☑ CE Article

Targeted Vision Function Goals and Use of Vision Resources in Ophthalmology Patients with Age-Related Macular Degeneration and Comorbid Depressive Symptoms

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Structured abstract: *Introduction:* This study characterizes self-reported functional vision goals and the use of low vision resources (for example, services and devices) in ophthalmology clinic patients with age-related macular degeneration (AMD) and comorbid depressive symptoms. *Methods:* From July 2009 to February 2013, we assessed 188 consecutive patients (age 65+; mean 84.0 years; 70.2% female) with AMD (best corrected distance acuity 20/70 or worse) enrolled in a 12-month randomized clinical trial to test the efficacy of a multicomponent intervention that combined low vision optometry and home-based occupational therapy to prevent depression (Low Vision Depression Prevention Trial [VITAL]). A geriatric nurse conducted in-home assessments to measure visual acuity and contrast sensitivity, self-reported functional vision, functional vision goals that were personally important yet difficult to achieve (targeted vision function goals), and the use of low vision resources (defined as services, devices and strategies utilized by low vision patients to compensate for visual deficits). This study reports on baseline data collected prior to randomization. *Results:* Only 9.6% of the sample had received formal low vision services. The five most common goals were newspaper reading, leisure and entertainment, computer use, personal communication, and correspondence. Participants engaged in targeted vision function goals less frequently since being diagnosed with AMD, despite using low vision resources and reporting low to moderate difficulty in using them. *Discussion:* Few patients with AMD seen in ophthalmology clinics received low vision rehabilitation. Patients who utilized resources engaged in goals less frequently since being diagnosed with AMD. *Implications for practitioners:* Patients with AMD are underutilizing low vision rehabilitation resources. Strategies for increasing low vision referrals are suggested.

Vision loss due to age-related macular degeneration (AMD) is a major source of disability among older adults. Anti-vascular endothelial growth factor (VEGF) treatment has stabilized or improved vision in some patients with neovascular AMD. Despite this revolutionary treatment, many patients continue to experience substantial vision loss, either because they have atrophic disease (for which there is no treatment), or because they have achieved maximal benefit from anti-VEGF treatment (Rosenfeld et al., 2006; Sloan & Hanrahan, 2014). For these patients, low vision rehabilitation is an important option for learning to live more effectively with low vision. Although effects vary, research supports the efficacy of low vision rehabilitation to improve reading speed (Coco-Martín et al., 2013; Nguyen & Trauzettel-Klosinski, 2009), social engagement (Brunnström, Sörensen, Alsterstad, & Sjöstrand, 2005; Scanlan & Cuddeford, 2004), psychological well-being (Horowitz, Brennan, Reinhardt, & MacMillan, 2006), and activities of daily living (Eklund & Dahlin Ivanoff, 2007; Markowitz, Kent, Schuchard, & Fletcher, 2008; McCabe, Nason, Demers Turco, Friedman, & Seddon, 2007; Stelmack, Moran, Dean, & Massof, 2007; Stelmack et al., 2008).

Despite the potential benefit of low vision rehabilitation, little is known about the low vision service, device, and strategy use in AMD patients outside of low vision clinic samples. Such knowledge is important to determine unmet rehabilitation and training needs. In this paper, we describe the use of low vision resources and important vision-related goals that were reported by a sample of patients with AMD who were treated by an ophthalmology clinic.

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Methods

Sample

The sample comprised all participants from the Low Vision Depression Prevention Trial (VITAL). VITAL was a randomized clinical trial to test the efficacy of a multicomponent intervention that combined low vision optometry and home-based occupational therapy to prevent depression in patients with AMD and comorbid subthreshold depressive symptoms. Details of the study are described in Rovner et al. (2014). All participants had two low vision optometry visits and were prescribed low vision devices. After the optometry visits, participants were randomized to behavioral activation (active treatment) or supportive therapy (control treatment). Behavioral activation was delivered by occupational therapists, and is a structured behavioral treatment that aims to increase adaptive behaviors and achieve valued goals. Supportive therapy was delivered by master's-level counselors, and is a nondirective, psychological treatment that provides emotional support and controls for attention. Both treatments were delivered in participants' homes over six sessions.

We enrolled 188 consecutive participants with AMD (from July 2009 to February 2013) from ophthalmology clinics in Philadelphia, Pennsylvania. Eligibility

criteria were: (1) age 65 years or older; (2) bilateral AMD; (3) best eye corrected visual acuity of 20/70 or worse; (4) five or more anti-VEGF injections if the better eye had neovascular disease (or no injections in the past 3 months); (5) moderate difficulty performing a valued activity; and (6) subthreshold depressive symptoms, defined as a Patient Health Questionnaire-9 (PHQ-9) score of 5 or more (Kroenke, Spitzer, & Williams, 2001), or depressed mood or anhedonia several days per week. We excluded patients with cognitive deficits (assessed by an abbreviated version of the Mini Mental State Exam) (Reischies & Geiselmann, 1997), impending anti-VEGF treatment, current depressive disorder (Diagnostic and Statistical Manual of Mental Disorders [DSM]) (American Psychiatric Association, 1994), or other ophthalmologic disease. Monthly, we reviewed medical charts of consecutive patients to identify those who met eligibility criteria. Recruitment letters were mailed to patients, and were followed by telephone calls to screen for eligibility. All procedures were approved by the Institutional Review Board at Thomas Jefferson University, and adhere to the tenets of the Declaration of Helsinki.

Before randomization, a research nurse visited participants in their homes to obtain informed consent and administer the baseline assessment. The nurse read all questions aloud to participants and recorded their responses. The cross-sectional analysis reported here is based on baseline data.

Measures

Demographic and background characteristics

These included sex, date of birth, marital status, education, and living situation.

Vision

The nurse assessed best corrected distance acuity and contrast sensitivity using a computerized assessment.

Functional vision

Self-reported functional vision was assessed with the Massof Activity Inventory (MAI) (Massof et al., 2005). The MAI is an adaptive instrument in which participants were asked to rate the importance and perceived difficulty in performing 50 common goals. For goals rated as being important yet difficult to carry out, participants were asked to rate the difficulty of executing goal-specific tasks. For example, tasks for the goal of reading the newspaper are reading headlines, classified ads, and the weather forecast. After administering the MAI, the assessor read to participants a list of all MAI goals that were rated as being personally important yet difficult to achieve. From this list, participants then identified up to four goals that were of greatest importance to them. The resulting list comprised the targeted vision function goals, and follow-up questions regarding resources used when attempting these goals were asked. The MAI contains questions about the importance and perceived difficulty with driving; however, we did not use the driving questions when formulating participants' targeted vision function goals since the study intervention did not address driving.

Use of resources

For each targeted vision function goal, participants were asked to list all devices, resources, and strategies they used to address the goal. This was an open-ended question; responses included devices (for

instance, a magnifier, a bright light, or an enlarged version of an object), assistance from others, and miscellaneous strategies (such as relying on voice rather than appearance or using a ruler to guide reading). For each resource listed for each of the targeted vision function goals, participants were asked: (1) "How difficult is it to use these resources when performing a goal?" (rated from 1 [extremely] to 4 [not at all]); (2) "Since you have been using these resources, how difficult is it to perform the goal?" (rated from 1 [much more] to 5 [much less]); and (3) "How often do you use these resources to perform or engage in the goal?" (rated from 1 [none of the time] to 4 [every time]). These three questions were only asked of participants who indicated that they used a resource for a particular targeted vision function goal. All participants were asked, "Compared to before you had AMD, how often do you perform the goal?" Responses ranged from 1 (more of the time) to 3 (less of the time). Participants were also asked whether they had ever received any of the following ("yes" or "no"): low vision rehabilitation, mobility training, or residential low vision rehabilitation.

Statistical analysis

We first identified the five most commonly chosen targeted vision function goals. For each of these goals, we present the number and percent of participants who: (1) used a resource to engage in the goal; (2) report that using a resource to engage in the goal was "extremely" or "very" difficult; (3) indicated that the goal was "somewhat" or "much less" difficult to carry out when using the resource; (4) used the resource "most" or "every" time that they engaged in the goal; and (5) engaged in the goal "less frequently" compared to before being diagnosed with AMD. We then present the frequency of participants who used various types of resources for each of the five most commonly selected targeted vision function goals.

Results

The study enrolled 188 participants (female [70.2%]; Caucasian [97.9%]; mean age, 84.0 years [*SD* = 6.8]; mean education 13.3 years [*SD* = 3.0]). The mean best eye distance acuity was .67 (*SD* = .38) (Snellen mean of 20/93 [*SD* = 20/48]). The mean best eye log contrast was 1.54 (*SD* = .53). Ninety-one (48.4%) had received anti-VEGF treatment. Eighteen (9.6%) had received low vision rehabilitation; 2 (1%) had residential low vision training; and 3 (1.6%) had mobility training.

The five most common targeted vision function goals (see Table 1) were reading the newspaper (38.3%), leisure and entertainment (35.6%), personal communication (35.6%), correspondence (31.9%), and computer use (21.8%). The corresponding goal-related tasks for each of these five goals are presented in Table 2. Figure 1 presents the percentage of participants who chose the five most commonly selected goals and the resources used for each goal. Resource type was grouped into the following categories: hand-held magnifier; illuminated magnifier; magnifier type not specified; bright or enhanced light; low vision glasses; electronic reading device such as Kindle or closed-circuit television; large objects (for instance, large print books); reliance on others (for example, having someone else pay bills); audio materials (such as audio books); and miscellaneous strategies (for instance, focusing on

Table 1
Frequency of targeted vision function goals.

Targeted vision function goal	*n*	%
Reading the newspaper	72	38.3
Leisure and entertainment	67	35.6
Personal communication	67	35.6
Correspondence	60	31.9
Computer use	41	21.8
Shopping	34	18.1
Sewing and needlework	30	16.0
Attending church	30	16.0
Managing finances	26	13.8
Travel	25	13.3
Using the telephone	22	11.7
Playing cards and games	20	10.6
Spectator events	14	7.4
Gardening and lawn care	14	7.4
Dining out	14	7.4
Knitting or crocheting	12	6.4
Sports	11	5.9
Following the news	10	5.3
Personal hygiene	9	4.8
Exercise	9	4.8
Recreational baking	8	4.3
Playing a musical instrument	7	3.7
Meal preparation	6	3.2

Note: Participants selected up to four targeted vision function goals at baseline. $N = 188$.

alternative attributes such as voice rather than facial expressions).

In Table 2, for each of the five most common goals, we show the percentage of participants who reported using resources for goal attainment, difficulty using the resource, difficulty executing the goal when using a resource, and frequency of goal engagement compared to before AMD diagnosis. Use of resources was moderately high, ranging from 32.8% of participants who selected personal communication to 73.3% of participants using a resource for correspondence. A pattern emerged showing that most participants reported little difficulty using their resources (except for personal communication, where 59% had difficulty), that the goal was less difficult when using the resource, and that the resource was used often when attempting the goal. Most participants reported engaging in their targeted vision function goals less frequently compared to before the AMD diagnosis (63% of participants who selected using a computer to 92% of those who selected reading the newspaper).

Discussion

Prior to enrolling in the VITAL study, less than 10% of the sample had ever received low vision services. We previously surveyed 80 ophthalmology patients with AMD and found that only 13% had accessed low vision services (Casten, Maloney, & Rovner, 2005). Although the current sample comprised participants with depressive symptoms, the low vision utilization rate continued to be low. Sunness, Schartz, Thompson, Sjaarda, and Elman (2009) noted that low vision referrals for patients with AMD have decreased since anti-VEGF treatment became standard care. Our results support the presence of low utilization rates.

Despite methodological limitations, research consistently shows that patients benefit from low vision rehabilitation. Although few clinical trials have evaluated its efficacy, studies that assessed patients before and after low vision rehabilitation show improved reading, mobility, and functional ability, and mixed effects for quality of life (Binns et al., 2012; Hooper, Jutai, Strong, & Russell-Minda, 2008). It is disconcerting that in the present sample, only slightly more than half of those whose targeted vision function goal was reading a newspaper were using a resource to do so.

Preservation of daily function is essential for longevity and cognitive function in

Table 2
Resource use for the five most common targeted vision goals.

Targeted vision function goals (TVFs)	*n*	%
TVF: Reading the newspaper (*n* = 72); example tasks: reading headlines, weather, and ads		
Use resource to read newspaper	37	51.4
Extremely or very difficult to use resource (*n* = 37)	15	40.1
Goal is somewhat or much less difficult when using resource (*n* = 37)	33	89.2
Resource used most or every time when reading newspaper (*n* = 37)	34	91.8
Read newspaper less frequently since AMD (*n* = 72)	66	91.7
TVF: Computer use (*n* = 41); example tasks: use keyboard, e-mail, use mouse, computer games		
Use resource when using computer	21	51.2
Extremely or very difficult to use resource (*n* = 21)	4	19.0
Goal is somewhat or much less difficult when using resource (*n* = 21)	21	100.0
Resource used most or every time when using computer (*n* = 21)	19	90.5
Use computer less frequently since AMD (*n* = 41)	26	63.0
TVF: Leisure and entertainment (*n* = 67); example tasks: watch television, read for pleasure, games, puzzles		
Use resource when engaging in leisure and entertainment	46	68.7
Extremely or very difficult to use resource (*n* = 46)	19	41.3
Goal is somewhat or much less difficult when using resource (*n* = 46)	44	95.7
Resource used most or every time for leisure and entertainment (*n* = 46)	41	89.1
Engage in leisure and entertainment less frequently since AMD (*n* = 67)	60	89.6
TVF: Correspondence (*n* = 60); example tasks: read mail, e-mail, sign name, write letters		
Use resource when corresponding	44	73.3
Extremely or very difficult to use resource (*n* = 44)	13	29.5
Goal is somewhat or much less difficult when using resource (*n* = 44)	42	95.4
Resource used most or every time for correspondence (*n* = 44)	39	88.6
Corresponding less frequently since AMD (*n* = 60)	45	75.0
TVF: Personal communication (*n* = 67); example tasks: understand people, read facial expressions		
Use resource when communicating	22	32.8
Extremely or very difficult to use resource (*n* = 22)	13	59.0
Goal is somewhat or much less difficult when using resource (*n* = 22)	22	100.0
Resource used most or every time for communicating (*n* = 22)	15	68.2
Communicating less frequently since AMD (*n* = 67)	61	91.0

Note: Follow-up questions were only asked of participants who reported using a resource for a particular goal.

older persons. Declines in instrumental activities of daily living due to vision loss are associated with increased mortality (Christ et al., 2014). We previously reported that patients with AMD who disengage from cognitively, socially, or physically stimulating activities are at risk for cognitive decline (Rovner, Casten, Leiby, & Tasman, 2009). Each of the five most commonly selected targeted vision function goals identified in this study is essential for either living independently or for continued engagement in leisure and social pursuits. Despite the availability of low vision rehabilitation to sustain these goals at the maximal possible level, few participants accessed indicated using the services, potentially increasing the risk of aversive health outcomes.

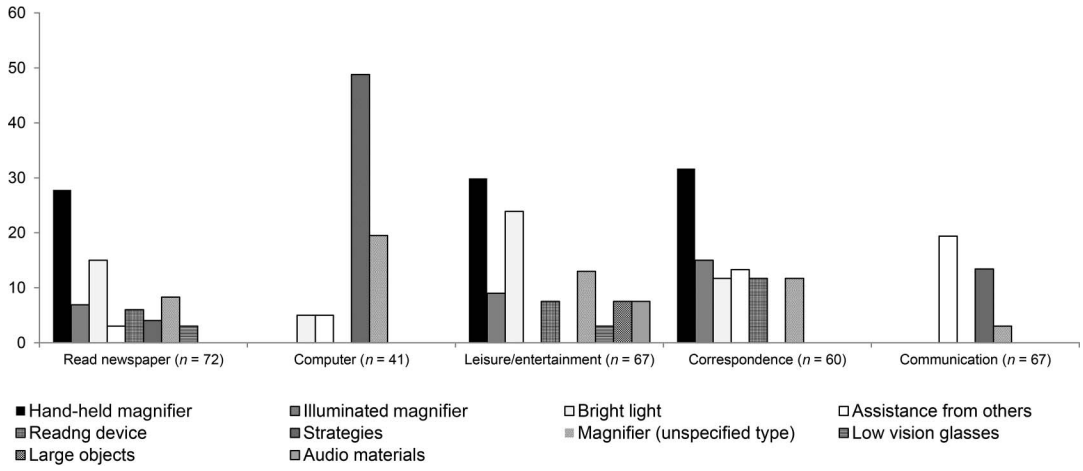

Figure 1. Percent of participants who used various types of resources by targeted vision function goal ($N = 188$). *Note:* Reading device examples include Kindle, CCTV, and iPad. Strategy examples include Identifying people by voice or shape, moving material closer to read, enlarging font on computer, and using a ruler to read. Examples of large objects include large print books, large print puzzles, et cetera.

There were no demographic or clinical characteristics in our sample that would have precluded participation in low vision rehabilitation. In fact, our sample mirrors those of typical users of low vision services in the United States (that is, aged 65 years or older, with mild depressive symptoms, and AMD as the primary cause of vision loss) (Goldstein et al., 2012; Overbury & Wittich, 2011; Owsley, McGwin, Lee, Wasserman, & Searcey, 2009).

All participants had subthreshold depressive symptoms, which are common in patients with AMD (Brody et al., 2001; Evans, Fletcher, & Wormald, 2007; Goldstein et al., 2012; Horowitz, Reinhardt, & Kennedy, 2005; Jones, Rovner, Crews, & Danielson, 2009; Overbury & Wittich, 2011; Owsley et al., 2009; Rovner & Ganguli, 1998). Nevertheless, our findings may not generalize to populations that have no depressive symptoms. There is a low likelihood, however, that depression exerts a large effect on service access and uptake, as the prevalence of depression or psychological issues in low vision rehabilitation samples ranges from about 14% to 45% (Goldstein et al., 2012; Owsley et al., 2009).

Our data showed a general pattern in which participants engaged in targeted vision function goals less often after they developed AMD. This pattern of activity disengagement is apparent despite frequent use of resources when attempting the goal, and low to moderate difficulty in using resources. It is possible that despite relative ease in using resources, task engagement continues to be difficult, thus explaining lower task frequency after being diagnosed with AMD. Only about 10% of the participants reported that they had ever received formal low vision rehabilitation, suggesting that most of the resources were self-selected. It is therefore possible that participants were using suboptimal resource(s) like incorrect magnification. Rates of activity engagement

may be higher in patients who utilize expert-recommended resources or who are taught appropriate strategies for maximizing function. Research shows that consultation with low vision experts is essential for the acquisition, integration, and continued use of low vision assistive devices (Copolillo & Teitelman, 2005). Furthermore, patients with AMD perceived their prescribed devices or aids as being valuable in the continuation of reading and tasks of daily living, and most used them regularly (Brown, Goldstein, Chan, Massof, & Ramulu, 2014; Eklund & Dahlin Ivanoff, 2006; Reeves, Harper, & Russell, 2004). Other research demonstrates high use of low vision devices after receiving rehabilitation among individuals who did not have AMD (Watson, De l'Aune, Long, Maino, & Stelmack, 1997; Watson, De l'Aune, Stelmack, Maino, & Long, 1997).

Few studies have surveyed the use of low vision resources and self-reported functional concerns in patients with AMD who attended ophthalmology clinics. Brown et al. (2014) documented rehabilitation needs in a large sample of low vision rehabilitation users, over half of whom had macular disease. Our findings complement this research by presenting the prevalence of vision-related functional deficits and high rates of service underutilization in individuals who are not receiving rehabilitation.

Strengths of the study include systematic recruitment and rigorous methods for assessing targeted vision function goals. We used an open-ended format to measure the use of resources. Imposing a forced-choice format may have resulted in underestimates of use (for instance, participants may have been unfamiliar with particular terminology). Other research supports an open-ended format to collect these types of data (Brown et al., 2014; Lamoureux et al., 2007).

The major limitation of our study is that the sample may not be generalizable to all patients with AMD for three reasons. First, approximately half of the sample had wet AMD, whereas only about 10% of the AMD population has neovascular disease. Second, participants volunteered to be in a study that required substantial effort and time. We were not able to obtain resource-use data on comparable patients who declined participation. Third, all participants had subthreshold depressive symptoms, which may have reduced motivation to pursue low vision rehabilitation or use devices. On the other hand, we excluded patients with more severe depressive disorders who would be less likely to access low vision services; thus, our data may overestimate the use of resources. Also, we were not able to determine the number of participants who were referred for low vision services but chose not to follow through, nor did we measure reasons for nonutilization. Overbury and Wittich's (2011) study of Canadian ophthalmology patients with AMD found that 21% who were referred for low vision services did not follow through. We expect a higher rate in the United States because of the out-of-pocket expenses associated with rehabilitation. Another limitation relates to the methodology for assessing frequency of and difficulty in using resources. These questions have not been validated in other samples. In addition, we did not assess driving as a potential targeted vision function goal. Brown et al.'s (2014) study showed that next to

problems with reading, problems with driving are a major complaint (albeit less so among older patients) in a sample of individuals with low vision. Also, the targeted vision function goals were selected on the basis of both perceived difficulty and importance, and thus our data do not address the use of resources for unimportant or low-difficulty goals. In addition, this study is cross-sectional, which limits our ability to interpret relationships between the individuals who used resources and those who did not for particular targeted vision function goals. Finally, due to the small number of participants who used specific resources, we were unable to discern differences among them.

With the aging of the population, the number of older adults with impaired vision will increase, and thus the need for low vision rehabilitation will increase as well. Following the recommendations of Wahl (2013), maintaining social and cognitive engagement and psychological well-being are critical to preserving function. As vision declines, competency in these domains often follows suit. Wahl (2013) suggests an "age-related psychoophthalmology" model in which multidisciplinary teams address the cognitive, social, emotional, functional, and everyday living needs of patients with AMD. Our findings demonstrate that these needs are not being met.

Implications for practitioners

Low resource use rates among people with low vision persist despite recent advances in availability and technology. One of the major causes of this lack of utilization of resources is the failure of ophthalmologists to increase patient awareness, which may reflect limited understanding on the part of ophthalmologists of the effect of even mild vision impairment on typical daily activities. Ophthalmologists do not regard vision loss with the same gravity as do their patients (Brown, Brown, & Sharma, 2000).

Other reasons for the lack of referrals to low vision rehabilitation services may include lack of emotional or financial reward to the physician, who may not want to tell patients that there is no immediate cure available for their condition. Many ophthalmologists have little time for counseling or referring. Lack of exposure to vision rehabilitation during residency training and inadequate emphasis on the emotional aspects of vision loss also contribute to the problem. Incorporating education about rehabilitation into training may improve awareness and referrals.

Suggestions for increasing referral rates include delegating the task of referral to ophthalmic technicians, who often screen ophthalmology patients. Such referrals can be easily facilitated via field reporting in electronic medical records (or electronic health records) to flag patients with indications of low vision. Electronic health records are being used in some ophthalmology practices to prompt referral to low vision services by flagging and initiating "automatic referral" (A. Free, personal communication, January 12, 2016).

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