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THE IMPACT OF A VIDEO INTERVENTION ON THE USE OF LOW VISION ASSISTIVE DEVICES

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Abstract

Purpose—An image-enhanced educational and motivational video was developed for patients with low vision and their caretakers. Impact on knowledge, self-efficacy, and attitudes was assessed.

Methods—The video incorporated cognitive restructuring to change emotional response; a “virtual home”; a veridical simulation of vision with AMD and contrast enhancement of the video. Subjects (median age 77.5) were randomized into control (N=79) and intervention (N=75) groups. Telephone interviews were at baseline, 2 weeks and 3 months. Main outcome measures were: knowledge (8 questions), self-efficacy score (7 questions), adaptive behaviors (10 questions), willingness to use devices, and emotional response (4-point scales).

Results—The intervention group showed a statistically significant improvement in knowledge, (difference of 1.1 out of 8 questions, $p < 0.001$). Change in use of books-on-tape was more for the intervention group than for controls ($p=0.005$). The intervention group increased use of books-on-tape from 28% to 51% whereas the control group did not (34% at both times). However, there was no significant change in the use of other assistive devices, including magnifiers. Both groups increased adaptive behaviors. There was no significant difference in change of self-efficacy score or in emotional affect between the two groups.

Conclusions—The video had small, but statistically significant impact on knowledge and willingness to use assistive devices. There was little impact on adaptive behaviors and emotional affect. The minimal changes in outcome were disappointing, but this does not minimize the importance of patient education, it just emphasizes how hard it is to effect change.

Keywords

Macular degeneration; AMD; low vision; patient education; intervention; vision impairment; partial sight; age related macular degeneration

Introduction

The National Eye Institute has defined low vision as a visual impairment, not correctable by standard glasses, contact lenses, medicine, or surgery that interferes with a person’s ability to perform everyday activities[National Eye Health Education Program, 1999 #52]. Age-related macular degeneration (AMD) is the second most common eye disorder in late life[Rahmani, 1996 #8], is the leading cause of (legal) blindness among European-descended people older

than 65 years[Friedman, 2004 #35] and is the leading cause of blindness among white persons (54.4% of the cases)[Congdon, 2004 #34]. Except for preliminary findings[Richer, 2004 #47] regarding the effectiveness of nutritional supplements, there is no known effective treatment for the dry type of macular degeneration, thus the vast majority of people with this condition must learn to adapt to the limitations associated with central vision loss. The treatments for the wet type only slow the progression of the disease or provide small improvement. Thus eventually all AMD patients have to deal with a significant vision loss. The prevalence is strongly associated with age and thus is expected to increase with the aging of the population. The impact on physical and economic status and quality of life can be severe. For example, low vision is likely to affect the ability to perform job-related functions (such as reading and writing) that in turn may lead to a loss of income (According to the Bureau of Labor Statistics [, 2004 #44], in 2004, 21.9% of people of ages 65–74 were still employed. Further, central retinal vision loss (as is common in AMD) may impact mobility (particularly on driving), which limit the patient's ability to participate in valued social or leisure activities, and to maintain functional independence.

When diagnosed with an incurable vision disorder such as age-related macular degeneration (AMD), many patients report feeling devastated. The emotional consequences of the disability caused by the vision impairment can be severe – including grief, depression, anxiety, confusion, fear, and suicide ideation[Tolman, 2005 #48;O'Donnell, 2005 #49;Hassell, 2006 #50]. While many rehabilitative services and assistive options exist, many patients do not take advantage of them[Vitale, 2006 #51]. It is commonly believed that this is because they are not informed by the diagnosing provider about the availability of these services or how to access them. A 1997 survey commissioned by the NEI[Prospect Associates, 1997 #7] seems to support that view reporting that, “most respondents said that their eye care professional provided little to no medical information about their vision problems and no information about how to cope with their conditions or diagnoses.” In addition, many respondents thought that their eye care professionals were too busy and did not have the time to explain much to them. Several ophthalmologists told patients that “they could do nothing more for them.” Consequently, they stopped visiting any eye care professional, not realizing that visual aids or other rehabilitative services were available. Although the public awareness of AMD may have slightly increased since 1997 (20% in Attebo [, 1997 #45], compared to 30% in Rosenthal[, 2003 #46]), it is not clear whether public awareness of potential rehabilitation options has increased as well. A study in Australia in 2003[Pollard, 2003 #43] identified the most common barriers to accessing low vision services as: awareness of services among the general public and eye care professionals; understanding of low vision; acceptance; transportation; and the referral process. These findings suggest that the lack of awareness of, and availability of, low vision services is a major problem. In contrast, a series of focus groups in the U.S. in 2001 conducted by NEI [National Eye Institute, 2001 #42] identified the following barriers to referral: cost of visual aids; transportation; patient motivation; and, length of time to obtain an appointment. Additional barriers to treatment-seeking often cited include: the misperception that vision impairment is a natural part of aging; a lack of awareness about rehabilitation treatment options; and a belief that services are only available for the blind, not for the partially sighted [Goldzweig, 2004 #23;Pollard, 2003 #43]. The limited training in ophthalmology residency programs in low vision concerns may contribute to a lack of comfort and skill in practicing ophthalmologists when discussing low vision referral and rehabilitation options with their patients.

Thus, the current state of low vision patient education and the availability of patient education materials is alarmingly suboptimal. Recognition of this situation led the National Eye Health Education Program (NEHEP)[National Eye Health Education Program #25], to develop a nationwide educational program about low vision and its rehabilitation including collaborative community health education initiatives, sponsorship of public service announcements,

extensive publications, and a traveling display for presentation in shopping malls. In complement to these efforts we developed, with funding from the National Eye Institute, an educational video; *Hope in Sight: Living with Macular Degeneration*¹. The video aims to address the educational, emotional, motivational needs associated with living with low vision due to AMD. The video uses a cognitive restructuring approach that aims to instill adaptive beliefs prior to attempting changes in actual behavior. The specific learning objectives of the video were to improve knowledge of: 1) anatomy of the eye and pathology of AMD; 2) types of rehabilitative devices available; 3) simple adaptive environmental changes to consider; 4) lifestyle changes; and 5) resources for information, services and devices. The motivational objectives were to increase the patient's self-efficacy in regard to obtaining and using assistive devices and encourage the use of rehabilitation resources, aids, and devices. This paper describes the development of the video program and reports the results of a randomized trial conducted to determine the effectiveness of the video in achieving these objectives.

Methods

Video Content Development and Production

The video content was developed in a six-step process. First, the initial content outline was developed based on our clinical experience and review of numerous available patient education videos and print materials. Second, the topics in the content outline were incorporated into discussion guides for three focus groups described below. Third, the content outline was reviewed and revised based on focus group findings. Script treatment was then developed from the revised outline. Fourth, a prototype video (about 10 minutes) was developed, which reflected the overall approach and tone of the script. The prototype included documentary style sample interviews with a man with AMD and his wife, as well as a sample of the virtual home sequence. The prototype images' contrast was enhanced as described below. Fifth, four participants from the previous focus groups (3 persons with low vision and one family member) reviewed the prototype. Overall, they praised both the content and its presentation format. The contrast enhancement facilitated their viewing, and they could see the unenhanced virtual home. They particularly liked this latter feature. An NIH study section reviewed the prototype and awarded the funds for the final development. Additions and changes were recommended by both groups. Sixth, the final content was developed and the video was produced as detailed below. A short list of referral and support resources was included at the conclusion of the video.

Two-hour sessions with three focus groups were conducted to determine the most important content of the video from three different perspectives. The first group included persons with AMD (4 females and 5 males). The second group was composed of care takers of persons with AMD (5 spouses, 1 daughter and 1 friend). The third group included providers of low vision rehabilitation services (3 ophthalmologists, 4 optometrists, 1 social worker, 2 occupational therapists). The focus groups discussions were guided by a leader and were recorded and transcribed.

Patient focus group participants described vividly their initial reactions of grief and despair to the diagnosis. Similar reactions were found in other focus groups dealing with vision loss. In the focus groups that were conducted to develop the National Eye Institute Visual Function Questionnaire[Mangione, 1998 #54], the emotional impact of AMD was identified as the fourth most common type of problem associated with their condition. The domain of emotional reaction to vision loss was initially not considered in the development of the Vision Impairment Profile[Weih, 2002 #55], but was subsequently included based on the outcome of the focus

¹*Hope In Sight* can be purchased from New England Research Institutes, 9 Galen Street, Watertown, MA 02472 (617) 923-7747 email: media@neriscience.com. Segments of the video can be viewed online at <http://www.eri.harvard.edu/faculty/peli/projects/hopeinsight.html>

groups. Our focus group participants expressed the need to communicate to patients a message of hope about their ability to adjust to the vision loss. This need was not probed in the other studies.

Based on the focus group inputs, we decided to use the concept of ‘cognitive restructuring’ as the theoretical framework for the development of the video script treatment. Cognitive restructuring[Rodin, 1983 #9;Lachman, 1992 #6] is an approach that instills adaptive beliefs such as greater perceived control, greater confidence in one’s abilities, and more realistic assessment of failures prior to attempting changes in actual behavior. This approach has been used successfully in intervention trials for exercise[Lachman, 1997 #5], fear of falling [Tennstedt, 1998 #10], and doctor/patient communication[Tennstedt, 2000 #11]. Within this framework, the video began by acknowledging the impact of the diagnosis and visual loss due to macular degeneration in the second eye (the risk of depression is particularly high when the second eye becomes affected[Tasman, 2005 #53]) as well as the despair and depression that often accompanies this diagnosis. In a documentary style, the video incorporated the stories of three real people with low vision due to AMD and their families, showing how they have moved emotionally from initial devastation and despair to acceptance and adjustment. The use of low vision devices by these people was portrayed to illustrate and underscore the adjustments and adaptations that have enabled them to maintain much independence. Increasing awareness and knowledge about the aids that are available to AMD patients, and showing real people that have survived initial diagnosis and have moved on to live productive and even joyful lives completed the framework of cognitive restructuring.

A dynamic simulation of vision with a central scotoma was provided for the benefit of the patient’s families. The simulation was made with specially developed software[Geisler, 1998 #1;Geisler, 2002 #2] that provides a more accurate rendition than has been available in the past. The simulation includes not only the effect of the disease induced blind spot[Pelli, 1990 #33] but also the spatial variability of the visual system and the dynamic nature of vision. Figure 1 shows a single frame of this simulation. Note that the resolution of the image decreases towards the edge of the image and that the patient naturally shifts the scotoma to the side to allow the more relevant portions of the scene (a face) to be visible. The video shows a pedestrian approaching the low vision person, and that as she approaches the viewer, thus becoming larger, more and more details of her face become visible. This illustrates also why magnification is an effective aid for low vision patients. A short video segment is available at: <http://www.eri.harvard.edu/faculty/peli/lab/videos/videos.htm>.

To illustrate environmental changes that could be made in the home to improve functionality, we used an animated 3-D ‘virtual home’ created in computer graphics. This technique allowed us to present a home environment generically and stylistically. Its simplicity facilitated clearer viewing and emphasis of the environmental changes, and the animation facilitates presentation of before and after views. It showed various ways that a person could make adjustments to different rooms in the house to make routine tasks easier. Figure 2 illustrates a few of the modifications to the kitchen, one of the five rooms that were covered, including a change of equipment, as well as the use of lighting and contrasting colors to enhance visibility. The graphics were produced in high contrast and at high magnification so that visually impaired viewers can better perceive the images’ content. The animations were also used to illustrate use of additional visual aids that were not portrayed in the three patients’ stories.

Caregivers in particular expressed confusion about the physiological nature and effects of this disease. Graphic animation was developed to illustrate the anatomy of the eye and the changes associated with AMD. In our experience the typical cross-sectional illustration of the eye is also not understood by most patients. Patients do not understand what is shown in the illustration and can not connect it to what they see of the eye. In fact many people we asked

pointed to the iris as the “ball” in the term “eyeball” indicating lack of knowledge of the spherical shape of the eye. Therefore, we developed the animation particularly for a naïve audience assuming no prior familiarity with any of the anatomy of the eye and orbit. The relation of various eye components to the visible view of the eye in the face was maintained throughout the animation using progressive transparency and peeling of layers. Those aspects that are relevant for the visual function, rather than the pathology or treatment, were emphasized. We used as much magnification as possible, very large text labels, large arrows, and audio description facilitated access to the material by visually impaired viewers (Figure 3). The narration emphasized that the macula is a tiny portion of the retina, with the rest of the retina remaining functional, so that much vision remains and might be used effectively. A short excerpt from the animation can be viewed at <http://www.eri.harvard.edu/faculty/peli/projects/hopeinsight.html>.

The video was processed with a contrast enhancement technique previously shown to improve perception by the target population[Peli, 1999 #12;Peli, 1991 #4]. The enhancement process amplified the contrast of the high spatial frequency components of the video. The enhancement parameters used were averages of parameters selected by individuals with AMD in a previous study[Peli, 1999 #12;Peli, 2005 #41]. Figure 4 illustrates the difference in appearance of the enhanced video compared to the original video image.

The patients’ focus group reviewed a sample of the enhanced video and confirmed that the enhancement facilitated viewing. The caregivers’ focus group viewed the same enhanced video segment and reported that the enhancement did not interfere with the ability to see the video or to enjoy it. When the video is shown to either normally sighted or visually impaired audiences they rarely if ever note spontaneously that the video is processed. In many cases even after direct questioning observers are not able to point to what might be different about the video. Thus the enhancement does not distort the image in a noticeable or bothersome way without direct comparison to the unenhanced video (as shown in fig. 4).

Assessment of Impact

Institutional Review Board(IRB) approval was obtained. The research followed the tenets of the Declaration of Helsinki. Informed consent was obtained from subjects after explanation of the nature and consequences of the study. Subjects were recruited from 5 public education events held by the Schepens Eye Research Institute in Florida during the winter of 2002. Recruitment materials and a project staff member were located in the lobby of venues where the events were held. Potential subjects were informed about the general purpose of the study, inclusion and exclusion criteria, and if still interested, were asked to sign-up to be contacted for telephone interviews. Subjects who signed up for interviews were mailed a (large print) study brochure and an informed consent form and asked to carefully review both items before the telephone screening call. The screening call reviewed the study requirements and obtained verbal informed consent prior to enrollment in the trial. The inclusion criteria were: having low vision (as defined by the NEI[National Eye Health Education Program, 1999 #52]), understand English, have access to a VCR and TV, and be able to hear well enough to participate in a telephone survey. Age was not considered for inclusion. 120 subjects were excluded (56 ineligible, 17 refused screening, 14 self-declared ineligible, 5 refused protocol, 4 gatekeeper refusals, and the remainder due to problems in contacting by telephone). Power analysis showed that we would need 128 completed instruments, 64 per group, to detect a medium effect size (0.50). Meta-analysis of patient education materials has found that audiovisual media generally have medium-sized effects on knowledge. Using one-sided testing and a 0.05 significance level, a sample size of 128 will yield 80% power. There were 156 participants at baseline. The 29 additional subjects were recruited to account for possible attrition. Participants who completed the study were paid a small stipend (\$75).

Standard demographic variables (age, gender, etc) were collected only in the baseline interview. Living arrangements, employment and health data were collected at baseline and follow-up interviews. At baseline and both follow up interviews knowledge of the eye, macular degeneration, and assistive devices were assessed. In addition, information was collected on the possible emotional responses (sadness, fear, confusion, peace) to low vision. Self-efficacy was measured in regard to obtaining and using assistive devices. Attitudes regarding the use of assistive devices were also determined.

Data were collected by telephone survey by trained interviewers using CATI (Computer Aided Telephone Interviewing) using CASES software[CSM Program, 2002 #13]. All subjects were interviewed once at the beginning of the study (baseline). At the conclusion of the baseline interview, the person was automatically assigned to the control or intervention group by the interview software. Participants randomized (using a randomized block design with block size=4) to the intervention group (N=75) were mailed the enhanced video and instructed to watch it before the next survey (post intervention) that took place two weeks after the baseline interview. The control group (N= 79), which did not receive the video, was also interviewed at 2 weeks ("2-week" interview). Both groups were interviewed for the third time ("3-month" interview) at 3 months after the baseline interview. The control group received the video after they did the 3-month interview. The survey center staff was not blinded to the assigned group of the participants.

Descriptive statistics were performed to specify the sample. Analysis of Covariance (ANCOVA) was used to examine the effect of the video on the change in knowledge, attitude and behavior from baseline to two endpoints. Some of the changes were expected to require some time to implement and were thus analyzed at the three month endpoint, whereas others could occur almost immediately without professional help and were thus analyzed at the 2 week point. Change in knowledge was assessed from baseline to post intervention 2 weeks later. The change in use of assistive devices was assessed from baseline to the 3-month interview. The change in self-efficacy was assessed from baseline to both the 2-week post intervention interview and the 3-month follow up, as was the change in emotional response. The ANCOVAs were always controlled for baseline values, and the models for knowledge and assistive devices controlled for covariates as well. Models for self-efficacy and emotional response were only controlled for covariates when treatment effects were found.

The covariates used were age, gender, marital status, education, years since diagnosis, number of people in household, employment, and health. Race was not used since 99% of the sample was white. Marital status was grouped in two ways: (married/living together vs. single) and (has ever been married/living together vs. never married). The ten education levels were grouped into the five categories less than High School, vs. High School or GED, vs. some, college or vocational training, vs. college, vs. post-college. Number of people in the household was grouped as 1 vs 2+. Employment was grouped as employed vs. not employed. Health was grouped as excellent/very good/good vs. fair/poor.

Because of the large number of (possibly correlated) covariates, models were fit adjusting for one covariate at a time. When both groupings of marital status were significant, the more significant version was chosen. The final model included only the covariates that were significant alone.

Chi-square tests were used to examine the effect of the video on the change in adaptive behaviors from baseline to the 3-month follow up. Error intervals reported are standard error of the mean.

Results

A total of 151 adults (54 men and 97 women) responded to all three interviews. Attrition was due to death, memory impairment, telephone number no longer in service, and could not reach participants after 15 attempts. As shown in Figure 5, 156 adults provided informed consent and complete data were obtained from 151 adults (men 54, women 97) and used in these analyses. Most (96%) reported their race as non-Hispanic White. Ages ranged from 39–92 years with a median of 77.5 years (only 18 subjects were under the age of 65). Intervention and control group participants had no significant differences in age, sex, education, marital status, years since diagnosis, living arrangement or general health status.

The mean number of years of vision impairment was 6.3 (± 8.2 SD), and most (87.4%) of the participants reported good health or better. The participants were relatively well educated, with 74.8% reporting at least some college. Over 80% were now retired. Most of the subjects were married (76%), with 81% having at least 2 people in their household. Table 1 details these demographics for the 151 participants who responded at all three time points.

Knowledge

The score for knowledge was calculated as the number of correct responses out of 8 questions on the survey. These were true/false questions that probed knowledge of eye anatomy and macular degeneration. The knowledge scores were 5.4 ± 0.2 at baseline for both the Video and for the Control groups – see figure 6). Multivariate analyses (ANCOVA) showed that participants in the intervention group had a significant improvement in knowledge, ($\text{Adj } R^2 = 0.381$; 1,144 df; $F = 23.81$, $p < 0.001$).

Both groups improved their scores. However, the improvement of the treatment group (1.41 points; 95% CI={0.80,2.02}) was significant whereas the improvement of the control group (0.48 points; 95% CI={-0.14,1.09}) was not. The 95% confidence interval for the change in knowledge for the treatment group is above 0, indicating a significant positive change. The confidence interval for the control group includes 0, indicating no significant change.

People who did better at baseline improved less (probably because they had less room for improvement – possible ceiling effect). People who were never married improved more: 1.48 vs. 0.40 points ($p=0.05$). People who lived alone also improved more 1.17 vs. 0.71 points ($p=0.068$ - this is not quite significant when one controls for marital status). People in better health improved more: 1.36 vs. 0.52 points (ANCOVA $p=0.005$). There are no significant interactions - the effects of marital status, living alone, and health are the same regardless of treatment arm.

Assistive Devices

The actual use of and willingness to use assistive devices were examined. Actual use was a binary variable representing a yes/no question regarding each device. Willingness was measured on a 4 point scale (“not willing”, “might be willing”, “very willing” and “do use”). The change in these variables was calculated from baseline to the 3-month interview. Results are presented in Figure 7. The change in use of books-on-tape was significantly more for the video group than for the control group ($p=0.005$; mean difference in change = 20% {6%,34%}); there were no significant covariates. The video group increased their use from 28% to 51% whereas the control group did not change (34% at both times).

The results of the ANCOVA show that willingness to use books-on-tape included a marginally significant treatment (video) effect ($\text{Adj } R^2 = 0.53$; 1, 147 df; $F = 3.24$, $p = 0.074$), as well as significant effects of baseline willingness ($p<0.001$) and marital status ($p=0.047$, married vs. single). The increase was 0.32 (95% CI={0.16,0.48}) for the controls, whereas for the

intervention group the increase was 0.51 (95% CI={0.34,0.68}). People who were more willing at baseline changed less (possible ceiling effect). People who were single increased their willingness more than those who were married: 0.55 vs. 0.29 points.

For magnifiers, actual use changed from 49% to 61% for the video group, but only from 44% to 48% for the control group. Although the change was greater for the video group, it was not statistically significant ($\text{Adj } R^2 = 0.21$; 1, 148 df; $F = 2.37$, $p = 0.126$; mean difference in change = 10% {-3%,23%}). Similarly, for talking appliances, actual use was unchanged for the control group (12%), whereas for the video group usage changed from 5% to 12% that again was not significant ($\text{Adj } R^2 = 0.28$; 1, 148 df; $F = 0.20$, $p = 0.654$; mean difference in change = 2% {-8%,13%}). The effect of the intervention on willingness to use magnifiers and talking appliances was not significant ($p=0.157$ and 0.300 , respectively). For magnifiers, the controls increased by 0.13 {-0.001,0.26} and the intervention group by 0.26 {0.13,0.39}; for talking appliances, the controls increased by 0.09 {-0.06,0.24} and the intervention group by 0.20 {0.05,0.36}.

Adaptive Behaviors

Adaptive behaviors, defined as making changes in home and lifestyle to adjust to vision impairment were examined. These questions were yes/no or “not applicable” questions asking if any changes were made in each room or activity. Both groups increased their adaptive behaviors in the home from baseline to the 3-month interview. The change in behaviors of the video group, however, was not significantly different from the change in behavior of the control group (Kitchen $p=0.39$; Bedroom $p=0.38$; Bathroom $p=0.67$; Living room $p=0.34$; Stairs $p=0.50$).

Self Efficacy

Self-efficacy, defined as confidence in ability to do such things as walking, taking care of personal needs, maintaining independence, maintaining relationships, obtaining information about their disease and accessing rehabilitative resources was assessed. The self-efficacy score was calculated as the sum of 7 questions on the survey. Each question asked how confident a person is in their ability to do a particular activity. Possible responses were “not very”, “somewhat”, “very” and “not applicable”. Two questions (dealing with driving and religious participation) were excluded because of the high prevalence of “Not Applicable” responses). The change in self-efficacy score was calculated from baseline to the 2-week interview and also from baseline to the 3-month interview. There was no significant difference in change of self-efficacy score between the control and video groups for either time ($p=0.58$ baseline to 2 weeks, $p=0.59$ baseline to 3 months). The controls decreased by -0.08 {-0.54,0.39} at 2 weeks and -0.18 {-0.67,0.31} at 3 months. The intervention group decreased by -0.27 {-0.74,0.21} at 2 weeks and increased by 0.02 {-0.48,0.51} at 3 months.

Emotional Response

Emotional response (how often subjects had feelings of fear, sadness, frustration, hopefulness, and peacefulness related to their vision impairment) was assessed using 5 questions about the frequency of these emotions and the responses were calculated on a 4-point scale. Possible responses were “never”, “rarely”, “sometimes” and “often”. Multivariate analyses (ANCOVA) showed that participants in the video group had no difference in affect than the control group (hopeful: $p=0.830$ baseline to 2 weeks, $p=0.139$ baseline to 3 months; afraid: $p=0.786$ baseline to 2 weeks, $p=0.604$ baseline to 3 months; sad: $p=0.778$ baseline to 2 weeks, $p=0.903$ baseline to 3 months; frustrated: $p=0.576$ baseline to 2 weeks, $p=0.303$ baseline to 3 months; peaceful: $p=0.992$ baseline to 2 weeks, $p=0.870$ baseline to 3 months).

Discussion

General knowledge of eye diseases has been demonstrated to be poor, even when patients are diagnosed with the disease[Gasch, 2000 #26;Pasagian-Macaulay, 1997 #31]. A few studies have shown that predictors of knowledge of eye diseases are sex (female), education level, English spoken in the home and recent visit to the eye doctor[Schoenfeld, 2001 #28;Livingston, 1998 #27]. In at least 2 studies, education and outreach has been effective in improving knowledge, care, and rate of eye examinations[Buonaccorso, 1999 #29;Philis-Tsimikas, 2001 #30].

The National Eye Institute has concluded that education is important and has set up an independent arm (NEHEP) to promote knowledge and training. The cost of education is miniscule compared to the costs incurred by blind individuals[Javitt, 1995 #32]. However, clinicians in the primary care settings generally lack the training, resources and time to perform all the elements of even the basic eye examination[Goldzweig, 2004 #23] much less conduct teaching sessions for their patients.

The video we developed was found to have a significant impact on the proximal outcomes (knowledge and willingness to use assistive devices). People who lived alone scored significantly worse at baseline ($p=0.051$) than those who did not live alone, but the magnitude of this difference is small (half a question). At the 2-week interview, there was no significant difference between those who lived alone and those who didn't ($p=0.633$). This suggests that people who live alone are a particularly good target for the educational intervention. Adults with low vision who lived with another person (spouse or other) may in effect have a *living* assistive device, and thus be less reliant on devices and appliances compared to those who live alone. A sighted companion may provide motivation and reinforcement to incorporate these changes and also provide greater access to information about these devices.

Researchers have used video as an intervention or part of an intervention to influence attitudes related to falling[Tennstedt, 1998 #10], to decrease cancer fatalism[Powe, 1999 #40], improve HIV risk reduction[Kalichman, 1999 #39], and to improve parent knowledge about antibiotics[Bauchner, 2001 #38]. In all but one of these studies[Powe, 1999 #40], the benefits in attitudinal, behavioral and knowledge outcomes were modest or the same compared to an alternative intervention. We interpret these results to be positive considering that the distribution of a video is generally less costly than the alternative interventions. The fact that there was little detectable impact on actual behavior and on emotional affect during this three-month study period despite a significant impact on knowledge was disappointing. This does not minimize the importance of patient education; it just emphasizes how hard it is to cause a change. This failure could be because of an inability of the measures used to find a difference or alternatively because there was no difference. The adaptive behavior questions (questions E1 through E10 in the questionnaires in the on-line appendix) probed changes in behavior, but did not address the reasons for the behavior change. For example, a change in kitchen appliances might be to acquire a talking device (a positive change), or the change might be to discard, because of vision, a no longer usable product (a negative change). Thus, if the intervention group made positive changes, but the control group made negative changes, our questions would be unable to distinguish between them. The self-efficacy questions (F1 through F9) were very specific and addressed the participant's confidence and thus did not suffer from this limitation.

It is important to note that the effect on knowledge was found even though the participants were recruited at a seminar in which they already acquired some basic knowledge of the disease and the rehabilitation before the baseline evaluation. A change in distal outcomes, like the purchase and use of assistive devices might require a more intense intervention or may require

more time to materialize. Access to care may have been a confounding issue, because in many locations a waiting period of three months or longer for an appointment with a low vision rehabilitation specialist is not unusual. However, it is possible that the lack of knowledge is not as much of a contributing factor as we and others have assumed. It is possible that other factors identified at the NEI focus groups [National Eye Institute, 2001 #42] such as cost of devices, lack of motivation and limited access to transportation have limited the impact of the acquired knowledge.

Several limitations of the study are acknowledged. First, the recruitment strategy of targeting attendees to a low vision related educational event may have resulted in a sample that was healthier and more independent than one accessed from a clinical setting. The event itself may have served a similar purpose as the video thus reducing its effect (however as noted above we still had a significant improvement in knowledge suggesting that the video was a more effective tool). If the sample was indeed positively skewed, then the impact of the intervention on adults with low vision may have been underestimated. Second, the sample was not ethnically or racially diverse (e.g., 96% non-Hispanic white) and thus not generalizable to the population of older adults. However, epidemiological studies suggest that the prevalence of AMD is higher in whites.

Other methods of teaching patients about AMD are possible. These include hearing about options directly from an ophthalmologist or optometrist face-to-face, and possibly holding and using the recommended devices. However these methods are much more time consuming, expensive and difficult to implement than an educational video. We feel that because of the uniformly high levels of satisfaction reported by viewers, the ease of administration and improvement in knowledge measured, that the video is a useful patient education tool. It is however, necessary to reexamine the basic assumption that education (at least in this format) is an effective tool to change behavior. The impact of other barriers to vision rehabilitation needs to be assessed as well.

As we found, getting a distribution channel that will place such a video at the hands of the intended target population is not an easy task. We believe that the most effective distribution will be at ophthalmology or optometry clinics. We are still looking for a way to affect such distribution even at a small scale.

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Figure 1.

The video includes a simulation of vision with a central scotoma provided for the benefit of the patient's families. The simulation depicts a more accurate rendition than has been available in the past. The resolution of the image decreases towards the edge and it dynamically illustrates that the patient naturally shifts the scotoma to the side to allow the more relevant portions of the scene to be visible. The beneficial effect of magnification was illustrated by the changing view of an approaching person.

Figure 2.

The virtual home animation includes environmental adaptations and use of visual aids such as the large digits wall clock shown to the left of the difficult to see clock that it replaced. Adaptations include installation of additional illumination, for example under the kitchen cabinets and the use of contrasting color surfaces such as the dual color cutting board (as shown here). Adaptations and visual aids are depicted for the kitchen, bathroom, bedroom, and living room.

Figure 3.

The anatomy and basic pathology of AMD are illustrated using a graphic animation. The animation assumes no prior familiarity with any of the anatomy of the eye and orbit and thus it starts with a full face image zooming to the eye as seen by an observer. The facial tissue around the globe then gradually fades as shown here to maintain the relationship between the exposed globe and the normally visible eye. The back of the eye is then gradually opened from the side to reveal a view of the retina while still maintaining the relationship to the face as shown here. These gradual transitions help persons unfamiliar with the anatomy locate various aspects. The animation is provided with as much magnification as possible and with large arrows pointing to items described in the audio. The animation further illustrates the location and nature of changes that occur with macular degeneration. The small portion of the retina affected is emphasized and compared with the large residual functioning retina.

Figure 4.

The non-animated parts of the video were enhanced using a technique that has been shown to improve the viewing experience for people with macular degeneration. This figure shows the difference between the enhanced (on the right) and original unenhanced version (on the left). The actual video only presented the enhanced images.

Figure 5.

Subjects were recruited at 5 educational/public relation events and after an initial telephone screening-interview they were randomized into treatment and control groups. For both groups, interviews were conducted at 2 weeks and 3 months. After the 3-month interview, the control group was given the video.

Figure 6.

Means and standard error of the means of the number of questions answered correctly out of 8 questions compared at baseline and at the 2-week interview. The treatment (video) group improved significantly more than the controls, a difference of about 1 extra question.

Figure 7.

The percent of people who use assistive devices at baseline and at Follow Up (3 months following the video) for (a) the control group and (b) the treatment (video) group. The change in use of Books On Tape was significantly more for the video group than the control group. Error bars indicate standard error of the mean. Although there is a similar tendency for the change in use of magnifiers and talking appliances to be greater for the video group, these changes were not significant. The means shown here do not exactly match the results reported from the models because the models adjust for covariates.

Table 1

Demographic data for the 151 people who responded at all three time points. Race was not used as a covariate since 99% of the sample was white.

	Video Group N=74	Control Group N=77
Age, mean (SD)	75.0 (9.6)	75.9 (8.8)
Gender, N (%)		
Male	29 (39%)	25 (33%)
Female	45 (61%)	52 (68%)
Household Size, N (%)		
1	12 (16%)	16 (21%)
2	59 (78%)	59 (77%)
3+	4 (5%)	2 (3%)
Marital Status, N (%)		
Married/living together	59 (80%)	57 (74%)
Divorced/separated	2 (3%)	3 (4%)
Widowed	9 (12%)	16 (21%)
Single	4 (5%)	1 (1%)
Education, N (%)		
< High School	1 (1%)	4 (5%)
High School or GED	19 (26%)	14 (18%)
Some college/vocational training	17 (23%)	24 (31%)
College	22 (30%)	14 (18%)
Post-college	15 (20%)	21 (27%)
Health, N (%)		
Excellent	14 (19%)	20 (26%)
Very good	31 (42%)	26 (34%)
Good	20 (27%)	21 (27%)
Fair	7 (10%)	8 (10%)
Poor	2 (3%)	2 (3%)
Employment		
Employed	5 (7%)	7 (9%)
Not employed	69 (93%)	70 (91%)