# Asthma and Health-Related Quality of Life

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#### **ABSTRACT**

The health-related quality of life (HRQoL) is assessed using instruments that have been validated scientifically. From the viewpoint of assessment, they are different from other clinical indices because the subjects themselves evaluate their own HRQoL (the patients in many clinical settings). As an index for evaluating health care services or outcomes, the HRQoL is as important as life expectancy. These instruments can be classified into generic and disease-specific instruments. There are numerous disease-specific instruments that can be used for patients with asthma, such as Juniper et al.'s Asthma Quality of Life Questionnaire (AQLQ), the Living with Asthma Questionnaire (LWAQ), the St. George's Respiratory Questionnaire (SGRQ), and Marks et al.'s Asthma Quality of Life Questionnaire (AQLQ). The characteristics of each instrument should be considered in the selection of specific HRQoL questionnaires for clinical research. Generally, the HRQoL is more disturbed in patients with severe asthma, and has been considered to be an important end-point in randomized controlled trials that involve asthma patients. We expect that further studies will also be performed in Japan.

#### **KEY WORDS**

Asthma Quality of Life Questionnaire (AQLQ), Health-Related Quality of Life (HRQoL), health status, Living with Asthma Questionnaire (LWAQ), Nottingham Health Profile (NHP), St. George's Respiratory Questionnaire (SGRQ)

#### INTRODUCTION

Unfortunately, the term quality of life (QoL) is frequently used as an abstract term in Japan. However, it is commonly accepted in the health care services and in relation to illness that QoL should be assessed using scientifically established instruments, mostly questionnaires. <sup>1-5</sup> In general, the QoL is a comprehensive concept influenced by factors such as economic status, occupation, and housing, which are not directly related to the health status. In the fields of health care services or in relation to health or illness, the term health-related quality of life (HRQoL) is preferred. <sup>1</sup>

It is a well-known fact that an immense amount of public resources is administered for health care services all over the world. However, healthcare providers are largely unaware that they are consuming public resources. Therefore, it is necessary to evaluate these health care services. Improvements in life expectancy and HRQoL can be considered as clinical indices for evaluating such an outcome. It would be

ideal if all medical interventions improved both life expectancy and HRQoL. However, many practices are actually performed on the presumption of improving these indices, and are based on experience rather than scientific evidence. For assessing individual treatment efficacy such as the effect of a drug, it is necessary to consider the HRQoL assessment as an outcome in randomized controlled trials. Moreover, HRQoL assessment provides the fundamental data for economic evaluation, for example cost-utility analysis.

From the viewpoint of assessment, the subjects themselves assess their own HRQoL, and it has been shown that it is difficult for healthcare providers to predict the HRQoL, even considering other clinical or physiological information. In health care services, information obtained directly from subjects by interviews, self-reported questionnaires, or diaries is referred to as patient-reported outcomes (PROs) or self-reported outcomes. The term PROs is used from the viewpoint of assessment rather than the content. It also raises the issue that many indicators for illness

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Email: koichi-nishimura@nifty.com Received 26 January 2004. ©2005 Japanese Society of Allergology or health have been assessed by healthcare providers rather than by the patients themselves. The HRQoL is the best-known among the PROs.<sup>6</sup>

## METHODS OF ASSESSMENT AND GENERIC INSTRUMENTS

The HRQoL is assessed by using self- or interviewer-administered questionnaires as instruments. <sup>7</sup> Although various questionnaires have been advocated and used as instruments depending on the purpose of the assessment, the reliability, validity, and responsiveness of each questionnaire must be proven in order to know whether the HRQoL can be assessed scientifically. It usually requires a long-term patient approach to perform the scientific verification of an instrument.

The HRQoL in general should be assessed comprehensively, including several subscales. Each question in a questionnaire is called an item, and domains, dimensions or components, which often consist of multiple items, correspond to each subscale (which is referred to as a profile). The HRQoL should include components such as symptoms, functional capacity, psychological status and social interactions. Furthermore, there is also a viewpoint that components such as degrees of occupational and intellectual function, economic aspects, and overall satisfaction, should also be included. Depending on the specific purpose, components that should be included are determined, and their scores are calculated with or without weighting, and then instruments are created in order to express the measured results as numerical values.

When assessing the HRQoL in patients with a specific disease, either a generic or a disease-specific instrument can be selected depending on the purpose. The greatest advantage of the former is that it can be applied as an epidemiological approach. For example, assessment by a generic instrument is necessary for comparison between different diseases.

Generic instruments including the Sickness Impact Profile (SIP), Nottingham Health Profile (NHP), and SF (short-form)-36 of the Medical Outcomes Study (MOS) have all been administered to patients with asthma in the literature. The SIP has been used as the standard questionnaire amongst the generic instruments in the past.<sup>8,9</sup> However, the clinical application of the SIP is complicated because it consists of many items, and it takes a long time to complete. Although the original purpose of the NHP developed in the United Kingdom was to assess perceived distress, 10-12 it has been used by many researchers as a method to assess the HRQoL. 13,14 The HRQoL assessment in the MOS, an international project developed around the United States, often uses a method with 36 items (short-form: SF-36).15 In studies on chronic diseases, the SF-36 is the most used generic instrument at the present.<sup>16</sup> The Japanese version of the SF-36 was established by Fukuhara and colleagues based on an analysis of the responses obtained from a general population sample. <sup>17,18</sup> The software for scoring is commercially available along with the Japanese standard values, and they are very convenient for end-users. The WHO first published the WHOQOL-100, a questionnaire with 100 items, and then the WHOQOL-BREF, an instrument with 26 items based on the former. The reliability and validity of the Japanese version has also been reported.

The author would like to introduce an example of using a generic instrument here. 19 A comparison of the HRQoL assessed with the NHP is illustrated in Figure 1 for patients with asthma and chronic obstructive pulmonary disease (COPD), and HIVinfected persons. The NHP scores in the patients with the former two diseases were investigated previously by this author. The other scores were obtained from HIV-infected persons in Japan by Watanabe and coworkers (The QoL Research Group of the AIDS Clinical Center and eight Regional AIDS Treatment hospitals in Japan supported by a Research Grant from the Ministry of Health, Labour and Welfare of Japan).<sup>19</sup> Since it is well-known that the HRQoL is adversely affected, COPD is a model disease for HRQoL research. Even though the figure does not account for age or gender, the NHP scores of the HIVinfected persons are more severely affected than those of the patients with asthma or COPD. In studies that compared the HRQoL of patients with asthma versus patients with COPD using generic instruments, the relative disturbance of patients with asthma is usually milder than that of patients with COPD. Moreover, in cross-sectional studies on patients with asthma, a deviation of the score distribution cannot be avoided when a generic instrument is used.

In order to be used for pharmaco-economic evaluation, including cost-utility analysis as well as quality-adjusted life year (QALY), a utility measure or a preference-based measure is necessary. Japanese versions of the EQ5D (EuroQol) and Health Utility Index (HUI) have been established for this purpose. Since there are also many reports using the EQ5D in chronic respiratory illnesses in western countries, there is a tendency to use it to measure outcomes for economic evaluation in randomized controlled trials in Europe and the United States.

## DISEASE-SPECIFIC INSTRUMENTS IN ASTHMA

In respiratory illnesses, there have been many studies investigating the HRQoL of patients with asthma as well as COPD and lung cancers, and numerous disease-specific instruments have been published (Table 1). The American Thoracic Society has set up the Quality of Life Resource (http://www.atsqol.org/) on its website, and listed instruments to assess the indices related to QoL and symptoms. For adults with

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