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## Reported effects of non-traditional treatments and complementary and alternative medicine by retinitis pigmentosa patients

Ava K Kiser, OD and Gislin Dagnelie, PhD

Johns Hopkins University, Wilmer Eye Institute; Lions Vision Center, Baltimore MD, USA

Ava K Kiser: abittne1@jhmi.edu

### Abstract

**Background**—Benefits of complementary and alternative medicine (CAM)-related interventions have been demonstrated for patients with chronic, systemic diseases in which stress, anxiety and disability are prevalent. Subjects with retinitis pigmentosa (RP) commonly indicate that they have ‘good’ and ‘bad’ vision days, stating that stress causes a decrease in vision and that vision improves when the stress is alleviated. We assessed CAM use by RP patients and its perceived effectiveness.

**Methods**—We enquired about nine CAM areas: meditation, mind-body therapies, yoga, movement therapies, energy therapies, acupuncture, massage therapy, spirituality/religion and herbal therapies/aromatherapy. Ninety-six RP patients with any level of vision completed an anonymous internet survey.

**Results**—Ninety-five per cent of respondents tried at least one of the nine CAM areas. Seventy-five per cent have used nutritional supplements, including lutein (47 per cent), bilberry (32), vitamin A palmitate (36) and docosahexaenoic acid (23 per cent). Some tried meditation (47) and yoga (31 per cent). Stress and anxiety levels were reported as improved in 93, 92 and 87 per cent of those who used yoga, meditation and mind-body therapies, respectively. Many of those who tried mind-body therapies (40) or acupuncture (50 per cent), used it with a desire to fight RP. Vision was subjectively affected in 65 per cent of acupuncture users and from 20 to 35 per cent of the users of the other CAM areas. Those who indicated that their vision was affected by at least one type of CAM (35 per cent) were statistically significantly more likely to require magnification to read (that is, they had lost more vision and RP had progressed), than those who did not believe vision was impacted (59 versus 84 per cent).

**Conclusions**—RP patients are using CAM and are experiencing some impact on vision and physical/emotional well-being. Clinicians and researchers should be aware of its use. Clinical trials with CAM interventions are necessary to attempt to validate these findings.

### Keywords

internet survey; low vision; questionnaire; retinitis pigmentosa; stress

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Retinitis pigmentosa (RP) is a leading cause of legal blindness in working-age individuals due to degeneration of retinal photoreceptor cells. RP patients experience night blindness and a slowly progressive loss of vision, which may eventually lead to loss of light

perception. Visual loss in RP is unpredictable, inexorable and forms a continuous threat to patients' independence. As visual loss in RP gradually progresses due to the natural course of the disease, patients lose their ability to perform valued activities, as well as their sense of control and self-confidence, causing them to view themselves and their future negatively. It is not surprising that RP patients, many of whom range in age from 10 to 40 years when diagnosed with this blinding disorder, are at high risk of stress. Negative psychological states, such as anxiety and depression,<sup>1</sup> as well as increased daytime sleepiness and sleep disturbances<sup>2</sup> are also prevalent among RP patients.

Previous work has demonstrated that psychophysical measures of vision are more variable in legally blind RP subjects than in normally sighted individuals.<sup>3</sup> RP subjects commonly indicate that they have 'good' and 'bad' vision days and that stress causes a decrease in vision, which improves when the stress is alleviated.<sup>4</sup> There appear to be no validated or accepted theories to explain the underlying mechanisms for these fluctuations in vision in RP. During a laboratory-induced stress condition, normally-sighted individuals with higher life-event stress experienced much greater decrements and variability in peripheral vision than those with lower life-event stress scores.<sup>5</sup> Real-life stressful situations in normally-sighted subjects produce greater peripheral visual field defects than laboratory-induced situations, which may be due to increased states of anxiety.<sup>6</sup>

Overall, mental effort is one of the factors that may contribute to stress during orientation and mobility in RP patients with reduced visual fields, as they require an increased number of fixations to view the surroundings and each fixation may require increased information processing to identify targets.<sup>7</sup> Increased mental workload, specifically counting and keeping track of auditory tones, caused a 13.6 per cent mean reduction in the Goldmann visual field of normally-sighted subjects.<sup>8</sup> There appear to be no publications evaluating the impact of laboratory-induced stress or increased mental processing on tests of vision in RP subjects.

Complementary and alternative medicine (CAM), as defined by the National Institute of Health's (NIH) National Center for Complementary and Alternative Medicine (NCCAM), is a group of diverse medical and health-care systems, practices and products that are not presently considered to be part of conventional medicine. The benefits of various CAM interventions are being demonstrated for chronic, systemic diseases other than RP.<sup>9</sup> There is good evidence in the literature that the psychological characteristics of a person<sup>10</sup> and the levels of distress may be altered or managed by interventions such as meditation or mind-body techniques.<sup>11</sup> Reported benefits of mindfulness training in depressed and anxious patients include an increased ability to relax, improved mood, greater self-awareness and self-worth, improved sleep and new ways of working with negative thoughts and emotions.<sup>12</sup>

Although the potential for CAM interventions to reduce the deleterious effects of stress on visual function in normally-sighted or visually impaired patients has not been investigated, acupuncture has shown promising results by increasing blood flow to the ocular vasculature<sup>13-15</sup> including the choroid,<sup>16</sup> as well as activating the visual cortex<sup>14,17,18</sup> in normally-sighted subjects. A pilot study involving children with visual impairment due to congenital optic atrophy and cortical causes reported some visual recovery following acupuncture.<sup>19</sup> Acupuncture significantly reduces anxiety compared to sham acupuncture or no acupuncture, during and at the end of cataract surgery performed under topical anaesthesia.<sup>20</sup>

Encouraging results have been observed in patients with epilepsy who showed improved contrast sensitivity following six months of yoga meditation.<sup>21</sup> These results may be

relevant to RP, as patients with epilepsy also show elevated and variable contrast sensitivity thresholds. These authors<sup>21</sup> proposed that contrast sensitivity improved due to the subjects' more relaxed state, decreased stress and better attention, allowing them to be more responsive to the stimuli, suggesting a possible effect on CNS factors underlying perceptual and sensory processing. In another study,<sup>22</sup> practitioners of meditation were able to detect light flashes of shorter duration than non-meditators, suggesting better visual perceptual sensitivity.

Several surgical or semi-invasive procedures and nutritional supplements have gained attention for possible effects on vision in RP. Treatments involving microcurrent stimulation, rheotherapy, hyperbaric oxygen<sup>23</sup> and ozonated blood have been reported by some RP patients to provide limited improvements in vision but there is no scientific proof that such treatments have a lasting effect or lead to slowing of the degeneration process.<sup>24,25</sup> More rational and careful approaches have included supplementation of compounds known to play a signalling or structural role in the retina, namely, vitamin A (or its precursor betacarotene) as the chromophore in rhodopsin,<sup>26</sup> docosahexaenoic acid (DHA) as a structural component of the photoreceptor outer segment membrane<sup>27</sup> and lutein as a protective short wavelength filter in the macular pigment layer and potential anti-oxidant.<sup>28</sup> Results of these trials have been promising but the effects are not entirely clear, partly due to substantial variability even among patients with similar levels of visual loss. Several placebo-controlled studies have evaluated bilberry extract supplementation for night vision among normally-sighted individuals but the most recent randomised controlled trials have not supported a positive effect and data in visually impaired subjects are lacking.<sup>29</sup> Preliminary results *in vitro* have suggested that specific dietary flavonoids may be beneficial for the treatment of patients with macular diseases associated with oxidative stress.<sup>30</sup>

According to a December 2006 survey, 70 per cent of American adults use the internet and 65 per cent use it daily.<sup>31</sup> Devices to assist visually impaired patients to access computers and the internet are being used successfully. They allow low vision patients to interact with others and obtain information. Therefore, it was deemed appropriate to develop a web-based anonymous questionnaire survey to target RP patients through an online internet mailing list forum. We aimed to ascertain whether RP patients are using CAM to in an attempt to relieve stress, anxiety, fatigue and depression, and possibly to reduce variability in their vision. We were also interested in whether these RP patients had tried or were currently using nutritional supplements, as well as other treatment options.

## METHODS

### Data collection

The protocol for the study was approved by the Institutional Review Board (IRB) of the Johns Hopkins University School of Medicine and followed the tenets of the Declaration of Helsinki. Data collection occurred from July 2006 through September 2006. RP patients were targeted through the Retinal Degenerations Mailing list (rplist@listserv.icors.org), an internet forum that is widely known and used by more than 575 subscribers internationally. They were invited to complete the questionnaire with the premise that we were trying to gain an impression of the extent to which RP patients are using various forms of therapy, exercise, diet et cetera and whether they believe such therapies helped their vision and RP status. They were instructed to complete the questionnaire, even if their experience with such therapies was very limited. The instructions stated that we were equally interested in hearing positive and negative experiences, that the questionnaire was anonymous and that it would not ask for identifiable information. The invitation to complete the survey stated that we were looking only for RP patients to respond to the questionnaire. The title of the questionnaire clearly states that is it for retinitis pigmentosa and the first item asks, 'How

long have you been diagnosed with RP?' Although it would have been possible for a patient with a retinal degeneration other than RP to complete the questionnaire, this is unlikely as the RP list has very few subscribers other than those with RP, and a few AMD patients and their caregivers.

Respondents were informed that the proposal to administer this questionnaire through a website had been reviewed by the IRB for Human Subjects Research of the Johns Hopkins University School of Medicine and that permission was granted to conduct this research without obtaining written informed consent from the respondents, as this would void the anonymity of the questionnaire. They were also informed that it would take 10 to 30 minutes to complete the questionnaire, depending on the screen reader or other software being used. The survey was designed to be compatible with JAWS (Freedom Scientific, St Petersburg, FL) screen readers, so those with severely advanced RP were not excluded.

### **Questionnaire development and content**

The survey instrument was modelled on validated questionnaires previously used in published work pertaining to CAM use<sup>32,33</sup> and was modified to apply to RP patients. CAM items on nutritional supplements and other treatments (stimulation or surgical) were included in the survey, if they were reported in the literature as used for RP. The other nine CAM areas were primarily based on definitions found on the website for NCCAM (<http://nccam.nih.gov/>). Our questionnaire included sections on demographics, RP visual status, use of various CAM supplements and therapies, perceived efficacy of CAM, reasons for using CAM, sources of information and potential barriers to CAM usage.

The questionnaire is reproduced in the Appendix. The first page of the questionnaire consisted of 12 items to obtain demographic information. This included an item asking about their current level of vision, which was self-reported by the respondents and therefore may have been based either on their own impressions or their recollections of test results obtained during an eye examination. Subscribers to this mailing list frequently discuss central versus peripheral visual changes and most are very well informed of their current visual status. Participation in the list has spurred many of them to revisit their eye-care practitioners and obtain specific measures of their vision. Demographic items were followed by questions regarding use of nutritional supplements (lutein, DHA, bilberry, vitamin A palmitate, soy flavonoids or other) and other treatments (microcurrent stimulation, rheotherapy, ozone treatments, hyperbaric oxygen treatments, Russian surgery<sup>23</sup> and Cuban surgery<sup>22</sup>). Pages two to 10 of the survey were similar but each asked about one of the nine CAM areas listed in Table 1. Respondents were given the opportunity to read the definitions and examples provided for each of these nine CAM areas, after they were asked how familiar they were with the CAM area and what were their sources of information. The last page of the questionnaire enquired whether respondents were interested in learning more about each of the nine CAM areas and gave them an opportunity to list any comments. The results were included in the analysis only if all 11 pages of the questionnaire were completed.

## **RESULTS**

### **Demographics of respondents**

We obtained complete responses from 96 RP patients and their demographics are listed in Tables 2 and 3. Regarding the highest level of education attained, two per cent had not completed high school, eight per cent had completed high school, 23 per cent completed some college, 38 per cent completed college and 29 per cent completed a graduate or doctoral degree.

## CAM areas

Ninety-one respondents (95 per cent) had tried at least one of the nine CAM areas, while 72 (75 per cent) had used nutritional supplements. Table 4 details how many tried each of the CAM areas, treatments and nutritional supplements. The average number of therapies tried per person was 3.1, when the nine CAM areas were analysed and 5.0 when the nutritional supplements were also included with the nine CAM areas. Figure 1 details how often the respondents used each of the CAM areas and nutritional supplements. Many (45 per cent) responded that they 'currently regularly' practise religion/spirituality, 10 per cent 'currently regularly' use meditation, massage and aromatherapies/herbal therapy, while between four and seven per cent of the respondents 'currently regularly' use each of the other CAM areas. Meditation and aromatherapies/herbal therapy were used a few times by 22 and 21 per cent of patients, respectively, and massage was used a few times by 29 per cent. Some respondents had never heard of movement (70 per cent) or energy (68 per cent) therapies, respectively, followed by 41 per cent who had no knowledge of mind-body therapies. Less than five per cent had never heard of each of the other CAM areas.

One item inquired about the motivations or reasons for using each of the CAM areas and the results are depicted in Figure 2. The respondents were able to select multiple answers and could choose from 'physical well-being', 'emotional well-being', 'might help, can't hurt', 'desire to fight RP' and 'to help with a disease other than RP'. Across each of the CAM areas, over one-half of respondents using CAM did so for physical and emotional well-being, while 63 per cent who tried acupuncture felt that it 'might help, can't hurt'. Mind-body therapies (40 per cent) and acupuncture (50 per cent) were the two CAM areas most associated with a 'desire to fight RP', among those who had tried them. This reason applied to 16 to 35 per cent of those who used the other CAM areas. Percentages for each of the CAM areas are given in the Figure 2.

We found that one-third of respondents practised mind-body therapies and spirituality/religion because they liked the emphasis that CAM places on treating the whole person, while fewer, 10 to 25 per cent, used each of the other CAM modalities for this reason. We also inquired about the use of CAM to help with diseases other than RP and the proportions were 14 per cent who used yoga, 8.5 per cent of those who used massage and six to seven per cent of those who used mind-body therapies, acupuncture, energy therapies and aromatherapies/herbal therapies. None of the respondents indicated that they used movement therapies solely for the purpose of combating diseases other than RP, while only three per cent used meditation and spirituality/religion for other conditions only.

Figure 3 demonstrates the proportion of patients who indicated that negative psychological states or vision were affected by practising CAM. Stress and anxiety levels were impacted in 93, 92 and 87 per cent of those who used yoga, meditation and mind-body therapies, respectively, as well as in 84 per cent of those who used spirituality/religion, 80 per cent of those who tried massage therapies and 78 per cent of those who tried energy and aromatherapies/herbal therapies. Fatigue levels were affected in 38 to 67 per cent of respondents for each of the CAM areas. Most felt that fatigue was affected by practising yoga, aromatherapies/herbal therapies, massage and energy therapies (67, 64, 63 and 61 per cent of respondents, respectively). Seventy-one per cent of patients indicated that depression was affected by practising spirituality/religion. All of the other CAM areas also affected depression in 44 to 63 per cent of respondents. Only five to eight per cent of those who used meditation, yoga and mind-body therapies felt that stress, anxiety, fatigue, depression or vision were not affected by its use.

Vision was subjectively affected in 61 and 36 per cent of users of acupuncture and movement therapies, respectively, as well as one-third of those who used energy and mind-



body therapies. Of the meditation, yoga, spirituality/religion and aromatherapies/herbal therapies users, 21 to 22 per cent felt that vision was affected, while massage affected vision in only 10 per cent.

A subgroup analysis of the 35 per cent of respondents who indicated that their vision was affected by at least one type of CAM revealed that they were more likely to require magnification to read (84 per cent), that is, they had lost more vision and therefore the RP had progressed more, than those who did not believe vision was impacted (59 per cent). This was statistically significant ( $p = 0.013$ ) using Fisher's exact test to compare those who felt that vision was or was not impacted to those who did or did not need magnification to read. An odds ratio calculation found that those who require magnification to read are 3.6 times more likely to report that their vision was impacted by CAM than those who do not use magnification for reading. There were no other significant differences in terms of demographics between the two subgroups.

Table 5 lists the possible barriers to CAM use, with the minimum (least often reported) and maximum (most often reported) CAM areas indicated, as well as the median across all nine CAM areas, for each barrier. Across the nine CAM areas, time was the largest barrier for a median of 32 per cent of respondents, followed by transportation and 'never thought of using it' among a median of 22 per cent of the RP patients. Although massage was the CAM area that most were interested in trying if they had not already, 43 per cent indicated that cost was a barrier. Cost, time and transportation were each only identified by six to nine per cent of respondents as barriers to practising religion/spirituality. Aromatherapy/herbal therapy was most associated with unknown benefits or lack of information by 26 per cent patients, and disbelief that it worked among 11 per cent of respondents. Acupuncture was most associated with possible risks or discomfort by 14 per cent of respondents. The barriers of time, transportation and cost would be anticipated, however, it was interesting that across all nine CAM areas, between 19 and 30 per cent of the respondents indicated that they had never thought of using CAM. These findings indicate that not all RP patients are aware of CAM. The strongest scepticism was expressed towards aromatherapy/herbal therapies (11 per cent did not believe it worked; 26 per cent had lack of information or were not certain of its benefits), along with some worry expressed about the risks or discomfort associated with acupuncture among 14 per cent.

Of the respondents who had never tried a particular type of CAM, 36 to 51 per cent indicated that they were somewhat interested in trying one, except for religion/spirituality, which only 15 per cent were somewhat interested in using. Twelve to 20 per cent of those who had never tried a CAM area stated that they would 'yes, definitely' try the CAM area, except for massage therapy, which 37 per cent were definitely willing to try.

The media, followed closely by friends, were the two most commonly reported sources of information for all CAM areas, except religion/spirituality, energy and massage therapies. Of those who had some knowledge about yoga and acupuncture, from 63 to 64 per cent had acquired their information at least in part from the media. Family, followed closely by friends, were the most common sources for information regarding religion/spirituality. Massage therapy practitioners and friends were the top, equally reported sources of information regarding massage by 54 per cent. Physicians were infrequently reported as a source of information, namely, by 23 and 13 per cent of those who had some knowledge of acupuncture and massage, respectively, and by less than 10 per cent for each of the other CAM areas. The internet was moderately used as a source for information, by 27 to 29 per cent of those who had some knowledge about meditation, yoga, acupuncture and aromatherapies/herbal therapies and by eight to 18 per cent of those with knowledge about the other CAM areas. When asked whether the respondents were interested in learning more

about each of the CAM areas, the answers were typically evenly distributed across 'yes', 'somewhat' and 'no', with approximately one-third of the responses for each of the answers. The two CAM areas that fell out of this trend were acupuncture, with 21 per cent stating 'yes' and 44 per cent indicating 'no', and religion/spirituality with 22 per cent stating 'yes' and 57 per cent indicating 'no'.

## DISCUSSION

The present study appears to be the first report of non-traditional treatments and CAM use specifically among RP patients. The demographics of the patients in terms of age, level of vision and time since diagnosis are of some interest. Although most literature, including data for the general US population,<sup>34</sup> suggests that the typical CAM user is female and better educated, not all surveys found a trend toward increased CAM use among that demographic.<sup>35</sup> Our findings did not support a gender-related predilection. The respondents who believed that vision was impacted by CAM tended to have lower levels of vision. One hypothesis to explain this finding is that when vision decreases to a level where magnification is required, reading and functioning become more stressful and CAM may help alleviate stress.

A strength of the study is that CAM was clearly defined for each of the nine areas, which should have helped minimise interpretation bias. For the nutritional supplements, alternative names or specific definitions were not given (for example, fish oil for DHA), although there was a blank for the respondents to indicate other supplements. Two respondents indicated use of Omega 3 but did not select DHA, so these responses were counted for DHA. The level of information among list subscribers is much higher than among 'average' RP patients, due to recurrent and intensive discussions of nutritional supplements and other topics and therefore, we anticipated that they would be familiar with the terms we used.

One of the limitations of our study is a potential sampling bias, as the RP patients were all members of the web-based mailing list who volunteered to complete the survey. Although we specified that we wanted input from those with any level of experience, as well as positive and negative thoughts on CAM, it may not be valid to generalise to all RP patients, as those volunteering to complete a survey may be more interested in the topic and in sharing their experiences. Web-based surveys have been administered to the participants of cancer-related mailing lists, to obtain information regarding perceptions about cancer-related mailing lists and how they are used.<sup>36</sup> A respondent rate of 21 per cent was obtained with the online surveys of cancer patients, which is similar to our respondent rate of 17 per cent.

We are unable to make direct comparisons between our survey and other population-based surveys evaluating CAM use for other chronic disabling diseases or among the general US population. The data collection methods differ in that no other surveys have been administered via a web-based mailing list and there was a possible selection bias in this study.

Web-based mailing list participants may be more informed or willing to seek alternative treatments, as they are actively engaged in discussing their condition and learning more about possible treatments. Therefore, it is not surprising that we found a high prevalence in the use of the nine CAM areas, which may indicate that the RP patients surveyed tended to be open to learning new behaviour, philosophies and health beliefs. The high average number of CAM therapies tried per person in our survey is similar to the average number of CAM areas used by US cancer patients.<sup>37</sup>

One weakness of this study is that the subjects were not asked whether vision improved or worsened during use of the alternative therapies. Given that 35 per cent of respondents felt

that vision was impacted by CAM, future surveys should ascertain which aspects of vision are affected (acuity, contrast, visual field et cetera), the duration of visual change, whether respondents believe that variations in vision or progression of RP were altered and if the vision was affected positively or negatively. The relatively small sample obtained from the web-based mailing list may have precluded us from obtaining more information to better classify the effects of CAM therapies with a low incidence of use.

The main sources of information for most of the CAM areas included the media and friends, confirming other reports among head, neck and lung cancer patients.<sup>33,38</sup> These sources suggest that patients may not be receiving accurate and appropriate information. It is also surprising that given the method of administration of the survey, the internet was used only by a minority for information about CAM. Physicians played only a small role as providers of CAM information, however, they could play a much larger role in this area. Presently, this may be challenging as there appears to be no research linking CAM use to visual outcomes or to the alleviation of negative psychological states among retinal degeneration patients.

There is ample evidence linking CAM use with reduction of negative mood states, stress, anxiety, depression and fatigue for other types of chronic, disabling diseases. Our findings indicate that only a minimal proportion of patients did not feel that these areas were impacted by CAM use. This suggests that CAM met the patients' expectations in terms of the potential to improve physical and emotional well-being. Clinicians are advised to consult published, peer-reviewed sources about CAM or selective good quality web-based information ([www.nccam.nih.gov](http://www.nccam.nih.gov)), to increase their knowledge about CAM and respond to patients' enquiries. During low vision evaluations, obtaining a thorough history, including negative mood states and CAM use, would facilitate communication between eye-care professionals and these patients.

## CONCLUSIONS

Many RP patients have tried complementary and alternative medicines or are interested in trying them. Across several CAM areas, stress and anxiety are subjectively affected for most, followed by fatigue and depression and vision in some of the respondents. Clinicians and researchers should be aware of the use of these therapies. When educating RP patients about CAM, it is important to consider and address the barriers to participation identified in this study. Clinical trials involving CAM interventions are urgently needed to attempt to validate the survey's results indicating some potential beneficial impact on vision, as well as physical and emotional well-being.

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## Appendix

### Welcome to the complementary and alternative medicine (CAM)

#### How long have you been diagnosed with RP?

- 0–5 years
- 5–10 years
- 10–20 years

- 20–30 years
- 30+ years

**What is your level of vision?**

- bare to no light perception
- I can see some forms and objects, but it is very difficult to read
- I can read with magnification
- I can read most things without magnification
- My central vision is 20/20 but have lost some of my peripheral vision

**What is your type of vision loss?**

- peripheral or side vision loss only
- peripheral or side vision loss first and then central loss later
- central vision loss first, then peripheral or side vision loss later
- only central vision loss

**What is your age?**

- under 18
- 18–30 years
- 30–40 years
- 40–50 years
- 50–60 years
- 60+ years

**What is your gender?**

- male
- female

**What is your ethnicity?**

- Caucasian
- African-American
- Hispanic
- Asian
- Mixed

**What is your marital status?**

- single
- married/living with partner
- separated or divorced or widowed

**What best describes your living situation?**

- alone

- with family
- with friends

**What is your geographic location?**

- United States, Northeast
- United States, South
- United States, Midwest
- United States, West
- Canada
- Latin America/Caribbean
- Europe
- Asia
- Africa
- Australia/New Zealand

**How would you describe the area in which you reside?**

- major metropolitan area
- medium-sized city
- rural

**What is your education level?**

- did not complete high school
- completed high school
- some college
- completed college
- completed graduate or doctoral degree

**What is your household income?**

- less than \$20,000
- \$20,000 to \$50,000
- \$50,000 to \$100,000
- above \$100,000

**What is your current general health status?**

- excellent
- very good
- good
- fair
- poor

**Do you take, or have you previously taken, any of the following supplements? Mark dosage if possible (choose all that apply)**

Currently/Briefly in past/For years, past/Off and on/Interested in trying

- multivitamin
- lutein
- DHA
- bilberry
- soy flavonoids
- other (specify)

**Are you currently undergoing, or have you previously received any of the following treatments? (choose all that apply)**

Currently/Briefly in past/For years, past/Off and on/Interested in trying

- microcurrent stimulation
- rheotherapy
- ozone treatments
- hyperbaric oxygen treatments
- Russian surgery
- Cuban surgery

**Each of the 9 areas of CAM listed in Table 1 were inserted in ‘...’ in the questionnaire items below:**

**A. How familiar are you with ...**

- I have never heard of it
- I have heard of it, but am not sure what it is
- I have some knowledge about what it is
- I have a lot of knowledge about what it is

**B. What are your sources of information about ... ? (select all that apply)**

- friends
- family
- the media
- a physician
- ... practitioners
- the Internet
- religious groups
- personal knowledge
- other patients who used it

**C. (give definition and examples of ... for item C here)**

**How often do you engage in ...**

- I have never tried it
- I have tried it once
- I have tried it a few times but do not practise it regularly
- I used to practise it regularly in the past but no longer do
- I currently practise it regularly

**C1. (if they answer item C with ‘I used to practise it regularly in the past but no longer do’ or ‘I currently practise it regularly’)**

**How often is ‘regularly’?**

- daily
- few times a week
- few times a month
- every few months

**C1a. (if they have tried it at least a few times or practise regularly)**

**What are your motivations or reasons for using ...? (choose all that apply)**

- to improve physical well-being
- to improve emotional well-being, provide hope and increase optimism
- ‘might help, can’t hurt’
- desire to do everything possible to fight RP
- emphasis CAM places on treating the whole person
- to help with a chronic disease other than RP

**C1b. (if they have tried it at least a few times or practise regularly)**

**Do you believe that practising ... affects your: (choose all that apply)**

- vision
- stress or anxiety levels
- fatigue levels
- depression levels
- I do not believe that ... affects any of these levels

**C1c. (if they select stress, anxiety, fatigue, or depression from item C1b)**

**How much is your (insert psychological factor) affected by practising ...?**

- only a little bit or somewhat
- a moderate amount
- significant or large impact

**C2. (if answer to item C is that they have tried it but don’t practise regularly)**

**Are you interested in practising ... more often?**



- no
- somewhat
- yes

**C3. (if answer to item C is that they've never tried it)**

**Are you interested in trying ...?**

- no
- somewhat
- yes

**D. (to everyone)**

**Do you think there are any negative or harmful effects from practising ...?**

- none
- some possible
- some known
- many possible
- many known

**D1. (if they answer with anything other than none in item D)**

**Are the negative effects based on:**

- your experiences
- experiences of someone you know personally
- what you have heard or read from the media or other sources
- just my opinion

**E. (to everyone)**

**What are the barriers to your participation in ... (choose all that apply)**

- cost/too expensive
- transportation
- time
- unknown benefits (lack of information about ...)
- do not believe it works
- possible risks or discomfort
- other health problems
- don't know where to access it
- never thought of ...
- discouraged by others (family or friends or physician)
- none

**F. (to everyone)**

**Have you used your health insurance coverage to pay for any of the areas of CAM in the previous questions?**

- yes (please list type[s] of CAM used and covered by insurance)
- no

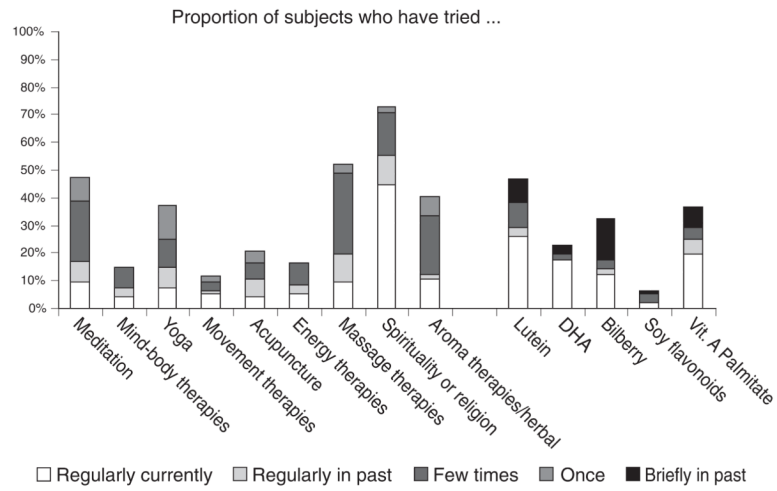
**G. (to everyone)**

**Are you interested in learning more about:**

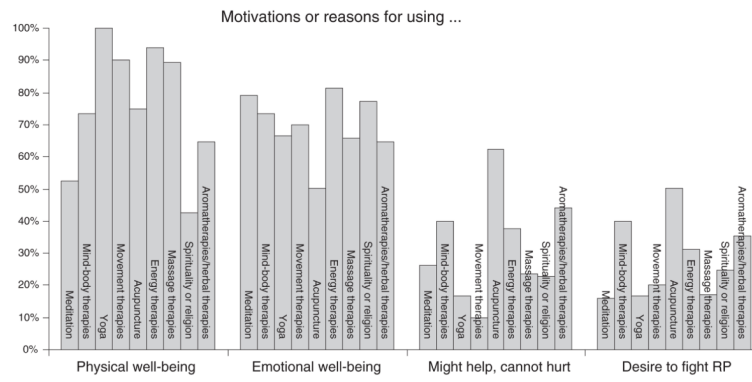
No Somewhat Yes, definitely

- meditation
- mind-body therapies
- yoga
- movement therapies
- acupuncture
- energy therapies
- massage therapies
- religious or spiritual
- herbal therapies/aromatherapy

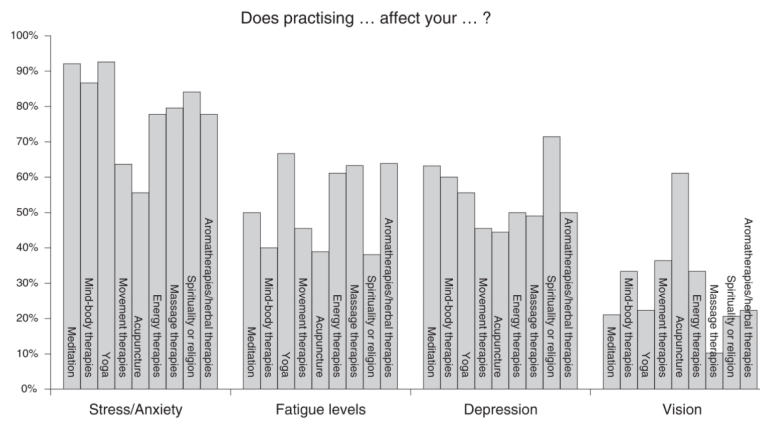
The following is a link to the website of the National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health (NIH):  
<http://nccam.nih.gov/>



**Figure 1.** Proportion of patients who have used each of the nine CAM areas, subdivided by frequency of CAM or nutritional supplement use



**Figure 2.** Proportion of patients indicating their motivations or reasons for using each of the nine CAM areas, among respondents who had tried the CAM modality



**Figure 3.** Proportion of patients indicating that negative psychological states or vision were affected by practising CAM, among respondents who had tried the CAM modality

**Table 1**

## Definitions of the nine CAM areas used in the questionnaire

<p><b>Nine CAM areas</b></p> <p><b>Meditation</b></p> <p><i>Definition:</i> In meditation, a person learns to focus his attention and suspend the stream of thoughts that normally occupy the mind. This practice is believed to result in a state of greater physical relaxation, mental calmness and psychological balance.</p> <p><b>Mind-body therapies</b></p> <p><i>Examples:</i> imagery, visualisation, special breathing techniques, relaxation techniques</p> <p><i>Definition:</i> Mind-body medicine focuses on the interactions among the brain, mind, body and behaviour, and the powerful ways in which emotional, mental, social, spiritual and behavioural factors can directly affect health.</p> <p><b>Yoga</b></p> <p><i>Examples:</i> Vinyasa, Hatha, Power, Ashtanga, Bikram, Hot yoga, Dahn</p> <p><i>Definition:</i> A system of exercises practised to promote control of the body and mind through various postures, breathing and meditation.</p> <p><b>Movement therapies</b></p> <p><i>Examples:</i> tai chi, qi gong, Feldenkrais method ('Awareness through movement'), Alexander movement techniques, Trager approach ('Mentastics').</p> <p><i>Definitions:</i></p> <ul style="list-style-type: none"> <li>• <i>Alexander technique:</i> Patient education/guidance in ways to improve posture and movement, and to use muscles efficiently.</li> <li>• <i>Feldenkrais method:</i> Group classes and hands-on lessons designed to improve the coordination of the whole person in comfortable, effective and intelligent movement.</li> <li>• <i>Trager bodywork:</i> Slight rocking and shaking of the patient's trunk and limbs in a rhythmic fashion.</li> </ul> <p><b>Energy therapies</b></p> <p><i>Examples:</i> acupuncture, biofeedback, cranio-sacral therapy, hypnosis, polarity, reflexology, reiki, zero balancing, therapeutic touch</p> <p><i>Definition:</i> Therapies involving energy fields are based on the concept that human beings are infused with a subtle form of energy. Vital energy is believed to flow throughout the material human body but it has not been unequivocally measured by means of conventional instrumentation. Nonetheless, therapists claim that they can work with this subtle energy, see it with their own eyes and use it to effect changes in the physical body and influence health.</p> <p><b>Acupuncture</b></p> <p><i>Definition:</i> The term acupuncture describes a family of procedures involving stimulation of anatomical points on the body by penetrating the skin with thin, solid, metallic needles that are manipulated by the hands or by electrical stimulation.</p> <p><b>Massage therapy</b></p> <p><i>Definition:</i> Assortment of techniques involving manipulation of the soft tissues of the body through pressure and movement.</p> <p><b>Spirituality/Religion</b></p> <p><i>Definition:</i> To utter or address a prayer or prayers to God, a deity or another object of worship. Having or showing belief in and reverence for God or the supernatural.</p> <p><b>Herbal therapies/Aromatherapy</b></p> <p><i>Definition:</i> A type of dietary supplement that contains herbs either singly or in mixtures (as in tea) ingested or inhaled for relaxation. An herb (also called a botanical) is a plant or plant part used for its scent, flavour and/or therapeutic properties.</p>
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**Table 2**

Demographics of the questionnaire respondents

<b>Demographics</b>						
RP diagnosis	15%: 0–5 yrs	16%: 5–10 yrs	25%: 10–20 yrs	27%: 20–30 yrs	17%: >30 yrs	
Age	3%: <18 yrs	5%: 19–30 yrs	22%: 30–40 yrs	27%: 40–50 yrs	27%: 50–60 yrs	16%: >60 yrs
General health	26% excellent	36% very good	27% good	7% fair	2% poor	
Income	13%: <\$20,000	35%: \$20–50,000	32%: \$50–100,000	20%: >\$100,000		
Gender	52% female	48% male				
Ethnicity	89% Caucasian	4% Asian		7% Hispanic or mixed		
Country	65% USA	19% Australia/New Zealand		16% other countries		
Location/Area	16% rural area	31% medium-sized city		53% major metropolitan area		
Living situation	21% alone	77% with family		2% with friends		
Marital status	22% single	65% married or living with partner		13% separated, divorced or widowed		

**Table 3**

The level of vision reported by the questionnaire respondents

<b>Level of vision</b>
3% with bare to no light perception
6% could see some light and objects but said it was very difficult to read
19% could read with magnification
29% could read most things without magnification
13% could still read with some difficulty but had lost some central and/or peripheral vision
30% had 6/6 central vision with correction but had lost some peripheral vision

**Table 4**

The numbers and proportions of questionnaire respondents who have tried or used nutritional supplements, non-traditional treatments or CAM

Have you ever tried or used ...?	No.	Proportion (%)
Any nutritional supplement	72	75.0
Lutein	45	46.9
DHA	22	22.9
Bilberry	31	32.3
Soy flavonoids	5	5.2
Vitamin A palmitate	35	36.5
Microcurrent stimulation	5	5.2
Rheotherapy	0	0.0
Ozone treatments	2	2.1
Hyperbaric oxygen treatments	0	0.0
Russian surgery	1	1.0
Cuban surgery	2	2.1
Any of the nine CAM areas	91	94.8
Meditation	45	46.9
Mind-body therapies	17	16.7
Yoga	30	31.3
Movement therapies	16	15.6
Acupuncture	21	20.8
Energy therapies	19	18.8
Massage therapies	51	53.1
Spirituality/religion	71	74.0
Aromatherapies/herbal therapy	40	41.7

**Table 5**

The proportion of questionnaire respondents who indicated the following barriers to CAM utilisation, with the minimum (least often reported) and maximum (most often reported) CAM areas indicated for each barrier, as well as the median across all nine CAM areas

	<b>Minimum CAM area</b>	<b>Maximum CAM area</b>	<b>Median</b>
Cost/too expensive	6% Spirituality/religion	43% Massage therapies	15%
Transportation	8% Spirituality/religion	32% Yoga	22%
Time	9% Spirituality/religion	42% Mind-body therapies	32%
Unknown benefits (lack of info.)	8% Massage therapies	26% Aromatherapies/herbal	19%
Do not believe it works	2% Mind-body therapies	11% Aromatherapies/herbal	4%
Possible risks or discomfort	1% Spirituality/religion; massage	14% Acupuncture	3%
Don't know where to access it	0% Energy therapies	11% Mind-body therapies	3%
Never thought of ...	19% Massage therapies	30% Spirituality/religion	22%
None	0% Movement; energy; massage	11% Meditation	1%