The realm of expressive writing (EW) has been vastly explored over the past 20 years. EW is the process of expressing one’s emotions through written disclosure of a past traumatic experience (Pennebaker and Beall, 1986), future traumatic experience (Dalton and Glenwick, 2009), or the best possible way one’s life could be envisioned (King, 2001). In a typical EW paradigm, randomized participants are assigned to either the control group who writes on mundane, non-emotional topics or the intervention group who writes on topics such as a traumatic experience. Frattaroli’s (2006) meta-analysis revealed that having at least three writing sessions for at least 15 minutes each were associated with increased health benefits. Over the past 20 years, research has shown that EW in comparison to control groups yielded benefits ranging from increased test scores (Dalton and Glenwick, 2009), finding employment more quickly after being laid off (Spera et al., 1994), to decreased viral load in HIV patients (Booth et al., 1997).

Although EW has been shown to benefit healthy populations, it has a much higher overall effect size on those with physical health problems (Frattaroli, 2006). After EW, breast cancer patients experienced improvements in their perception of social support (Gellaitry et al., 2010). HIV patients experienced an increase in positive

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Abstract
This study implemented and evaluated the effectiveness of an expressive writing intervention among patients with Stargardt’s disease, a rare disease due to macular degeneration. Participants were randomly assigned to either an expressive writing intervention or a neutral writing condition. Participants completed measures at three time points: baseline, 3 weeks, and 6 weeks post-intervention. Psychological health outcomes improved at the 3-week follow-up for the intervention condition compared to control. Self-reported physical health improved at the 6-week follow-up in the intervention condition compared to control. These results suggest that expressive writing may be an effective, practical, and low-cost intervention for those with Stargardt’s disease.

Keywords
cost-effectiveness, disability, distress, intervention, physical symptoms
affect, global sense of meaning, HIV cognitive adaptability, and HIV quality of life (Wagner, 2004). Fibromyalgia patients experienced reduced pain, fatigue, and a better feeling of psychological well-being (Broderick et al., 2005). Thus, we expected that EW would improve general physical health and illness-related symptoms.

The aforementioned studies are examples of the different benefits EW has offered to chronically ill populations. However, rare disease populations have yet to be studied. It is possible that they may gain even more health benefits. The visually impaired population has been overlooked and warrants examination. Stargardt’s disease is a rare disease and currently affects about 25,000 individuals in the United States and causes vision acuity to decrease to between 20/100 and 20/400. Stargardt’s disease is the juvenile form of age-related macular degeneration (AMD) (U.S. National Library of Medicine, 2013). Due to its rareness, the psychosocial aspects of Stargardt’s disease have not been studied. However, studies have suggested that among AMD patients, quality of life is lower than that of those with other chronic diseases, such as obstructive pulmonary disease and AIDS (Williams et al., 1998). Research also shows that about one in three people in the AMD population is plagued with depression, a statistic much higher than that of the sighted population in the United States (Brody et al., 2001; Rovner et al., 2002). The AMD population experiences declines not only in mental health but also in their physical health. Recent research has shown that minimally depressed patients with AMD, who are not clinically diagnosed with depression, experience decrements in visual function that cannot be accounted for by the severity of their eye disease or general medical problems (Rovner et al., 2007).

This study aimed to examine whether EW among patients with Stargardt’s disease could improve general outcomes such as physical and psychological symptoms, stress, and social support, as well as disease-specific health such as vision-relevant quality of life. EW has been shown to decrease psychological distress. In a study of college freshman, EW was produced with a decrease in depressive symptoms at 2 months post-intervention (Sloan et al., 2009). Another investigation found that EW was successful in reducing symptoms of depression and somatic symptoms for the distressed population of parents of children with leukemia (Martino et al., 2013). In Frattaroli’s (2006) meta-analysis, EW was shown to have a significant effect on lowering depressive symptoms, thus making this an ideal population to introduce to EW. We hypothesized that EW would reduce depressive symptoms and improve vision-specific mental health among people with Stargardt’s.

The literature suggests that stress may plague this subset of the low-vision community. More specifically, in a study comparing stress levels of those with AMD to their same-aged, full-vision counterparts, those with AMD had significantly higher daily stress (Davis et al., 1995). Those with AMD and Stargardt’s disease face unique stressors that they often are perceived as a “fraud” because they maintain some vision despite their legally blind status. Their vision does not completely deteriorate, and it seems to others that they can function in the same manner as a person with full vision, thus violating the stereotype that blindness refers to complete blindness. This stereotype violation may lead to increased stress in interacting with others because they may be seen as a fraud (Wong et al., 2004). For example, these individuals do not typically need a seeing-eye dog or a cane to navigate their surroundings, but may not be able to recognize the face of an acquaintance walking down a hallway. It was hypothesized that perceived stress would decrease in the experimental group post-intervention.

One way to manage stress is to have the support of others. Support can come from a variety of sources such as family, friends, colleagues, mentors, and rehabilitation specialists. Those with higher social support also have better adjustment to low vision (Davis et al., 1995; Taylor and Upton, 1988). A study of an older low-vision population found that women and men who have a high level of support from
family and friends have better psychological functioning (McIlvane and Reinhardt, 2001). Reinhardt (1996) found that social support provided by friends and family members is valuable for people who are visually impaired; participants in the study had higher life satisfaction, fewer depressive symptoms, and better adjustment when compared to the visually impaired participants without high social support. An EW study within a breast cancer population found that those in the experimental condition were more satisfied with the emotional support they received compared to participants in the control condition (Gellaitry et al., 2010). Writers may realize that they actually have the support desired, and they may begin to interact more positively with their social support system. Hence, we hypothesized that those in the experimental condition would perceive more social support when compared to the control condition, post-intervention.

Overview and goals of this study

This study examined whether health outcomes associated with Stargardt’s disease improved as a result of an EW intervention. Participants were randomly assigned to write either about a non-emotional control topic or about their most stressful experience with Stargardt’s. The hypotheses for this study are listed in the following:

1. Participants in the intervention condition were expected to report better physical health (improved general health and decreases in illness symptoms) compared to the control condition.
2. Participants in the intervention condition were expected to report improved psychological health (decreases in depressive symptoms and perceived stress as well as increases in vision-specific mental health and social support) compared to participants in the control group.

Method

Participants

This study was approved by the Institutional Review Board at the University of Houston. The eligibility of participants is as follows: all participants were at least 18 years or older, fluent in reading and writing English, and diagnosed with Stargardt’s. Participants were recruited through four methods from October 2011 to April 2012: (1) weekly posts on five international Stargardt’s Facebook support groups, (2) Lighthouse International and 31 local chapters of Foundation Fighting Blindness (both of these large-scale support groups included information about the study in their newsletters), (3) via 136 local support groups for those with low vision (who handed out study information at their meetings), and (4) retina specialists registered with the American Society of Retina Specialists. In total, 399 doctors agreed to email the study’s flyer to their patients or hand the flyer out to Stargardt’s patients who came into their office. All recruitment materials contained a link to the consent form on SurveyMonkey.com. Participants and those who helped in the recruitment process (e.g. research assistants, secretaries at optometrist offices, and Facebook support group correspondents) were told that the study was designed to gain insight into the lives of those with Stargardt’s.

A total of 81 eligible patients agreed to participate in the study and completed baseline measures. They were randomly assigned to the EW intervention ($n = 38$) or the neutral writing conditions ($n = 43$). A total of 48 (59.3%) finished the writing sessions (writers), with 22 in the intervention and 26 in the control group. There were no condition (experimental or control) or demographic differences (i.e. education, gender, marital status, age, and country of residence) between participants who completed the writing sessions and those who discontinued the study. However, those who did not complete the writing task had significantly higher perceived stress at the study baseline compared to writers: $t(71) = 2.49, p = 0.02$. Those who did
not complete the writing task also reported marginally significant higher depressive symptoms at the study baseline compared to writers: \( t(71) = 1.80, p = 0.08 \). This indicates that those who were more depressed and had higher perceived stress were less likely to finish the writing.

Among the 48 participants who completed the writing tasks, 37 (75.5%) participants finished the 3-week follow-up, and 35 (72.9%) completed the 6-week follow-up. There were also no condition, demographic, or individual differences for those who finished the 3- or 6-week follow-up compared to those who did not. Three reminders were sent for each part of the study until the participant completed the section; if the participant did not complete the section after the third reminder, an email was sent asking the reason the participant did not wish to continue the study. Among those who dropped out of the study, four participants responded to that email; three participants responded that the study was too time consuming and one participant responded that they were on vacation without Internet access.

**Procedure**

Once the consent form was electronically signed, participants were emailed the link for the baseline survey through the email contact provided at the time of endorsing the consent form. All future contact with the participant was also conducted via this email address. Participants were able to complete all parts of the study at their own leisure in the privacy of their own home via a secure website, Surveymonkey.com. After completion of the baseline measures, participants were randomized via a random number generator to either the control or the experimental condition.

The control group was instructed to write about their day completely factually with no emotions, while the experimental group members were asked to write about their most stressful Stargardt’s-related experiences and to reveal their deepest emotions without regard for spelling or grammar. Participants wrote for 20 minutes on three separate days during a 1-week period. Immediately following the final writing session, participants filled out the manipulation check to assess how emotional and personal they felt their writings were. Three and 6 weeks after completion of the last writing, participants were emailed the link to the 3- and 6-week follow-up surveys containing the outcome measures below.

**Demographics and outcome measures**

**Demographics.** Participants completed questions designed to assess basic demographic information. Demographic variables included age, gender, ethnicity, education, age of diagnosis, socioeconomic status, visual acuity, and whom they live with.

**Visual Function Questionnaire.** The Visual Function Questionnaire (VFQ) was used to assess how the subjects’ visual functioning affects their daily life using a 6-point Likert scale (Mangione et al., 2001). The VFQ-25 consists of 12 subscales; we chose to use two subscales assessing the General Health (one question, “In general, would you say your overall health is”) and Vision Specific Mental Health (\( \alpha = .76 \)) (four questions, e.g., “I feel frustrated a lot of the time because of my eyesight”) for the study due to their relevance to our hypotheses.

**Perceived Stress Scale.** The Perceived Stress Scale (PSS) includes 14 items (\( \alpha = .88 \)) measured on a 5-point Likert scale (0 = never to 4 = often) (Cohen et al., 1993). Items focus on events in the previous month that may have caused stress for respondents. For example, items include “In the last month, how often have you been upset because of something that happened unexpectedly?” and “In the last month, how often have you felt that things were going your way?”

**Center for Epidemiologic Studies Depression.** The Center for Epidemiologic Studies Depression
(CES-D) Scale is 10 items and was used to measure depression level (Radloff, 1977). A sample item is “I felt that I could not shake off the blues even with help from my family or friends.” Items are measured on a 4-point scale, ranging from “rarely or none of the time (less than 1 day of the week)” to “most or all of the time (5–7 days)” ($\alpha = .79$).

Medical Outcomes Study Social Support Scale. The Medical Outcomes Study (MOS) was used to evaluate subjects’ perceived access to emotional and informational support (eight items, e.g., “You have someone to give you good advice about a crisis”), tangible support (four items, e.g., “You have someone to take you to the doctor if you needed it”) and affectionate support (three items, e.g., “You have someone to love you and make you feel wanted”) (Sherbourne and Stewart, 1991). An additional subscale (three items) evaluates positive social interactions (e.g. “You have someone to do something enjoyable with”) ($\alpha = .96$). The subscales were combined for a total score of which included all 19 items.

Self-reported physical symptoms. This 10-item self-report instrument (Lu and Stanton, 2010) was designed to measure people’s tendency to note and report a broad array of physical symptoms and sensations. Participants indicated how often they experienced 10 acute illness symptoms including headache, coughing, stiff muscles, and sore throat. (This measure was modified from Pennebaker (1982) and King and Emmons (1990).)

Manipulation check

Upon completion of the last writing session, participants were asked about their writing experience. On an 11-point rating scale, participants answered four questions about their feelings regarding their writing and the experiment (Pennebaker et al., 1990). For example, participants rated the extent to which they revealed emotions, felt sad or depressed, and gained more insight from the study.

Writing instructions

Control Condition

In today’s session, I would like for you to write about exactly what you have done today since you woke up this morning, and what you plan to do after you finish the writing. For example, you made breakfast, met your friends at lunch, planned to do some gardening, and so forth. It is important that you describe things exactly as they occurred. In order to do this, your description should be as objective as possible, focusing on specific events rather than on your thoughts or feelings about them. Everything you write is completely anonymous and confidential. The only rule we have is that you write continuously for the entire time in 20 minutes. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out.

Experimental Condition

Over the next three days, I want you to write about your deepest emotions and thoughts about the most upsetting experience in your life with Stargardt’s. You should really let go and explore your feelings and thoughts about it. In your writing, you might tie this experience to your childhood, your relationship with your parents, people you have loved or love now, or even your career. How is this experience related to who you would like to become, who you have been in the past, or who you are now?

Many people have not had a single traumatic experience but all of us have had major conflicts or stressors in our lives and you can write about them as well. You can write about the same issue every day or a series of different issues. Everything you write is completely confidential. The only rule we have is that you must write continuously for the entire time in 20 minutes. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Whatever you choose to write about, however, it is critical that you really let go and explore your very deepest emotions and thoughts.
Results

Sample characteristics

A total of 48 participants completed the writing tasks. Their age ranged from 20 to 71 years (M = 41.67, standard deviation (SD) = 12.58), they were primarily female (68.8%), Caucasian (89.6), college educated (83.4%), and residing in North America (89.2%; the remaining five participants (10.8%) were from Europe). In terms of education, 16.2 percent reported completing high school or trade school, 62.2 percent earned a bachelor’s degree, 16.2 percent were awarded a master’s degree, and 2.7 percent were conferred a doctorate degree (see Table 1).

Preliminary analyses

Preliminary data analyses were conducted in order to examine descriptive analyses of the sample, outliers, distribution of variables, missing data, and to ensure that statistical assumptions were met. To test whether randomization yielded equivalent groups, chi-square analyses were conducted to compare differences in demographic variables across conditions. The results demonstrated that the percentage of participants in each condition did not significantly differ by gender, income, ethnicity, country of residency (American vs. non-American), or any members of the household (e.g. spouse, children, pets) (all ps > .05). t-Test analyses were conducted on the baseline health outcomes. There were no baseline differences for any of the outcome variables.

Independent sample t-tests were performed on the manipulation check items to examine whether there were significant differences in writing due to condition. All the manipulation check items showed significant group differences (p > .001). Consistent with our expectation, the manipulation check indicated that those in the experimental group had more personal writing (M = 8.82, SD = 1.58) than the control (M = 5.61, SD = 2.31) and the experimental group had revealed more emotions (M = 8.78, SD = 1.41) than the control (M = 2.92, SD = 2.05). In addition, the experimental group felt more depressed or sad (M = 4.69, SD = 3.32) than the control (M = 2.50, SD = 1.79), and the experimental group (M = 7.56, SD = 2.62) thought they gained more from the study than the control (M = 4.61, SD = 3.01).

Primary analyses main effects

To test hypothesis 1, those who are in the experimental group would have increased physical health (improved general health and decreases in self-reported physical symptoms), and two
analyses of covariance (ANCOVAs) were conducted for each follow-up. Baseline values of each outcome variable were controlled for as the covariate, experimental conditions served as the independent variable, and the outcome variables (general health and self-reported physical symptoms) at each time point were used as the dependent variables.

At the 3-week follow-up, there was a marginally significant difference in general health between the control and the experimental conditions, \( F(1, 27) = 3.51, p = .07, \eta^2 = .12 \), indicating better general health for those in the experimental condition. There were no significant group differences between the control and the experimental conditions for self-reported physical symptoms at the 3-week follow-up.

At the 6-week follow-up, results supported the hypothesis that the experimental group would have improved general health and decreased self-reported physical symptoms when compared to the control group. The experimental group reported better general health compared with the control group, \( F(1, 22) = 6.088, p = .02, \eta^2 = .22 \). The experimental group reported fewer physical symptoms compared to the control group, \( F(1, 25) = 4.77, p = .04, \eta^2 = .16 \). To test hypothesis 2, those who were in the experimental group would have increased psychological health (increased vision-specific mental health and social support, and decreases in depression and perceived stress), and four ANCOVAs were conducted for each follow-up (see Table 2 for adjusted means, standard error, significance, and effect size at the 3-week follow-up, and Table 3 for the 6-week follow-up values).

As hypothesized, at the 3-week follow-up, vision-specific mental health was significantly higher for the experimental group when compared to the control group, \( F(1, 26) = 6.89, p = .02, \eta^2 = .22 \). Perceived stress for the experimental group was significantly lower than the control group, \( F(1, 26) = 7.60, p = .01, \eta^2 = .23 \). Also, the experimental group had significantly higher perceived social support than those in the control group, \( F(1, 32) = 4.15, p = .05, \eta^2 = .11 \).

At the 6-week follow-up, the difference in vision-specific mental health was only marginally significant when comparing the experimental and control groups, \( F(1, 21), = 3.72, p = .07, \eta^2 = .15 \). There were no significant group differences in perceived stress or social support. There were no group differences in depressive symptoms at the 3- and 6-week follow-ups (see Tables 2 and 3 for results).

**Discussion**

This study was intended to test the effects of EW on both the physical and psychological health of those diagnosed with Stargardt’s, which is the first rare disease population investigated with regard to EW. It was hypothesized that those who wrote about their most stressful experiences and expressed their deepest thoughts and feelings about Stargardt’s would have better psychological and physical health outcomes than those who wrote factually about their day. The findings provide evidence that there are psychological health benefits in vision-specific mental health, perceived stress, and social support at the 3-week follow-up and physical health benefits in general health and self-reported physical symptoms at the 6-week follow-up.

The resulting decrease in physical symptoms (\( \eta^2 = .16 \)) and increase in general health (\( \eta^2 = .22 \)) were higher than expected when compared with the previous literature. Frataroli’s (2006) meta-analysis indicated a moderate effect size for self-reported physical health (\( \eta^2 = .056 \)). However, many of the studies in the meta-analysis were conducted with a healthy sample. The meta-analysis also found that those who have poorer health benefited more from EW compared with healthy individuals. The physical symptoms assessed in this study were common illness symptoms such as running nose or headaches. It is possible that the larger effect size occurred because the present sample may be more predisposed to illness symptoms, such as headaches due to chronic stress and vision strain. Furthermore, the increased psychological distress of living with this rare disease may
make individuals more susceptible to illness (cold, flu, or pain). The finding that physical symptoms improve at 6-week follow-up but not 3-week follow-up is also consistent with the literature that self-reported physical health benefits emerge at later follow-ups (e.g., Stanton et al., 2002). Studies have shown that heighted stress level was associated with more flu symptoms (Cohen and Williamson, 1991). This study showed that at the 3-week follow-up EW reduced stress, which may allow the immune system to function more optimally, thus leading to a reduction in illness symptoms at the 6-week follow-up.

The results for perceived stress decreases at the 3-week follow-up were expected and consistent with Wolitzky-Taylor and Telch (2010), who showed a decrease in perceived stress after an EW intervention. Those who have AMD have been found to have significantly more stress than their same-aged, full-vision counterparts (Davis et al., 1995). Although those with AMD and Stargardt’s are at different stages in life, many of the stressors are similar. Participants often wrote difficulties with others not understanding their condition, consistent with Wong et al. (2004). The impact of EW on stress disappeared at the 6-week follow-up, indicating that the effect of writing might not last long in the realm of stress and frequent writing sessions may be required for lasting benefits. It is also noted that those who had higher stress levels were more likely to drop out from the study. Perhaps the effects of writing

| Table 2. Group differences in outcome variables at the 3-week follow-up. |
|----------------------------------|---------|------|------|------|------|------|------|------|
|                                  | Experimental | Control | Mean | SD | N | Mean | SD | N | F | df | p | η² |
| Self-reported physical symptoms  | 3.69 | 2.05 | 14 | 5.21 | 2.30 | 18 | 1.62 | 1.29 | 0.49 | 0.02 |
| Vision general health            | 69.23 | 20.80 | 13 | 60.29 | 23.48 | 17 | 3.51 | 1.27 | 0.07 | 0.12 |
| Depression                       | 1.82 | 0.60 | 12 | 1.77 | 0.31 | 16 | 0.35 | 1.25 | 0.56 | 0.01 |
| Social support total             | 86.67 | 13.41 | 15 | 71.26 | 23.28 | 20 | 4.15 | 1.32 | 0.05 | 0.11 |
| Perceived stress                 | 1.97 | 0.65 | 13 | 2.6 | 0.54 | 16 | 7.6 | 1.26 | 0.01 | 0.23 |
| Vision-specific mental health    | 57.69 | 28.77 | 13 | 43.33 | 17.75 | 15 | 6.89 | 1.25 | 0.02 | 0.22 |

SD: standard deviation; df: degree of freedom.

| Table 3. Group differences in outcome variables at the 6-week follow-up. |
|----------------------------------|---------|------|------|------|------|------|------|
|                                  | Experimental | Control | Mean | SD | N | Mean | SD | N | F | df | p | η² |
| Self-reported physical symptoms  | 2.63 | 1.86 | 12 | 5.57 | 2.79 | 16 | 4.77 | 1.25 | 0.04 | 0.16 |
| Vision general health            | 70.45 | 18.77 | 11 | 58.93 | 25.21 | 14 | 6.09 | 1.22 | 0.02 | 0.22 |
| Depression                       | 1.84 | 0.52 | 11 | 1.72 | 0.37 | 14 | 0.72 | 1.22 | 0.40 | 0.03 |
| Social support total             | 84.62 | 21.1 | 16 | 71.61 | 22.42 | 19 | 0.71 | 1.32 | 0.41 | 0.02 |
| Perceived stress                 | 1.53 | 0.56 | 12 | 1.7 | 0.30 | 15 | 0.7 | 1.24 | 0.41 | 0.03 |
| Vision-specific mental health    | 54.55 | 24.38 | 11 | 38.94 | 19.62 | 13 | 3.72 | 1.21 | 0.07 | 0.15 |

SD: standard deviation; df: degree of freedom.
would be more pronounced among those with higher levels of stress. This experience may not be unique to the Stargardt’s population and may be applicable to other rare disease populations.

Participants in the experimental group also had an improvement in vision-specific mental health at the 3-week follow-up; this effect lessened at the 6-week follow-up. In their written essays, some participants highlighted some positive things that have come from having Stargardt’s. They mentioned how the loss of sight increased their other senses and skills related to those senses (i.e. knitting better because of a better sense of touch), while others mentioned becoming closer with their friends and loved ones (i.e. having more time with family and loved ones while getting rides and other assistance). Although this is the first EW study specifically looking at vision-specific mental health, similar results in illness-specific mental health were found in those with irritable bowel syndrome with regard to functional bowel disease–related cognition (Halpert et al., 2010).

Despite improvement in physical symptoms and perceived stress, depressive symptoms did not improve due to writing. In fact, in many EW studies, only physical symptoms but not psychological symptoms were improved (Lu and Stanton, 2010; Stanton et al., 2002). Depressive symptomatology in this sample was low to begin with. Participants who volunteered for this study may have had less depressive symptomatology than the Stargardt’s population as a whole. Indicated by the attrition analysis, those who had higher depressive symptoms were more likely to drop out of the study before completing the writings. We cannot rule out the possibility that depression may have improved if those who were depressed participated in the intervention.

Several limitations are worth noting. The study has a relative small sample size. Because Stargardt’s is a rare disease, it was difficult to find those who were eligible for the study. We made significant efforts to recruit participants through multiple venues so that we could have a more representative sample. Despite the lack of monetary compensation, participants volunteered their time and were very enthusiastic about the study.

With many participants being legally blind, taking the surveys may have caused some eye strain and discomfort. It is possible that those who did not complete the writing tasks would have continued if the study materials were on a friendlier medium as reading and writing may have caused further distress. Although many participants openly discuss the use of large screens and text magnifying programs that provide larger font which makes it easier for them to view. Furthermore, many participants were recruited via online support groups and were comfortable using the computer. Future studies may conduct phone interviews for the questionnaires and have the participants write online or with pen and paper.

We have demonstrated in this study that online writing intervention is feasible in this population. Future studies utilizing a pen-and-paper writing and survey method could potentially benefit those who are not computer literate or do not have access to Internet. As Stargardt’s is an ongoing life occurrence, new stressors or disease-related stressful situations occur frequently. Future studies using a more intense or long-term writing intervention may be particularly effective. Many elements of self-concealment arose in the writings (i.e. not wanting to disclose their low vision to their bosses or acquaintances). Previous studies have shown that self-concealment is related to lower needs satisfaction and higher pain (Uysal and Lu, 2011); future studies should investigate the psychological and physical effects of self-concealment among people with Stargardt’s and other rare diseases that could be easily concealed. Self-concealment in this population could lead to an increase in anxiety in social situations. Furthermore, this intervention may be used in conjunction with an existing adjustment program. It is also possible that daily writing might also reduce stress to a greater extent than were demonstrated here, but this needs to be examined in future studies as well.

Possible mechanisms of how EW works still need to be explored with regard to rare disease
populations. It is likely that those with rare diseases may be more likely to suppress their emotions if there is stigma surrounding their illness and if their support system does not understand the emotions or situations that the person is trying to describe. EW may be the ideal outlet by providing the writer with a safe place to express themselves without fear of judgment and to gain clarity.

Differences in writing instructions should also be explored (Murray, 2009). Perhaps writing a short story about a fly on the wall observing an interaction with an individual diagnosed with Stargardt’s and another full vision individual may be beneficial for an individual who feels unhappy with how others interact with them. Possibly, this opportunity to write a story from the fly’s viewpoint could provide perspective and allow the individual with Stargardt’s to see where the other person is coming from. Moreover, as suggested by Nicholls (2009), the sharing of the written Stargardt’s experiences for feedback and insight from other individuals with Stargardt’s has not been explored and could be beneficial. This would allow for individuals to get positive feedback on how a situation has been handled or suggestions on how to handle that situation more effectively if it should arise again.

The study has implications for practice. EW is useful to patients as a safe, cost-effective, and private outlet for their stressors. Despite this sample being all adults, EW has also been shown to be an effective tool for school-age children (Horn et al., 2011) and could be an effective intervention for the many individuals with Stargardt’s who are diagnosed before the age of 18 years. The intervention is easy to engage in at the privacy of the patients’ home and whenever it is convenient for them. Patients do not need to worry about being criticized or misunderstood by others. The intervention is also free as long as the participant has a computer or pen-and-paper handy. If replicated in a larger randomized control trial with more representative sample, vision rehabilitation programs and retina specialists could promote this EW intervention to patients experiencing distress about their disease, illness, or pain.

Acknowledgements
The authors thank Nicole Richardson for her help in collecting these data. Qian Lu was supported by the American Cancer Society (Grant MRSGT-10-011-01-CPPB, Q. Lu, Principal Investigator).

Funding
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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