

Seasonal Variation in Daily Ratings of Pain and Rash of a Lupus Patient

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Abstract

Lupus erythematosus is an autoimmune disease, affecting over one million Americans. Lupus patients commonly report experiencing increased pain with various weather patterns and barometric pressure fluctuations. Journaling or charting such experiences is thought to help a patient exercise some control over a seemingly unmanageable condition. This perspective inspired the data collection that gave rise to the current study, a case-study of an eighteen-year lupus sufferer who charted lupus-associated pain, rash presence, and barometric pressure for sixteen years. The goal of the present study was to describe and explain the patterns of pain and rash ratings charted by this patient. Analysis was conducted on eight years of charting (2000-2007). Hand-drawn charts were digitized using Engauge digitizing software. Hierarchical linear modeling (HLM) was used to examine relationships among pain, barometric pressure, season, and rash with years treated as individuals. Though statistical power was limited by the number of available years, patterns for several variables were noteworthy. Rash intensity was a significant predictor of pain ($p = 0.024$). While both rash intensity and pain varied across seasons, these variables showed somewhat different patterns over time. Mean pain ratings were highest in summer and lowest in autumn, while mean rash intensity ratings were highest in spring and lowest in autumn. Barometric pressure may partially account for some of the seasonal effects on pain and rash; however, it was not a significant predictor of either in HLM analyses. These findings offer insight to the variable experiences of a lupus sufferer. Patient intuitions and therapeutic charting have led to the discovery of striking pain patterns. Further research is underway to investigate the nature of these seasonal patterns and to determine if daily variability in barometric pressure will account for them.

Keywords: Systemic lupus erythematosus, Pain, Season

1. Background

1.1 systemic lupus erythematosus

Lupus erythematosus is an autoimmune disease. The body becomes allergic to itself, producing an abundance of antibodies that are directed against body tissue¹. Both the humoral and cellular aspects of the immune system are affected by lupus, and most of the antibodies are directed against cell nuclei. Lupus patients produce many different types of antibodies, but the most common are the antinuclear antibodies (ANA), produced in 95% of patients². The typical lupus patient has a positive ANA test and at least one or two other autoantibodies¹.

The American College of Rheumatology (ACR) developed criteria for a lupus diagnosis. If a patient fulfills four of the eleven criteria, a diagnosis of systemic lupus erythematosus is confirmed. Four criteria are skin-related: sun sensitivity, mouth sores, butterfly rashes (lupus rash over the cheeks and nose), and discoid rash (thick, disklike, scarring rash). Four criteria involve specific organ areas, including the lining of the heart or lung, the kidneys, the central nervous system, and joints. Three criteria are specifically related to relevant laboratory abnormalities, such as abnormal blood counts, positive ANA testing, and other blood antibody irregularities¹.

Lupus patients commonly complain of joint pain or swelling as well as skin rashes and fatigue¹. Purely biological explanations for such pain experiences are inadequate. It is necessary to adopt the biopsychosocial view of health and illness when attempting to treat lupus patients' symptoms. This view emphasizes the interactions among biological, psychological, and social influences and the ways these interactions shape patients' experiences and reactions to pain. Empirical support has led to the adoption of biopsychosocial treatment approaches for chronic pain management³.

Lupus patients often report increased sensitivity to weather changes or sunlight. Barometric pressure changes may result in increased stiffness and aching in the joints¹. However, this phenomenon is not well documented, and most evidence is anecdotal. Sensitivity to ultraviolet light is more common; many patients report that the sun gives them a rash or causes them to feel fatigued, achy, or feverish¹. A 2004 study on seasonal variation in lupus disease activity revealed that skin-related symptoms were more prevalent in the spring and summer months, compared to the winter. In this laboratory study, participants' pain interpretations were not considered. The ECLAM (European Consensus Lupus Activity Measurement) score was used as an index for disease activity. The ECLAM consists of fifteen clinical and laboratory variables, but no measures of subjective pain experiences⁷.

1.2 pain and pain management

Pain has cognitive and behavioral aspects. Coping is believed to be a process that can be altered by a patient's assessment of the situation. In chronic pain situations, coping takes the form of strategies utilized by the individual to manage daily pain. Because pain is an individualized experience, a wide variety of coping styles must be taught; what is helpful for one patient may be maladaptive for another. Regardless of disease pathology, chronic pain treatment must help the patient gain a sense of control over the effects of pain and modify the affective, behavioral, cognitive, and sensory characteristics of the pain experience³.

The cognitive-behavioral approach to pain management includes a variety of techniques and interventions intended to change a patient's experience by altering cognitions and behaviors. The increased acceptance of the biopsychosocial view of medicine has led many practitioners to treat chronic pain with cognitive-behavioral therapy (CBT). Most clinical approaches include education about pain perception and coping, promote a reconceptualization of the pain process, provide new ways for responding to pain, and encourage physical activity. Engstrom reports significant reductions in reported pain levels for patients who have undergone CBT interventions compared to a placebo medication group. Keefe et al. found similar results with an educational-information program⁴.

Therapeutic writing or journaling is a cognitive-behavioral therapy that has long been used as a way to deal with trauma and assist in emotional healing. However, controlled scientific studies on this subject have only recently been conducted⁵. A 2006 study by Danoff-Burg et al. examined the effects of expressive writing on the pain levels of lupus and rheumatoid arthritis patients. It was found that participants in the benefit-finding and expressive-writing groups experienced lower fatigue after three months compared with a control group⁶. Journaling is a valuable source of information about a patient's pain experience. Through the use of a daily pain diary, patients can document pain frequency, duration, and intensity as well as sleep patterns and medications. The diary allows the patient and practitioner to examine pain patterns without relying on memory. The pain diary can be used to monitor stressful life events. These stressors may be correlated with pain levels and coping responses. With this knowledge, practitioners can provide ultimate care to patients⁴.

One form of pain diary is the McGill Pain Questionnaire (MPQ). Developed in 1971 by Melzack and Torgerson, this questionnaire provided a new way to describe and measure pain. Their pain questionnaire provides a quick way to measure a subjective pain experience and has demonstrated validity and reliability. It includes an extensive vocabulary of pain descriptor words, allowing patients to more adequately describe their pain experiences. The MPQ contains 102 words divided into classes and subclasses. With these words the patient can describe the diverse aspects of a pain experience⁸.

1.3 purpose

This research project is a case-study of an eighteen-year lupus sufferer who kept a detailed pain diary in the form of charts. After noticing that his pain was affected by changing weather patterns, the patient recorded the daily barometric pressure and made pain and rash ratings. It was hypothesized that barometric pressure would predict pain ratings. Because weather patterns are often season-specific, it was hypothesized that season would be a

predictor of pain and rash intensity. It was also hypothesized that rash intensity would be correlated with higher pain ratings.

The literature on the connection between lupus pain and weather is extremely limited and anecdotal at best. The personal records of this patient are a valuable resource. The charts provide insight into the variable experiences of a lupus patient as well as much needed documentation for a phenomenon that is not well researched.

2. Method

2.1 participant

The participant in the present study was a male systemic lupus erythematosus patient, designated Patient X. Patient X was diagnosed with lupus in 1989 after a positive ANA and a negative test for Lyme disease. The onset of SLE was believed to be triggered by acute appendicitis and/or the subsequent appendectomy. During the days after the appendectomy, the patient experienced pain in the muscle area just above the knees and a full body rash. Ongoing symptoms have included muscle pain above the knees, lichen planus in the mouth, which is aggravated by certain foods, and fatigue. These symptoms have varied in intensity over time. Most lupus flares are relatively short (approximately twelve to thirty-six hours) and are experiences of intense, often full-body pain. The patient uses Salsalate and aspirin for pain control, usually for only a few days at a time. Various prescription drugs were also taken during longer periods of intense pain.

Patient X began charting in May 1991. Charts initially included the degree of aching leg pain and the severity of skin rash. Daily barometric pressure measurements and weather patterns were later added to the charts after the patient noticed a correlation between disease flares and certain weather types. Various life events, including vacations, dental surgery, and major life changes, were included in the charts. Prescription drugs and other disease symptoms were also noted. Patient X began charting after reading of the benefits of journaling or charting as a way of maintaining a certain degree of control over the disease pain and promoting a balanced lifestyle.

2.2 procedure

Patient X's hand-drawn charts from Winter 2000 to Fall 2007 were scanned and digitized using Engauge digitizing software. The time plots of barometric pressure, pain, and rash were all digitized. Using the software, axes were defined and numerical values were assigned to the points on the charts. An arbitrary 0-10 scale was used for pain and rash charts; 0 indicated no pain/rash and 10 corresponded to high pain or rash intensity. Values higher than ten occurred and were quantified by the software accordingly. The barometric pressure of central Kansas was measured in millimeters mercury and the chart coordinates corresponded to patient measurements of pressure using a Swift Instruments, Inc. Scientist Model #477 barometer. Patient X never had the barometer calibrated post-manufacture, but measurements were assumed to be consistent.

The McGill Pain Questionnaire was also administered to Patient X. The patient was instructed to fill out the entire questionnaire to reflect his worst pain experience ever (summer 2007). The questionnaire was then shortened to include only questions about present pain. Patient X was instructed to fill out these shorter questionnaires every other day for approximately two weeks. In total, seven short questionnaires were completed. The shorter questionnaires included space for the patient to note present symptoms, the current weather, and barometric pressure.

2.3 data analysis

The Engauge software created numerical data that was inserted into a spreadsheet file. Numerical values for barometric pressure, pain, and rash intensity all corresponded to a specific date. An individual file was created for each chart (approximately six months of data) and a larger composite file was created with all data. The composite file included date, barometric pressure, pain degree, rash degree, season, and the presence or absence of health and life events. Health events included dental surgery and illness. Life events included vacation times and moving to a new home. Seasons were numerically coded; winter was "1", spring was "2", and so forth. This composite file was a level one file, which was analyzed using Hierarchical Linear Modeling (HLM 6.0 software, Scientific Software International). Because of the nature of the case-study design, years were treated as individuals in the HLM models.

Patient X's charts included gaps of time with no data. These dates were retained, but the corresponding barometric pressure, rash, and pain columns were left empty. Days that had been inadvertently omitted by Patient X

from the charts were added to the composite file to ensure that months were the same number of days from year to year. To ensure that all the years were of equal length, the data from February 29th, 2004 and February 29th, 2000 were omitted. Pain and rash intensity ratings were made daily, resulting in 2,433 days of data for analysis.

HLM was used to test the predictor variables (season, month, and barometric pressure) and their effects on the outcome variables (pain and rash). All models were saved, and significant or almost significant interactions were illustrated graphically using R software⁹. The criterion for statistical significance was a p-value of 0.05 or less.

The data from the McGill Pain Questionnaires were analyzed according to the methods outlined in Melzack's "The McGill Pain Questionnaire: Major Properties and Scoring Methods"¹⁰. The questionnaires were scored by adding the rank values of pain descriptor words in the four categories (sensory, evaluative, affective, and miscellaneous). The scores for the individual categories were summed to obtain a total score. These numerical scores are the pain rating index (PRI-R). The total number of words chosen (NWC) was also calculated.

3. Results

The HLM model for rash intensity and pain is displayed in Figure 1. Rash intensity is the predictor variable, and pain is the outcome variable. There were no significant interactions with the level two variable (year). Pain was a significant predictor of rash intensity ($p = 0.024$). In this model, RASH codes for rash intensity and PAIN is the code for pain rating.

LEVEL 1 MODEL

$$PAIN = \pi_0 + \pi_1(RASH) + e$$

LEVEL 2 MODEL

$$\pi_0 = \beta_{00} + r_0$$

$$\pi_1 = \beta_{10} + r_1$$

Figure 1. HLM model of rash

Season was not a significant predictor of pain ($p = 0.127$). The coefficient for the relationship between pain and season is positive, indicating that mean pain ratings are higher in summer than in winter. When displayed graphically, the season-pain relationship is better understood. Figure 2 clearly shows that mean pain ratings are highest in the summer and lowest in autumn. It is important to note that pain variability is greater during the spring and summer months. Many high pain ratings were made during these months, as evidenced by the large number of outliers. During the winter months, it was rare for pain ratings to exceed ten on the zero-to-ten scale.

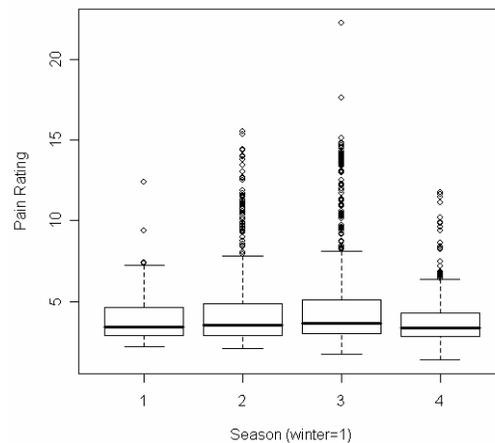


Figure 2. Seasonal patterns in pain ratings

Season was not a predictor of rash intensity ($p = 0.349$). The coefficient for the relationship between season and rash intensity is negative, indicating that mean rash intensity ratings are higher in spring and lowest in autumn. The box plot in Figure 3 illustrates this relationship. On the x-axis, spring is labeled “2” and autumn is “4.” Rash intensity ratings were highest during the spring and were highly variable, as indicated by the large number of outliers. Compared to the rash intensity ratings made during the summer months, the pattern during spring is drastically different.

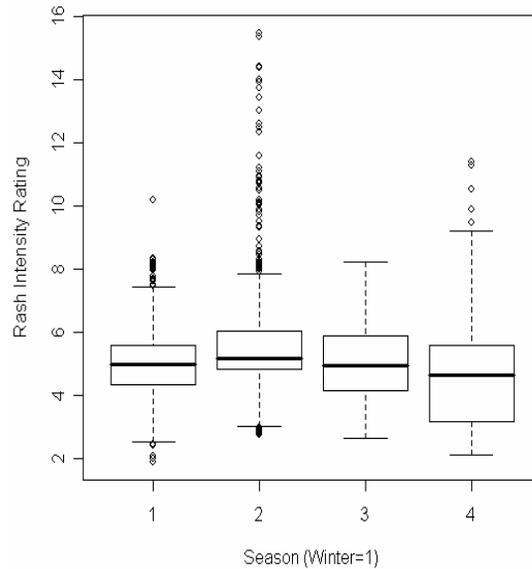


Figure 3. Seasonal patterns in rash intensity ratings

Barometric pressure was not a significant predictor of pain ($p = 0.238$) or rash ($p = 0.404$). These findings are contrary to Patient X’s personal hypotheses and pain experiences, which is a striking finding. To avoid making a Type II error, further data analyses are necessary before the hypothesis that barometric pressure is a determinant of pain can be rejected.

The results from the McGill Pain Questionnaires indicate that pain experiences are quite variable from day to day. Between the dates of February 2nd, 2008, and February 22nd, 2008, Patient X experienced only mild pain and a “normal” arm and leg rash. Summer 2007 was believed to be the time when Patient X experienced the worst lupus pain. The retrospective survey of summer 2007 proved that an intense pain experience is very different from mild pain experiences. The pain during summer 2007 was described as “excruciating”, compared to the “mild” pain that Patient X is currently experiencing.

The following table displays the results from the McGill Pain Questionnaires. The numerical values provide a quantitative index of pain, and this allows mild pain experiences to be better compared with more intense pain experiences. The words in the top row are pain categories designated by the McGill Pain Questionnaire. The number of words chosen does not necessarily correlate with the total pain rating index. For example, the questionnaire for summer 2007 had nine words chosen and the questionnaire for February 14th, 2008, also had nine words chosen. However, the pain rating index for summer 2007 is almost three times higher than the index for February 14th. For February 8th, 2008, through February 22nd, 2008, the mean pain rating index was seven and the mean number of words chosen was 5.7 words.

Table 1. pain rating index values for MPQ

Date	Sensory	Affective	Evaluative	Miscellaneous	Total	NWC
Summer 2007	11	7	5	9	32	9
2/8/2008	7	0	1	1	9	5
2/10/2008	1	0	1	3	5	5
2/12/2008	3	0	0	2	5	5
2/14/2008	7	1	1	2	11	9
2/16/2008	7	1	1	3	12	9
2/20/2008	3	0	0	2	5	5
2/22/2008	1	0	0	1	2	2

4. Discussion

While most findings were not statistically significant, the emerging patterns between pain, rash, and season are noteworthy, indicating that the hypotheses should not be rejected purely on the basis of statistical significance. Rash intensity was a significant predictor of pain. However, the seasonal patterns for these two variables were not identical. The highest pain ratings were during the summer months, with the highest ratings in August. Rash intensity ratings were highest during the spring months. It is interesting that these two patterns are different, especially since pain and rash intensity are strongly correlated. Kansas is known for its variable weather; the summer and spring months are quite different in terms of rainfall, humidity, and temperature. It is possible that these varying weather conditions may partially account for the different trends.

Weather-related lupus literature indicates that sunlight can aggravate skin symptoms, such as rashes, in lupus patients⁷. Kansas summers tend to be sunny, so it seems that lupus-related skin symptoms would be more intense during the months of June, July, and August. However, the pattern from the charts does not support this intuition. The outdoor habits of Patient X have not been investigated. If the patient limits sun exposure during the heated summer months and spends more time outdoors during the spring, the pattern of rash intensity might be better explained. Alternatively, the lupus skin rash may be unrelated to sun exposure. Patient X's rash may be aggravated by other environmental agents, such as seasonal allergens.

According to Patient X, the greatest variation in barometric pressure occurs during the winter. The summer curve for pressure is not as variable and is smoother. Wallace writes that changes in barometric pressure may be associated with symptoms of increased stiffness and aching in the joints¹. Based on Patient X's observations and Wallace's work, the highest pain ratings should be during the winter months. However, statistical analysis found the opposite of this to be true.

Further analysis of the barometric pressure data may reveal different results. In this analysis, barometric pressure for all dates was compared to pain ratings. If specific incidences of high pain ratings and their corresponding barometric pressures are isolated and analyzed on an individual basis, a different pattern between pressure and pain may emerge. It is important to note that Patient X is not constantly experiencing pain. The majority of days are accompanied by stable pain and rash intensity ratings. If these periods of unchanging data were omitted, statistical power could be enhanced.

It seems natural that rash intensity would be a significant predictor of pain. The skin rash is common among lupus patients. For Patient X, this rash occurs mainly on the arms and legs. As the intensity of the lupus rash changes, it is likely that Patient X's quality of life is affected. A more negative quality of life may impact one's subjective pain experience. However, if a patient is in a period of more intense pain, his or her perception of rash intensity may be altered. It is clear that lupus symptoms are extremely complex and intertwined. Despite the statistical significance of the relationship between pain and rash intensity, it seems unlikely that rash intensity is the only predictor of pain.

The McGill Pain Questionnaire data provided another first-hand account of lupus pain. These data were more descriptive than the pain data of the charts; the descriptive words allowed for a better understanding of the pain experience. Even within a period of relatively mild pain, there was much variability among the pain descriptor words. During the period of intense pain (summer 2007), pain was judged to be more severe and complex.

Statistical power in the present study was greatly limited by the number of years analyzed. Approximately eight years (or ninety-two months) were analyzed. Over eighteen years of charting have been completed, and Patient X

continues to chart to this day. By adding the data from the 1990s and 2007-2008 to the composite file, patterns may be strengthened to the point of significance.

Patient X indicated that other environmental factors influence his pain experiences. He hypothesized that temperature, humidity, wind speed, and wind direction may affect his symptoms. Future analyses including these variables could be conducted in an attempt to gain a better understanding of the possible lupus and weather connections.

The therapeutic effects of charting for Patient X were not examined. It is unclear whether charting actually is a helpful coping strategy when dealing with pain. It is possible that Patient X is more aware of his pain when he is actively charting. During vacation periods, Patient X does not chart his symptoms. Pain may be less noticeable during these periods because Patient X is not actively appraising his symptoms. This hypothesis could be investigated during interviews with Patient X. In addition, an experimental manipulation could be conducted in which the patient tries alternative cognitive-behavioral therapies or engages in no CBT.

This study was a case-study and is not easily generalized to the experiences of other lupus patients. However, the findings of this research are still noteworthy due to the lack of empirical support for the relationship between lupus flares and weather changes. The meticulous charting of Patient X has provided valuable information on the variable experiences of a lupus sufferer. While it is seemingly impossible to isolate a single causative agent, further research and analysis will hopefully provide additional support for the patterns discovered in this study.

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