QUALITY OF LIFE MEASUREMENTS OF LOW VISION PATIENTS WITH AND WITHOUT INTERVENTION UTILIZATION

by

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ABSTRACT

Background: A large quantity of research has shown that having a low vision condition can decrease an individual's quality of life. However, research is lacking as to which low vision interventions are most effective at increasing an individual's perception of their quality of life. This study aims to determine how vision affects the perception of quality of life and whether or not devices and support groups are able to enhance this perception. Furthermore, this study aims to investigate the efficacy of specific interventions in increasing the quality of life in the low vision population. *Methods:* In order to obtain diverse responses, information was gathered from patient populations in various settings, including eye care clinics, low vision support groups, and low vision rehabilitation centers. Data was collected in survey form in order to assess the effects of permanent visual loss and low vision interventions on the perception of quality of life. *Results:* The participants responded to a set of survey questions regarding their perception of the severity of their disease, the effect of their condition on their quality of life, and the effects of low vision devices, support groups, and external support bases on their quality of life. Specific low vision devices and support groups were capable of producing increases in quality of life, though the perception of one's severity of visual loss did not show statistically significant changes with low vision services received or support group attendance. The most widely used devices included the closed-circuit television (CCTV), white cane, illuminated handheld magnifier, and Talking Book. *Conclusion:* Low vision has a significant effect on quality of life, but rehabilitation interventions (devices, support groups, etc.) can be utilized to enhance the quality of life for these individuals. However,

these interventions do not seem to affect the individual's perceived severity of visual impairment.

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CHAPTER 1

INTRODUCTION

There is great variation in how the term "low vision" is defined; however, it is widely accepted within the vision rehabilitation community that anyone with non-correctable vision loss that interferes with activities of daily living is considered visually impaired.[1,2] In order to specify the extent of one's low vision, the amount of impairment or disability can be determined; the first is usually measured by means of visual acuity or visual field, and the second is measured by how easily a person can perform particular tasks.[1] Fortunately, there are very few individuals completely devoid of sight. Even those considered legally blind typically have some remaining vision that can be maximized when incorporating low vision rehabilitation; the result of rehabilitation is oftentimes an enhanced quality of life.[2]

When last measured, approximately 39 million people in the world were blind, making blindness one of the most common disabilities.[2] The number of blind individuals in the United States will continue to increase as the Baby Boomer generation ages. In the United States, the prevalence of different conditions causing blindness has been well-correlated with age and ethnicity. Age-related macular degeneration is the most common ocular condition causing blindness in Caucasian individuals, but cataract, glaucoma, and diabetic retinopathy are the most prevalent causes of blindness in African Americans and Hispanics.[1] Low vision is tertiary to arthritis and heart disease as the leading cause for

individuals over the age of 70 in industrialized countries to require aid with activities of daily living.[1]

There are a couple of classifications commonly used in the United States to categorize low vision. The World Health Organization, or WHO, defines low vision as a best-corrected visual acuity that is worse than 0.5 logMAR or 20/60 on the Snellen chart, but better than 1.3 logMAR or 20/400 on the Snellen chart in the better of the two eyes.[1,2] Visual field loss can also be categorized as low vision if it is less than 20 degrees in the better-seeing eye with best-corrected vision.[1] The WHO defines complete blindness as a best-corrected visual acuity less than 1.3 logMar or a visual field no larger than 10 degrees centrally in the better-seeing eye with best-corrected vision. United States law defines blindness a bit differently, with a visual acuity of 1.0 logMar or 20/200 or worse or a visual field of 20 degrees or less in the better-seeing eye.[1,2] Both visual acuity and visual field are essential to take into account when determining the degree of disability a person may have when completing activities of daily living. Additionally, contrast sensitivity likely provides a better measurement of a person's ability with functions like night driving, mobility, and other tasks that require distance and depth judgment.[3]

There are a multitude of options that can be used in the rehabilitation of the low vision individual; the goal of these interventions is to aid in the facility, efficiency, and safety of completing daily activities. Though many people with low vision would benefit from low vision rehabilitation, only about 20-25% of this population has been seen by a professional in low vision.[2] Some barriers to rehabilitation, from the perspectives of individuals with low vision, include misconceptions of low vision services, cost of services, miscommunication by eye doctors, lack of awareness or means of

transportation, pride, negative views of society and loved ones, and self-denial of severity of visual loss.[4] For those that seek low vision rehabilitation, the treatment options available include, but are not limited to, the following: spectacle-mounted magnifiers, handheld or spectacle-mounted telescopes, handheld and stand magnifiers, electronic magnification systems, and environmental modifications.[2] There are many other resources that can be utilized by individuals with low vision to maintain or regain their independence and the ability to carry out the hobbies and tasks that they desire; these options include educational and vocational counseling, orientation and mobility training, guide dog training, social work, counseling, vision rehabilitation therapy, and bioptic telescope training for driving in certain states. Each of these services has the aim of enhancing the individual's overall quality of life by allowing them to live productively and independently.

Researchers have deduced that feeling supported is critical for individuals with chronic impairment and disability to be able to adjust well and obtain a high quality of life.[5] The social cognition approach to social support states that a person's perception of support is related to their sense of acceptance. Perceived support is important to individuals with vision loss, especially in those that develop functional disability and emotional and mental instability as a result of their devastating loss. Therefore, accepting assistance in the form of a support group or the support of friends and family is essential to individuals as they learn to cope with their vision loss. It has been concluded from research that a person may be more capable of dealing with stressful situations independently if they perceive that supportive individuals are available if necessary.[5] It is likely that the presence of such a support base in the life of a low vision individual would

allow them to accept their condition more easily, by the mere knowledge that help is present if needed.

This study aims to identify which low vision interventions have been successful at enhancing perceived quality of life. Furthermore, an additional goal is to determine whether or not support systems in the form of family members, friends, and support groups are able to increase the individual's quality of life and whether or not the presence of these support bases can positively affect the individual's perception of the severity of their disease. The final purpose was to determine whether the absence or presence of professional low vision assistance has an effect on the individual's perceived severity of the disease.

CHAPTER 2

METHODS

Patients: The subjects that participated in this study consisted of 40 patients (mean age=77.2, age range 24- 93 years) from Grand Rapids Ophthalmology clinic, the Association of the Blind and Visually Impaired in Grand Rapids, MI, and a low vision support group in Anderson, IN. The subjects presented to these locations for disease treatment and management or low vision assistance. Patients participated in this study in January, February, and March of 2015.

Methods: Subjects were surveyed orally and were asked for their age, race, cause of visual impairment, previous low vision treatment, perceived quality of life prior to vision loss, perceived severity of vision loss, and low vision device usage. The survey also gathered information as to whether or not their quality of life had decreased with the progression of their condition and how low vision devices and support groups had enhanced their quality of life. A rating scale from 1 to 10 was used to assign a value to the categories of quality of life, severity of vision loss, and ability of low vision devices and support groups to enhance quality of life, with "1" being the lowest quality, severity, or enhancement, and "10" being the highest quality, severity, or enhancement. Verbal responses were recorded on paper and entered into an Excel spreadsheet. The results were then analyzed using calculated means, standard deviations, variances, and t-tests with probability determination to determine overall efficacy of low vision services, devices,

and support groups and to develop correlations between these interventions and perceived disease severity and quality of life.

CHAPTER 3

RESULTS

In total, there were 40 participants in the study. The mean age of the studied population was 77.2 (SD=16.8), with a range of 24-93 years. The ocular conditions represented in this population included wet and dry age-related macular degeneration (20), glaucoma (5), retinal vein occlusion (2), Stargardt's disease (2), visual field loss due to stroke (2), retinitis pigmentosa (2), bilateral retinal detachment (1), presumed ocular histoplasmosis (1), nanophthalmos (1), anophthalmos (1), retinopathy of prematurity (1), optic neuropathy (1), and aphakia status-post congenital cataract extraction (1).

In the sample of low vision individuals without a congenital condition, the average rating for the perception of quality of life prior to being diagnosed with the visual condition was 9 out of 10. Four of the individuals that completed the survey had congenital conditions that caused no recognizable difference in perceived quality of life since birth. After developing their ocular conditions, 80.6% of the individuals with acquired disease felt as though their quality of life had decreased. 19.4% did not feel as though their ocular condition had decreased their quality of life. The mean perceived severity of the ocular conditions of all individuals in the study was 7.9 out of 10, with 10 signifying the most severe vision loss possible.

Table 1 shows the most widely used low vision devices in the sample population and the mean rating given to the device in terms of how it improved the individual's ease

and quality of life since the time of their diagnosis. Table 1 also displays how support group attendance had enhanced the individual's quality of life since being diagnosed with their condition. Additional devices used by the subjects were not included in statistical analysis, as the low prevalence of their usage in the tested population was insufficient to develop conclusions as to their efficacy at increasing perceived quality of life. These devices included bioptic telescopes, guide dogs, non-illuminated stand magnifiers, the Jitterbug cell phone, gel pens, the Booksense device, headborne magnifiers, tactile cues in the home, barcode readers, talking clocks and watches, and tints.

Table 1. Most Widely Used Devices and Quality of Life Enhancement

Device	# of patients	Average rating	SD	Variance
Handheld illuminated magnifier	9	7.8	2.28	5.19
CCTV	10	9.5	0.85	0.72
White cane	7	10	0	0
Talking Book	9	9.9	0.33	0.11
Support group	31	7.3	2.25	5.06

Some useful information can be gleaned from the results of Table 1. Table 1 shows that the low vision intervention most widely used by the sampled population was that of the support group, with 77.5% of the population participating in a group. Opinions as to how successful the support group was at enhancing quality of life were quite variable, however. The intervention with the highest average rating was that of the white cane. Although it was not the most commonly utilized aid in this sample population, the rating statistics of the white cane showed a standard deviation and variance of 0, illustrating that this device has been crucial to enhancing the quality of life for every

individual in the sample has utilized it. The audio or Talking Book was the low vision device that provided the second highest rating and second lowest standard deviation and variance, providing evidence that each person that uses these books has had a notable increase in quality of life as a result. The device with the third highest rating was the closed circuit television, or CCTV, which has a moderate standard deviation and variance. The handheld illuminated magnifier showed the next highest rating, but also the highest standard deviation and variance, so there was greater variability in how useful this device was for individuals.

Of the total number of subjects sampled, 13 of the 40 (32.5%) had not seen a specialist in low vision prior to the day of the survey. Those subjects that completed the survey at the Association for the Blind and Visually Impaired would be receiving new low vision aids at the conclusion of their visit, and follow-up would be conducted as to the usefulness of the devices for the individual. These follow-ups were not taken into consideration in this study. The low vision aids that were to be distributed were as follows: illuminated stand magnifiers (7), illuminated handheld magnifiers (6), Ottlite gooseneck lamps (5), pocket magnifier (2), tint (2), gel pens (2), orientation and mobility training (2), Max TV telescope (1), CCTV (1), and a Kindle (1).

Analysis was performed to determine whether the absence or presence of professional low vision assistance had an effect on the individual's perceived severity of the disease. A t-test and p-value were used to determine this correlation. A mean severity of 7.92 (n=13) out of 10 was used for the group of individuals receiving no professional low vision services prior to the day of the survey and a mean severity of 7.85 (n=27) was used for the group of individuals who had received low vision assistance prior to taking

the survey. For this data set, the results of the t-test were $t(38)=0.125$, $p<0.901$. Table 2 shows the results of this calculation. At first glance, it appears as though low vision services received correlate well with a lower perceived severity of disease. However, the probability that the difference between the mean severities in the two groups is due to chance is less than 0.901 or 90.1%. In other words, there is a good possibility that this observation was due purely to chance, making this information statistically insignificant. Therefore, there is not a high correlation between low vision services received and the perceived severity of the ocular condition.

Table 2: T-test for Mean Severity in Those Receiving Low Vision Services and Those Not Receiving Services

Group	n	Mean severity	Variance of severity
Low vision services	27	7.85	2.90
No low vision services	13	7.92	2.74
		t=0.125	p=0.901

In the sample population, 92% of the individuals felt that they had a strong support base of family and/or friends and 77.5% were currently attending a low vision support group. The mean rating for how the support group had enhanced the individual's quality of life was 7.3 out of 10, with 10 being the highest possible amount of enhancement. Of the attendees, 89% believed that every person with a severe visual impairment would benefit from attending a support group.

Another t-test was performed to determine whether a correlation existed between support group attendance and the perceived severity of one's ocular condition, in hopes of determining whether or not perceived severity was less in those that were receiving

regular means of support. The results of this t-test were $t(38)=-1.17, p<0.249$, again showing no strong correlation between attendance and perceived severity. Table 3 shows the results of this calculation.

Table 3. T-test for Mean Severity in Attendees and Non-attendees of Support Groups

Group	n	Mean severity	Variance of severity
Support group attendees	31	7.71	3.06
Non-attendees	9	8.44	1.54
		t=-1.17	p=0.249

CHAPTER 4

DISCUSSION

Recent studies on low vision impairment have shown that it can adversely affect quality of life, social interaction, and independence.[6] Specific research on age-related macular degeneration has provided evidence of resultant psychological distress and depression that compares to that of people with other severe, chronic health conditions. In our study, over 80% of the patients reported a marked decrease in the quality of their life with the progression of their visual condition. In a similar fashion, Gill et al. (2013) stated that patients with moderate age-related macular degeneration (ARMD) have declared a 40% decrease in the quality of their life; patients with very severe ARMD have reported a 63% decrease in the quality of their life.[7] However, significant increases in quality of life can be obtained with a low vision referral, even in patients with mild forms of ARMD. Previous research has demonstrated that more than eight out of ten patients that have sought low vision services feel as though they have benefited from some form of rehabilitation.[8]

A study by Slakter and Stur (2005) also determined that low vision rehabilitation has a positive effect on the quality of life in low vision individuals.[6] In this study, the functional status and quality of life of low vision patients were assessed one week before receiving low vision services and again three months after receiving services. The majority of the patients studied had ARMD and diabetic retinopathy. The assessments

used to describe quality of life included the Short Form-36, Visual Function-14, and NEI-VFQ. Results of the Short Form-36 showed that the low vision patients produced lower scores than similar age-averages for the normal U.S. population, individuals with congestive heart failure, and clinically depressed individuals. All assessments used, outside of the Short Form-36, indicated that the patients' quality of life had improved after receiving low vision rehabilitation. 98.7% of the sample population also stated that their functional status had improved after receiving the low vision services. Although the effect of general low vision rehabilitation on quality of life was not tested specifically in our study, it is clear from our data that specific interventions have proven to be successful at enhancing quality of life. These interventions are commonly prescribed or recommended as a result of the low vision rehabilitation examination.

Research by Nguyen et. al (2009) has provided evidence that distributing low vision devices (high plus lenses, illuminated stand and handheld magnifiers, telescopes, CCTVs, etc.) can significantly improve the reading speed of individuals with low vision.[8] In this study, the reading speed of standard newspaper print increased by 40 ± 15 words per minute (wpm) in those with visual acuity ≤0.1 and by 64±28 wpm in those with visual acuity ≥0.1. Fluent reading was established to correspond to a rate of >70 wpm; prior to receiving low vision aids, the mean rate of the sample population was <30 wpm and after receiving the aids, it was 72 wpm. As reading problems tend to be the chief complaint of individuals with low vision, obtaining fluent reading is very likely to increase the quality of one's life. Furthermore, a study by Margrain (2000) determined that only 23% of patients entering a low vision clinic were able to read standard newsprint on arrival at the clinic; with an adequate low vision aid, 88% of the patients

were able to read newspaper print.[9] The particular devices used in Margrain's study included the following: a high power reading addition, hand magnifier, illuminated hand magnifier, stand magnifier, and illuminated stand magnifier, many of which are the same types of devices used by the participants in our study.

The most widely used devices within the sample population in our study were the CCTV, white cane, illuminated handheld magnifier, and audio book. Each of these was shown to enhance the quality of the individual's life since the time of their diagnosis. No conclusions could be reached with the less commonly used devices. Though the users of these devices typically provided positive feedback, there was an insufficient sample population to provide an adequate conclusion about their efficacy.

The mean rating of the CCTV in regards to its ability to enhance quality of life for the low vision individual in this study was high; other studies have shown similar evidence as to its ability to have a positive psychological impact for its users. Burggraaff et. al (2012) designed a study to evaluate whether or not training with a CCTV has an effect on an individual's quality of life.[10] The individuals in the treatment group that received training with the CCTV showed an increase in their health-related quality of life, as determined by a patient questionnaire. Those that received training with the CCTV also perceived fewer problems on the vision-related quality of life questionnaire, fewer symptoms of depression, and better adjustment to visual loss; however, the overall difference of these measurements in comparison to the control group was minimal. No other significant differences were noted between the treatment group and control group, which did not receive training with the CCTV. However, a noteworthy finding was observed between the baseline and final measurements of both groups, which occurred

prior to receiving the CCTV and after using the CCTV over a period of three months. Significant improvement was found on the adaptation, reading, and fine work elements of the low vision quality of life questionnaire, indicating the great effect that this device can have on an individual's subjective reading ability and quality of life. Another study by Burggraaff et. al (2012) provided objective evidence that the CCTV increases reading acuity, maximum reading speed, and decreases the number of reading errors made, as compared to reading without a CCTV.[11] A compilation of research by Virgili et. al showed that a stand-mounted CCTV produces a mean reading speed of 12 words per minute higher than with a best prescribed optical device; the mean duration of comfortable reading was 13.7 minutes higher with the CCTV than the best prescribed optical device.[1] Additionally, the CCTV gave a mean reading speed of 45.5 wpm higher than the participant's optical device. It has been stated that the ability to read is the most highly valued daily task and that it is directly correlated with an individual's quality of life.[5] With this evidence of an increased perceived (as well as objective) reading ability with the CCTV, it is likely to enhance quality of life; this is also evident by the survey data collected in our study.

Mobility constraints due to low vision lead to a loss of independence, decreased social interaction, decreased quality of life, and increased incidence of depression.[14] The white cane had the highest mean rating and lowest variance of any device used by the sample population, likely due to a combination of these factors. The aim of this device is to give legally blind individuals the freedom to travel independently by compensating for reduced visual information; the cane, together with the senses of touch and hearing, allow the individual to cope with their vision loss and achieve this goal.[12] When used in

combination with orientation and mobility training, individuals with low vision are more effectively able to use white canes to manipulate and negotiate the outside world both safely and independently. Soong et al. investigated the effect of orientation and mobility training on the mobility performance of visually impaired individuals.[13] Soong found a mild, but not statistically significant, decrease in the number of errors made by visually impaired individuals on an indoor obstacle course with the use of assistive devices like the white cane. However, an average of even one less mobility error made should be considered important in that visually impaired individuals rely on these devices in potentially dangerous situations, such as crossing the street. A single mistake could potentially have a marked effect on the well-being of the individual. Moreover, the cane notifies others of one's impairment in such situations.[14]

The handheld illuminated magnifier produced a relatively high rating of 7.8 out of 10, but with great variability in its ability to enhance quality of life. The illuminated handheld magnifier aims to increase both the magnification and contrast of a target. Optical devices like the handheld magnifier are very portable and typically cost less than CCTVs; they work better for magnifying short texts such as on prescription bottles, food labels, and package instructions than stand-mounted CCTVs or other stand magnifiers.[15] However, handheld magnifiers have limitations of their own. With increased magnification power, there is a decrease in the field of view, or the size of the magnifier. This means that although the text appears larger, the user of the magnifier is limited as to the area of space that can be magnified at one time. As a consequence, the user must manipulate the magnifier more when reading text than would be necessary with a magnifier with less power and a larger field of view. Due to this constraint, magnifiers

have limited maximum magnification due to too small of a field of view to be useful or comfortable. Those individuals that are not able to obtain sufficient magnification with optical devices like the handheld magnifier must resort to alternate devices capable of greater magnification without the decrease in field of view; these devices typically fall into the category of electronic magnification systems, of which the CCTV is an example. These limitations likely account for the variability of subjective rating in our study.

There has been very little research into this type of intervention, but the Talking Books were very well received by the participants of this study.[16] This service provided by the National Library Service for the Blind and Physically Handicapped offers free audiobooks, Braille books, magazines, and audio equipment to program members; the borrowers receive and return the books by postage-free mail. The Talking Book program gives individuals the freedom to "read" the materials they desire when they are unable to read standard print.

It was hypothesized that peer interaction in the form of a support group would enhance quality of life and perhaps decrease the perceived severity of one's disease. Indeed, support groups were rated as being highly effective at enhancing the low vision individual's quality of life. Past research supports the claim that a perception of support is effective at allowing an individual with a chronic impairment to adapt well to their loss and obtain an enhanced quality of life.[5] Though having a sense of support has allowed such individuals to deal better with stressful situations like their visual loss, this perceived support may not contribute to how one perceives the severity of their condition. Indeed, this study showed no strong correlation between support group attendance or low

vision services and perceived severity of disease. There is likely another predominant determining factor for perceived severity, requiring further study.

There are many confounding factors in regards to the results of our study. New technology is constantly being created to aid in low vision rehabilitation, and much of it offers widespread application to make everyday tasks easier and more enjoyable. Only a few examples of this technology presented themselves in the data gathered in this study (the Jitterbug, iPad/iPod, computer software), so one might conclude that these devices are not very useful. However, it is important to call to mention the high mean age of the participants; this generation of individuals has a tendency to refrain from the newest technology due to its learning curve and unfamiliarity. Only two individuals from our study made regular use of the iPad, and they were well below the mean age of the sample population. The first individual, aged 24, was able to adjust well to iPad usage, and gave it a rating of 10 out of 10 possible points in its ability to enhance quality of life; the second, a 56-year-old, had a harder time learning how to utilize the different features of the iPad and gave it a rating of 6 out of 10.

Conclusions were drawn to support this idea in a study by Gill et al. that compared the reading accuracy of individuals with age-related macular degeneration with digital readers and printed media.[7] Participants in the study were able to consistently read faster on the Apple iPad with increased text sizes (size 24 or greater) than with paper media. The researchers attributed this to the higher contrast and bright background of the iPad, which allows patients with decreased contrast sensitivity and central visual acuity from ARMD to read at a faster rate on the iPad than with printed paper. However, observations from the study indicated that patients preferred paper media to the iPad due

to its ease of use, with patient age and the lack of technology familiarity cited as contributing factors. Interestingly, patients stated that they preferred the clarity of the reading material on the iPad over that of the paper. Haji et al. came up with similar conclusions in their study of iPad usage in individuals with low vision.[17] In this study of patients with a best-corrected visual acuity of 20/100 or less in both eyes, 94% were able to read standard size or smaller newsprint from a New York Times webpage on the iPad, whereas only 22% were able to read the webpage without the iPad.[5] Thus, the iPad and other new technologies may emerge as more widely used devices in a similar study in the upcoming years.

The cost of low vision services and devices can be a barrier to low vision patients.[4] In the study by Nguyen et al., 47% of the low vision patients were able to use simple low vision aids (high plus reading additions, magnifiers, etc.) to read standard newsprint, whereas 42% required a CCTV to achieve the necessary magnification to see this print.[8] However, a new closed circuit television system can cost around $2,000-3,000. A literature review by Lam and Leat (2013) discussed studies in the United States, Canada, and Finland that gave evidence that individuals with low vision have a higher likelihood of being unemployed or having a lower income than the rest of the population.[4] Additionally, a West Virginia study showed that individuals with vision impairment had a 2.5 times higher likelihood of having an income of less than $20,000 a year. Patients in these studies cited cost of services and devices as one of the major barriers to accessing low vision aid. For the purposes of this study, the popularity and average rating for more expensive devices (ex. CCTV) might have been much higher if all of the individuals with severe ocular conditions could afford to use one. The

perception of the severity of an individual's condition might also change if they could afford to use a device that would allow them to maximize the potential of their remaining vision. Becoming less functionally impaired with the use of an adequate device would likely increase the individual's quality of life.

Another possible confound could occur with a participant giving a low rating to a particular device due to incorrect or inappropriate use. Insufficient training with a device or an inappropriate device power could lead to an artificially low rating; the same person with the proper training and magnification might give a much higher score with the same type of device. Research done by Goodrich et al. (1977) has shown that ten days of training and practice with a low vision aid, including CCTVs and other optical devices, is sufficient to increase reading speed and duration.[18]

CHAPTER 5

CONCLUSION

Visual impairment is capable of causing a significant effect on an individual's perception of their quality of life. However, low vision interventions can be used by individuals with low vision to maximize function and achieve an enhanced quality of life. Although the perception of the severity of one's condition may not improve with rehabilitative efforts, the individual may be able to gain independence and increased functionality as a result.

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APPENDIX A

IRB APPROVAL FORM