or widowed	32 (28.8)	19 (57.6)		
Educational Level	Primary school or more	23 (20.7)	4 (12.1)	1.89 (0.6-5.94)	0.198
	none	88 (79.3)	29 (87.9)		
Literacy	literate	28 (25.2)	5 (15.2)	1.89 (0.67-5.36)	0.166
	illiterate	83 (74.8)	28 (84.8)		
Previous Cat-OP	yes	19 (17.1)	5 (15.2)	1.16 (0.4-3.38)	0.513
	no	92 (82.9)	28 (84.8)		
Assets*	0	78 (70.3)	22 (66.6)	1.0	
	1 or 2	25 (22.5)	7 (21.3)	1.01 (0.38-2.64)	0.99
	3 or 4	8 (7.2)	4 (12.1)	0.56 (0.16-2.05)	0.37
Household Size	Bigger (4 or more)	89 (80.1)	24 (72.7)	2.0 (0.72-5.56)	0.18
	Small (1-3 persons)	13 (11.7)	7 (21.2)		
	Refused to answer	9 (8.2)	2 (6.1)		
Gender	Male	74 (66.7)	12 (36.4)	3.5 (1.55-7.88)	<b>0.002</b>
	Female	37 (33.3)	21 (63.6)		
Visual Acuity (WHO)*	Normal	35 (31.5)	10 (30.3)	1.0	
	Visual Impairment	43 (38.7)	15 (45.5)	0.82 (0.33-2.05)	0.67
	SVI and blindness	33 (29.8)	8 (24.3)	1.18 (0.41-3.35)	0.76
QoL scores		51.72	44.42	3.13	<b>0.002</b>

\*Anova: for Assets: F:0.396; p-value: 0.674

for Visual Acuity: F: 0.278; p-value: 0.758

- Married people are 3 times more likely to accept surgery
- Males are 3 times more likely to accept surgery compared to females



- People with a poor QoL score are more likely to accept surgery compared to people with a good QoL score
- **There was no association between visual acuity and acceptance**
- The other socio-demographic characteristics were not associated with acceptance

It should be noted that married people are more likely to be males (see Table 1) and this indicates that the relationship between marital status and acceptance may be due to the association with gender.

**Table 3: Sociodemographic factors predicting QOL scores in the study population (n=144)**

Variable		Number (#)	QoL-score (mean)	SD	Students T-test	p-value
Age	>= 70	56	53.98	14.23	3.2	<b>0.002</b>
	< 70	88	47.55	9.89		
Marital Status	unmarried or widowed	51	51.59	13.55	1.129	0.261
	married	93	49.20	11.27		
Educational Level	none	117	51.51	12.68	3.1	<b>0.002</b>
	Primary school or more	27	43.70	6.40		
Literacy	illiterate	111	52.19	12.54	4.09	<b>&lt;0.001</b>
	literate	33	42.85	6.94		
Previous Cat-OP	no	120	50.95	12.32	2.02	<b>0.046</b>
	yes	24	45.54	10.20		
Assets*	0	100	51.42	12.78		
	1 or 2	32	48.88	10.31	1.024	0.308
	3 or 4	12	41.75	7.01	2.57	<b>0.012</b>
Household Size	1 to 3	20	46.80	9.47		
	4 or more	113	50.56	12.59	-1.27	0.206
	No answer	11	50.73	11.68	-1.02	0.317
Gender	Female	58	51.09	12.69	0.842	0.401
	Male	86	49.35	11.77		

\*Anova: for Assets: F: 3.73; p-value: **0.026**

- Older people were more likely to have a poor QoL score compared to younger people
- People without formal education had a poor QoL score.
- Additionally, people who were illiterate were more likely to have a poor QoL score
- People with fewer assets had a poor QoL score.
- Literacy and education were strongly correlated; the most important factor with QoL score was literacy
- There was no association between gender and QoL score.
- People who were poorer (few assets), older, and illiterate had poor QoL scores.

**Table 4: QOL-scores and visual acuity (WHO classification)**

Variable		Number (#)	QoL score		Students T-test	p-value
			(mean)	SD		
Visual Acuity (WHO)	Normal	45	42.44	7.37		
	Visual Impairment	58	49.50	8.909	-4.29	<0.001
	SVI and Blindness	41	59.17	14.24	-6.93	<0.001

\*Anova: F: 2.665 p-value :< 0.001

**Table 5: QoL-scores and WHO grades of visual impairment among groups (acceptance/refusal) (n=144)**

Variable		Accepted			Refused			Students T-test	p-value
		N	QoL-score (Mean)	SD	N	QoL-score (Mean)	SD		
Visual Acuity (WHO)	Normal	35	43.20	7.70	10	39.80	4.47	1.3	0.202
	Visual Impairment	43	51.05	9.04	15	45.07	7.06	2.32	<b>0.024</b>
	SVI and Blindness	33	61.64	13.56	8	49.00	13.1	2.38	<b>0.022</b>
Total		111	51.72	12.52	33	44.42	8.78	3.13	<b>0.002</b>

\*Anova: Accepted: F: 27.428. p-value: <0.001.

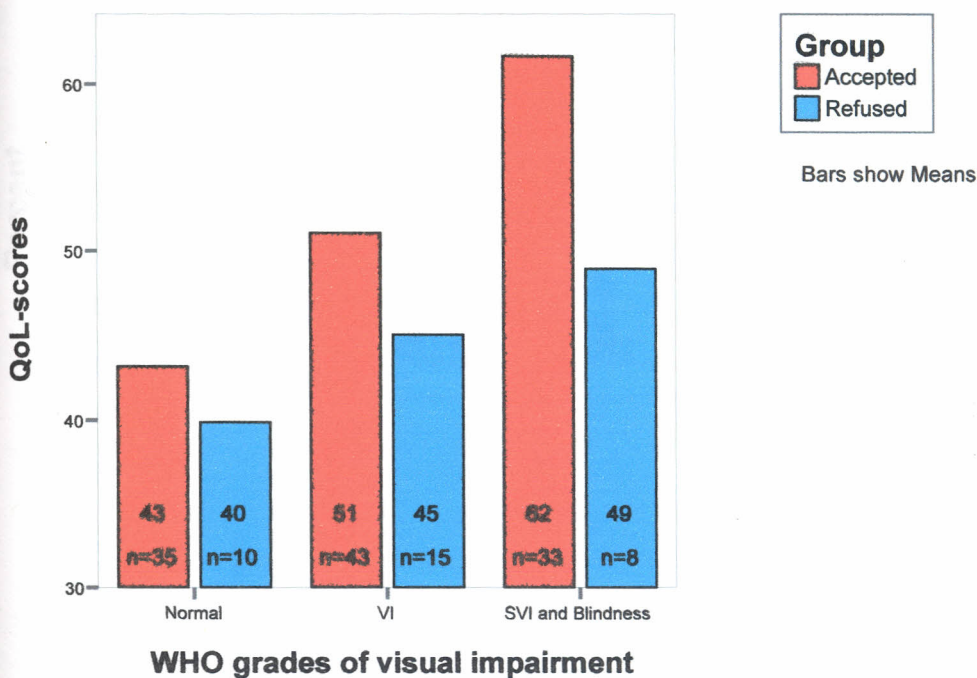
Refused: F: 2.797 p-value: 0.077

- Visual acuity was strongly related to QoL scores; blind people had the poorest QoL score.
- Among the people who accepted surgery, the strong correlation between VA and QoL remains. However, among the refused group, the correlation between VA and QoL is less strong.



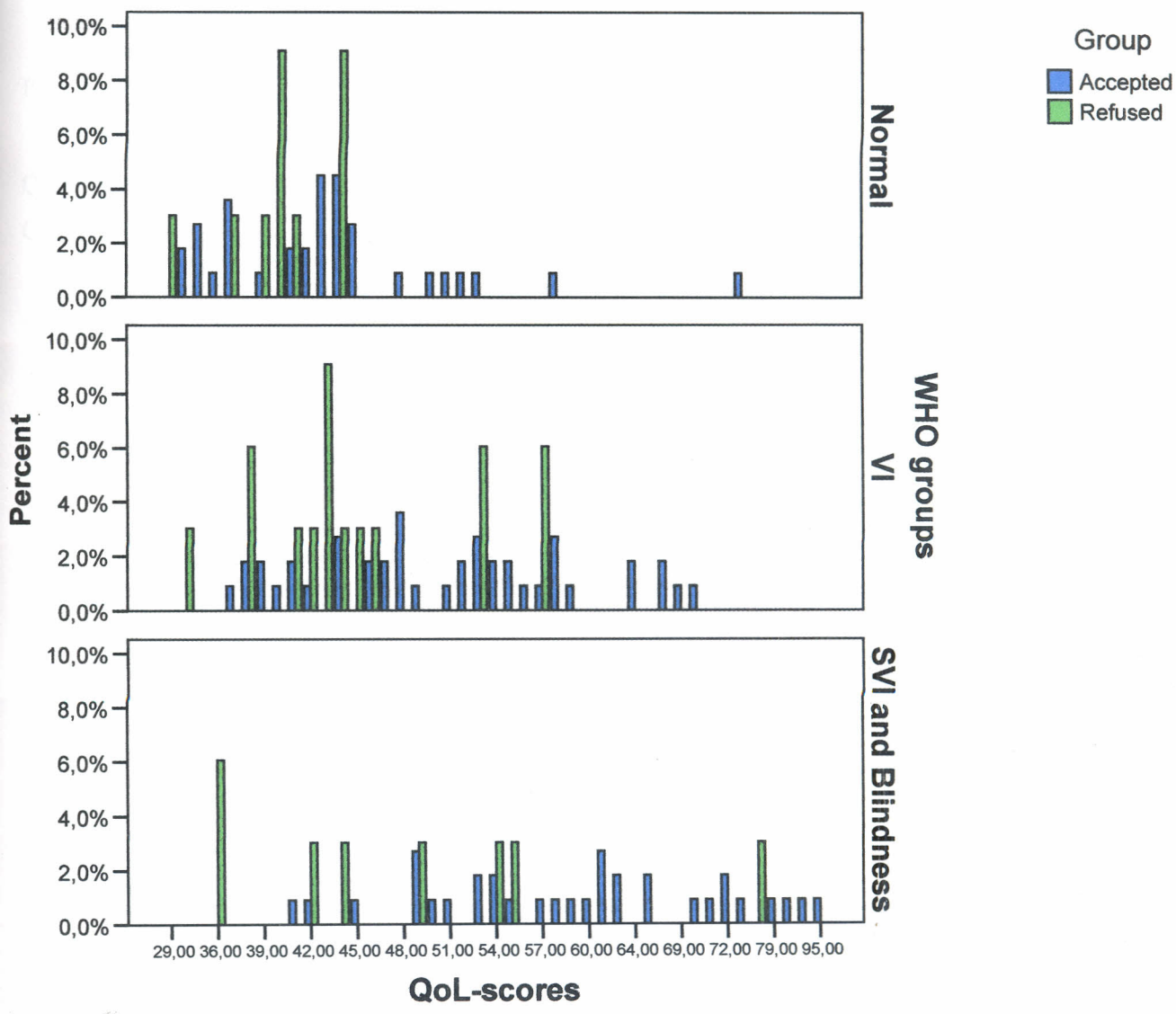
- The spread of the QoL scores was most pronounced among people with SVI/blindness compared to those with normal vision (See diagram below).
- The difference in QoL scores between the accepted and refused group was most pronounced among those with SVI/Blindness. There was minimal difference among those with normal vision.

**Figure 5: QoL scores and WHO grades of visual impairment (by acceptance/refusal)**  
(n=144)



QoL scores and VA are strongly related (as expected). The difference in QoL score between those who accept and those who refuse is highest among those severely impaired/blind.

**Figure 6: Distribution of QoL scores among WHO grades of visual impairment (by acceptance/refusal) (n=144)**



- People with low VA have a greater range in QoL score than those with normal vision, this means that the perception of severely impaired vision or even blindness varies greatly among the individuals.
- People with less severe reduction in sight or normal sight show less variation in their scores.

**Table 6: Factors associated with acceptance of surgery (Logistic Regression Model) (n=144)**

Parameters in the model	Independent odds of accepting surgery	
	Odds Ratio (95% CI)	p value
QoL score*	1.08 (1.06-1.11)	0.001
Gender=male	4.40 (2.82-6.85)	0.015

\* For every point increase in QoL there is a 1.08 fold higher chance that surgery is accepted.

Factors included in the model which did not predict outcome included marital status (p=0.23), (strong correlation between marital status and gender),

- Parameters included in the model (from table 2) included QoL score, gender, and marital status. However, marital status was removed from the model because of the strong correlation with gender.
- Overall, men were 4.4 times more likely to accept surgery compared to women independent of (or regardless of) their QoL score.

**Parameters influencing acceptance (independently) are QoL score and gender.**

**When using the model above with the QoL subscales (General vision, etc.) the strongest association between Accepting/Refusing surgery was seen with the psychosocial subscale (p<0,001).**



**Table 7: Factors associated with QoL-Scores (Linear Regression Model) (n=144)**

Independent correlation coefficient of QoL score

Parameters in the model	$\beta$ (SE)	p value
Visual acuity (WHO 3 stage)	7.49 (1.15)	<0.001
Literacy (illiterate/literate)	-5.196 (2.11)	<0.001

As visual acuity decreases, QoL decreases and people who are illiterate are likely to have a lower QoL compared to those who are literate.

Additional factors included in the model, but not associated independently with QoL included age, marital status, education, assets, and previous cataract operation.

- Parameters included in the model were all of those statistically significant ( $p < 0.05$ ) with QoL (socio demographic and visual acuity, see Table 3 and 4)
- Only visual acuity and literacy demonstrated an independent association with QoL; the other factors (age, marital status, education, assets, and previous cataract operation) were not statistically associated with QoL. Some variables (e.g., education) were strongly associated with literacy.

### **Limitations**

There are limitations of our regression models. The main limitation in our study is the low sample size, especially in the refusal group. With a higher sample size other variables influencing QoL or Acceptance/Refusal might as well become significant. However, the main independent variables like QoL score for acceptance and Visual Acuity for QoL scores will most likely remain the same.

**Table 8: Individual questions and group (acceptance/refusal) (n=144)**

Subscale*	Question	Accepted		Refused		Students	
		Mean	SD	Mean	SD	T-test	P-value
GV	q1	4.21	0.51	4.03	0.30	1.903	0.059
VS	q2	1.51	0.71	1.33	0.54	1.343	0.182
GF	q3	2.30	1.27	2.18	1.26	0.46	0.647
GF	q4	2.41	1.20	1.91	1.07	2.133	0.035
VS	q5	4.00	0.60	3.82	0.81	1.4	0.164
GF	q6	2.90	1.15	2.67	1.19	1.018	0.31
GF	q7	1.26	0.76	1.09	0.52	1.205	0.23
<i>GF</i>	<i>q8</i>	<i>1.25</i>	<i>0.71</i>	<i>1.06</i>	<i>0.35</i>	<i>1.502</i>	<i>0.135</i>
GF	q9	2.43	1.41	1.70	1.24	2.709	<b>0.008</b>
GF	q10	1.48	1.05	1.06	0.35	2.236	<b>0.027</b>
GF	q11	4.46	0.66	4.21	0.74	1.843	0.067
GF	q12	1.54	0.99	1.24	0.66	1.625	0.106
GF	q13	2.70	1.21	2.39	1.14	1.302	0.195
VS	q14	4.19	0.68	3.88	0.74	2.253	<b>0.026</b>
GF	q15	4.18	0.88	3.85	0.83	1.93	0.056
GF	q16	1.55	0.99	1.21	0.65	1.844	0.067
PS	q17	1.66	1.25	1.09	0.52	2.541	<b>0.012</b>
PS	q18	2.17	1.29	1.45	0.90	2.973	<b>0.003</b>
PS	q19	1.59	1.15	1.18	0.58	1.944	0.054
PS	q20	3.94	1.16	3.06	1.39	3.631	<b>&lt;0.001</b>

**GV: General vision**

**GF: General functioning**

**VS: Visual symptoms**

**PS: Psychosocial**

**Questions (statistically significant difference among groups):**

9: How much difficulty do you have in seeing the level in a container when pouring?

10: Because of your eyesight, how much difficulty do you have in going to activities outside of the house (e.g. sporting events, shopping, religious events)?

14: How much difficulty do you have in seeing when coming inside after being in bright sunlight?

17: Because of your eyesight, how often have you been hesitant to participate in social functions?

18: Because of your eyesight, how often have you found that you are ashamed or embarrassed?

20: Because of your eyesight, how often do you worry that you may lose your remaining eyesight?

**Table 9: Qol Subscales and group (acceptance/refusal) (n=144)**

Subscale	Accepted		Refused		Students T-test	P-value
	Mean	Std. Deviation	Mean	Std. Deviation		
General Vision	4.21	0.51	4.03	0.31	1.9	0.059
General Functioning	28.46	8.98	24.58	6.57	2.31	<b>0.023</b>
Visual Symptoms	9.70	1.34	9.03	1.29	2.56	<b>0.012</b>
Psychosocial	9.35	3.15	6.79	2.15	4.38	<b>&lt;0.001</b>



**Table 10: QoL dimensions and group (acceptance/refusal) (n=144)**

Dimension	Accepted		Refused		Students T-test	p-value
	Mean	Std. Deviation	Mean	Std. Deviation		
General vision	4.21	0.51	4.03	0.31	1.90	0.059
Ocular pain/discomfort	1.51	0.71	1.33	0.54	1.34	0.182
Distance Vision difficulty	13.34	4.09	11.76	3.24	2.04	<b>0.043</b>
Near Vision difficulty	12.31	3.89	10.52	3.04	2.43	<b>0.016</b>
Glare	4.00	0.60	3.82	0.81	1.40	0.164
Light/Dark Adaptation	4.19	0.68	3.88	0.74	2.25	<b>0.026</b>
Colour Vision difficulty	1.26	0.76	1.09	0.52	1.21	0.230
Role Limitations	1.55	0.99	1.21	0.65	1.84	0.067
Social functioning limitations	1.66	1.25	1.09	0.52	2.54	<b>0.012</b>
Mental Well-being	6.11	1.88	4.52	1.80	4.30	<b>&lt;0.001</b>
Dependency	1.59	1.15	1.18	0.58	1.94	0.054

- The QoL questionnaire has 20 questions and can be divided into 4 sub-scales. General vision has only one question. General functioning has 12 questions. Visual symptoms have 3 questions and psychosocial has 4 questions. In addition, the 20 questions can be divided into 11 dimensions (e.g., pain, glare, light-dark adaptation)
- The statistically significant difference in QoL between people who accept versus those who refuse surgery is found only among 6 of the 20 questions, of which 3 are among the psycho-social sub scale. Three of the 4 sub-scales show significant differences; only general vision is not statistically different. The strongest association is using the psychosocial sub-scale.
- Among the 11 dimensions, statistical significance was found for 5. The most important difference was for the dimension of mental well-being.

## QUALITY OF PREVIOUS CATARACT SURGERY

24 people in our study had already had cataract surgery in one eye. 12 were operated on the right eye and 12 were operated on the left eye. The place and time of previous cataract surgery was not recorded in the context of our study. Visual acuity was measured as presenting acuity without further refraction or use of pinhole.

**Table 11: Outcome of previous cataract surgery**

Outcome:	Right eyes # (%)	Left eyes # (%)	Total #(%)
Good outcome (6/18 or better)	8 (66.7)	7 (58.3)	15 (62.5)
Borderline outcome (6/24 to 6/60)	2 (16.7)	3 (25)	5 (20.8)
Poor outcome (Less than 6/60)	2 (16.7)	2 (16.7)	4 (16.7)

The place of previous surgery was not determined. Several other eye-care provider used to do eye-camps in Kwale District, so that patients might have had surgery elsewhere (Lions-Club, *Lighthouse Mombasa, etc.*).

## 8.0 DISCUSSION

The concept of visual impairment differs greatly among different societies, as well as among different members of the same society. A visual impairment of 6/9 might be subjectively unacceptable to a young, literate person living in an industrialized country, whereas an elderly farmer in a rural area of a developing country will hardly present any complains about his sight to his doctor. In general, the more advanced a society is the higher are the peoples' expectations of good sight. This finding has various reasons; the most important might be the high level of literacy, wide utilization of modern media, TV, Internet, which require good vision and easy and readily available eye care services. Traditional beliefs and attitudes also have a strong impact on someone's perception of blindness or severe loss of vision. In the western world there is a strong belief that illnesses are an existing, but potentially curable, burden of mankind. This belief might be less strong in developing countries, where diseases are often considered to be a curse, god given or simply a natural part of the aging process; tendencies described as fatalistic perceptions. The same principles are also true regarding sight and the perception of reduced sight. Regional and cultural differences in the perception of visual impairment have been reported by several authors<sup>75-79</sup>. Measurement of sight is usually done using Snellen charts; but these scales completely lack information about the effect of reduced sight on an individual. The perception of visual impairment can be objectively measured by vision related quality of life scales, which have been widely used for this purpose. The patient gives a 'difficulty rating' for each item. Responses are scored (e. g. 1-no problem to 5-severe problem). The WHO Questionnaire PBD 20 was used for this study; the minimal score was 20 points, the maximum score 100. A low score indicates a high quality of life and little affect from impaired sight. The mean in the QoL scores in our study varied from 42.4 for people with normal vision in one eye, but cataract related vision impairment in the other, to 59.2 for people with severe visual impairment and blind people (Table 4). Considering the scale categories for the Questionnaire, this result suggests a "moderately" impaired quality of life with an average grading of "moderate problem" for each question. Normative data for the WHO/ PBD 20 exists from a recent study done by Polack et al. They used the questionnaire on a study population in Nakuru, Kenya. They removed question No.5, which asks for difficulties in seeing because of bright light, because they found it unsuitable. With therefore only 19 questions people with normal vision (VA better or equal 6/18) had a mean score of 25.4 and people with cataract related visual impairment (visual acuity less than 6/18) a mean score of 59.7. This score is higher compared to our



findings. It suggests higher perceived disability due to visual impairment compared to our study population. The data suggests that people from Kwale District in general feel less impaired when considering equal reduction in visual acuity, measured by Snellen or illiterate E charts than those in Nakuru District in central Kenya. People from the socioeconomically more privileged Nakuru region may have higher expectations of their vision than the relatively poor rural population studied in Kwale District .

To the best of our knowledge the WHO questionnaire has only been used in the study from Nakuru. Comparisons with existing quality of life data from other studies and other societies are difficult to make. There is high heterogeneity in the used QoL scales; several dozens of questionnaires assessing vision related Quality of Life exist. Some have three-steps, others four- or five-step gradings, some have less than 20 questions, others over 30. Most are adjusted to the particular society and ask about difficulties in daily life according to the study setup and location. This makes the studies difficult to compare .

### **What influences QoL scores?**

Visual Acuity is the strongest predictor of QoL scores (Table 4). Other predictors are age, educational level, literacy, possession of assets and previous cataract operation (Table 3). Gender had no influence on the QoL scores. This finding is consistent with findings from two large Indian trials <sup>77,78</sup>, but in contrast to the findings in one study from Nepal <sup>76</sup>, where women were found to have poorer QoL scores. A linear regression model was used to identify independently associated factors with QoL scores. Visual acuity was, as expected, independently associated. Interestingly, from the other variables, only literacy showed independent correlation. Illiterate people had poorer QoL scores than literate people. This association was weaker than visual acuity (p-value: 0.015 compared to <0.001). We believe that this finding has to be looked at from a more comprehensive perspective. Illiteracy was associated with poor socioeconomic status and unsurprisingly with a poor level of education . Both these factors are known to have a strong association with poorer QoL scores <sup>71,75</sup>. Studies showed an independent association between low educational levels and QoL scores <sup>77,78</sup>. Whether literacy on its own impacts QoL scores is questionable. The study from Nepal showed no independent association between Literacy and QoL scores.

Literacy has to be seen as the result of poor education and as such leads to poorer QoL scores. We do not believe that illiteracy on its own, without considering educational level, independently impacts QoL scores.

The socioeconomic status, although not independently associated with the QoL-scores, influences responses in QoL questionnaires regardless of the visual acuity. We showed in this study that QoL was poorer in people with lower socioeconomic status (p for trend: 0.026). This is in accordance with the vast majority of studies on quality of life/self-rated health and sociodemographic conditions <sup>75-78, 83</sup>. However, the question remains why people with poorer educational level and lower socioeconomic status show poorer QoL scores.

Several theories exist which explain the correlation between underprivileged socioeconomic status and poorer self-rated quality of life. The materialist/structural theory suggests an important role of the physical environment e.g. working conditions, material conditions, and housing environment. The behavioural/lifestyles explanation emerged when individual risk factors such as smoking, alcohol use, and physical inactivity were identified as determinants of health. According to this theory, social differences in health are explained by an less healthy lifestyle among those less privileged. The psychosocial theory proposes that unhealthy habits are a reaction to stress and a way to alleviate frustration. Social capital, social support, and autonomy represent key elements for good quality of life and are more often found in people of higher socioeconomic status and educational level <sup>84</sup>.

We believe that a combination of all three theories can best explain the association between poorer QoL scores and low educational level/socioeconomic status in this study population. Illiterate people are more likely to be less autonomous, socioeconomic underprivileged and face more problems in daily life, e. g. adhering correctly to a doctor's instructions, than their literate age-mates.

Interestingly, the relationship between poorer socioeconomic status and poorer QoL scores is valid only for individuals when compared within the same society. Kwale belongs to the poorest regions in Kenya, but people in our study have better scores than people from the Nakuru district, where people are generally better off economically. It is thought that there are no absolute wealth-variables which can predict Quality of Life. The quality in life and self-rated health are usually judged by comparison with other members of the same social environment.



## What disables use of eye-care facilities?

Barriers to cataract surgery have been identified in several occasions. They can be grouped into barriers created by the health care provider, by the society or by the individual himself. One barrier, which is of uppermost importance for people living in developing countries, is the costs of cataract surgery. Unlike in the developed world there is no functional health insurance system for the vast majority of people. Concerning cataract surgery there are two main aspects of costs. The direct cost of surgery, which is the hospital bill for cataract surgery and the indirect costs, which involve transport to and from the hospital and food while at the hospital. Costs have been identified by many authors as a significant factor preventing people from accessing cataract surgery facilities<sup>47-49</sup>. However, recent findings from Tanzania show that costs are often used as an excuse for refusal of surgery which is easily accepted by health workers<sup>50</sup>. The real reasons for refusal were hidden behind this. In a study in South Africa uptake was reported to be very low despite being offered very low cost (US \$3.00) or offered free of charge. Costs were not a major barrier; they were only mentioned by two of 24 people who refused cataract surgery<sup>51</sup>. Similarly, in a study in rural Malawi, where surgery was free and transport to the hospital provided, cost was not a major problem. Interestingly, cataract patients of lower socioeconomic status were more likely to accept cataract surgery than those from higher socioeconomic status<sup>52</sup>. There is an ongoing debate about the advisability of charging people for health care services and in particular cataract surgery. Most centres charge something but offer free services in areas of great need<sup>49</sup>.

KDEC runs a well established outreach programme which covers the costs of the surgery including transport to the clinic and back. Indirect costs, such as wage losses are not covered by the center. However, in our study-population the vast majority of patients did not have an income. So wage losses are not a concern. In contrast to other studies, it can be suggested that costs were not a main barrier to cataract surgery in this study.

It has been shown that barriers should also be considered from a gender perspective<sup>42,44,45</sup>. In studies where cataract surgery was not offered free of charge, significant differences in the acceptance rates between men and women were found. Men were generally more likely to accept surgery than women<sup>67,81</sup>. The same finding is true for the population studied in this dissertation. Overall, being male was associated with a 4.4 higher chance to accept surgery than being female. The reasons are complex. It is likely that women do not have the authority in the household to seek, on their own, surgical services.<sup>81</sup> *This might explain why women are much*



less likely to accept surgery than men in this context. Furthermore it was suggested that possessions in the household and decisions regarding use of family resources is held by men. In studies, where the patients were charged for cataract surgery, men were more likely to get money for cataract surgery from their own funds, while women were more dependent on their children and other sources <sup>8,67,81</sup>. The KDEC outreach programme is structured in such a way that the recommendation for cataract surgery is made at the screening site. If patients agree, they will be brought to the hospital the same day and operated on the next day. Once screened and recommended for surgery, patients have to make an immediate decision. It seems that males are more able to do so, maybe because of their relatively higher independence. Women often stated that they could not make decisions on surgery without former consultations with family members. Many of them therefore lost the opportunity to access free surgery. In addition, we found large socio-demographic differences between men and women with operable cataract. Men were richer (had more assets), had a higher literacy rate and more formal education (Table 1). However, there were no differences in cataract related variables between men and women. The visual acuity, quality of life score and previous cataract operation rate did not differ significantly. Furthermore men were more likely to be married and to live in a bigger household. 90.7% of men but only 25.9% of women in our study were married. This may be due to the sociodemographic and cultural factors of Kwale District, which is strongly influenced by Islamic culture. Polygamy is widely practised, so when a man dies, he will leave several widows, but few men remain single when their wife dies. Another possible explanation for the high rate of widows among our female study population could be that widows are per se more likely to present at a screening site, whereas married women might be held back by daily duties or simply being denied to attend <sup>81</sup>.

In summary, we believe that the strong community based programme run by KDEC has reduced common barriers such as lack of awareness, accessibility or costs. The main barriers that restrict access to the screening programme and/or acceptance of cataract surgery were related to gender, marital status and the individual's perception of his/her reduced sight.

### **What influences the decision to accept cataract surgery?**

In this study the strongest association with refusal of surgery was found in the variables QoL score, gender and literacy. Acceptance was greatest among men with higher QoL scores. We used a multifactor logistic regression model to look further into factors independently associated with acceptance or refusal. QoL scores were strongly associated with acceptance or refusal of

cataract surgery. For every point increase in the QoL score there was a 1.08 fold higher chance that surgery is accepted (Table 6). This means, for example, that a patient who is 10 points higher on the QoL score will be 2.2 times more likely to accept surgery than the one he is compared to. The strongest association between acceptance and refusal was found in the psychosocial subscale (Table 9). Mean score was 9.35 for people who accepted and 6.8 for people who refused surgery (p-value:<0.001). Unsurprisingly, people, who are socially and psychologically more affected by their visual impairment, are more likely to accept surgery. It seems that the measurement of psychosocial impairment is an excellent predictor for someone's decision to accept surgery. We believe that this subscale best reflects how visually disabled someone feels. It seems, infact, to be more useful than questions concerning visual symptoms and general functioning.

Five of the 11 dimensions of the questionnaire showed a statistically significant difference among people who accepted and people who refused surgery (Table 8). Three of them were related to visual symptoms such as difficulties in near and far vision, two referred to psychosocial problems. The least differences in scores were found for the dimensions of ocular pain/discomfort, glare and colour vision difficulties. These dimensions were either not relevant for visual impairment due to cataract, such as ocular pain, or did not alter among the groups in our study population, such as glare or disturbance from bright light.

Scores of colour vision difficulties remained relatively unaffected by decreasing visual acuity. The mean score was low (1.26 for acceptors and 1.09 for non-acceptors), which signalises a low grade of impairment. The WHO/PBO 20 items questionnaire was not exclusively designed for people affected by cataract-related visual impairment, but is also suitable for other diseases like glaucoma. The question about ocular pain might be dispensable when interviewing for cataract impairment.

Literacy showed a strong correlation with gender and was not an independent factor for acceptance or refusal in our model. Being male was associated with a 6.9 times higher chance of being literate (Table 1). Marital status had some impact on the decision on cataract surgery. A tendency that unmarried women were more likely to accept surgery was noted. However, this difference was not statistically significant (p-value:0.285). Being married did not independently influence the decision whether to accept surgery or not. This is in contrast to a study from Tanzania, where it was found that unmarried women and men had a higher chance of accepting surgery<sup>8</sup>. Other studies have revealed similar findings<sup>52</sup>. Unlike in our study, cataract surgery



was not provided free in these studies. The findings suggest that cost remains an important barrier towards cataract surgery; especially for married women who depend on family resources. Offering free or highly subsidised surgery especially enables married women to access cataract surgery.

Visual Acuity as well as age had no significant influence on acceptance or refusal. This, in spite of the fact that visual acuity as well as age influence QoL scores.

Visual acuity alone can not predict someone's decision whether to accept or refuse free surgery. This is an interesting finding, as the surgeons decision to recommend cataract surgery is usually strongly based on visual acuity, especially if there is a language barriers between patient and doctor.

### **Outcome of cataract surgery**

Although it was not a major objective in this study to analyze outcome of previous cataract surgery, during interviews we collected visual acuity of 24 previously operated eyes. Among those 62.5% had a good outcome. However 16.7 % had a poor outcome. This finding is consistent with findings from other studies in developing countries<sup>57-64</sup>. A multicenter study of 8 centres in Africa and Asia revealed a good outcome for 68.5% and a poor outcome for 5.1% of cataract operated patients<sup>82</sup>. Other studies from developing countries showed poorer outcome ranging between 21 to 53%<sup>59-64</sup>. Several studies have demonstrated that fear of not regaining sight and fear of the operation itself are important barriers which prevent patients coming for surgery<sup>8,41,42,51,52</sup>. It is therefore imperative that, besides increasing the number of operations, the outcome of cataract operations must be good<sup>82</sup>. If the causes of poor outcome are known through audit then it should be possible to address these causes and improve the results of surgery.

Quality of surgery and a good outcome is a highly important factor in convincing and attracting potential cataract patients. It can be anticipated that in a society with a negative tendency toward eye surgery a failed case with poor outcome makes a strong impact on the decisions of others. A negative impact might persist even if the individual knows of many positive surgical outcome in his community. The reasons for poor outcome could not be determined in the context of our study. This requires further research.



## 9.0 CONCLUSION

In our study there was a strong correlation between Visual Acuity and vision related QoL-scores, as expected. People with poorer Visual Acuity have poorer QoL scores. The other variable independently influencing QoL score was Literacy. The relationship between QoL score and Literacy is less clear than for visual acuity and might require further research.

People with poor visual acuity were not more likely to accept surgery than people with better vision. There was no statistically significant relationship between visual acuity and someone's decision to accept or refuse free surgery. Visual Acuity alone is an unsatisfactory predictor of uptake of cataract surgery. The strongest predictor of acceptance was the QoL score. People with poorer scores were more likely to accept surgery than people with better scores. The other factor that influenced acceptance was the gender. Males were 4.4 times more likely to accept than females.

Interestingly, most of the women in our study population were not married. It can be speculated that in this society widows enjoy greater independence than married women, enabling them to attend free eye-screenings. However, marital status had no influence on the decision making processes concerning acceptance of free cataract surgery.

Concerning QoL scores, the strongest difference among people who accept and people who refuse surgery was found in the psychosocial subscale. The questions asked in this section refer to categories of mental well-being, dependency and social functioning limitations. Whereas questions about visual symptoms are related to visual acuity and a replacement by VA-measurements (Snellen charts) is thinkable, psychosocial impact is impossible to quantify.. The strong relationship between psychosocial impairment and willingness to accept surgery shows the importance of qualitative factors over visual acuity alone.

## 10.0 RECOMMENDATIONS

It is advisable to promote empowerment of women on family major decisions. Also, involvement of communities, various governmental and NGOs, may help address the matter in the respective communities. It might furthermore be advisable that women, seeking help from eye-care providers, are accompanied by their husbands or other decision makers in the family. This would facilitate decisions on necessary medical treatment options<sup>83</sup>.

Illiteracy and lack of education were shown to have a strong influence on patients' perception of their visual impairment and may be an additive factor for poor uptake of cataract surgery. As the level of literacy increases so does acceptance of cataract surgery.

QoL scores, maybe even reduced to a few questions about psychosocial impairment, can be a helpful tool for understanding someone's decision to accept or refuse free cataract surgery. It may be of great help to the clinician to determine whether the patient will benefit from surgery; poor scores will also be helpful to convince family members of the need of surgery and will maybe even show the patient himself his social and psychological limitations due to his visual impairment. In setups with high-volume cataract surgery little time is reserved for patients' individual perceptions, wishes and expectations. However, QoL scales should be considered whenever doubts concerning the recommendation of cataract surgery for a patient exist.

Finally, it appears useful to promote reduction in the numbers of different quality of life questionnaires used to facilitate comparisons of studies done in different societies and regions.

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## 12.0 APPENDIX

### 1. CONSENT FORM

I..... of Box ..... and/or district/town ..... hereby give consent to be included in this study which entails participation in an structured interview. A standardized questionnaire will be used to determine my age, sex, education, literacy, marital status and socioeconomic status. A second questionnaire will ask me about my subjective visual impairment.

The data will be kept confidential, my name shall not be noted in the questionnaire. The results from this study will lead to a better understanding of decision making processes towards accepting cataract surgery.

Date.....

Signed.....

**ATTACHMENT: Proposed WHO/PBD Visual Functioning Questionnaire  
(20 item)**

*The first questions are about your overall eyesight. I will read out a choice of five answers and you will choose the one that describes you best.*

		1. Very good	2. Good	3. Moderate	4. Bad	5. Very bad
1	Overall, how would you rate your <u>eyesight</u> using both eyes – with <u>glasses</u> or contact lenses if you wear them?					
2	How much <u>pain or discomfort</u> do you have in your eyes (e.g. burning, itching, aching)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

(NOTE: If the responses were "Very good" and "None" to the above two questions, END the interview.)

*In the next section, I am going to ask you how much difficulty, if any, you have doing certain activities. I will read out a choice of five answers and you will choose the one that describes you best.*

		1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
3	Because of your eyesight, how much difficulty do you have in <u>going down steps or stairs</u> ?					
4	How much difficulty do you have in <u>noticing obstacles</u> while you are walking alone (e.g. animals or vehicles)?					
5	How much difficulty do you have in <u>seeing because of glare</u> from bright lights?					
6	Because of your eyesight, how much difficulty do you have in <u>searching for something</u> on a crowded shelf?					
7	How much difficulty do you have in <u>seeing differences in colours</u> ?					
8	Because of your eyesight, how much difficulty do you have in <u>recognizing the face of a person standing near you</u> ?					
9	How much difficulty do you have in <u>seeing the level</u> in a container when pouring?					

SS



10	Because of your eyesight, how much difficulty do you have in <u>going to activities outside of the house</u> (e.g. sporting events, shopping, religious events)?					
11	Because of your eyesight, how much difficulty do you have in <u>recognizing people you know from a distance of 20 metres?</u>					
12	How much difficulty do you have in <u>seeing close objects</u> (e.g. making out differences in coins or notes, reading newsprint)?					
13	How much difficulty do you have in <u>seeing irregularities in the path</u> when walking (e.g. potholes)?					
14	How much difficulty do you have in <u>seeing when coming inside after being in bright sunlight?</u>					
15	How much difficulty do you have in <u>doing activities that require you to see well close up</u> (e.g. sewing, using hand tools)?					
16	Because of your eyesight, how much difficulty do you have in <u>carrying out your usual work?</u>					

*In the next section, I am going to ask you how you feel because of your vision problem. I will read out a choice of five answers and you will choose the one that describes you best*

		1. Never	2. Rarely	3. Sometimes	4. Often	5. Very often
17	Because of your eyesight, how often have you been <u>hesitant to participate in social functions?</u>					
18	Because of your eyesight, how often have you found that you are <u>ashamed or embarrassed?</u>					
19	Because of your eyesight, how often have you felt that you are a <u>burden on others?</u>					
20	Because of your eyesight, how often do you <u>worry that you may lose your remaining eyesight?</u>					

### 3. Biospecific Data Collection Form

Name of client and village, district			
Study number			
Q1	Sex of respondent	Male	1
		Female	0
Q2	How old are you? <i>Age of respondent (in years)</i>	<i>Write in number</i>	
Q3	Operated in the eyes?	RE	LE
		No	0
		Yes	1
Q4	Do you wear glasses for distance?	No	0
		Yes	1
Q5	Visual Acuity (with distance glasses if used).	RE	LE
		>6/18	1
		6/18	2
		6/24	3
		6/36	4
		6/60	5
		5/60	6
		4/60	7
		3/60	8
		2/60	9
		1/60	10
		HM	11
		PL	12
		NPL	13
Q6	Education	None	0
		Primary school	1
		> Primary school	2
Q7	Literacy	No	0
		Yes	1
Q8	Currently married	No	0
		Yes	1
Q9	Possession of Radio	No	0
		Yes	1
Q10	Possession of Bicycle	No	0
		Yes	1
Q11	Possession of Cell Phone	No	0
		Yes	1
Q12	Possession of Watch	No	0
		Yes	1

Q13	What is the main cash income source for the household? <i>(Write in, e. g. selling maize)</i>	
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**Q14 Who lives in the same household as you (max. 5 people)?**

Relationship (e.g. husband, son, etc.)	Profession	Own income (write yes or no)	Comments (e.g. currently absent, sick at home etc.)



4. WHO/PBD VFQ 20 (Swahili)

		1. Nzuri sana	2. Nzuri	3. Kadiri	4. Mbovu	5. Mbovu sana
1.	Kwa ujumla unawezaje kupima uwezo wako wa kuona ukitumia macho yako mawili ukiwa na miwani ya macho?					
		1. Hamna	2. Kiasi	3. Kadiri	4.Mwingi	5.Mwingi sana
2.	Una uchungu kiasi gani au tatizo lolote kwa macho yako? (Kwa mfano uchungu mkali, kujikuna au kuumwa)					
		1. Hamna	2.Kiasi	3.Kadiri	4.Nyingi	5.Nyingi sana
3	Kwa sababu ya tatizo la kuona, una shida yoyote ukipanda juu au kushuka chini ya jengo la gorofa ukitumia ngazi?					
4.	Una shida yoyote kutambua vitu unapotembea kivyako?					
5.	Una shida kiasi gani kwa kuona kukiwa na mwangaza mwingi?					
6.	Kwa sababu ya tatizo la kuona, una shida yoyote ukitafuta kitu chochote miongoni mwa vingine?					
7.	Una shida kiasi gani kutambua rangi tofauti tofauti?					
8.	Kwa sababu ya tatizo la kuona, una shida yoyote kutambua uso wa yeyote aliye karibu nawe?					
9.	Una shida yoyote kutambua viwango kwa vifaa vyo vyote unapo mwaga vitu?					
10.	Kwa sababu ya tatizo la kuona, una shida yoyote ukifanya shughuli zozote ukiwa nje ya jengo kwa mfano michezo, kwenda kanisani au ukifanya ununuzi wa bidhaa?					

		1. Hamna	2. Kiasi	3. Kadiri	4. Nyingi	5. Nyingi sana
11.	Kwa sababu ya tatizo la kuona, una shida yoyote kumtambua mtu unayemfhamu kwa umbali wa mita 20?					
12.	Una shida yoyote kutambua vitu vilivyo karibu nawe kama vile gazeti au pesa sarafu au noti?					
13.	Una shida yoyote kutambua ulegevu wa barabara unapotembea kama vile mabonde?					
14.	Una shida yoyote unapoingia ndani ya jengo utokapo nje panapo mwangaza mwingi wa jua?					
15.	Una shida yoyote unapofanya kazi inayohitaji uangalifu mwingi kama vile kushona nguo au kutumia vyombo vya mikono?					
16.	Unapata shida yoyote unapofanya kazi zako za kawaida?					
		1.Hata kamwe	2.Nadra	3.Mara nyingine	4.Mara nyingi	5.Mara nyingi sana
17.	Kwa sababu ya tatizo la kuona,umewahi kujizuia kushiriki kwa shughuli za kijamii kwa sababu ya ubovu wa macho yako?					
18.	Kwa sababu ya tatizo la kuona, ni mara ngapi umeshawahi kujionea aibu au haya kutokana na hali yako ya macho?					
19.	Kwa sababu ya tatizo la kuona, ni mara ngapi umejisikia kuwa mzigo kwa wengine kwa sababu ya shida yako ya macho?					
20.	Kwa sababu ya tatizo la kuona, ni mara ngapi umejihisi kutaabika kuwa utapoteza uwezo wako wa kuona ulio salia?					