

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

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Structured 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

1 *Introduction*

2 The National Eye Institute has defined low vision as a visual impairment, not correctable by standard
3 glasses, contact lenses, medicine, or surgery that interferes with a person's ability to perform everyday
4 activities[National Eye Health Education Program, 1999 #52]. Age-related macular degeneration (AMD)
5 is the second most common eye disorder in late life[Rahmani, 1996 #8], is the leading cause of (legal)
6 blindness among European-descended people older than 65 years[Friedman, 2004 #35] and is
7 the leading cause of blindness among white persons (54.4% of the cases)[Congdon, 2004 #34]. Except for
8 preliminary findings[Richer, 2004 #47] regarding the effectiveness of nutritional supplements, there is no
9 known effective treatment for the dry type of macular degeneration, thus the vast majority of people with
10 this condition must learn to adapt to the limitations associated with central vision loss. The treatments for
11 the wet type only slow the progression of the disease or provide small improvement. Thus eventually all
12 AMD patients have to deal with a significant vision loss. The prevalence is strongly associated with age
13 and thus is expected to increase with the aging of the population. The impact on physical and economic
14 status and quality of life can be severe. For example, low vision is likely to affect the ability to perform
15 job-related functions (such as reading and writing) that in turn may lead to a loss of income (According to
16 the Bureau of Labor Statistics[, 2004 #44], in 2004, 21.9% of people of ages 65-74 were still employed.
17 Further, central retinal vision loss (as is common in AMD) may impact mobility (particularly on driving),
18 which limit the patient's ability to participate in valued social or leisure activities, and to maintain
19 functional independence.

20 When diagnosed with an incurable vision disorder such as age-related macular degeneration
21 (AMD), many patients report feeling devastated. The emotional consequences of the disability caused by
22 the vision impairment can be severe – including grief, depression, anxiety, confusion, fear, and suicide
23 ideation[Tolman, 2005 #48;O'Donnell, 2005 #49;Hassell, 2006 #50]. While many rehabilitative services
24 and assistive options exist, many patients do not take advantage of them[Vitale, 2006 #51]. It is
25 commonly believed that this is because they are not informed by the diagnosing provider about the
26 availability of these services or how to access them. A 1997 survey commissioned by the NEI[Prospect

27 Associates, 1997 #7] seems to support that view reporting that, "most respondents said that their eye care
28 professional provided little to no medical information about their vision problems and no information
29 about how to cope with their conditions or diagnoses." In addition, many respondents thought that their
30 eye care professionals were too busy and did not have the time to explain much to them. Several
31 ophthalmologists told patients that "they could do nothing more for them." Consequently, they stopped
32 visiting any eye care professional, not realizing that visual aids or other rehabilitative services were
33 available. Although the public awareness of AMD may have slightly increased since 1997 (20% in Attebo
34 [, 1997 #45], compared to 30% in Rosenthal[, 2003 #46]), it is not clear whether public awareness of
35 potential rehabilitation options has increased as well. A study in Australia in 2003[Pollard, 2003 #43]
36 identified the most common barriers to accessing low vision services as: awareness of services among the
37 general public and eye care professionals; understanding of low vision; acceptance; transportation; and
38 the referral process. These findings suggest that the lack of awareness of, and availability of, low vision
39 services is a major problem. In contrast, a series of focus groups in the U.S. in 2001 conducted by
40 NEI[National Eye Institute, 2001 #42] identified the following barriers to referral: cost of visual aids;
41 transportation; patient motivation; and, length of time to obtain an appointment. Additional barriers to
42 treatment-seeking often cited include: the misperception that vision impairment is a natural part of aging;
43 a lack of awareness about rehabilitation treatment options; and a belief that services are only available for
44 the blind, not for the partially sighted[Goldzweig, 2004 #23;Pollard, 2003 #43]. The limited training in
45 ophthalmology residency programs in low vision concerns may contribute to a lack of comfort and skill
46 in practicing ophthalmologists when discussing low vision referral and rehabilitation options with their
47 patients.

48 Thus, the current state of low vision patient education and the availability of patient education
49 materials is alarmingly suboptimal. Recognition of this situation led the National Eye Health Education
50 Program (NEHEP)[National Eye Health Education Program #25], to develop a nationwide educational
51 program about low vision and its rehabilitation including collaborative community health education
52 initiatives, sponsorship of public service announcements, extensive publications, and a traveling display
53 for presentation in shopping malls. In complement to these efforts we developed, with funding from the

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

64 *Methods*

65 **Video Content Development and Production**

66 The video content was developed in a six-step process. First, the initial content outline was developed
67 based on our clinical experience and review of numerous available patient education videos and print
68 materials. Second, the topics in the content outline were incorporated into discussion guides for three
69 focus groups described below. Third, the content outline was reviewed and revised based on focus group
70 findings. Script treatment was then developed from the revised outline. Fourth, a prototype video
71 (about 10 minutes) was developed, which reflected the overall approach and tone of the script.
72 The prototype included documentary style sample interviews with a man with AMD and his
73 wife, as well as a sample of the virtual home sequence. The prototype images' contrast was
74 enhanced as described below. Fifth, four participants from the previous focus groups (3 persons
75 with low vision and one family member) reviewed the prototype. Overall, they praised both the
76 content and its presentation format. The contrast enhancement facilitated their viewing, and they

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>

77 could see the unenhanced virtual home. They particularly liked this latter feature. An NIH study
78 section reviewed the prototype and awarded the funds for the final development. Additions and
79 changes were recommended by both groups. Sixth, the final content was developed and the
80 video was produced as detailed below. A short list of referral and support resources was
81 included at the conclusion of the video.

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

88 Patient focus group participants described vividly their initial reactions of grief and despair to the
89 diagnosis. Similar reactions were found in other focus groups dealing with vision loss. In the focus groups
90 that were conducted to develop the National Eye Institute Visual Function Questionnaire[Mangione, 1998
91 #54], the emotional impact of AMD was identified as the fourth most common type of problem associated
92 with their condition. The domain of emotional reaction to vision loss was initially not considered in the
93 development of the Vision Impairment Profile[Weih, 2002 #55], but was subsequently included based on
94 the outcome of the focus groups. Our focus group participants expressed the need to communicate to
95 patients a message of hope about their ability to adjust to the vision loss. This need was not probed in the
96 other studies.

97 Based on the focus group inputs, we decided to use the concept of ‘cognitive restructuring’ as the
98 theoretical framework for the development of the video script treatment. Cognitive restructuring[Rodin,
99 1983 #9;Lachman, 1992 #6] is an approach that instills adaptive beliefs such as greater perceived control,
100 greater confidence in one’s abilities, and more realistic assessment of failures prior to attempting changes
101 in actual behavior. This approach has been used successfully in intervention trials for exercise[Lachman,
102 1997 #5], fear of falling[Tennstedt, 1998 #10], and doctor/patient communication[Tennstedt, 2000 #11].

103 Within this framework, the video began by acknowledging the impact of the diagnosis and visual loss due
104 to macular degeneration in the second eye (the risk of depression is particularly high when the second eye
105 becomes affected[Tasman, 2005 #53]) as well as the despair and depression that often accompanies this
106 diagnosis. In a documentary style, the video incorporated the stories of three real people with low vision
107 due to AMD and their families, showing how they have moved emotionally from initial devastation and
108 despair to acceptance and adjustment. The use of low vision devices by these people was portrayed to
109 illustrate and underscore the adjustments and adaptations that have enabled them to maintain much
110 independence. Increasing awareness and knowledge about the aids that are available to AMD patients,
111 and showing real people that have survived initial diagnosis and have moved on to live productive and
112 even joyful lives completed the framework of cognitive restructuring.

113 A dynamic simulation of vision with a central scotoma was provided for the benefit of the
114 patient's families. The simulation was made with specially developed software[Geisler, 1998 #1;Geisler,
115 2002 #2] that provides a more accurate rendition than has been available in the past. The simulation
116 includes not only the effect of the disease induced blind spot[Pelli, 1990 #33] but also the spatial
117 variability of the visual system and the dynamic nature of vision. Figure 1 shows a single frame of this
118 simulation. Note that the resolution of the image decreases towards the edge of the image and that the
119 patient naturally shifts the scotoma to the side to allow the more relevant portions of the scene (a face) to
120 be visible. The video shows a pedestrian approaching the low vision person, and that as she approaches
121 the viewer, thus becoming larger, more and more details of her face become visible. This illustrates also
122 why magnification is an effective aid for low vision patients. A short video segment is available at:
123 <http://www.eri.harvard.edu/faculty/peli/lab/videos/videos.htm>.

124 FIGURE 1 GOES ABOUT HERE

125 To illustrate environmental changes that could be made in the home to improve functionality, we
126 used an animated 3-D 'virtual home' created in computer graphics. This technique allowed us to present
127 a home environment generically and stylistically. Its simplicity facilitated clearer viewing and emphasis
128 of the environmental changes, and the animation facilitates presentation of before and after views. It

129 showed various ways that a person could make adjustments to different rooms in the house to make
130 routine tasks easier. Figure 2 illustrates a few of the modifications to the kitchen, one of the five rooms
131 that were covered, including a change of equipment, as well as the use of lighting and contrasting colors
132 to enhance visibility. The graphics were produced in high contrast and at high magnification so that
133 visually impaired viewers can better perceive the images' content. The animations were also used to
134 illustrate use of additional visual aids that were not portrayed in the three patients' stories.

135 FIGURE 2 GOES ABOUT HERE

136
137 Caregivers in particular expressed confusion about the physiological nature and effects of this
138 disease. Graphic animation was developed to illustrate the anatomy of the eye and the changes associated
139 with AMD. In our experience the typical cross-sectional illustration of the eye is also not understood by
140 most patients. Patients do not understand what is shown in the illustration and can not connect it to what
141 they see of the eye. In fact many people we asked pointed to the iris as the "ball" in the term "eyeball"
142 indicating lack of knowledge of the spherical shape of the eye. Therefore, we developed the animation
143 particularly for a naïve audience assuming no prior familiarity with any of the anatomy of the eye and
144 orbit. The relation of various eye components to the visible view of the eye in the face was maintained
145 throughout the animation using progressive transparency and peeling of layers. Those aspects that are
146 relevant for the visual function, rather than the pathology or treatment, were emphasized. We used as
147 much magnification as possible, very large text labels, large arrows, and audio description facilitated
148 access to the material by visually impaired viewers (Figure 3). The narration emphasized that the macula
149 is a tiny portion of the retina, with the rest of the retina remaining functional, so that much vision remains
150 and might be used effectively. A short excerpt from the animation can be viewed at
151 <http://www.eri.harvard.edu/faculty/peli/projects/hopeinsight.html>.

152 FIGURE 3 GOES ABOUT HERE

153
154 The video was processed with a contrast enhancement technique previously shown to improve
155 perception by the target population[Peli, 1999 #12;Peli, 1991 #4]. The enhancement process amplified

156 the contrast of the high spatial frequency components of the video. The enhancement parameters used
157 were averages of parameters selected by individuals with AMD in a previous study[Peli, 1999 #12;Peli,
158 2005 #41]. Figure 4 illustrates the difference in appearance of the enhanced video compared to the
159 original video image.

160 The patients' focus group reviewed a sample of the enhanced video and confirmed that the
161 enhancement facilitated viewing. The caregivers' focus group viewed the same enhanced video segment
162 and reported that the enhancement did not interfere with the ability to see the video or to enjoy it. When
163 the video is shown to either normally sighted or visually impaired audiences they rarely if ever note
164 spontaneously that the video is processed. In many cases even after direct questioning observers are not
165 able to point to what might be different about the video. Thus the enhancement does not distort the image
166 in a noticeable or bothersome way without direct comparison to the unenhanced video (as shown in fig.
167 4).

168 FIGURE 4 GOES ABOUT HERE
169

170 **Assessment of Impact**

171 Institutional Review Board(IRB) approval was obtained. The research followed the tenets of the
172 Declaration of Helsinki. Informed consent was obtained from subjects after explanation of the nature and
173 consequences of the study. Subjects were recruited from 5 public education events held by the Schepens
174 Eye Research Institute in Florida during the winter of 2002. Recruitment materials and a project staff
175 member were located in the lobby of venues where the events were held. Potential subjects were
176 informed about the general purpose of the study, inclusion and exclusion criteria, and if still interested,
177 were asked to sign-up to be contacted for telephone interviews. Subjects who signed up for interviews
178 were mailed a (large print) study brochure and an informed consent form and asked to carefully review
179 both items before the telephone screening call. The screening call reviewed the study requirements and
180 obtained verbal informed consent prior to enrollment in the trial. The inclusion criteria were: having low
181 vision (as defined by the NEI[National Eye Health Education Program, 1999 #52]), understand English,
182 have access to a VCR and TV, and be able to hear well enough to participate in a telephone survey. Age

183 was not considered for inclusion. 120 subjects were excluded (56 ineligible, 17 refused screening, 14
184 self-declared ineligible, 5 refused protocol, 4 gatekeeper refusals, and the remainder due to problems in
185 contacting by telephone). Power analysis showed that we would need 128 completed instruments, 64 per
186 group, to detect a medium effect size (0.50). Meta-analysis of patient education materials has found that
187 audiovisual media generally have medium-sized effects on knowledge. Using one-sided testing and a 0.05
188 significance level, a sample size of 128 will yield 80% power. There were 156 participants at baseline.
189 The 29 additional subjects were recruited to account for possible attrition. Participants who completed the
190 study were paid a small stipend (\$75).

191
192 Standard demographic variables (age, gender, etc) were collected only in the baseline interview.
193 Living arrangements, employment and health data were collected at baseline and follow-up interviews.
194 At baseline and both follow up interviews knowledge of the eye, macular degeneration, and assistive
195 devices were assessed. In addition, information was collected on the possible emotional responses
196 (sadness, fear, confusion, peace) to low vision. Self-efficacy was measured in regard to obtaining and
197 using assistive devices. Attitudes regarding the use of assistive devices were also determined.

198
199 Data were collected by telephone survey by trained interviewers using CATI (Computer Aided
200 Telephone Interviewing) using CASES software[CSM Program, 2002 #13]. All subjects were
201 interviewed once at the beginning of the study (baseline). At the conclusion of the baseline interview, the
202 person was automatically assigned to the control or intervention group by the interview software.
203 Participants randomized (using a randomized block design with block size=4) to the intervention group
204 (N=75) were mailed the enhanced video and instructed to watch it before the next survey (post
205 intervention) that took place two weeks after the baseline interview. The control group (N= 79), which
206 did not receive the video, was also interviewed at 2 weeks ("2-week" interview). Both groups were
207 interviewed for the third time ("3-month" interview) at 3 months after the baseline interview. The control

208 group received the video after they did the 3-month interview. The survey center staff was not blinded to
209 the assigned group of the participants.

210
211 FIGURE 5 GOES ABOUT HERE.

212
213 Descriptive statistics were performed to specify the sample. Analysis of Covariance (ANCOVA)
214 was used to examine the effect of the video on the change in knowledge, attitude and behavior from
215 baseline to two endpoints. Some of the changes were expected to require some time to implement and
216 were thus analyzed at the three month endpoint, whereas others could occur almost immediately without
217 professional help and were thus analyzed at the 2 week point. Change in knowledge was assessed from
218 baseline to post intervention 2 weeks later. The change in use of assistive devices was assessed from
219 baseline to the 3-month interview. The change in self-efficacy was assessed from baseline to both the 2-
220 week post intervention interview and the 3-month follow up, as was the change in emotional response.
221 The ANCOVAs were always controlled for baseline values, and the models for knowledge and assistive
222 devices controlled for covariates as well. Models for self-efficacy and emotional response were only
223 controlled for covariates when treatment effects were found.

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

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

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

236

237 ***Results***

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

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

250

251 TABLE 1 GOES ABOUT HERE

252

253 **Knowledge**

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

259 Both groups improved their scores. However, the improvement of the treatment group
260 (1.41 points; 95% CI={0.80,2.02}) was significant whereas the improvement of the control
261 group (0.48 points; 95% CI={-0.14,1.09}) was not. The 95% confidence interval for the change
262 in knowledge for the treatment group is above 0, indicating a significant positive change. The
263 confidence interval for the control group includes 0, indicating no significant change.

264 People who did better at baseline improved less (probably because they had less room for
265 improvement – possible ceiling effect). People who were never married improved more: 1.48 vs. 0.40
266 points ($p=0.05$). People who lived alone also improved more 1.17 vs. 0.71 points ($p=0.068$ - this is not
267 quite significant when one controls for marital status). People in better health improved more: 1.36 vs.
268 0.52 points (ANCOVA $p=0.005$). There are no significant interactions - the effects of marital status,
269 living alone, and health are the same regardless of treatment arm.

270 FIGURE 6 GOES ABOUT HERE

271 **Assistive Devices**

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

280

281 The results of the ANCOVA show that willingness to use books-on-tape included a marginally significant
282 treatment (video) effect (Adj $R^2 = 0.53$; 1, 147 df; $F = 3.24$, $p = 0.074$), as well as significant effects of
283 baseline willingness ($p<0.001$) and marital status ($p=0.047$, married vs. single). The increase was 0.32

284 (95% CI={0.16,0.48}) for the controls, whereas for the intervention group the increase was 0.51 (95%
285 CI={0.34,0.68}). People who were more willing at baseline changed less (possible ceiling effect).
286 People who were single increased their willingness more than those who were married: 0.55 vs. 0.29
287 points.

288 For magnifiers, actual use changed from 49% to 61% for the video group, but only from 44% to 48% for
289 the control group. Although the change was greater for the video group, it was not statistically significant
290 (Adj $R^2 = 0.21$; 1, 148 df; $F = 2.37$, $p = 0.126$; mean difference in change = 10% {-3%,23%}). Similarly,
291 for talking appliances, actual use was unchanged for the control group (12%), whereas for the video group
292 usage changed from 5% to 12% that again was not significant (Adj $R^2 = 0.28$; 1, 148 df; $F = 0.20$, $p =$
293 0.654 ; mean difference in change = 2% {-8%,13%}) The effect of the intervention on willingness to use
294 magnifiers and talking appliances was not significant ($p=0.157$ and 0.300 , respectively). For magnifiers,
295 the controls increased by 0.13 {-0.001,0.26} and the intervention group by 0.26 {0.13,0.39}; for talking
296 appliances, the controls increased by 0.09 {-0.06,0.24} and the intervention group by 0.20 {0.05,0.36}.

297 Figure 7 GOES ABOUT HERE.

298 **Adaptive Behaviors**

299 Adaptive behaviors, defined as making changes in home and lifestyle to adjust to vision
300 impairment were examined. These questions were yes/no or “not applicable” questions asking if any
301 changes were made in each room or activity. Both groups increased their adaptive behaviors in the home
302 from baseline to the 3-month interview. The change in behaviors of the video group, however, was not
303 significantly different from the change in behavior of the control group (Kitchen $p=0.39$; Bedroom
304 $p=0.38$; Bathroom $p=0.67$; Living room $p=0.34$; Stairs $p=0.50$).

305 **Self Efficacy**

306 Self-efficacy, defined as confidence in ability to do such things as walking, taking care of
307 personal needs, maintaining independence, maintaining relationships, obtaining information about their
308 disease and accessing rehabilitative resources was assessed. The self-efficacy score was calculated as the
309 sum of 7 questions on the survey. Each question asked how confident a person is in their ability to do a

310 particular activity. Possible responses were “not very”, “somewhat”, “very” and “not applicable”. Two
311 questions (dealing with driving and religious participation) were excluded because of the high prevalence
312 of “Not Applicable” responses). The change in self-efficacy score was calculated from baseline to the 2-
313 week interview and also from baseline to the 3-month interview. There was no significant difference in
314 change of self-efficacy score between the control and video groups for either time (p=0.58 baseline to 2
315 weeks, p=0.59 baseline to 3 months). The controls decreased by -0.08 {-0.54,0.39} at 2 weeks and -0.18
316 {-0.67,0.31} at 3 months. The intervention group decreased by -0.27 {-0.74,0.21} at 2 weeks and
317 increased by 0.02 {-0.48,0.51} at 3 months.

318 **Emotional Response**

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

327

328 ***Discussion***

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

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

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

349 Researchers have used video as an intervention or part of an intervention to influence attitudes
350 related to falling[Tennstedt, 1998 #10], to decrease cancer fatalism[Powe, 1999 #40], improve HIV risk
351 reduction[Kalichman, 1999 #39], and to improve parent knowledge about antibiotics[Bauchner, 2001
352 #38]. In all but one of these studies[Powe, 1999 #40], the benefits in attitudinal, behavioral and
353 knowledge outcomes were modest or the same compared to an alternative intervention. We interpret these
354 results to be positive considering that the distribution of a video is generally less costly than the
355 alternative interventions. The fact that there was little detectable impact on actual behavior and on
356 emotional affect during this three-month study period despite a significant impact on knowledge was
357 disappointing. This does not minimize the importance of patient education; it just emphasizes how hard it
358 is to cause a change. This failure could be because of an inability of the measures used to find a difference
359 or alternatively because there was no difference. The adaptive behavior questions (questions E1 through
360 E10 in the questionnaires in the on-line appendix) probed changes in behavior, but did not address the

361 reasons for the behavior change. For example, a change in kitchen appliances might be to acquire a
362 talking device (a positive change), or the change might be to discard, because of vision, a no longer
363 usable product (a negative change). Thus, if the intervention group made positive changes, but the control
364 group made negative changes, our questions would be unable to distinguish between them. The self-
365 efficacy questions (F1 through F9) were very specific and addressed the participant's confidence and thus
366 did not suffer from this limitation.

367 It is important to note that the effect on knowledge was found even though the participants were
368 recruited at a seminar in which they already acquired some basic knowledge of the disease and the
369 rehabilitation before the baseline evaluation. A change in distal outcomes, like the purchase and use of
370 assistive devices might require a more intense intervention or may require more time to materialize.
371 Access to care may have been a confounding issue, because in many locations a waiting period of three
372 months or longer for an appointment with a low vision rehabilitation specialist is not unusual. However,
373 it is possible that the lack of knowledge is not as much of a contributing factor as we and others have
374 assumed. It is possible that other factors identified at the NEI focus groups[National Eye Institute, 2001
375 #42] such as cost of devices, lack of motivation and limited access to transportation have limited the
376 impact of the acquired knowledge.

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

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

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

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Figure Legends

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.

Tables

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%)

Figure 1

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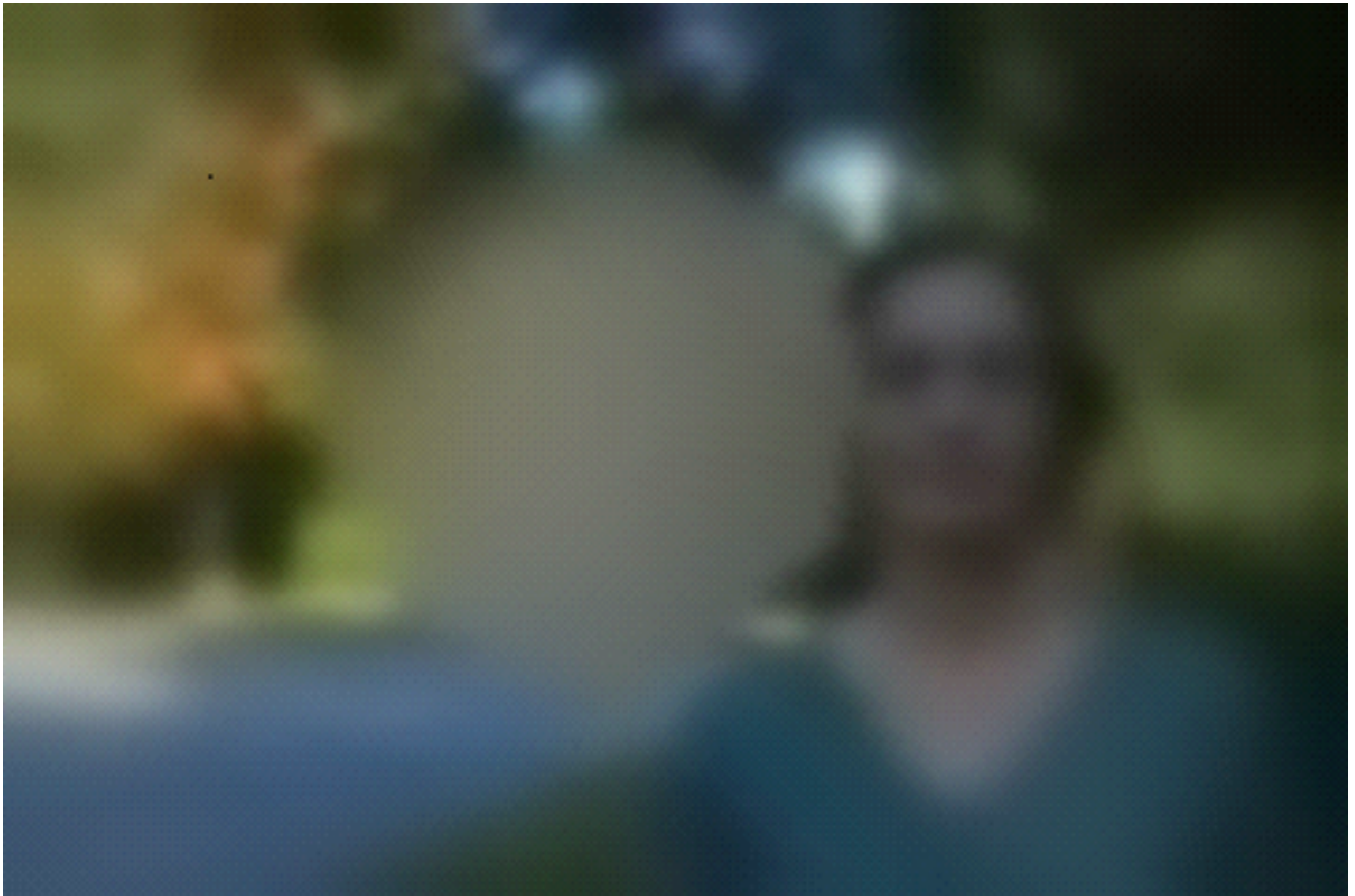


Figure 2a
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Figure 2b
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Figure 3
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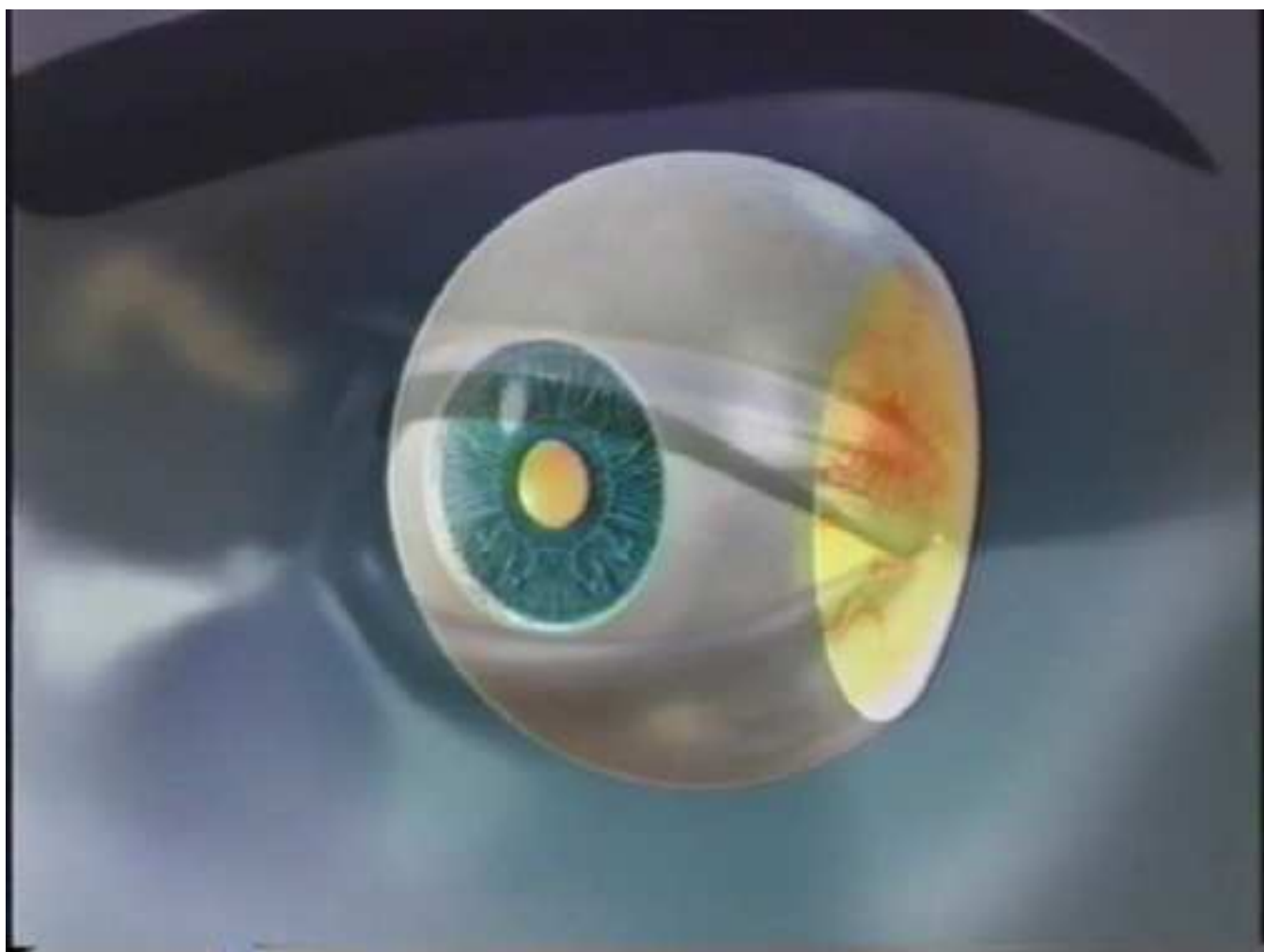


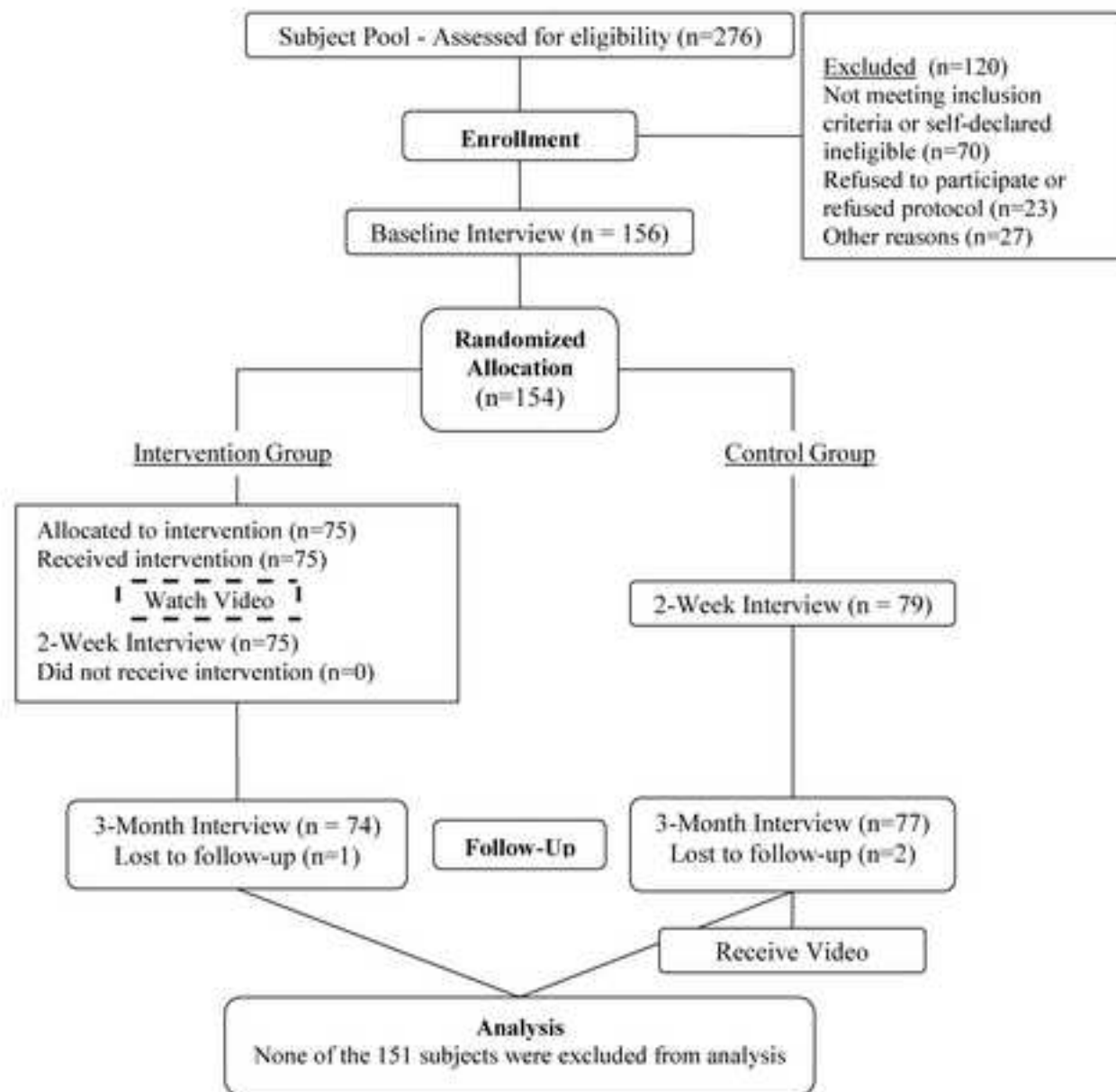
Figure 4

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Figure 5

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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

Figure 6

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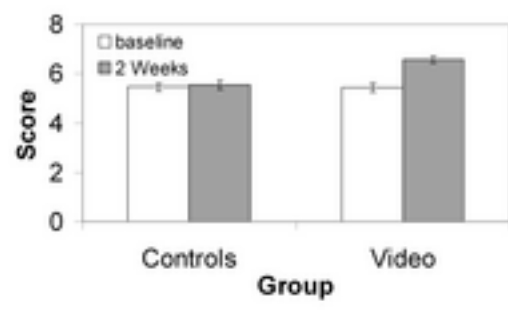


Figure 7a
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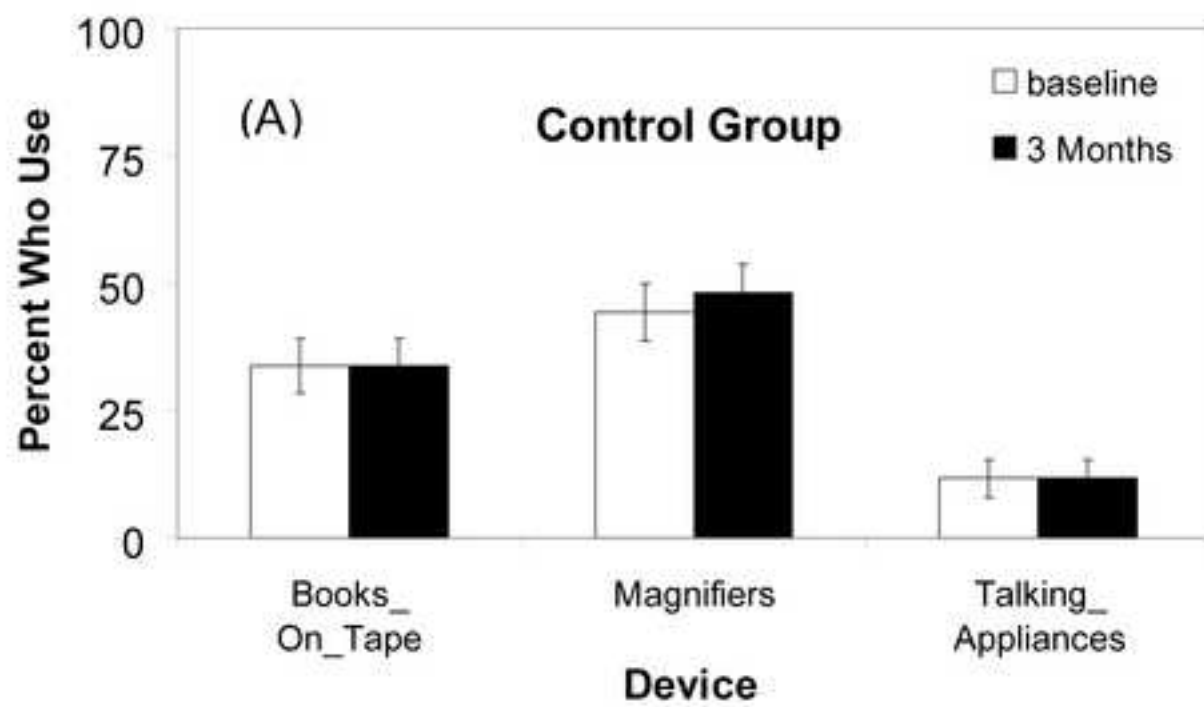


Figure 7b
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