The Use of a Decision Board to Elicit Brazilian Patients’ and Physicians’ Preferences for Treatment: The Case of Lupus Nephritis

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ABSTRACT

Objectives: To find preferences for treatment expressed by lupus patients and physicians (who were asked to assume they have lupus) and to explore if certain variables explain these preferences. Methods: One hundred seventy-two patients and 202 physicians were interviewed using a lupus nephritis decision board that describes the treatment options and their potential benefits and risks. Clinical and sociodemographic variables were collected. Participants were asked to indicate their preferred treatment and provide justification for their choice. Descriptive statistics, t-tests, and Pearson’s chi-square tests were used to determine the significance of differences in the decisions made by the two groups. A logistic regression model determined which factors contributed to treatment decisions. Results: The average age of study participants was 34 ± 8 years for patients and 31 ± 7 years for physicians. Sixty-eight percent of patients and 96% of physicians (P < 0.001) selected the oral option. Patients and physicians justified their choice of treatment using different arguments (P < 0.001 in each case). Logistic regression showed that risk potential (P < 0.001) and a history of joint involvement (P = 0.011) were the arguments used most often to explain a patient’s decision and the risk of side effects was most relevant among physicians (P < 0.001). Conclusions: Using a decision board, patients and physicians were found to have different preferences for treatment when faced with the same treatment options. Further, the variables that influence their preferences are different. Keywords: decision aids, patient preference, shared decision making, systemic lupus erythematosus.

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Introduction

The growing involvement of patients in their health care decisions has given them a more active role in the patient–physician relationship [1,2]. Many studies have looked at this theme and show that different factors will influence patient preferences for their health care [3–6]. Some studies have looked at the relevance of parameters such as pain, clinical history, socioeconomic context, and the willingness to accept the risk that clinical decisions might have adverse outcomes [6–9]. Many authors have also pointed to discrepancies between patient and physician preferences in terms of the therapeutic handling of different diseases, including the techniques used to approach this point [10,11]. These issues are parameters that must be looked at from the point of view of preference-based medicine [5–11].

Systemic lupus erythematosus (SLE) is a chronic inflammatory autoimmune disease of varying progress and prognosis [12]. Lupus nephritis (LN) is the renal complication of SLE. It occurs in 40% to 60% of patients at some stage of the disease [12,13]. Survival has increased in recent decades due to a better understanding of the mechanisms of the disease and the therapeutic arsenal available [12,14]. The target of treatment is to promote remission of renal disease and impede its progression to endstage renal disease [12,13]. All of the prognostic studies have identified LN as a predictor of a negative outcome [12–14]. Therapeutic handling of LN remains controversial due to the different risks and benefits resulting from the use of the immunosuppressive drugs available to treat LN [12–14]. Several studies have been exploring patient preferences on the context of lupus disease. However, they usually do not use a decision tool to help the process of decision making [15–21].

A decision support tool, such as a decision board (DB), displays a number of clinical issues and the consequences of each option to enable solving the issue using a process that is both standardized and free of bias [22]. The DB is a simple tool that displays more than one therapeutic option to be valued and decided on [22–25]. It is low cost and can be easily updated.

The development and validating of a Brazilian DB for LN for patients in Brazil was the first step in our study and has been described in a previous article [24]. Although several studies have attempted to assess the existence of discrepancies between physician and patient preferences regarding the same health care issue, most have used physicians who specialize in the disease in question [15–21]. In our study, we deliberately did not use rheumatologists for the reasons explained in more detail below. The objectives of this study were: 1) to find out the preferences for treatment expressed by SLE patients and by physicians who were asked to assume that they themselves had SLE, when faced with two options to treat LN using the Brazilian DB for LN, and 2) to

Conflicts of interest: The authors have indicated that they have no conflicts of interest with regard to the content of this article.

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1098-3015/$36.00 – see front matter Copyright © 2011, International Society for Pharmacoeconomics and Outcomes Research (ISPOR). Published by Elsevier Inc.

doi:10.1016/j.jval.2011.05.015
explore if certain variables explain these preferences and if these variables differ between the patients and the physicians.

**Materials and Methods**

This was a cross-sectional study [26]. Patients were selected consecutively on the date they were seen at a university tertiary hospital clinic, which is an authority in the country on the care of complex diseases like SLE. Over the period of one year, patients and physicians were invited to take part in the study.

Nonrheumatologist physicians were selected from the personnel files of the same institution. An Email message was sent to each of these physicians describing the nature of the study and inviting them to come in for an interview. Those who agreed to participate and met the criteria for selection were included in the study. Interviews with consenting physicians were scheduled during normal working hours at the hospital.

The following criteria were used to include patients: women between ages 18 and 50 years with a 12-month or longer diagnosis of SLE according to the modified classification criteria published by the American College of Rheumatology and any clinical manifestation of the disease. In addition, patients had to be able to read and write, according to their own statement, agree to participate in the study, and sign a statement of free and informed consent. Patients presenting active lupus psychosis or any form of cognitive disability that would make it difficult for them to understand the questionnaires were excluded, as were patients whose records were unavailable at the time of the interview.

The following criteria were used to include physicians: female academic physicians, practitioners, and physicians in training. Rheumatologists were excluded from the study to avoid a bias based on specific knowledge of the disease or the practices in the services they work for. We only recruited female physicians because the disease primarily affects women.

The LN DB was used during individual interviews [25]. The content was presented and added to during the course of the interview. (A) Summary presentation of disease information, with an emphasis on lupus nephritis. (B) A description of the treatment options: method of administration, likelihood of remission and a list of the eight potential side effects that the literature reports as having the highest prevalence. The interviewee then selects, from the list of eight side effects, those which she finds most bothersome. (C) Data on the probability of experiencing each of the three side effects selected by the individual interviewee as the most undesirable.
The statistical analysis showed that the treatment choice was influenced by the probability of disease remission, risk/benefit trade-off, and practicality. Risk justifications were those where the most important factor in choosing the treatment was how the drug was administered and how it would affect the interviewee’s day-to-day activities [15–25]. The methodology used to categorize the justifications was presented in an article on developing and validating the Brazilian LN DB [25]. Following the DB presentation, patients were asked to fill out the clinical and health related quality of life questionnaire. The clinical questionnaires used were Systemic Lupus Erythematous Disease Activity Index (SLEDAI) [27], and Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC-DI) [28]. Health-related quality of life was assessed using the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36). Previous studies had already translated and tested the validity of the Portuguese language version of this tool [29,30]. Socioeconomic variables were assessed using the Brazilian Economic Classification Criterion (BECC) questionnaire, a validated tool used to classify people into socioeconomic categories (ranging from A to E, with A being the highest) [31]. In our study we wanted to test the hypothesis that patients and physicians will choose different treatments for LN when presented with the same clinical scenario using the DB. This hypothesis was formulated based on the following premises: 1) the socioeconomic and cultural contexts are different for the physician and patient groups included in the study; and 2) physicians tend to have some technical information about the disease and a different frame of mind in terms of understanding of diseases in general. By excluding rheumatologists we believe we came as close as possible to contrasting the medical approach with the lay person approach to assessing the value of a treatment.

Initially we assessed the preferences of each group for treatment (ie, choice of preferred treatment) following the DB presentation. We then tested if a statistical difference between treatment preferences exists, after which we tried to find out which variables might explain the treatment preferences of each group. The following variables were used to test the hypothesis: 1) decision variables (i.e., side effects selected, treatment decision, and justification); 2) socioeconomic variables (i.e., income, the BECC, and years of schooling); 3) clinical variables (i.e., severity). In this study, we defined severity as two or more of the following: prior and/or current use of cyclophosphamide; prior and/or current use of other immunosuppressive agents; increased disease activity defined as an SLEDAI score of eight or more; and increased chronicity, defined as an SLICC-DI score of five or more. Severity was adopted as a dichotomous variable.

The project was approved by the Committee for Ethics in Research of our institution.

<p>| Table 1 – Demographic and socioeconomic characteristics of the study population* |
|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Patients</th>
<th>Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age – average (SD)</td>
<td>34.3 (8)</td>
</tr>
<tr>
<td>2. Race – N (%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>68 (39.5)</td>
</tr>
<tr>
<td>Non-white</td>
<td>104 (60.5)</td>
</tr>
<tr>
<td>3. Marital status (N%)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>58 (33.5)</td>
</tr>
<tr>
<td>Married</td>
<td>95 (55.2)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>16 (9.3)</td>
</tr>
<tr>
<td>Windowed</td>
<td>2 (1.1)</td>
</tr>
<tr>
<td>Other†</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>4. No. of children</td>
<td></td>
</tr>
<tr>
<td>0–1</td>
<td>103 (59.1)</td>
</tr>
<tr>
<td>2–3</td>
<td>62 (35.9)</td>
</tr>
<tr>
<td>≥4</td>
<td>7 (4.0)</td>
</tr>
<tr>
<td>5. BECC (income, in US$ equivalent)</td>
<td></td>
</tr>
<tr>
<td>A1 (3000.00)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>A2 (2100.00)</td>
<td>2 (1.2)</td>
</tr>
<tr>
<td>B1 (980.00)</td>
<td>7 (4.1)</td>
</tr>
<tr>
<td>B2 (550.00)</td>
<td>31 (18.0)</td>
</tr>
<tr>
<td>C (327.00)</td>
<td>87 (50.5)</td>
</tr>
<tr>
<td>D (212.00)</td>
<td>44 (25.5)</td>
</tr>
<tr>
<td>E (103.50)</td>
<td>1 (0.6)</td>
</tr>
</tbody>
</table>

P < 0.001 for all comparisons.

BECC, Brazilian Economic Classification Criterion.
* Values are the number (%) unless otherwise indicated.
† Other: Assigned (government donation, squatter’s rights, UNIFESP resident housing).

Results

We interviewed 172 patients and 202 physicians during 1 year. The average age was 34 ± 8 years for patients and 51 ± 7 years for physicians. All of the patients approached agreed to participate in the study and 8% of the physicians approached refused, all of them in training and claiming not to have time to participate. Everyone who participated in the survey provided data. Most of the patient group was made up of mulatto (i.e., Brazilian mixed race [35,36]) persons (45%) and most of the physician group (67%) was white. Demographic, quality of life, and clinical characteristics are described in Tables 1, 2, and 3, respectively. Regarding the BECC distribution, 76% of patients were classified as C and D and 18% as B2. In the physician group, the BECC distribution was class A2 (33.2%), followed by B1 (24.8%), and A1 (20.3%) (Table 1). All of the SF-36 domain scores were lower for patients than physicians (P < 0.001 for each comparison). The average time spent on the DB was 20 ±
11 minutes for patients and 9 ± 4 minutes for physicians. The frequency of the three worst side effects selected by patients was: cancer caused by the drug (44.2%), hair loss (21.6%), and severe infection (19.1%). Among physicians the order of selected side effects was cancer caused by the drug (45.5%), severe infection (33.1%), and sterility (12.5%). The difference in side effects selected by the two groups was statistically significant (P < 0.001), as shown in Table 4. Option 1 was the preferred treatment choice by 68% of patients and 98% of physicians (P < 0.001), as shown in Table 4. Based on the univariate analysis, the variables selected for the multivariate patient model were: cancer, severe infection, decision justification, SLEDAI, skin involvement, joint involvement, maternity (yes/no), number of inhabitants, socioeconomic class, income, and SF-36. The final model was adjusted excluding variables step by step to arrive at a reduced model. Multivariate analysis shows that patient decisions were guided primarily by the potential risk posed by the drug, represented by a risk based justification, compared to an effectiveness-based justification (P < 0.001; odds ratio 31.8; 95% confidence interval 8.2–122.9) or a practicality based justification (P < 0.001; OR 6.0; 95% CI 2.5–14.2). Patients with prior joint involvement were less likely to select Option 1, compared to patients with no joint involvement (P = 0.011; OR 5.3; 95% CI 1.4–19.5) (Table 5).

In the physician group, the same explanatory variables were used to build the univariate model, with the exception of the clinical variables. This model showed that physicians who justified their decision based on risk tended to select Option 1, compared to an effectiveness-based justification (P < 0.001; odds ratio 3.12; 95% confidence interval 1.4–19.5) (Table 4). Based on a univariate analysis, the variables selected for the multivariate patient model were: cancer, severe infection, decision justification, SLEDAI, skin involvement, joint involvement, maternity (yes/no), number of inhabitants, socioeconomic class, income, and SF-36. The final model was adjusted excluding variables step by step to arrive at a reduced model. Multivariate analysis shows that patient decisions were guided primarily by the potential risk posed by the drug, represented by a risk based justification, compared to an effectiveness-based justification (P < 0.001; odds ratio 31.8; 95% confidence interval 8.2–122.9) or a practicality based justification (P < 0.001; OR 6.0; 95% CI 2.5–14.2). Patients with prior joint involvement were less likely to select Option 1, compared to patients with no joint involvement (P = 0.011; OR 5.3; 95% CI 1.4–19.5) (Table 5).

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Discussion

This study addresses the preferences for treatment of two different groups facing the same scenario. Both groups consisted of individuals of the same sex and of a similar age group. The other demographic characteristics are different for the two groups, among them socioeconomic level and BECC scores (Table 1) [31]. The health-related quality of life profile also yielded different results for both groups. The patient group had the lowest SF-36 scores in all domains, probably as a result of the disease itself (Table 2). Because the institution was a tertiary center, the severity of the disease reflected this, as shown in Table 3. The two groups selected different side effect as being more important (Table 4). Regarding the treatment options, both groups tended to prefer Option 1. Results showed that the decisions were based on different justifications (P < 0.001), which were a reflection of what is important for each interviewee when making treatment decisions (Table 5).

We asked physician to imagine they were patients (i.e., to imagine that they have LN). This strategy has strengths and limitations. The strengths lie in the fact that, by considering themselves patients, potentially the physicians will make their decisions from the point of view of a patient. Different from other studies that have assessed the preference of physicians and patients, we tried to assess the physician choice, encouraging them to place themselves on the other side and make their decisions accordingly [15–21]. By excluding rheumatologists, we avoid decisions that are influenced by clinical practice and well known evidence. In this way, we can elicit physician preferences and understand how they make their own health care decisions. This information may help us understand how medical knowledge and training can influence choices. This in turn can contribute to the design of education strategies that can help both patients and physicians communicate and deliberate while attempting to choose the best treatment for the patient [15–25].

This study was structured to simulate the practical clinical reality of the institution where it was developed. A previous study done in Brazil explored patients’ and physicians’ perceptions about rheumatoid arthritis care. A study by Ferraz et al. [34] observed that patient and rheumatologists had different opinion about the health care provided. This study had a limitation that the answers provided by the rheumatologists who participated in the study were based on the guidelines used during that period of time rather than on what really happened [18–21,34].

A limitation of our study is that decisions made based on a hypothetical scenario may not necessarily reflect the decisions that would be made in a real situation. We believe, however, that the strengths outweigh the potential limitation. In addition, patients included in the study faced a hypothetical situation because individual preference seems to be determined by personal attitudes toward safety and convenience, by past experience, and by the perception of current disease status.

Conclusions

Physician and patient decisions are influenced by different factors, leading to potential discrepancies when facing the same issue to be assessed. Treatment choice has to be discussed with patients, because individual preference seems to be determined by personal attitudes toward safety and convenience. This being the case, both groups faced hypothetical situations [15–21]. Regarding the side effects chosen, although the side effect most often selected as being the worst was cancer by both groups (44% for patients and 45% for physicians), the rest were quite different (P < 0.001). We still do not understand the factors that could influence these decisions [25]. Other studies that assess patient preferences suggest similar results, although none made use of a support tool. There is a need for studies to explore this area [25].

Acknowledgments

The authors thank Dr. Ruy Geraldo Bevilacqua and Angela Paes for help with statistics.

Source of financial support: São Paulo Research Foundation (Fundação de Amparo à Pesquisa do Estado de São Paulo).

References


