

# Prepared Patients: Internet Information Seeking by New Rheumatology Patients

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**Objective.** To investigate to what extent and why new rheumatology patients access medical information online prior to first appointments and secondarily to ask whether they discuss information gained from the Internet with physicians.

**Methods.** Research was conducted in a teaching rheumatology clinic with a nonrandom sample of 120 English-speaking adults presenting for first appointments in rheumatology. Quantitative and qualitative data were gained in pre- and postappointment patient surveys and interviews, including online information gathering prior to first appointment, demographics, health status, information usage in patient-physician interactions, and satisfaction. Data were analyzed for significant relationships across variables and for qualitative insights into quantitative outcome measures.

**Results.** Of all patients, 87.5% looked up their symptoms or suspected condition prior to their first appointment and 62.5% of all patients sought that information on the Internet. Only 20% of online information seekers discussed that information with their physicians. Age and sex were significant predictors of Internet information seeking. Physician and patient appointment satisfaction was significantly higher when Internet information was discussed; however, most patients did not discuss their information seeking because they primarily feared being perceived as challenging their physician.

**Conclusion.** The majority of patients research their conditions online prior to initial appointments, but are unlikely to discuss that research with physicians even though discussion is related to higher satisfaction. Physicians may want to consider strategies for enabling communication about online research.

## INTRODUCTION

The Internet is an important resource for patient information. Studies in Scotland (1), Korea (2), Germany (3), The Netherlands (4), and a comparative study in Cyprus, Greece, and Britain (5) have shown that between 5% and 45% of rheumatology patients report Internet usage. Of those that use the Internet, a maximum of 55.8% search for

medical information. Studies using the Internet to collect data have gained insight into the kinds of Web sites frequented (6) and information quality (7), but little is known about which rheumatology patients in the US are going online, why, and whether they are discussing online health information (OHI) with physicians.

In American patient populations (not rheumatology specific), survey estimates of Internet information seeking vary from 25% to 53% (8–12). In the general population, a repeated study found that the percentage of people who seek OHI has stabilized to 63% in 2002, 66% in 2004, and 64% in 2006 (13). Demographically, OHI seekers tend to be women in stable relationships with higher incomes and levels of education (8–10,14–19). The association with age is more contentious, with some studies associating it with youth (15), others with middle age (14,18), and some suggesting that older adults seek OHI (20) at rates equal to those of adolescents (21). There are also indications that health status is associated with OHI research. Although 1 nonpatient survey found that people who self-reported being in good or excellent health were more likely to seek OHI (22), other surveys have found that people who have 1 or more of 5 chronic conditions (diabetes, hypertension, cancer, heart problems, and depression) (23) or self-report fair or poor health (24) use the Internet more than their

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healthier counterparts (25). Among rheumatology patients, going online has been associated with youth (1–3,5), marriage (1), employment (1,2), wealth (2), and education (2,3,5); health status has not been studied.

Whereas most studies rely on patient surveys, 1 survey queried physicians, most of whom reported that <20% of patients had ever mentioned OHI (12). General population surveys report higher figures of 33% (13) to 41% (8). Given the higher percentages of online research and reporting according to patient studies, there may be a discrepancy between the amount of OHI seeking patients do and the amount that they communicate to physicians (26).

A few studies explored patterns of OHI in relevant contexts in relation to appointments. In a general population survey, only 27% of those surveyed had sought OHI prior to an appointment (27). One study queried patients at primary care clinics and found that 13% sought OHI before the appointment as opposed to 43% after an appointment; 45% did not seek OHI in relation to appointments (11). These low figures imply that people seek OHI at lower rates prior to appointments than they do at other times.

Few studies have explored patients' reasons for seeking OHI. In The Netherlands, rheumatology patients reported going online to "seek information," with fewer looking for "mutual support" and "care provider contact" (4). Others suggest that people seek OHI because it is accessible, fast, and free (21,28). There are also indications that patients avoid seeking medical information, online or otherwise, and prefer to trust physicians (29).

Therefore, from the literature we would expect fewer than 27–45% of rheumatology patients to go online prior to appointments and that they would do so to seek information. The present study offers both quantitative and qualitative data to examine which patients seek OHI, why they do so, and which patients voice that information during consultations. It contributes to understanding the behavior of rheumatology patients at initial appointments and potentially improving clinical interactions in the Internet age.

## PATIENTS AND METHODS

This study was part of a larger study on how patient access to OHI shapes clinical interactions and illness experiences. It was approved by the University of California at Los Angeles Internal Review Board with additional protection provided by a Certificate of Confidentiality from the US Department of Health and Human Services.

**Participant recruitment.** All new patients of the 8 participating rheumatologists in 2 tertiary clinics in Los Angeles were recruited through flyers from December 2003 to December 2004 and were screened for conversational fluency in English. A total of 175 patients were invited to participate; 54 declined. The dominant reason for declining was discomfort at being audio recorded; confidentiality regulations did not permit gathering data on nonparticipants. The 121 subjects were opportunistically recruited from all patients new to the rheumatology clinic

and were a nonrandom sample. One child (age <10 years) was excluded; the remaining 120 subjects were  $\geq 17$  years of age.

**Data collection.** Immediately prior to appointments, open-ended interviews were conducted with patients, asking "Have you done any reading or research about the condition that brought you here today?" Information seeking was considered "before" the appointment if the patient connected it with the appointment; patients answered no to this question in spite of previous research mentioned later in the interview if they did not associate it with the appointment. If answered affirmatively, followup questions included 1) when the information seeking was done, 2) how much time was spent, and 3) what sources were used. Detailed notes were taken during interviews, including verbatim transcripts of short statements. Quotations were either written word for word or paraphrased without change to the meaning of the original statement.

Patient diagnoses were gathered at first or followup appointments to determine whether diagnosis was related to information-seeking behavior. All patients completed the Wong-Baker Faces Pain scale, a valid and reliable pain scale for use among diverse ethnic and age populations (30–34). This scale depicts faces from a no-distress anchor to an image representing unbearable or worst possible pain. Subjects gave 3 ratings (on a 0–10 scale) of current pain, the worst pain level in the previous 2 weeks, and the best pain level in the previous 2 weeks. Patients completed the Medical Outcomes Study Short Form 36 (35–37) and a scale on helplessness (38) as part of the parent study, although often not at first appointments, and these were not analyzed here. Physician-patient consultations were audio recorded and timed from entrance to exit of the clinician. Physicians were asked not to initiate discussions about online information. After appointments, patients completed a 3-item satisfaction scale and were asked whether they had mentioned any OHI to the physician. Physicians completed a 3-item measure of physician satisfaction, whether the patient mentioned OHI, and a global evaluation of patient physical well-being: good/improving, good/stable, poor/stable, or poor/declining. Reports that patients had discussed OHI during consultations were confirmed by audio recordings. These methods were repeated at any subsequent appointments through July 2005. Due to space constraints, we reported only the data on OHI seeking prior to initial appointments and whether patients brought up that information during consultations.

**Statistical analysis.** We examined the population data for significant correlations between demographic variables, health status, appointment length, diagnosis, satisfaction, and OHI. Appropriate statistics were calculated depending on the nature of the variables. For normally distributed continuous data, Pearson's correlation coefficients were calculated, and for ordinal or non-normally distributed variables, Spearman's correlation coefficients or chi-square statistics were calculated. Continuous variables with significant associations, specifically age and pain, were grouped based on numeric distribution for each

Table 1. Demographic results and online information seeking

Variable	Sample, no. (%) (n = 120)	Online information seeking, no. (%)*
Sex		
Women	92 (76.6)	62 (67.4)
Men	28 (23.3)	13 (46.4)
Age, years		
17–39	36 (30.0)	22 (61.1)
40–49	32 (26.7)	29 (90.6)
≥50	52 (43.3)	24 (46.2)
Marital status		
Married/living with partner	61 (51.7)	42 (68.9)
Single, divorced, widowed	59 (49.2)	33 (55.9)
Household income†		
<\$40,000	40 (35.4)	26 (65.0)
\$40,000–\$100,000	44 (38.9)	28 (63.6)
≥\$100,000	29 (25.7)	18 (62.1)
Education‡		
At least high school diploma	19 (17.0)	11 (57.9)
Some or complete 4-year college	80 (71.4)	54 (67.5)
Graduate/postdoctoral education	13 (11.6)	6 (46.2)
Diagnosis§		
Rheumatoid arthritis	22 (18.3)	10 (45.5)
Systemic sclerosis	21 (17.6)	17 (81.0)
Systemic lupus erythematosus	13 (10.8)	10 (76.9)
Osteoarthritis	12 (10.0)	6 (50.0)
Undifferentiated connective tissue	5 (4.2)	3 (60.0)
Miscellaneous autoimmune disease¶	20 (16.7)	12 (60.0)
Miscellaneous nonautoimmune disease#	25 (20.8)	16 (64.0)

\* Percent within category of patients who sought medical information online.  
† Data not available for 7 subjects.  
‡ Data not available for 8 subjects.  
§ Data not available for 2 subjects.  
¶ Includes primary rheumatic diagnoses of polymyositis (n = 3), psoriatic arthritis (n = 2), ankylosing spondylitis (n = 2), polychondritis (n = 1), dermatomyositis (n = 1), retinochoroidopathy (n = 1), ulcerative colitis (n = 1), Wegener's granulomatosis (n = 2), Raynaud's syndrome (n = 1), antiphospholipid syndrome (n = 2), sarcoidosis (n = 1), Hashimoto thyroiditis (n = 1), and Sjögren's syndrome (n = 2).  
# Includes primary diagnoses of fibromyalgia (n = 6), tendinitis (n = 3), carpal tunnel (n = 2), osteopenia (n = 1), osteoporosis (n = 2), pericarditis (n = 1), lymphoma (n = 1), gout (n = 1), bursitis (n = 1), spinal misalignment (n = 1), reactive arthritis (n = 1), and muscular overuse soreness (n = 5).

variable to create approximately equivalent groups in order to run logistic regressions in a forward stepwise method based on the Wald's test predicting for Internet use. Significance was interpreted as proposed by Franzblau (39). Statistical analyses were performed using SPSS software, version 11 (SPSS, Chicago, IL).

**Qualitative data.** Using HyperResearch 2.6 (ResearchWare, Randolph, MA), the data were independently reviewed and coded for recurrent patterns by 2 of the anthropologists on the team. Any discrepancy in coding required joint review of the patient file and creation of new codes if consensus could not be reached. Consequent to the quantitative findings, the qualitative data were sorted into relevant categories and analyzed for patterns in each quantitative category.

## RESULTS

**Quantitative results. Population description.** The demographics of the 120 participating patients are shown in

Table 1. In summary, the majority of patients were women and were married or living with a significant other, mean age 43.7 years, mean household income \$40,000–\$60,000, and mean education was some college training, which are similar to the rheumatic patient demographics of other studies in tertiary clinics in the Los Angeles area (40–42) and the income demographics of Los Angeles County (43). The 8 physicians (age range 30–60 years; 3 women) were board-certified rheumatologists who saw patients between 1 and 4 half-days per week.

**Patients' use of the Internet.** A total of 105 (87.5%) participants gathered medical information prior to their initial visit. Of these patients, 24 (22.8%) only sought information from non-Internet media (e.g., magazines, books, television) or from family and friends. The remaining 81 participants obtained information from the Internet, 75 (92.6%) of whom went online themselves. Sixty-nine of these 75 patients looked exclusively for OHI. Given that the amount of information shared between family members is unknown, only those patients who went online themselves were included in the statistical analyses.

Bivariate relationships with OHI and independent vari-

Table 2. Logistic regression results predicting Internet usage

Variable	B	SEM	Wald statistic	df	Significance	Exp (B)
Age*			10.237	2	0.006	
Group 1 (17–39 years)	−0.571	0.486	1.381	1	0.240	0.565
Group 2 (40–49 years)	1.323	0.627	4.448	1	0.035	3.754
Sex†	−1.112	0.493	5.082	1	0.024	0.329
Constant	0.621	0.397	2.449	1	0.118	1.861

\* Age was divided into 3 groups: 17–39, 40–49, ≥50 years.  
† Sex was coded as 1 = women and 0 = men.

ables, including demographics, reported pain, physician global assessment, patient and physician satisfaction, length of appointment, and type of rheumatic disease, were independently examined. The only variables showing significance were sex ( $\chi^2(1) = 4.025$ ,  $P < 0.05$ ), continuous variables of age ( $\chi^2(2) = 16.76$ ,  $P < 0.001$ ), and worst pain ( $\chi^2(7) = 15.72$ ,  $P < 0.05$ ). Women were more likely to report going online than men (67.4% versus 46.4%).

Logistic regression analysis was conducted to identify significant predictors of patient OHI seeking prior to appointments. Three independent variables were examined: patient age (3 groups), patient sex (2 groups), and reported pain (3 groups). A model predicting OHI seeking by patient age and sex emerged as significant ( $\chi^2(3) = 17.42$ ,  $P < 0.001$ ) (Table 2). Patients age 40–49 years (90.6%) were significantly more likely to seek OHI than any other age group (Figure 1). Women (67.4%) were also more likely to seek OHI.

*The Internet and physician-patient interaction.* Only 15 (20%) patients discussed OHI they had gathered with their physician. These patients were not significantly different from the total subject population in terms of demographics, physician health assessment, length of appointment, or type of disease, nor were these associated with the sex or age of the physician. However, bivariate correlations showed that patients with higher reported pain were significantly less likely to discuss OHI with the physician

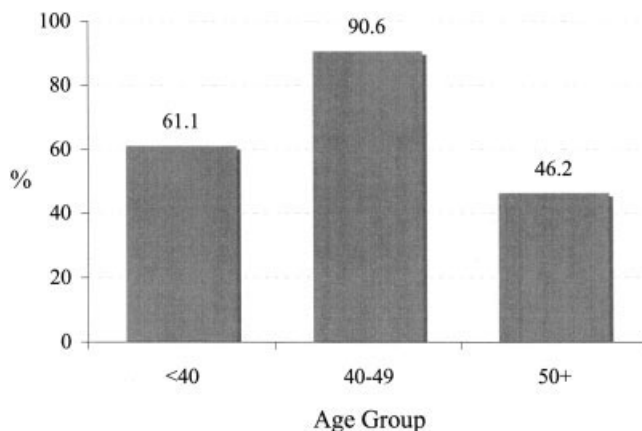


Figure 1. Percentage of reported Internet use.

( $r = -0.230$ ,  $P = 0.018$ ). Satisfaction with consultations was significantly higher for both patients ( $r = 0.192$ ,  $P = 0.042$ ) and physicians ( $r = 0.207$ ,  $P = 0.030$ ) if the patient discussed OHI during the appointment.

To explain why patients sought OHI, why they did not generally talk with their physicians about that information, and why they particularly did not talk with physicians if they were in a great deal of pain, we turn to the results of the interview data.

**Qualitative results.** Six reasons (Table 3) emerged from the interviews explaining why patients sought OHI. Of those patients who sought OHI, 35% were likely to report multiple reasons. Seventeen patients did not volunteer any reason for seeking OHI.

*To gather general information on suspected condition (45%).* Most commonly, patients reported seeking general information about their suspected condition online prior to appointments. For example, when asked if she had done

Table 3. Summary of patient reasons for going online for medical information and not mentioning it in consultations

Reasons	Percentage reporting*
Reported reasons for going online for medical information	
To gather general information	45
To research treatment or medication options	17
To be active in their health care	15
To check physician competency	13
To self-diagnose	12
To find people with similar experiences	9
To find a physician	9
Reported reasons for not mentioning online research	
Did not want to challenge physician	12
Thought of it as background information only	10.6
Thought of online information as problematic	9.3
Unnecessary because physician was thorough	5
Patients should not have to mention it	1

\* Percentages are of all online health information seekers.

any research on the test result that led to the referral to the rheumatologist, a patient answered, "Oh tons. I know everything there is to know about it." And when asked where she did the research, she replied, "All on the Internet."

*To research treatment or medication options (17%).* Some patients explicitly reported that they went online to find the treatment or medication options open to them if they had their suspected condition. For example, one woman previously diagnosed with rheumatoid arthritis reported, "I've gone to some websites—mostly looking for more natural forms of treatments. Alternatives to taking all the medications."

*To be active in their health care (15%).* Patients were not seeking OHI to challenge their physicians, but rather wanted to be able to ask informed questions, understand what the physician would tell them, and as 6 of them explicitly mentioned, fulfill their duty of being responsible for their own health care. One patient's wife remarked that seeking OHI was a way "to be part of our own treatment." Another patient described it as, "You'll only get the best care if you work to get the best care."

*To check physician competency (13%).* Some patients sought OHI specifically because they did not trust the care offered by previous physicians. One patient reported, "[My former doctor said] . . . that I would be cured. But I knew that was impossible with scleroderma. So I really started doing my own research. The more I kept looking, the more I kept finding, but I really had to look for it. The doctor didn't do anything. . . . And she wouldn't answer any of my questions about scleroderma. I had to do it all myself."

*To self-diagnose (12%).* Some patients who had a history of being undiagnosed by previous physicians explicitly sought OHI to try to diagnose themselves. For example, one patient remarked that after one physician had told her that nothing was wrong, "I knew something was wrong, so I started reading online to find out what it was. . . . I was trying to diagnose myself."

*To find people with similar experiences (9%).* Some patients had gone online to find others who had had similar experiences, symptoms, or diagnoses as their own. As one patient put it, "Sometimes though I use the Internet as a support group. I don't have time to really go to a support group. . . . But they have chat groups online and I go to those."

*To find a physician (9%).* Some patients used the Internet to find a rheumatologist specializing in their specific disease. Proximity was a concern for some, but others were simply looking for the best physician, using multiple sites to identify physicians whose names were linked with research to a particular disease.

Overall, patients in their 40s were significantly more likely to report going online to find a physician ( $\chi^2(2) = 7.645, P = 0.022$ ) and were modestly more likely to do online research in order to be active in their own health care ( $\chi^2(2) = 5.430, P = 0.066$ ). Only women reported going online to try to diagnose themselves, but statistically this was not significant ( $\chi^2(2) = 2.961, P = 0.114$ ; Fisher's exact test). Otherwise, patients' reported reasons generally did not suggest strong associations with sex, age, or pain.

Why, then, did the majority of informed patients not discuss their findings with their physicians?

#### **Reasons why patients did not mention their research.**

Analyses of the postappointment interviews revealed 5 reasons for not mentioning OHI (Table 3). Patients did not give multiple reasons and the majority gave no reason, but there are indications in the interviews that some simply had not thought of it.

*Did not want to challenge physician (12%).* Patients were concerned that discussing their condition from an informed point of view would be considered "challenging," and they were reluctant to come across as confrontational. One patient theorized that patients were "dealing with their health which is so personal and we're so vulnerable about our health. We think that if eventually we get better, then what we had to go through with the doctors was worth it." Another patient told of an instance in which she refrained from bringing up a medication she had found online: "[The doctor] suggested that I switch to the minocycline. I'm so glad he brought it up. I wanted to ask, but I didn't want to tell him what to do. You know, with doctors, it's difficult. Because they don't like it when patients come in and tell them that they want this and that."

*Thought of research as background information only (10.6%).* Some participants never considered discussing their OHI with their physician. One woman who had spent 10 hours the previous day seeking OHI for her suspected condition commented that it "was background reading. That was general. And [the doctor] was looking at me. . . . I wanted to hear what she had to say about me, looking over all my symptoms and medical history. And the Internet stuff was sort of my background information in order to be able to understand what she said to me."

*Online information was problematic (9.3%).* Several participants commented that OHI was confusing or potentially untrustworthy. The spouse of one patient remarked, "I've read some articles through PubMed and did a Google search for about 2 hours. Then I talked with [the physician] for about 15 minutes. That's about it. A little information can be a dangerous thing, and I don't want to jump to conclusions." The patient added, "That's the problem with the Internet. It gives a little information, just enough to get you into trouble."

*Physician was thorough (5%).* A few patients reported that the physician had proven so thorough and knowledgeable that they felt it unnecessary to mention OHI. As one patient said, "He is a wonderful doctor, very thorough. I felt so refreshed to feel like someone who knows this disease is taking the reins and I didn't have to."

*Patients should not have to mention it (1%).* One patient maintained that she didn't mention OHI because a good physician should not have to be told: "The one who treats me ordinarily [a generalist], I do not have to tell him anything or ask anything. He just knows what is wrong with me and what I want to know. A patient shouldn't have to explain."

Fisher's exact test cross tabulations suggested that those patients who went online to check physician competency were likely to not want to challenge physicians

( $\chi^2(2) = 7.961, P = 0.07$ ) or felt that the physician was thorough ( $\chi^2(2) = 9.404, P = 0.034$ ). Likewise, those that went online to try to self-diagnose were likely to not want to challenge physicians ( $\chi^2(2) = 9.360, P = 0.020$ ; Fisher's exact test). The reasons patients gave for not mentioning OHI were not associated with sex, age, or pain.

**Patients who mentioned OHI.** The 15 patients who mentioned OHI did so to discuss alternative understandings or treatments. These patients commonly brought in printouts of online materials to verify the information they had found. But patients were cautious and backed off if they read the physicians' reactions as negative: "I think [the physician and I] got off to a rocky start. Maybe he thinks I'm too involved in my therapy, but we sort of smoothed that out and eventually it seemed to go well." This patient also commented that he thought his former rheumatologist may have written a note in his chart about him being a difficult or overly involved patient. In short, those patients who mentioned OHI perceived a risk in doing so.

There was no relationship between discussing OHI and reported reasons for going online, sex, or age. Reported worst pain showed marginal associations: those reporting no pain were least likely to mention Internet research (16.7%) and people with very low (25%) or very high (25%) levels of pain were more likely to mention it ( $\chi^2(2) = 8.269, P = 0.082$ ).

## DISCUSSION

Our finding that the majority of rheumatology patients sought OHI before initial appointments is higher than previous studies among patients in general and rheumatology patients in particular would indicate. Age is a significant predictor of Internet use overall, and people in their 40s are most likely to seek OHI. Women are also more likely to seek OHI. Notably, our findings did not wholly corroborate the demographics of the other studies among rheumatology patients (1–5). This might be partially explained by age, as Gordon et al (1) report population demographics with similar sex distribution (76% women) but an older median age of 58 years. Another possible factor is disease uncertainty (44); most of the studies did not stipulate how established patients were, although Gordon et al (1) included only patients returning for at least their third appointment. The higher percentage of patients seeking OHI in our study may reflect a higher need for information among new patients uncertain of a diagnosis. Further research is necessary to examine whether women and people in their 40s experience higher levels of uncertainty, or, alternatively, if they have stronger desires to control their health through OHI. Other explanations include the different time periods in which studies of Internet usage were conducted and potential geographic differences in Internet use (5,45).

Our data confirm findings that sicker patients are more likely to seek OHI (23,24). We used 2 measures of health status in addition to diagnosis, but only pain was significantly correlated with seeking OHI. Pain was negatively

correlated with patient-initiated discussions about OHI. This suggests that patients who report higher levels of pain are both more likely to seek OHI and less likely to discuss that information.

The significant associations between sex, age, and pain level are not associated with reasons for seeking OHI, except for the association between age and finding a physician online. People primarily sought OHI to be generally informed (4), although they had other reasons as well (Table 3). This suggests that the majority of new rheumatology patients may have a need for information about their condition. Further research needs to be done to examine whether seeking OHI and the reasons for it remain constant for established patients.

The satisfaction correlations are intriguing. It may be that detailed analysis comparing consultations in which OHI was discussed with those in which it was not will show other indications of successful clinical interactions (46). The correlation of physician satisfaction with discussion of OHI was surprising, given studies reporting that physicians have complex and often negative reactions to patients bringing in OHI (26,29,47–49). It is possible that patients mentioning OHI to physicians is mutually satisfying because it potentially promotes patient insight into their condition.

There are some limitations to this study. It does not address information-seeking behavior of non-English-speaking patients, which warrants further research, particularly given indications that there may be population differences in OHI seeking among rheumatology patients (1,2,5). This study did not find that higher education, income, and youth predicted Internet use; a larger study would be needed to test these negative findings. Our finding that many patients seek OHI prior to appointments contrasts with the literature, but like previous studies (11,27) we did not measure a specific time frame. For those eventually diagnosed with scleroderma and systemic lupus erythematosus, there are indications of significant OHI seeking that warrant further attention. Caution must be used in interpreting satisfaction ratings that may conflate other factors with the clinical encounter (50).

This study found that the majority of new rheumatology patients have sought OHI prior to initial appointments. However, patients are unlikely to mention OHI, even though both patient and physician satisfaction is likely to be higher if they do. This suggests that, even given the time limitations in today's clinical practice, physicians may want to encourage patients to discuss the health information they have likely already found.

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## AUTHOR CONTRIBUTIONS

Dr. Hay had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study design.** Hay, Furst.

**Acquisition of data.** Hay, Cadigan, Khanna, Strathmann, Altman, McMahan, Kokhab, Furst.

**Analysis and interpretation of data.** Hay, Cadigan, Khanna, Lieber, Furst.

**Manuscript preparation.** Hay, Cadigan, Khanna, Lieber, Altman, McMahan, Furst.

**Statistical analysis.** Hay, Lieber, Furst.

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