The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases

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ABSTRACT

Objectives: The objective of this study was to investigate the impact of health literacy (HL) on health-related quality of life (HRQoL) and utility assessment among patients with rheumatic diseases.

Methods: HL was measured by the rapid estimate of adult literacy in medicine (REALM) and was characterized as low or adequate. HRQoL and utility scores were assessed using the SF-36, SF-6D, and EQ-5D. Comparisons of sociodemographics and HRQoL in patients with low or adequate HL were made using t test, chi-square, or Mann–Whitney U tests. Spearman’s correlation and partial correlations were used to study the relationship between HL, HRQoL, and utility scores, with significant correlations further explored using multiple linear regression models.

Results: Data were analyzed from 199 subjects. Patients with adequate HL had significantly higher education levels, better dwelling status, lower disease activity, and better physical functioning (PF). There was a significant although weak correlation between HL level and PF. After adjustment, HL level was shown to independently explain 3.7% of the variance in the PF score. Nevertheless, there was no impact of HL on utility assessment or other HRQoL domains.

Conclusion: HL did not impact HRQoL in general, but was found to have a weak impact on the PF of patients with rheumatic diseases.

Keywords: health literacy, health utility, HRQoL, rheumatic disease.

Introduction

In general, health literacy is defined by the American Medical Association as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment” [1]. Patients with rheumatic diseases with limited health literacy were reported to be more likely to misinterpret prescription labels, have poorer disease knowledge, and have more hospital visits [2–5]. As highlighted however in a recent review by Rudd et al. [6], most of the studies on health literacy in rheumatology have focused on the assessment of readability of health education materials, health literacy levels of patients with rheumatic diseases, or the suitability of health education materials for the intended study population. That is, little is known about the potential impact of health literacy on the health-related outcomes of patients with rheumatic diseases.

In spite of biophysiological differences among different types of rheumatic diseases, patients with these diseases share some common outcomes, specifically disabilities in their physical, mental, and social functioning [7–10]. Because biomedical measures sometimes may not sensitively indicate the improvement in symptoms and health status, health-related quality of life (HRQoL) has been increasingly incorporated as a complementary and essential outcome measure to assess changes in the physical, psychological, social, and somatic functioning and well-being of these patients [11,12].

Given the perceived challenge of inadequate health literacy in the self-management skills of rheumatic diseases, patients with inadequate health literacy may have problems in following physicians’ instructions, reading prescription labels, comprehending patient education materials, etc., which might lead to compromised treatment outcomes and poorer HRQoL during the chronic disease management. It is therefore crucially important to explore whether health literacy influences HRQoL as an outcome among patients with rheumatic diseases [13]. Furthermore, utility scores generated from generic, preference-based HRQoL measures such as EQ-5D and SF-6D have been widely used in cost-utility analyses to determine the cost-effectiveness of pharmacological and surgical interventions in rheumatology for approval and subsidy decisions [14,15]. Therefore, the exploration of the impact of health literacy on utility assessment would also be of great interest in determining whether it is necessary to incorporate health literacy as a potential factor influencing the results of cost-utility analysis of disease management programs among these patients. To address these issues and to help bridge the gap between health literacy and outcomes research in patients with rheumatic diseases, the current study aimed to explore the impact of health literacy on the HRQoL and utility assessment among patients with rheumatic diseases.

Methods

Subjects and Study Design

Consenting English-speaking patients with rheumatic diseases without cognitive problems who were over 18 years old and seen at a tertiary referral center in Singapore were recruited by convenience sampling in this Institutional Review Board-approved study. Eligible patients were first asked to read out the 66 medical
terms in the rapid estimate of adult literacy in medicine (REALM) to the interviewer. Patients were next asked to self-complete a generic HRQoL measure (SF-36), two utility measures (EQ-5D and SF-6D), and a pre-tested questionnaire to obtain information on patients’ characteristics. If the eligible patient reported that he or she was illiterate, he/she was given a REALM score of 0, and HRQoL and subject characteristics were obtained through an interview—however, all subjects studied had some degree of literacy.

**Measure**

**REALM**

REALM is a 66-item word recognition test to assess the ability of an adult patient to read common medical words and lay terms relating to body parts and illnesses. It was designed to assist medical professionals in estimating a patient’s literacy level so that oral instructions and written education materials could be appropriately provided. According to the REALM scoring scheme, patients in the current study were categorized into two groups as low health literacy (0–60) or adequate health literacy (61–66) to reflect their ability to read materials below or above the ninth grade level [16]. For details of the REALM scoring scheme, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part I at: http://www.ispor.org/Publications/value/ ViHsupplementary/ViH12s3_Thumboo.asp.

**Statistical Analysis**

Data were entered into a Microsoft Excel spreadsheet (Microsoft Corporation, Redmond, WA) and analyzed using SPSS 12.0 (SPSS Inc., Chicago, IL). All tests were two-tailed and were conducted at a significance level of 0.05. Descriptive analysis was used to characterize sociodemographics (age, sex, ethnicity, education level, work status, and dwelling type), medical information (presence of acute disease[s] and comorbidities, primary diagnosis, and activity and severity of the diagnosis), and scores of REALM, SF-36, EQ-5D, and SF-6D. The sociodemographic and other characteristics between patients with adequate and inadequate health literacy were compared using the Student’s t test for continuous variables with a normal distribution, the Mann–Whitney U nonparametric test for variables without a normal distribution, and the chi-square test for categorical variables.

Relationships between various external variables and HRQoL and utility scores were explored by univariate analyses using Mann–Whitney or Kruskal–Wallis tests for categorical independent variables, or Spearman’s correlation for continuous independent variables. Correlations between health literacy level and HRQoL and utility scores were studied in two steps, first with bivariate Spearman’s correlation and then second with partial correlation after the adjustment for other potentially significant variables in the univariate analysis (P < 0.1). Magnitude of correlation was interpreted according to the criteria proposed by Guyatt et al. [17]: less than 0.2 as very weak, more than 0.2 but less than 0.35 as weak, more than 0.35 but less than 0.5 as moderate, and more than 0.5 as strong. If there was a statistically significant correlation, two-step multiple regression models were also constructed to further study the potential impact of health literacy on HRQoL or utility scores. In all the models, HRQoL or utility score was analyzed as the dependent variable. In the first step, health literacy level was included as the only independent variable. In the second step, the impact of health literacy level was studied after the adjustment for potential confounding external variables identified in the univariate analysis (P < 0.1).

**Results**

**Subject Characteristics**

Of 220 eligible subjects, 90.5% (n = 199) participated. The majority of the patients was female, Chinese, and with more than 10 years of education (70.5% female, 74.0% Chinese, and 79.5% with at least 10 years of education). Based on REALM scores, 112 patients (56.3%) were categorized as having adequate health literacy, and 87 patients were categorized as having low health literacy. As compared with low health literacy subjects, subjects with adequate health literacy were older, had more years of education, a higher chance of living in private housing, and less disease activity for their primary diagnosis. For details, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part II, Table S1 at: http://www.ispor.org/Publications/value/ViHsupplementary/ViH12s3_Thumboo.asp.

**Comparison of HRQoL and Utility Scores in Patients with Rheumatic Diseases by Health Literacy Levels**

It was found that the physical functioning (PF) score of patients with adequate health literacy was significantly higher than those with inadequate health literacy (Median [interquartile range] of PF: 80 [60, 90] vs. 70 [45, 85], respectively, P = 0.004). Apart from the difference in PF scores between these groups, there were no other significant differences between the two groups in the remaining SF-36 domains. Besides, no statistically significant difference was found in either EQ-5D or SF-6D utility scores between patients with adequate health literacy and those with inadequate health literacy. For details, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part II, Table S2 at: http://www.ispor.org/Publications/value/ViHsupplementary/ViH12s3_Thumboo.asp.

**Correlation between Health Literacy Levels and HRQoL and Utility Scores**

In the exploration of correlation between health literacy level and HRQoL score, as measured by SF-36, it was found that in univariate analysis, health literacy level was significantly correlated with PF, however, this correlation was considered weak (Spearman’s correlation coefficient = 0.20, P = 0.006). Other variables significantly associated with PF scores in univariate analyses were age, education level, working status, presence of comorbidities, and activity of the primary diagnosis. After the adjustment for these five external variables in the partial correlation between the health literacy level and PF, the Spearman’s correlation coefficient was 0.23 (P = 0.002). This suggests that patients with rheumatic diseases with inadequate health literacy were more prone to worse PF after adjusting for the influence of these other variables. As for the remaining SF-36 domains however, no statistically significant relationship was found by either bivariate or partial correlation analysis.

As for the exploration of correlation between health literacy and utility scores, it was found that utilities scores, as measured by SF-6D and EQ-5D scores, were not significantly correlated with health literacy in either bivariate or partial correlations in which the respective significant external variables identified in
the separate univariate analysis had been adjusted. For details, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part II, Table S3 at: http://www.ispor.org/Publications/value/ViH12s3_Thumboo.asp.

**Impact of Health Literacy Level on PF**

Because health literacy level was found to be only significantly associated with PF, further exploration of the impact of health literacy on PF was performed using multiple linear regression models. When health literacy level was the only independent variable (Step 1), it explained up to 3.6% (adjusted $R^2$) of the variance in PF scores. When the five potential influential external variables (age, education level, working status, presence of comorbidities, and activity of the primary diagnosis) that have shown statistically significant associations with PF scores were adjusted for (Step 2), health literacy level was found to independently and significantly explain up to 3.7% (adjusted $R^2$) of the variance in PF scores, with the other five external variables explaining up to 20.5% (adjusted $R^2$) and the total of seven variables explaining up to 24.0% (adjusted $R^2$) of the variance in PF scores. Furthermore, based on the standardized regression coefficient, it was also found that patients who were younger ($-0.26$), working ($0.16$), having lower disease activity ($-0.30$), and with adequate health literacy ($0.21$) were more likely to have better PF. For details, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part II, Table S4 at: http://www.ispor.org/Publications/value/ViH12s3_Thumboo.asp.

**Discussion**

In this cross-sectional study among patients with rheumatic diseases, we found that health literacy level did not impact HRQoL in general. Although there was a statistically significant correlation between health literacy level and PF that persisted after adjusting for other variables, the strength of this correlation was weak and had an explanatory power of less than 4%. Furthermore, we did not find any significant impact of health literacy on the remaining seven SF-36 domains, nor on utility scores measured using the SF-6D and EQ-5D. To the best of our knowledge, this is among the first studies investigating the impact of health literacy level on HRQoL and utility assessment in patients with rheumatic diseases. Our findings may provide useful information and important implications for the health literacy issues on patients with rheumatic diseases in several ways detailed below.

First, the weak yet significantly positive association between health literacy and PF raises potential concerns over the problem of inadequate health literacy for various stakeholders in the management of rheumatic diseases. Our findings suggest that PF could be the most affected HRQoL domain by health literacy levels as compared with the other domains measured by SF-36. Because preservation of the physical function is among the top priorities in the long-term care of patients with rheumatic diseases, our results suggest that physicians need to make extra efforts to effectively convey medical instructions to those with limited health literacy, and ensure their compliance and proper execution on a regular basis [18,19]. Similarly, health education materials for such patients need to be developed in such a way that they are well comprehended by patients with inadequate health literacy to optimize their positive impact on PF in such patients. From a patients’ perspective, those with inadequate health literacy could be encouraged to take a more active role in communicating with their health-care providers to maximize the possibility of improving their health status. It was also interesting to note that the correlation between health literacy and HRQoL outcomes detected in the current study was actually much higher than those found in other studies on patients with other chronic diseases such as cancer (no association), depression (no association), and asthma ($r = -0.02, P < 0.01$) [20–22].

Second, it would be of special interest to the medical decision-makers to know that health literacy level was not an influential factor of the final utility scores of patients with rheumatic diseases measured by EQ-5D and SF-6D. Utility scores elicited from patients with rheumatic diseases have been used to determine the effectiveness or the further cost-effectiveness of different interventions for the purposes of treatment selection and intervention reimbursement [23]. Our results are reassuring in this regard because they suggest that health literacy does not influence utility scores in patients with rheumatic diseases. Thus, there is unlikely to be a need to intentionally stratify recruitment of subjects on the basis of their health literacy.

Third, the high prevalence (44%) of patients with inadequate health literacy as identified by REALM in the current study further contributes to the increase in awareness of health literacy problems in patients with rheumatic diseases. According to the earlier cross-sectional studies on patients with systemic lupus erythematosus or rheumatoid arthritis, the percentage of patients with inadequate health literacy ranged from 10% to 48% [24–26]. Therefore, the administration of a health literacy test could be recommended as a one-time screening test in routine health-care settings to identify patients with rheumatic diseases with limited health literacy to deliver more tailored consultation and education.

We recognize several limitations of this study. First, because the current study population included patients belonging to different categories of rheumatic diseases, no disease-specific HRQoL measure was used. Although SF-36 appears to be the best available generic measure to evaluate the health status of patients with rheumatic diseases, it might not be as sensitive as some other disease-specific HRQoL measures to capture small but meaningful differences in certain domains of HRQoL affected by a given disease. Second, the current scoring thresholds and categorization of REALM were set based on a ninth grade education level. Thus, it might not be sensitive enough to sufficiently differentiate health literacy at different grade levels. Besides, there is an ongoing debate regarding the use of REALM, a word recognition test, to evaluate the comprehension capability, that is, the functional health literacy level of the patient [27]. Furthermore, it has been recently argued that apart from functional health literacy, the other two conceptual components, namely, communicative and critical health literacy, might also influence the final health outcomes [28]. These could be the possible reasons why the correlation between health literacy level and HRQoL was generally lacking, and only a weak yet significant correlation was found between health literacy level and PF. Further research using a disease-specific HRQoL measure and also a more comprehensive and sensitive health literacy test is suggested to confirm the findings in this exploratory study.

Third, some characteristics of the study population may potentially mask the correlation between health literacy levels and other domains of HRQoL. Because the study population was mainly composed of those with mild severity and disease activity, their mental health and other HRQoL functioning might be less affected than patients with more severe conditions. Therefore, to verify the lack of correlation between health literacy and other
Conclusion

This study showed that health literacy did not impact HRQoL in general, but had a weak impact on the PF of patients with rheumatic diseases. To confirm and expand the results of the current study, it is suggested that further studies be conducted on patients with specific rheumatic diseases using disease-specific HRQoL instruments.

References


For additional references 2–28, see The Impact of Health Literacy on Health-Related Quality of Life (HRQoL) and Utility Assessment among Patients with Rheumatic Diseases Value in Health Supporting Information, part III at: http://www.ispor.org/Publications/value/ ViHsupplementary/ViH12s3_Thumboo.asp.