

# Patient Perspective in Outcome Assessments — Perceptions or Something More?

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**ABSTRACT.** Health status measures constitute an essential part of outcome assessments in patients with rheumatic diseases. Currently used health status measures typically assess patient perceptions within various dimensions of health. The issue of widening patient perspective in outcome assessments was raised at OMERACT 2000 and further activities were initiated at the subsequent American College of Rheumatology meetings. Measuring patient perceptions of health is considered the standard approach in clinical practice, controlled clinical trials, and longitudinal observation studies, as well as in other types of epidemiological research. However, the traditionally used instruments also have limitations based on the relevance of the questionnaire items, sensitivity to change in longitudinal observational studies, and intraindividual variations over time. Patient priorities or preferences for improvement in health may be an alternative for the assessment of important patient outcomes. Data support that patient priorities for improvement in health are associated with their perception, but that overlap is incomplete and that complimentary information may be achieved. Expectations about future health and satisfaction with health may also represent alternative approaches. Thus, an open research agenda is required for the future, including different approaches regarding both endpoints and methodological issues. (J Rheumatol 2003;30:873–6)

*Key Indexing Terms:*

PRIORITIES RHEUMATOID ARTHRITIS HEALTH STATUS MEASURE HEALTH CARE

In today's society, democratic principles are based on information, opportunity to choose between different options, and responsibility of the individual. A health service in line with these ideals would not only have knowledge of the patient's perspective and preferences but would include it in research and in clinical practice. Studies have shown discrepant views between patients and clinicians on patient health<sup>1-4</sup>, which again clearly may influence divergent descriptions of and priorities for care and treatment. The lack of a patient-centered approach to assessing needs for care may lead to ignorance of key symptoms and issues preferred by individuals<sup>5</sup>.

This review will focus on the perspectives that patients with rheumatoid arthritis (RA) have on their own health. However, patients' views or perceptions on the health care they receive are not included.

## Health Status Measures

Since the introduction of questionnaires to systematically assess the perceptions of patients across physical and other outcomes in 1980<sup>6,7</sup> a large amount of data have appeared in

support of health status measures as an essential part of outcome assessment; moreover, questionnaire data are valid predictors of other health-related outcomes, including mortality<sup>8</sup>.

Currently, widely used health status measures typically assess the patient's perceptions within various dimensions of health, e.g., their self-reported ability to perform activities, their self-reported pain intensity or mental distress. With increasing focus on putting the patient at the center of the provision of care<sup>9</sup>, it is relevant to ask if health perception scores only are the best way of reflecting patients' own priorities in terms of their need for care. Further, it may also be possible that outcome measures could be improved in terms of truth and responsiveness by incorporating other considerations about health, e.g., patient satisfaction with health, expectations about their future health, and preferences or priorities for improvement in different areas of health.

## Patient Perspective

The issue of widening patient perspective in outcome assessment was raised at the OMERACT 5 Conference in 2000, and a review on this topic was included in the proceedings<sup>10</sup>. This article focuses on individualized functional priority questionnaires that allow patients to specify and prioritize their personal disease-related problems.

OMERACT 5 initiated some new, subsequent activities in this area. A multidisciplinary network group was established during the 2000 American College of Rheumatology (ACR) Scientific Meeting in Philadelphia to develop valid

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outcome instruments that could incorporate the perspective of the patient — including concepts such as perceptions, priorities for improvement, expectations, or satisfaction with health — and to prepare evidence and arguments for their possible inclusion into the “core set” of outcome measures in RA. Group members concurred on the need for including these concepts when eliciting the patient perspective.

The group had an informal session just prior to the 2001 ACR meeting in San Francisco. Issues discussed included use of focus groups to more clearly establish patient views and opinions about their health, limitations on the use of currently accepted functional assessments across different cultures and societies, the personal impact of disability, the most appropriate method for assessing pain, and patient priorities for improvement across different areas of health. The discussion covered a broad range of research that applies traditional quantitative approaches as well as qualitative research.

### Health Perceptions

Measuring patients' perceptions of health is considered the standard approach in clinical practice, in controlled clinical trials and longitudinal observational studies, as well as in other types of epidemiological research. This is done in a variety of rheumatic diseases either by applying scales focusing on one dimension of health [e.g., the disability score obtained by the Health Assessment Questionnaire (HAQ), the pain intensity score obtained by a visual analog scale (VAS)] or by using instruments capturing information on several dimensions of health. Instruments of this class are either disease-specific, e.g., the Arthritis Impact Measurement Scale 2 (AIMS2, arthritis)<sup>11</sup> and WOMAC (osteoarthritis)<sup>12</sup>, or generic, e.g., the Medical Outcome Study Short Form-36 (SF-36)<sup>13</sup>. In general, such measures have proven to be valid and responsive<sup>14,15</sup>. However, in longterm epidemiological studies changes in disability scores are slow<sup>16</sup> and reproducibility is not very satisfactory<sup>17</sup>. Data from repeated examinations have demonstrated major intraindividual variations over time, highlighting that the health status scores should be interpreted with caution when they are used in clinical decision making on the individual level<sup>17</sup>. For example, the 95% limits of agreement for HAQ score in RA has been shown to be 0.48<sup>17</sup>, 0.45 for the modified HAQ, and 20 for the physical component of SF-36<sup>18</sup>. These data at least indicate that further research should improve the performance of currently used health status measures.

### Expectations About Future Health

Data on patient self-reported expectations about their future health are very sparse. Such data are most commonly related to expectations about, for example, the quality of care and health care provision. There are no data to support that

examination of patient expectations about future health provides information that is complementary or adds important information to measures that capture perceived health status.

### Satisfaction with Health

Some studies have addressed patient satisfaction with health within different domains. As early as 1983, Pincus, *et al* examined patient satisfaction with their performance of daily activities within the MHAQ format, in addition to examining their difficulties with the performance of the same activities<sup>19</sup>. The authors indicate that assessment of satisfaction may provide some complimentary information, but this part of the instrument was not further developed or explored in depth. When AIMS was revised as AIMS2<sup>11</sup>, patient satisfaction with their health in the 12 different areas was examined, but this part of the questionnaire has never been the main focus in research or clinical practice. Other attempts to develop specific instruments to focus on satisfaction include the Satisfaction with Abilities and Well-being Scale<sup>20</sup>. Several studies have indicated that dissatisfaction with the performance of illness-related activities can exaggerate psychological distress<sup>21,22</sup>.

### Preferences/Priorities for Improvement in Health

It is reasonable to assume that reported preferences for improvement would be important. It is not evident that, for example, a HAQ score or a pain VAS score reflects the importance for the patient to achieve improved physical function or relief of pain, respectively. Therefore, several attempts have been made to incorporate patient values and priorities into assessment of health status.

Patient preferences are addressed in the McMaster Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR)<sup>23</sup> and in the Problem Elicitation Technique (PET)<sup>10,14</sup>. The MACTAR and PET mainly ask the patients to indicate which functional ability they would like to see improved. Pain is seen as an obstacle to performance of activities, but is not used as a separate standardized outcome alternative<sup>24</sup>. Both MACTAR and PET have been found to be responsive in clinical trials<sup>10,14,24</sup>, but feasibility is limited when using versions of the instruments that require an interviewer.

Another approach has been the development of a performance based instrument, The Canadian Occupational Performance Measure (COPM), which captures client-centered outcomes. The COPM measures individuals' perceptions of disability by identifying those tasks that are important to them and difficult to perform<sup>25</sup>.

When the AIMS was revised, the aspect of examining patients' priorities for improvement in health was taken into account. The patients were asked to report 3 out of 12 areas of health (mobility, walking and bending, hand and finger function, arm function, self-care tasks, household tasks,

social activity, support from family and friends, arthritis pain, work, level of tension, mood) in which they would most like to see improvement<sup>11</sup>. This version of the AIMS2 questionnaire has been used to collect information about the areas of health in which patients would most like to see improvement, but major studies combining the preferences and perception scores have not been published.

It may be suggested that awareness of patients' preferences may offer health professionals the opportunity to include patients' own values and priorities when performing patient care<sup>26</sup>. This again may lead to more effective and efficient delivery of health care<sup>27</sup>. It has been consistently found that pain is the area where most patients would like to see improvement, both in RA<sup>11,28,29</sup> (and P. Minnock, personal communication) (Figure 1) and osteoarthritis<sup>30</sup>. On the other hand, it is doubtful that pain intensity is the area most health professionals or rheumatologists concentrate on when managing patients with RA. Thus, it is possible that awareness of the patients' preferences for improvement may be one salient premise for priorities in health care. This is further underlined by differences in perception between health professionals and patients regarding patient health status and need for care<sup>1-4</sup>.

As expected, patient priorities for improvement in different health areas are closely related to the level of health status in that particular area. Thus, patients with increased levels of pain prioritize improvement in pain more often than patients with lower pain levels<sup>29</sup>. Since preference for improvement within one particular area of health was associated with worse health status in that area, it may be relevant to ask whether assessment of health status would be a sufficient indicator of patient preferences. However, about 50% of patients within the lowest quartile of pain scores still reported pain as an area of health where they would like to see improvement<sup>29</sup>. This discrepancy indicates

that assessment of patient preferences for improvement in health provides complementary information to traditional health status assessments, but further research is required to clarify this issue.

Although the AIMS2 has been used to explore priorities for improvement across different health dimensions, it may not be the ideal instrument for further exploration of this part of the patient perspective in outcome assessment. As many as 6 items represent the physical functions, whereas only one item represents pain. The distribution of preferences reported (Figure 1)<sup>11,28,29</sup> (and P. Minnock, personal communication) could have been different if, for example, major dimensions of health, e.g., physical functions, social functioning, pain, fatigue and mental distress, were represented by only one item each.

Unpublished results using a new approach in the assessment of perception and preferences for improvement support that patient priorities for improvement in health dimensions are statistically related to levels of health status in that particular dimension, but these preliminary data also suggest that the combination of both approaches may provide additional information (Heiberg T, *et al*, unpublished data).

### The Way Forward

Patient perspective in health assessment is important, from both a clinical and scientific viewpoint. Further, focusing on the patient is very relevant in today's society, in which health care requires patients' consent and participation<sup>31</sup>. Patient rights have been declared in many documents and the Bone and Joint Decade has advocated stronger incorporation of patient views, as well as the patient's right to define their needs for health care. Data support that patient priorities for improvement in health are associated with their perception, but the overlap is incomplete. Thus, assessment

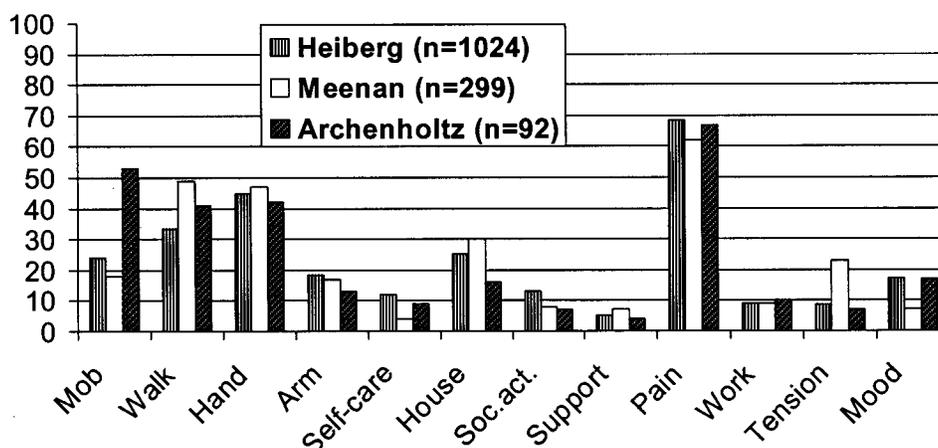


Figure 1. Proportions of RA patients reporting priorities for improvement in health in various areas of health, assessed by AIMS2<sup>11</sup>. Data from Meenan, *et al*, Arthritis Rheum 1992;35:1-10<sup>11</sup>; Archenholtz and Bjelle, J Rheumatol 1997;24:1370-7<sup>28</sup>; and Heiberg, *et al*, Arthritis Rheum 2002;47:391-7<sup>29</sup>.

of patient preferences for improvement in various areas of health may provide information that is complementary to the assessment of health status alone. Combining the 2 sources of information may be a future approach, as was done in the MACTAR by weighting priorities. However, the research agenda should at this stage be very open, including several approaches, regarding both endpoints and methodological issues. Finally, proposals of new measures should be validated within the concepts of OMERACT<sup>32</sup>.

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