Willingness-to-Pay Stated Preferences for 8 Health-Related Quality-of-Life Domains in Psoriatic Arthritis: A Pilot Study

Stephanie W. Hu, BS, Elizabeth W. Holt, MPH, M. Elaine Husni, MD, MPH, and Abrar A. Qureshi, MD, MPH

Objectives: Psoriatic arthritis (PsA) is a seronegative inflammatory arthritis found in up to 5 to 42% of patients with psoriasis. As current instruments do not fully capture health-related quality of life (HR-QOL) in PsA from the patient’s perspective, we piloted a novel application of “willingness-to-pay” (WTP) as a Patient Reported Outcome to measure the relative impact of PsA in 8 domains of HR-QOL.

Methods: Fifty-nine PsA patients were interviewed on 8 WTP HR-QOL domains (physical, emotional, sleep, work, social, self-care, intimacy, and concentration). Participants were asked to rank the 8 domains of health in order of HR-QOL impact. In each domain, participants were asked whether PsA affected that domain, whether they were willing to pay for a cure in that domain, and the amount they were willing to pay. Median WTP amounts were compared with the proportion of participants affected by and willing to pay in each domain. Responses in US dollars were interpreted as strength of preference rather than absolute monetary values.

Results: The majority of participants were white (98%), ≥45 years of age (70%), insured (98%), and earned >$65,000/yr (66%). The physical domain was most affected by PsA; intimacy and concentration were ranked lowest. Participants reported a wide range of WTP amounts ($0 to $1,000,000), and median WTP amounts were highest in the physical, work, sleep, and self-care domains. Related domains elicited median WTP amounts that were highly correlated. No significant differences in median WTP amounts were found across ages, genders, and income levels for the different domains.

Conclusions: WTP is a novel quantitative patient-perspective measure that is comprehensible and feasible to administer in PsA patients. It represents a unique tool for capturing the complex manifestations of PsA and its impact on the individual, allowing the quantification of specific HR-QOL parameters and providing the potential for comparison across various disease processes in a given individual. © 2010 Elsevier Inc. All rights reserved. Semin Arthritis Rheum 39:384-397

Keywords: psoriatic arthritis, willingness to pay, health-related quality of life, patient reported outcome, contingent valuation

Psoriatic arthritis (PsA) has been defined as a unique, progressive, and often destructive form of seronegative inflammatory arthritis associated with psoriasis. While its exact prevalence is unknown, estimates vary from 0.3 to 1% of the population, with a reported prevalence of 5 to 42% in patients with psoriasis (1-3). Typically, PsA presents as a mild, oligoarticular disease but can become polyarticular with time and progresses to a severe, erosive condition in at least 20% of patients. Aggressive disease is seen more commonly in those who exhibit polyarticular PsA at presentation (4). In addition to progression of clinical and radiological damage, health-related quality of life (HR-QOL) is reduced among patients with PsA (5,6). In 2006, Zink and coworkers reported that patients suffering from PsA seen in rheumatologic care...
have a burden of illness comparable to that of patients with other inflammatory arthritis such as rheumatoid arthritis (RA) or ankylosing spondylitis (7).

Given the functional and psychosocial impact of PsA, it has become increasingly important to include both physician-assessed clinical endpoints and patient-reported outcomes (PROs) to obtain a comprehensive view of the disease process, its treatment, and its impact on quality of life (QOL) from the patient perspective. HR-QOL is a multidimensional construct that describes the physical, social, and psychological well-being of individuals within the context of a medical condition or its treatment (8). It is an increasingly important component of both patient care and clinical research, and 2 broad categories of HR-QOL instruments are health status surveys and health value/preference/utility assessments (9). The former describes function in 1 or more QOL domains and has been commonly used in dermatology. However, health status assessment tools have not been able to fully capture the complex interaction between disease state, body function, and activities, participation, and personal factors involved in heterogeneous disease entities like PsA. In addition, while the more commonly used skin-specific indices—the Skindex metrics and the Dermatology Quality of Life Index—are well-established with face and construct validity, reliability, and responsiveness, they do not measure constructs that have generic significance in the absence of skin disease and do not capture data that may be objectified and used in future studies (10-12). Similarly, while results of generic instruments allow for comparison with the general population or across disease states, they may lack the sensitivity to detect meaningful changes in HR-QOL specifically impacted by skin disease and fail to allow determination of relative patient preferences in specific aspects of HR-QOL (11). Moreover, given the incongruent relationships between disease severity and HR-QOL found in the literature (13), generic measures may also neglect domains that are deemed pertinent and important by individual patients.

To address the need for a more appropriate tool in PsA, we developed a novel instrument that evaluates the HR-QOL of PsA patients through the willingness-to-pay (WTP) method, 1 of the methods in the utility measures category of HR-QOL instruments. As a PRO, WTP represents a quantitative indicator of the perceived value of goods (or interventions in health care) in US dollars. By measuring the value of an intervention in monetary terms, WTP is a proxy for strength of preference and provides the researcher with a numeric value that can be compared across populations and disease groups, allowing future work to be compared with this standardized metric. WTP has been utilized in many settings, initially in the environmental economics literature as a means to measure stated preferences for goods not sold in a marketplace (14) but has been increasingly adopted as a means to value health care options (15). In this arena, WTP is used to elicit, through contingent valuation, a patient’s preference for relief from the impact of disease on a particular domain of health. In 2005, Fautrel and coworkers examined the WTP of Canadian patients with RA for a hypothetical cure for the disease under private and public payment scenarios (16). Recently, the application of WTP has expanded to other studies that assess the preferences of dermatology patients and the burden of skin disease (17-21). We have previously used WTP to elicit patient preferences for a telemedicine service in patients with melanoma and psoriasis (22), and most recently, piloted this instrument in measuring HR-QOL impact in psoriasis (23).

As health care resources become more limited and the medical community emphasizes the practice of evidence-based medicine, pharmacoeconomic analyses become increasingly important. WTP allows QOL to be more accurately incorporated into cost-effectiveness and cost-benefit analyses (24). The WTP methodology has also been advocated as superior to quality-adjusted life-years as a measure of benefit of health care programs due to its more comprehensive valuation of benefits and potential to improve social efficiency (25). Additionally, its tolerance of externalities and uncertainty within individual valuations further enhances the feasibility of WTP in assessing the adverse impact of disease states on patients’ HR-QOL (26).

Our goal in this study is to pilot the WTP instrument and evaluate its feasibility in quantifying the specific HR-QOL domains affected by PsA. As elicited WTP values correspond to the monetary valuation of the burden of disease and its impact on HR-QOL, we hypothesized that domain(s) of health impacting PsA patients most severely will elicit a larger WTP amount if a hypothetical cure were available to relieve symptoms in these domains. This correlation between HR-QOL and WTP would demonstrate the validity of the WTP method for the evaluation of HR-QOL parameters, evaluating not only the burden of skin disease but specifically evaluating the impact of PsA on 8 HR-QOL domains. Such a WTP-based instrument is anticipated to provide clinicians in both dermatology and rheumatology with a more insightful and comprehensive gauge of the true impact of PsA on the individual patient.

**METHODS**

**Study Population**

Participants were recruited by letters mailed to patients with a diagnosis of chronic PsA (duration >2 years), seen at the Brigham and Women’s Hospital’s Dermatology Clinic and Arthritis Center between June 2006 and August 2006. Patients were then approached and verbally recruited by the coinvestigator (S.H.) before their appointments at the dermatology clinic and the Arthritis Center. Participants were required to be 18 years of age or older and English-speaking and to possess a history of PsA...
of at least 2 years in duration. The final study population consisted of the first 60 patients with a history of PsA who met eligibility criteria and were willing to participate after a verbal description of the study.

**Instrument Design**

An initial list of health domains affected by PsA was generated by analyzing the Skindex-29 distribution of scaled scores (27), the Short-Form 36 (28), patient data available from multicenter studies, informal open patient interviews, and expert opinion from dermatologists, as has been done previously using a 1-round Delphi method (29). We analyzed this initial list and found that 8 domains were inclusive of the majority of suggestions elicited by the respondents, provider groups, and previous tools. The same domains were utilized in this instrument as for our instrument for psoriasis (23) so as to allow for the quantitative assessment of these disease processes on a common scale. The tool was further reviewed by rheumatologists at the Brigham and Women’s Hospital for preliminary content validity.

We employed an open-ended technique to evaluate WTP stated-preferences in US dollars for 8 QOL domains based on previously validated measures: intimacy, physical comfort, self-care, ability to work or volunteer, ability to concentrate, emotional health, social comfort, and ability to sleep (see Table 1 for definitions). Informed consent was obtained from all participants, who were subsequently interviewed by a trained interviewer (S.H.) over 30 minutes. Participants were first asked to complete the Health Assessment Questionnaire (HAQ) (30), designed to evaluate a relatively objective burden of disease based on functionality and disability in rheumatologic disease on a scale from 0 (smallest burden of disease) to 3 (greatest burden of disease). No aids and devices were utilized. Participants then completed the PsA and Overall Health Visual Analog Scales (VAS), which ranged from 0 (worst) to 10 (best) and reflected the patient’s perception of PsA disease severity and overall health, respectively. Participants then ranked from 1 (most affected by PsA) to 8 (least affected by PsA) the 8 domains of health in the context of their current PsA. Participants were then asked to consider if a given domain was impacted at all by PsA. Only if they responded in the affirmative were WTP questions for the domains then posed in the order in which participants were shown the domains for ranking. These questions were framed to elicit how much they would be willing to pay to eliminate all impairment in a particular domain of health such that a cure, and not only symptom relief, would be achieved. After all 8 questions were asked, participants were able to change their ranking of the domains or their WTP values for any domain. Demographic information was collected at the conclusion of the interview.

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### Table 1 Definitions of the 8 Domains of Health Evaluated in this Study

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Intimacy</td>
<td>Closeness with someone special like a husband, wife, boyfriend, girlfriend, or partner</td>
</tr>
<tr>
<td>Physical Comfort</td>
<td>Moving or stretching your skin comfortably</td>
</tr>
<tr>
<td>Self-Care</td>
<td>Taking care of your own body and health</td>
</tr>
<tr>
<td>Ability to Work or Volunteer</td>
<td>Activity that takes up a major part of your day</td>
</tr>
<tr>
<td>Ability to Concentrate</td>
<td>Focusing on a task that you are trying to accomplish without getting distracted</td>
</tr>
<tr>
<td>Emotional Health</td>
<td>Your feelings or emotions</td>
</tr>
<tr>
<td>Social Comfort</td>
<td>How you feel when you are around people you know or are meeting for the first time</td>
</tr>
<tr>
<td>Ability to Sleep</td>
<td>To rest or refresh yourself through rest</td>
</tr>
</tbody>
</table>

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**Analysis**

All statistical analyses were performed using software (SAS Institute, Inc., Cary, NC) for analysis. Frequencies and percentages were calculated for categorical variables; Spearman’s correlation coefficients were used to assess correlations between continuous variables, and Wilcoxon rank sum tests were used to assess differences in median WTP amounts across genders, ages, and income levels. χ² tests and odds ratios were used to assess relationships between participant demographics and whether a participant was affected by a domain or willing to pay for a cure in that domain. Patient VAS scores and WTP amounts were also compared with HAQ scores. P values less than 0.05 were considered to be statistically significant. All median and interquartile (IQR) range calculations included patients who reported that they were affected in a domain but were willing to pay $0 for cure, which we believe most accurately reflects the preferences of the patient population.

**RESULTS**

A total of 60 patients were recruited to participate in the study. Patient demographic characteristics are shown in Table 2. One participant was excluded from the analysis because of the extreme amounts this participant was willing to pay (> $1 billion) and uncertain English profi-
ciency. The majority of PsA patients were white (98%), ranging in age from 23 to 89 years with 30% <45 years and 70% ≥45 years. Men were more frequently represented (at 57%) than women (43%). A wide range of annual household income levels were reported: values ranged from $10,000 to more than $125,000; 66% of participants had annual household incomes of more than $65,000. Most participants (85%) had some college or higher education.

The median score for the Overall Health VAS was 7.0 (IQR 5.0, 8.0) and median VAS for PsA-related health was 7.0 (IQR 5.0, 8.0). Low HAQ scores (median = 0.40, IQR 0.05, 0.85) showed low overall disease severity for this study population. The Overall Health VAS score was significantly correlated with the PsA VAS score ($r = 0.51, P < 0.0001$). As expected, the HAQ score and the Overall Health VAS score ($r = -0.67, P < 0.0001$), as well as the HAQ score and the PsA VAS scores ($r = -0.63, P < 0.0001$) were inversely correlated.

The top 4 domains impacted by PsA were physical comfort (88%), emotional health (63%), sleep (60%), and work (57%) (Table 3). Eighty-seven percent of participants ranked physical comfort among the top 4 areas most affected by PsA (domains receiving a ranking of 1-4 were designated “highly ranked”). Eighty-eight percent of all participants were willing to pay for relief of the symptoms of PsA that would provide them with the physical comfort they desired. Of all participants, 68, 60, and 45% ranked the emotional health, sleep, and work domains, respectively, in the top 4 relative to other domains, and 63, 59, and 56% were willing to pay for a cure in these domains (Table 3). Social comfort and intimacy clearly emerged as the domains least affected by PsA (Table 3). These domains were consistently the lowest ranked domains and the domains for which participants were willing to pay less for a cure.

In addition, although participants reported a wide range of WTP amounts ($0 to $1,000,000), the WTP amounts for the self-care, work, and sleep domains were highly correlated with that for physical comfort (Spearman’s $r = 0.82$, $P < 0.0001$; $r = 0.91$, $P < 0.0001$; $r = 0.74$, $P < 0.0001$ for correlations between physical and self-care, work, and sleep, respectively) (Table 4). Similarly, the WTP amounts for the intimacy and social domains were also highly correlated with each other (Spearman’s $r = 0.89$, $P < 0.0001$).

Although a greater proportion of women than men ranked concentration in the top 4, no other significant differences by gender were found in whether or not a domain was ranked highly (ie, in the top 4), whether or not participants stated that PsA affected a domain, whether or not participants were willing to pay, and the amount they were willing to pay (Fig. 1). No significant differences by income level were seen in the top 4 rankings of domains; however, a greater proportion of those with higher incomes (defined as ≥$65,000 annually) stated that PsA affected the work and self-care domains than

<table>
<thead>
<tr>
<th>Table 2 Demographic Characteristics of Study Population</th>
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<tbody>
<tr>
<td>Characteristic</td>
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<tr>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>45 years</td>
</tr>
<tr>
<td>≥45 years</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Hispanic</td>
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<tr>
<td>Non-Hispanic White/Caucasian</td>
</tr>
<tr>
<td>Annual income</td>
</tr>
<tr>
<td>≤$35,000</td>
</tr>
<tr>
<td>$35,001 to $65,000</td>
</tr>
<tr>
<td>$65,001 to $95,000</td>
</tr>
<tr>
<td>$95,001</td>
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<tr>
<td>Education level</td>
</tr>
<tr>
<td>High school or less</td>
</tr>
<tr>
<td>Some college</td>
</tr>
<tr>
<td>College graduate</td>
</tr>
<tr>
<td>Graduate school</td>
</tr>
<tr>
<td>Health insurance coverage</td>
</tr>
<tr>
<td>One or more other medical conditions</td>
</tr>
<tr>
<td>reported</td>
</tr>
<tr>
<td>Overall Health Visual Analog Score</td>
</tr>
<tr>
<td>Psoriasis Visual Analog Score</td>
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<tr>
<td>Health Assessment Questionnaire</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Table 3 Domains of Health Affected by PsA and Amounts Willing to Pay for Relief from Symptoms</th>
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</thead>
<tbody>
<tr>
<td>Participants Believing Domain to be Affected by PsA (%)</td>
</tr>
<tr>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Physical comfort</td>
</tr>
<tr>
<td>Emotional health</td>
</tr>
<tr>
<td>Sleep</td>
</tr>
<tr>
<td>Work</td>
</tr>
<tr>
<td>Social comfort</td>
</tr>
<tr>
<td>Self-care</td>
</tr>
<tr>
<td>Intimacy</td>
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<tr>
<td>Concentration</td>
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</table>
those with lower incomes (crude OR = 3.5, 95% CI = 1.06, 11.53; crude OR = 3.4, 95% CI = 1.06, 10.59). In addition, while there were no significant differences by income level in willingness to pay for a PsA cure in any of the 8 domains, participants with higher incomes were willing to pay higher amounts in the work, sleep, concentration, and emotional domains. Last, no significant differences were detected in whether or not age affected how particular domains were ranked, although a greater proportion of older patients stated that they were willing to pay for a PsA cure in the work domain than their younger counterparts (crude OR = 4.5, 95% CI = 1.25, 15.93).

When asked if participants wanted to change ranking of health aspects at the end of the interview, 7 of 60 (12%) elected to change.

DISCUSSION

We have developed and pilot-tested a novel application of the WTP PRO to measure HR-QOL in PsA patients. This exploratory study demonstrated the feasibility of utilizing the WTP approach to measure the relative impact of PsA on HR-QOL across wide-ranging domains in a select population of patients with PsA. A similar study has already demonstrated its use in psoriasis patients (23) and the extension of this tool to PsA may allow future comparison of their impact on burden of illness of individual patients, thus providing the opportunity for meaningful interpretation of patient preferences.

In this pilot study, we have shown that the WTP method is feasible and can generate quantitative information about individual domains affecting HR-QOL in patients. Physical comfort, emotional health, sleep, and work emerged as the 4 domains with the greatest percentages of participants who were willing to pay for a PsA cure in the work domain than their younger counterparts (crude OR = 4.5, 95% CI = 1.25, 15.93).

Table 4 Spearman’s Correlation Coefficients for Median WTP Amounts Across Domains*

<table>
<thead>
<tr>
<th></th>
<th>Physical</th>
<th>Emotional</th>
<th>Sleep</th>
<th>Work/Volunteer</th>
<th>Social</th>
<th>Self-Care</th>
<th>Intimacy</th>
<th>Concentration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>—</td>
<td>0.62</td>
<td>0.73</td>
<td>0.91</td>
<td>0.66</td>
<td>0.82</td>
<td>0.37</td>
<td>0.87</td>
</tr>
<tr>
<td>Emotional</td>
<td>0.62</td>
<td>—</td>
<td>0.86</td>
<td>0.85</td>
<td>0.66</td>
<td>0.73</td>
<td>0.49</td>
<td>0.98</td>
</tr>
<tr>
<td>Sleep</td>
<td>0.74</td>
<td>0.86</td>
<td>—</td>
<td>0.96</td>
<td>0.71</td>
<td>0.81</td>
<td>0.50</td>
<td>0.87</td>
</tr>
<tr>
<td>Work/volunteer</td>
<td>0.91</td>
<td>0.85</td>
<td>0.96</td>
<td>—</td>
<td>0.76</td>
<td>0.86</td>
<td>0.52</td>
<td>0.84</td>
</tr>
<tr>
<td>Social</td>
<td>0.66</td>
<td>0.66</td>
<td>0.71</td>
<td>0.76</td>
<td>—</td>
<td>0.59</td>
<td>0.91</td>
<td>0.77</td>
</tr>
<tr>
<td>Self-care</td>
<td>0.82</td>
<td>0.73</td>
<td>0.81</td>
<td>0.86</td>
<td>0.59</td>
<td>—</td>
<td>0.60</td>
<td>0.69</td>
</tr>
<tr>
<td>Intimacy</td>
<td>0.37</td>
<td>0.49</td>
<td>0.50</td>
<td>0.52</td>
<td>0.89</td>
<td>0.60</td>
<td>—</td>
<td>0.60</td>
</tr>
<tr>
<td>Concentration</td>
<td>0.87</td>
<td>0.98</td>
<td>0.87</td>
<td>0.84</td>
<td>0.77</td>
<td>0.69</td>
<td>0.60</td>
<td>—</td>
</tr>
</tbody>
</table>

*P < 0.05 for all correlations.

Figure 1 Median WTP amount by income level (bars represent 75th percentile values; n = 59). (Color version of figure is available online.)
the domain for which participants were most willing to pay for a cure following physical comfort, the median amount participants were willing to pay dropped to fourth, following physical comfort, sleep, and work; similarly, social comfort was ranked fourth at 53%, but participants were willing to pay only a median amount of $2000 for a cure in this domain. However, rather than representing discrepancies in the validity of the tool, these trends may in fact provide valuable insight into the nature of the disease process itself and its impact on specific aspects of HR-QOL in this population. As this was a pilot study of small sample size, we have avoided conducting post-hoc analyses to examine these interactions. The fact that only 12% of participants elected to change the order of their initial rankings for the 8 domains affected by PsA after consideration of WTP and WTP amounts further reflects the effectiveness of the WTP instrument in accurately capturing the correlation between rankings and WTP and thus between participants’ true burden of disease and the PRO.

Many participants were willing to pay similar amounts across domains. It is possible that while individual participants are able to discriminate among the various domains during ranking, they may perceive the differences as insufficient to affect their desire to eliminate symptoms monetarily. However, as shown in Table 4, overall analysis of the study population for median WTP amounts across all domains revealed high correlations (Spearman’s $r > 0.70$) in related domains. For example, the physical comfort, sleep, work, and self-care domains emerged together with highly correlated amounts that participants were willing to pay for a cure. WTP amounts were also highly correlated for the intimacy and social domains. In addition, the WTP amounts for concentration and physical comfort, emotional health, sleep, work/volunteer, and social comfort were also highly correlated, which can also be reasonably surmised. These correlations may represent evidence of internal consistency among related domains that may further support the construct validity of the WTP instrument, as domains encompassing similar aspects of life elicit similar amounts that participants were willing to pay. These correlations also suggest that the WTP instrument can effectively elicit accurate and consistent patient preferences.

We evaluated whether factors such as gender, income, and age affected our WTP results, as these have been known to impact WTP (23). Also to be expected, those with higher incomes willing to pay higher median amounts. The median amounts were also significantly higher in the physical comfort, sleep, work, and self-care health domains, again the domains that encompass the more physical components of life and more likely to be compromised by PsA. Interestingly, how participants responded to questions about the work domain differed depending on their income level and age. Those whose annual household incomes were > $65,000 per year were more likely to state that PsA affected their work (unadjusted OR, 3.5; 95% CI, 1.06, 11.52). Those who were older (≥45 years) were also more likely to state that PsA affected their work (unadjusted OR, 4.1; 95% CI, 1.14, 14.42) and that they would be willing to pay for a cure in the work domain than younger patients (4.5, 1.25, 15.93). These differences may relate to the impact of lost productivity to these groups with differing economic situations. Older patients may also have a higher likelihood of experiencing benefit from interventions. Moreover, age effect may also simply represent a higher ability to pay. Despite these trends, however, the lack of other significant differences across ages, genders, and income brackets demonstrate the generalizability of the WTP tool across these demographic subgroups. While multivariate analyses may benefit future studies because WTP preferences are PROs that can be affected by age, gender, and socioeconomic status, univariate results in this pilot study help to support use of the WTP method.

A limitation of the study, however, conducted in a select sample of mostly white, educated patients treated at an academic medical center, resides in the inability to collect information from patients of greater ethnic, cultural, and socioeconomic diversity. In addition, the sample size, although adequate to test the properties of an initial pilot instrument, was modest. These restrictions may render the study population unrepresentative of the general PsA population and limit the generalizability of the results. In addition, the lack of consideration of participants’ total wealth and assets in eliciting WTP amounts may be a limitation; however, this was not considered because the inherent nature of such questions render them difficult to impose on participants, and accurate responses may be difficult to elicit due to the significant level of cognitive burden required. Moreover, income level generally serves as a reasonable correlate of overall wealth and may function as a proxy for this parameter.

The WTP questionnaire used in this study was readily comprehensible by participants and easy to administer. Given the opportunity to ask for clarifications of the interviewer and the availability of definitions and examples of the domains, almost all participants completed the interview in a shorter timeframe than was allotted. However, it is possible that the interviewing process in this pilot study may not be feasible in certain clinical or research settings. To this end, we are currently engaged in the development of a computer-based questionnaire with interactive software, which would allow self-administration to further simplify data collection. We aim to provide similar opportunities for questions and clarifications by building in popup windows and links to more detailed descriptions of potentially complex terminology and concepts.

Despite the complexities involved in utilizing an open-ended method of questioning in WTP, we selected this approach in the present pilot study to avoid the biasing of valuation that may result from anchoring participants to predetermined values based on little prior data. More-
over, bidding methods often require a large sample size to produce meaningful results, which our study did not allow (31,32). Future contingent valuation studies may derive benefit from employing payment-card methods, in which participants choose the range of values in which their own value lies from a series provided to them (with pretesting to select reasonable ranges). Follow-up bidding, in which participants are invited to bid up or down within the range selected, can then define the value more precisely (33).

WTP measured via contingent valuation is not without limitations. The concept itself is complex, with inherent difficulties in obtaining valid and reliable estimates of participants’ WTP. However, this may be overcome by meticulous attention to question content, wording, and delivery of the instrument, such that participants’ understanding of the evaluation method and the valuation task is strengthened. Additionally, WTP is subject to hypothetical bias; the amount an individual is willing to pay in a theoretical situation often exceeds that in a factual circumstance (34,35). Despite this challenge, Loomis and coworkers have shown that the difference between the stated and actual WTP can be reduced by improving the survey design (35).

Data from this pilot study, combined with data from our recent psoriasis study (23), will be used to develop a common scale by which psoriasis and PsA impact can be measured in clinical research studies. Moreover, we believe that information on WTP stated preferences will be useful to gauge the impact of dermatologic and rheumatologic conditions such as PsA on patients’ lives both overall and in specific domains, which may influence the therapeutic decision-making process for individuals and translate into more targeted therapy for patients in the future. Additionally, as an instrument developed through review and compilation of a comprehensive HR-QOL assessment battery, the WTP questionnaire provides a source of information for the HR-QOL of participants that is richer than that of most assessment tools currently available. An instrument utilizing WTP as the PRO also allows the clinician or researcher to gain a deeper understanding of true patient preferences that may guide resource allocation and treatment decisions.

APPENDIX: PSORIATIC ARTHRITIS WILLINGNESS-TO-PAY QUESTIONNAIRE

Disclaimer: Brigham and Women’s Hospital has made no investigation and makes no representations or warranties, express or implied, as to the questionnaire, Brigham and Women’s Hospital makes no representations or warranties of merchantability or fitness for any particular purpose or that the use of the questionnaire will not infringe any patients, copyrights, trademarks or other rights of any third party. In no event shall data generated by or conclusions drawn from use of the questionnaire be used for the provision of patient care. Brigham and Women’s Hospital shall not be liable for any direct, indirect or consequential damages to licensee or any third party, or with respect to any claim by any third party, on account of or arising from use of the questionnaire.

Burden of Psoriatic Arthritis Along 8 Dimensions: Intimacy, Physical Comfort, Concentration, Functionality, Emotional Health, Social Comfort, Self-Care, and Sleep

When patient arrives, assign a number to their file in sequential order from 000 to 999.

Interview Script

1. Think about your current overall health. Place a new VAS card in front of the subject. On the scale from 0 to 10 in front of you, where 0 is death and 10 is best imaginable health, please mark where you would rate your current overall health?

2. Other than psoriatic arthritis, has a doctor told you that you have any other diseases or medical conditions?

□ Yes

□ No

[If yes, then ask] What are they?

3. Now think ONLY about your current psoriatic arthritis [Place VAS card for psoriatic arthritis in front of subject.]. On another 0 to 10 scale, like the last 1 but this time with 0 equal to the worst psoriatic arthritis imaginable and 10 equal to no psoriatic arthritis at all, tell me where you would rate your current psoriatic arthritis?

Now I am going to ask you to consider how psoriatic arthritis, not any other medical conditions, affects different areas of your life. [Place card listing the 8 dimensions in front of subject.] Take a moment to consider how psoriatic arthritis affects these areas of your life. You will use this card for reference while you complete the next task.
4. Please place these cards in order. [Give subject 8 cards with dimensions and read each of the examples to them.] The top card should be the area that is most bothered by psoriatic arthritis and the bottom card should be the area that is least bothered by psoriatic arthritis. [Make a note of the order on the VAS card.]

For the next few questions, think ONLY about your PSORIATIC ARTHRITIS right now. I am going to ask you questions about each of the areas that you just considered and ranked. If you need an example or do not remember what 1 of the areas is, just ask [if subject asks, read examples on the VAS card to clarify] and we will reread the examples to you.

5. Intimacy. Think about your level of intimacy (closeness) with someone special. [Place Area 1 card in front of subject: closeness with someone special; hugging, kissing, sharing time together.] Does your psoriatic arthritis affect your ability to be intimate? I have placed a card in front of you that shows your choices.

☐ Option A—Psoriatic arthritis affects my ability to be intimate.

☐ Option B—Psoriatic arthritis does not affect my ability to be intimate.

**If no, end scenario here and move on to next dimension.**

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you could have the intimacy that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your ability to be intimate would remain (forever omitted) as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED level of intimacy?

☐ Yes

☐ No

[If yes, than ask] How much money would you be willing to pay? $_____

6. Physical comfort. Think about your ability to be physically comfortable. [Place VAS card in front of subject: moving or stretching your skin and joints freely; pain, itching, burning, tightness, pulling or stinging.] Does your psoriatic arthritis affect your ability to be physically comfortable? I have placed a card in front of you that shows your choices.

☐ Option A—Psoriatic arthritis affects my ability to be physically comfortable.

☐ Option B—Psoriatic arthritis does not affect my ability to be physically comfortable.

**If no, end scenario here and move on to next dimension.**

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you could have the physical comfort that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your physical comfort would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED level of physical comfortable?

☐ Yes

☐ No

[If yes, than ask] How much money would you be willing to pay? $_____

7. Self-care. Think about your ability to care for yourself. [Place VAS card in front of subject: taking care of your own body, health, and hygiene: dressing yourself (including shoelaces and buttons), shampooing or combing your hair, brushing your teeth, exercising, standing up from a chair, arising from the bed, cutting your meal, lifting a full cup or glass to your mouth, washing and drying your body, getting on and off the toilet, raising a 5-lb. object above your head, bending down to pick up clothing from the floor, open a car door, open previously opened jars, turn faucets on and off.] Does your psoriatic arthritis affect your ability to be care for yourself? I have placed a card in front of you that shows your choices.
Option A—Psoriatic arthritis affects my ability to care for myself.

Option B—Psoriatic arthritis does not affect my ability to be care for myself.

**If no, end scenario here and move on to next dimension.

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you could care for yourself in the way that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your ability to care for yourself would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED ability to care for yourself?

□ Yes

□ No

[If yes, than ask] How much money would you be willing to pay? $_____

8. Work, volunteer, home care. Think about your ability to work, volunteer, or take care of your home. [Place VAS card in front of subject: working outside of the home at a job, volunteering in the community, managing the home and/or garden, or caring for children.] Does your psoriatic arthritis affect your ability to care for yourself? I have placed a card in front of you that shows your choices.

□ Option A—Psoriatic arthritis affects my ability to work, volunteer, or take care of my home.

□ Option B—Psoriatic arthritis does not affect my ability to work, volunteer, or take care of my home.

**If no, end scenario here and move on to next dimension.

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you could work, volunteer, or take care of your home the way that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your ability to work, volunteer, or take care of your home would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED ability to work, volunteer, or take care of your home?

□ Yes

□ No

[If yes, than ask] How much money would you be willing to pay? $_____

9. Concentration. Think about your ability to concentrate. [Place VAS card in front of subject: focus on a task that you are trying to accomplish without getting distracted, ie, driving or reading.] Does your psoriatic arthritis affect your ability to concentrate? I have placed a card in front of you that shows your choices.

□ Option A—Psoriatic arthritis affects my ability to concentrate.

□ Option B—Psoriatic arthritis does not affect my ability to concentrate.

**If no, end scenario here and move on to next dimension.

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you could concentrate the way that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your ability to concentrate would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED ability to concentrate?
10. Emotional health. Think about your emotional health. [Place VAS card in front of subject: feelings and emotions, including anxiety, happiness, depression, sadness, anger, or fear.] Does your psoriatic arthritis affect your emotional health? I have placed a card in front of you that shows your choices.

☐ Option A—Psoriatic arthritis affects my emotional health.

☐ Option B—Psoriatic arthritis does not affect my emotional health.

**If no, end scenario here and move on to next dimension.

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you would have the emotional health that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your emotional health would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED emotional health?

☐ Yes

☐ No

[If yes, than ask] How much money would you be willing to pay? $_____

11. Social comfort. Think about your comfort around others. [Place VAS card in front of subject: how you feel when you are around other people, i.e., shaking hands and talking to people you have never met.] Does your psoriatic arthritis affect your comfort around others? I have placed a card in front of you that shows your choices.

☐ Option A—Psoriatic arthritis affects my comfort around others.

☐ Option B—Psoriatic arthritis does not affect my comfort around others.

**If no, end scenario here and move on to next dimension.

[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you would have the comfort around others that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your comfort around others would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED comfort around others?

☐ Yes

☐ No

[If yes, than ask] How much money would you be willing to pay? $_____

12. Sleep. Think about your ability to sleep. [Place VAS card in front of subject: rest or refresh yourself through the night; falling asleep, staying asleep.] Does your psoriatic arthritis affect your ability to sleep? I have placed a card in front of you that shows your choices.

☐ Option A—Psoriatic arthritis affects my ability to sleep.

☐ Option B—Psoriatic arthritis does not affect ability to sleep.

**If no, end scenario here and move on to next dimension.
[If they select Option A, then ask] Imagine a cure was available that would treat your psoriatic arthritis so that you would have the ability to sleep that you DESIRE. The cure is 100% effective, there are no side effects, the change would be permanent, and it would work immediately. Without this cure, your ability to sleep would remain as it is right now. Would you be willing to pay out of your own pocket for this cure if it would enable you to have your DESIRED ability to sleep?

☐ Yes
☐ No

[If yes, than ask] How much money would you be willing to pay? $_____  

13. Earlier in the interview, we asked you to consider how psoriatic arthritis affects different areas of your life. [Place card listing the 8 dimensions in front of subject] You then placed these [put VAS cards with dimensions and examples in ranked order in front of subject] cards in order. The top card is the area that was most bothered by psoriatic arthritis and the bottom is the area that was least bothered by psoriatic arthritis.

14. After showing people how much they would be willing to pay for each domain, ask: You told us you would be willing to pay these amounts to return to your desired level for each of the areas. Would you like to change the order of your cards after seeing how much you were willing to pay? [If anything is changed, make a note of the new order on VAS card.]

15. Would you like to change how much you were willing to pay after seeing the rankings?

☐ Yes
☐ No

16. What would you change and what is the new amount you are willing to pay?

1. 
2. 
3. 
4.

We are done with the questions about your psoriatic arthritis. Now I am going to ask you some questions about yourself.

17. Do you work outside of the home during the day?

☐ Yes
☐ No

18. How long do you have to wait to get an appointment with your Dermatologist when you have an urgent problem?

☐ Shorter than 2 weeks
☐ 2 weeks to 4 weeks
☐ 4 weeks to 6 weeks
☐ 6 weeks to 8 weeks
☐ Longer than 8 weeks

19. How long does it take you to get from home to your doctor’s office? _________

20. Do you have health insurance?

☐ Yes
☐ No
[If yes to insurance question, then ask] Do you have to pay a copay when you visit the dermatologist?  
☐ Yes  
☐ No  

[If yes, then ask] How much? $_____  

[If no to insurance question, then ask] How much do you have to pay out of your own pocket for an appointment with your dermatologist? $_____  

21. How old are you? _____ years old  

22. From the choices shown, what is your ethnicity? [Show Question 21 card, mark the 1 that fits their response.]  
☐ Hispanic or Latino  
☐ Not Hispanic or Latino  
☐ Unknown (not reported)  

23. From the choices shown, what is your race? [Show Question 22 card, mark the 1 that fits their response.]  
☐ White  
☐ African American  
☐ American Indian/Alaskan Native  
☐ Asian  
☐ Native Hawaiian or Other Pacific  
☐ Other  
☐ More than 1 race  
☐ Unknown or not reported  

24. What is the highest level of education you have had? [Show Question 22 card, mark the 1 that fits their response.]  
☐ Less than or some high school  
☐ High school graduate  
☐ Some college  
☐ College  
☐ Graduate degree  

25. How many people are in your household? __________ people.  

26. From the choices shown, what is your total annual household income? [Show Question 21 card, mark the 1 that fits their response.]  
☐ less than $10,000  
☐ $10,001 to $15,000  
☐ $15,001 to $25,000  
☐ $25,001 to $35,000
Would you like to be contacted for upcoming research studies of a similar nature by our group? Yes/No

If yes, can we contact you via email or telephone?

EMAIL __________ TELEPHONE ________________

Objective data to record during interview:

What is the patient’s gender?
27. □ Male
28. □ Female

Objective data regarding disease severity to be obtained from chart:

Psoriatic arthritis

● HAQ

REFERENCES