Involvement, satisfaction and unmet health care needs in patients with psoriatic arthritis

Y.-Y. Leung1, L. S. Tam2, K. W. Lee3, M. H. Leung4, E. W. Kun1 and E. K. Li2

Objective. To examine the involvement in care, participation in medical decision, satisfaction of health care and unmet needs in patients with PsA. To explore factors related to involvement and satisfaction with care.

Methods. One hundred and five patients with PsA attending four regional hospital rheumatology outpatient clinics were invited and consented to self-administer questionnaires, including socio-demographic data, quality of life with SF-12, involvement in medical decision, satisfaction with care and unmet health care needs.

Results. The overall perceived knowledge of disease was moderate. Good disease knowledge and good physical functioning were positively associated with involvement in care. Age, sex and pain scores were not associated with involvement in multivariate analysis. A low score in at least one question on involvement was the single independent negative predictor for satisfaction with health care. Only a minority (9%) was actively participating in medical decision-making. Among non-participants, 61.5% expressed the wish to participate. In aspects of education of disease, advice for exercise, psychological support and social support, respectively, 68.3, 73.3, 29.3 and 41.6% of the patients expressed unmet needs.

Conclusion. Low involvement is negatively associated with satisfaction with health care in PsA. Good knowledge of disease and good physical functioning is positively associated with involvement. The current study supports patient education as an important factor associated with involvement of and satisfaction with care in PsA patients. Such patients have a high desire for information and numerous unmet health care needs. There is a need for improvement in the delivery of care to patients with PsA.

Key words: Psoriatic arthritis, Patient involvement, Patient satisfaction, Unmet healthcare needs.

Introduction

A patient-centred approach in managing chronic illness has been increasingly advocated. This encourages patients to participate in and share control in treatment and management decisions that take into account individual preference within social contexts [1]. Patients’ participation in medical decision-making may improve outcomes and lead to better adjustment [2–4]. Patient education is important in the empowerment of patients, such that they can be involved in making medical decisions, and bring about improvements in health status [5–8]. Other factors like age, sex, level of self-efficacy, depression and health status also play important roles in disease outcomes [7–10]. Patients who are satisfied with health care are more likely to be involved in medical decision-making, and to be compliant with treatment strategies and less likely to experience adverse health outcomes [9, 11–13].

PsA is a well-recognized cause of chronic joint damage, disability and poor quality of life (QoL) [14–16]. For many years, the attention on PsA has been less than other arthropathies. To provide good-quality health care to this group of patients, their health care needs should be identified. An Italian study highlighted the desire for information among patients with psoriasis [17]. No study has investigated the involvement and satisfaction in health care and the unmet health care needs in PsA. This study was undertaken to explore the involvement and satisfaction with health care and the unmet health care needs in patients with PsA. We also evaluated factors that lead to involvement and participation in medical decision in patients with PsA.

Methods

Patients

Consecutive patients with PsA attending four regional rheumatology outpatient clinics were recruited. All patients were adults aged ≥18 yrs and fulfilled CASPAR criteria for PsA [18]. Patients were requested and consented to self-administer questionnaires on demographic data, QoL, adequacy of perceived care, participation in medical decision, satisfaction with health care and specific health care needs. The study protocol was reviewed and approved by the respective clinical research ethics committees.

Demographic data and clinical variables

Demographic data included age, sex, educational level, marital status and employment. Patients were asked on their own level of perceived knowledge on PsA. The level of PsA knowledge was scored on a 5-point scale from 1 (very adequate) to 5 (totally inadequate). Clinical variables including pain score and fatigue were assessed on 0–100 visual analogue scales (VAS); patients’ global perception of skin and general health status were assessed on 0–10 VAS. Mobility and comorbidities were recorded. QoL was assessed by the standard SF-12 Health Survey (SF-12). SF-12 has been validated in Chinese population [19]. The Physical Component Summary (PCS) and Mental Component Summary (MCS) scores were computed.

Involvement and satisfaction in care

Patients were asked the following three questions on involvement in health care. (i) How do you grade your received information regarding your disease and treatment? (ii) How do you grade your received information on exercise and joint protection? (iii) How do you grade the adequacy of psychological support you received? Each question was scored on a five-point scale from 1 (very adequate), 2 (quite adequate), 3 (acceptable), 4 (inadequate) to 5 (totally inadequate). The wordings of the scores suggest that the scores of involvement are not on a linear scale. Results were thus dichotomized to high involvement with scores 1–3 and low involvement with scores 4 or 5. Satisfaction with health care was...
assessed by a separate question, scoring from 1 (very satisfied) to 5 (totally dissatisfied). In analysis, satisfaction with health care was segregated into high or low satisfaction.

**Participation in medical decision-making**

Patients were asked whether they had been participating in medical decision-making, on a three-point scale: 1 (no participation), 2 (some participation) and 3 (active participation). Patients with some or active participation were categorized as ‘participants’, while those with no participation were categorized as ‘non-participants’. Patients’ wish to participate in medical decision-making was recorded as ‘yes’ or ‘no’ answers.

**Unmet health care needs**

The unmet health care needs were explored by the following questions. (i) Do you wish for more information on your disease? (ii) Do you wish for more information about exercise and joint protection? (iii) Do you wish for more counselling support? (iv) Do you wish for more social support? Answers were recorded as: 1 (yes), 2 (no opinion) or 3 (no).

**Statistical analysis**

Involvement in care and satisfaction with care were dichotomized to high (scores 1–3) and low (scores 4 and 5) scores for analysis. Patients having a low score in at least one question of involvement in health care were identified as low involvement group. Participation in medical decision was dichotomized to ‘participants’ if they had at least some participation and ‘non-participants’ if no participation. Statistical comparisons between patients with low and high involvement in health care, participation and satisfaction were performed by t-test for the continuous variables, and two-sided chi-square test for independent variables. Variables with P-value < 0.25 in the univariate analysis were entered into linear regression analysis. All hypotheses were two-tailed and P-values < 0.05 were considered statistically significant. Analyses were performed using the Statistical Package for Social Science (SPSS for Windows, version 10.0, SPSS Inc., Chicago, IL, USA).

**Results**

One hundred and five PsA patients were studied. Demographic data on health status of the cohort are shown in Table 1. A total of 21.1% of the patients reported having received inadequate information about their disease and treatment, 34% reported having inadequate information for exercising and joint protection and 37.6% reported having inadequate psychological support.

Fifty percent of the patients scored low in at least one question on involvement. Forty-three percent reported low satisfaction to health care while only 11% and 1% reported quite and very satisfied with health care, respectively.

A total of 79 (76.7%) patients reported having no participation in medical decision-making (non-participants), 14.6% had some participation in medical decision-making, while only 8.7% felt themselves as actively participating. Among those 79 patients currently not participating in making medical decision, 61.5% expressed the wish to participate.

Level of involvement and satisfaction with health care were significantly related (chi-square test $P < 0.001$). Of the patients who scored low in at least one domain of involvement, 75% reported dissatisfaction compared with 13.7% of the rest.

Patients with high scores on involvement reported less pain, had better knowledge of disease, better skin condition, better physical functioning and mental health (Table 2). There was no association with age and educational level. In multivariate analysis, better physical function and better knowledge of disease were related to higher involvement (Table 3). Patients with better satisfaction with health care were younger, had better knowledge of their disease, better skin condition and better mental health (Table 2). In multivariate analyses, low score in at least one question on involvement was the single negative association factor with satisfaction with health care. By removing this involvement factor from the model, good mental health was associated with satisfaction with care (Table 3).

**Table 2. Comparison of PsA patients with high and low scores on participation in medical decision and global satisfaction**

<table>
<thead>
<tr>
<th>Low involvement in at least one domain</th>
<th>Participation in medical decision</th>
<th>Global satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No (n = 51)</strong></td>
<td><strong>Yes (n = 51)</strong></td>
<td><strong>Yes (n = 22)</strong></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>48.2 ± 12.2</td>
<td>51.8 ± 12.1</td>
<td>44.2 ± 10.5</td>
</tr>
<tr>
<td>Female, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>47.1</td>
<td>54.9</td>
<td>28.6</td>
</tr>
<tr>
<td>Disease duration, yrs</td>
<td>9.8 ± 7.1</td>
<td>9.6 ± 6.8</td>
</tr>
<tr>
<td>Living with spouse, %</td>
<td>66</td>
<td>72.5</td>
</tr>
<tr>
<td>Education &gt; 9 yrs, %</td>
<td>44</td>
<td>47.9</td>
</tr>
<tr>
<td>Unemployment, %</td>
<td>10</td>
<td>7.8</td>
</tr>
<tr>
<td>Social welfare dependence, %</td>
<td>17.6</td>
<td>15.7</td>
</tr>
<tr>
<td>&gt;2 comorbidities, %</td>
<td>25.5</td>
<td>28</td>
</tr>
<tr>
<td>Self-knowledge of disease*</td>
<td>2.73 ± 0.53</td>
<td>3.35 ± 1.02**</td>
</tr>
<tr>
<td>Pain (0–100)</td>
<td>39.2 ± 24.6</td>
<td>50.1 ± 25.4*</td>
</tr>
<tr>
<td>Patients’ global (0–10)</td>
<td>4.38 ± 2.22</td>
<td>4.85 ± 2.19</td>
</tr>
<tr>
<td>Skin global (0–10)</td>
<td>4.84 ± 2.61</td>
<td>5.52 ± 2.31*</td>
</tr>
<tr>
<td>PCS (10–0)</td>
<td>39.47 ± 1.76</td>
<td>39.21 ± 0.99*</td>
</tr>
<tr>
<td>MCS (0–100)</td>
<td>45.05 ± 11.16</td>
<td>40.78 ± 10.59*</td>
</tr>
</tbody>
</table>

*Higher score indicates poorer knowledge. PCS = physical component summary of SF-12; MCS: MCS of SF-12; Patients’ global: patients’ global perception of health; Skin global: patients’ global assessment of skin condition.
On exploration of patients’ health care and social needs, high percentages of patients expressed unmet needs in various aspects (Fig. 1). The proportions of patients who were interested in joining various care programmes are illustrated in Fig. 1.

### Discussion

Satisfaction with care is increasingly seen as an indicator of quality of health care [11, 20]. In addition, a high satisfaction could help patients to adhere to treatment [21]. This is the first study to explore factors associated with better involvement in health care and overall satisfaction in a cohort of PsA of moderate size. We have demonstrated that involvement in health care and overall satisfaction are closely interrelated. High level of perceived knowledge of disease and good physical functioning were positively associated with involvement. A low score on at least one question on involvement was the single independent negative predictor for satisfaction. This corresponds with previous studies on patients with other chronic arthritis [9, 12, 13].

Patient education is an integral part of patient involvement. In this study, high knowledge of disease was associated with higher involvement and satisfaction, and supports that patient education should be one of the cornerstones for good care in patients with PsA. This agrees with studies in RA and AS [12, 13, 22, 23]. In other studies, education programmes aiming to enhance patient’s efficacy facilitated involvement and improve satisfaction [7, 8].

Despite the fact that our patients had long-standing disease, a sizeable percentage (21.6%) reported low scores for PsA knowledge. The overall PsA knowledge scoring was only moderate (3.04 ± 0.87). Even among those with high level of perceived knowledge of disease, 65% expressed their wish in wanting more information. This shows that PsA patients in our cohort had high desire for information. A high desire for information has also been reported among patients with RA [22, 23] and psoriasis [17]. A reason for this great desire for information might be that the disease entity is relatively ‘new’. Many patients thought themselves as having RA as they were told years ago. Second, the fluctuating and progressive nature of arthritis may also create a need for ongoing concern. Moreover, the rapid development of new treatment modalities focused on the need for new information.

On the other hand, information-seeking behaviour and participation in medical decision may be different domains. A half of our patients had reasonable involvement in health care, but only a minority of them was actually participating in medical decision-making. This suggests that patients want to be informed but may not necessarily want to make medical decisions. Several studies including one in RA patients also demonstrated the dissociation between information-seeking behaviour and decision-making preference [23–25]. An interesting part not dealt with in our study is that, among those with no participation in medical decision, however, 61.5% expressed the wish to participate. Braddock et al. [26] examined the completeness with which primary care doctors involve patients in decision-making. Of the 1057 encounters tape-recorded, only 9% fulfilled the definition of completeness for shared decision-making. It seems that rheumatologists should be more proactive in giving information and to develop skills to facilitate patient involvement and decision making.

This is also the first study to explore the domains of health care needs in patients with PsA. Unmet health care needs could have resulted from patients’ health status as well as the adequacy of health care facilities. As one of the main issues of unmet health care need is on the delivery of care and access to various health care services, we focused only on the health care areas that patients feel inadequate at the time of assessment. Although preliminary, it reveals that this cohort of patients would need more health care services. This may give clues to the priority of target areas for improvement. There were alarming desires for information about disease and advice on exercise, even among those with good perceived knowledge of disease. This again echoes with the high desire of information among PsA patients as discussed previously. In addition, a high percentage of patients expressed interest in joining various care programmes, indicating that they are motivated to participation. This indicates a need for further improvement in the delivery of care among patients with PsA.

There are several limitations to our study. First, the cross-sectional design cannot tell the cause and effect relation and whether improvement of patient education could improve involvement and satisfaction. Another limitation is that the questionnaire we used to assess patients’ knowledge, involvement in health care and satisfaction has not been tested for psychometric properties. The measurement of involvement in health care and satisfaction were not expected to be on a linear scale. A graduated relationship between patient education and improving patient outcomes cannot be demonstrated. However, the association with disease knowledge and patient involvement has been clearly shown. Age and years of formal education were not associated with involvement. This indicates that the organization and content of care may be stronger factors to influence patient’s involvement, and implies room for improvement in the delivery of care by health care providers.

A big area of unmet needs that we have not explored in this study is the access to rheumatology services, like access to rheumatologists in times of disease exacerbation, adequacy of consultation time, continuity of patient care, etc. These parameters are expected to have influences on overall satisfaction with health care. In addition, we did not study the differential effect of

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### Table 3. Multivariate regression analysis of variables associated with involvement and satisfaction

<table>
<thead>
<tr>
<th>Clinical variables</th>
<th>β</th>
<th>95% confidence interval</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement</td>
<td>PCS</td>
<td>0.204</td>
<td>0.001, 0.020</td>
</tr>
<tr>
<td></td>
<td>PsA knowledge</td>
<td>-0.354</td>
<td>-0.308, -0.095</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>Low involvement</td>
<td>-0.664</td>
<td>-0.810, -0.504</td>
</tr>
<tr>
<td></td>
<td>MCS</td>
<td>0.255</td>
<td>0.002, 0.020</td>
</tr>
</tbody>
</table>

*Higher score indicates poorer knowledge. Low score in at least one question of involvement was removed from model. PCS: PCS of SF12; MCS: MCS of SF12; Low involvement: low score (3.04±0.87).

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FIG. 1. Unmet needs of PsA patients.

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Percentage of patients expressing unmet needs in various aspects:

| Need for information of disease | 65.50% |
| Need for advice on exercise    | 68.30% |
| Need for counselling           | 73.30% |
| Need for social support        | 51.60% |
| Use of alternative medicine   | 33.70% |

Percentage of patients interested in joining various social programs:

| Educational talk               | 50.5% |
| Rehabilitation programme       | 90.0% |
| Patient self-help group        | 32.0% |
| Personal counselling           | 22.1% |
| Social gathering               | 31.1% |

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On involvement and satisfaction, 65% expressed their wish in wanting more information. This shows that PsA patients in our cohort had high desire for information. A high desire for information has also been reported among patients with RA [22, 23] and psoriasis [17]. A reason for this great desire for information might be that the disease entity is relatively ‘new’. Many patients thought themselves as having RA as they were told years ago. Second, the fluctuating and progressive nature of arthritis may also create a need for ongoing concern. Moreover, the rapid development of new treatment modalities focused on the need for new information.

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health care provided by doctors or nurses. An English study has shown that knowledge and satisfaction with health care improved by seeing a rheumatology nurse practitioner [27].

In conclusion, higher involvement in and satisfaction with health care are closely related. Our study suggests that education is an integral part of successful management of patients with PsA. Patients with PsA have high desire for information and have numerous unmet health care needs. There is a need for improvement of the care delivered to patients with PsA.

### Rheumatology key messages

- PsA patients have a high desire for information and numerous unmet health care needs.
- Patient education is an important factor associated with involvement of and satisfaction with care for PsA patients.

### Acknowledgements

We thank all the PsA patients for their considerable time and effort contributed toward this project. We would also like to thank our rheumatology nurses and research assistants Bik Ki Chan, Eva Hsu, Tena Li, Lorraine Tsang and Mei Tze Wong for their contributions in data collection and entry.

### Disclosure statement: The authors have declared no conflicts of interest.

### References