

## Health Related Quality of Life Questionnaires and Cross-Cultural Adaptation Problems

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### Abstract:

*Since the concepts of health and illness may differ from society to society, the perception of quality of life can be affected by cultural influences and beliefs. It is obvious that the cross cultural differences between eastern and western cultures have great importance in the field of health care setting as well as in other fields. As a result of an increased demand for measuring the quality of life in health care, clinicians and researchers without a suitable Health Related Quality of Life (HRQoL) questionnaire in their own language, generally prefer subjecting a questionnaire previously validated in another language to a cross-cultural adaptation process because it is seen as a resource-saving strategy. During the adaptation process of a HRQoL questionnaire, the researchers not only do translations, but also make every effort to maintain a cultural equivalence. Especially in the adaptation of some measures originated from western countries to eastern countries, it is important to reflect significant cultural differences. Discrepancies in socioeconomic status, health perceptions,*

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*religion and traditional beliefs should be considered in the modification of a quality of life questionnaire.*

**Key words:** Cross-cultural adaptation, Health Related Quality of Life Questionnaires, Quality of life

## **Introduction**

Quality of Life (QoL) is defined as an individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.<sup>1</sup> In medicine, Health Related Quality of Life (HRQoL) is a component of the overall quality of life that is determined primarily by the person's health, and which can be influenced by clinical interventions.<sup>2</sup>

In recent years, HRQoL and its measurability have been studied extensively by the aim of providing more accurate assessments of individuals' or populations' health and of the benefits and harm that may result from health care.<sup>3</sup> It is argued that HRQoL instruments provide a tool to assess the impact of disease, the effect of treatment and other variables affecting people's lives.<sup>4</sup> Within this scope, HRQoL measures enable individuals to describe the experiences developed in health and illness in a quantitative way. Its main aim is to change subjective measures into objective ones. HRQoL measures are increasingly used in clinical trials to determine the impact of medical intervention on the quality of life, and by public health researchers to assess the outcome of health care services.<sup>5</sup> Today, since the resources in health care services are limited, the 'quality of life' criterion has been used to choose patients for treatment or for non-treatment.<sup>6</sup> Despite their some positive contributions into the medical field, quality of life questionnaires have also been controversial from ethical perspective.<sup>7</sup>

## **Cross-Cultural Adaptation of Health Related Quality of Life Questionnaires**

As a result of an increased demand for measuring the quality of life in health care, clinicians and researchers without a suitable HRQoL measure in their own language prefer subjecting a measure previously validated in another language to a cross-cultural adaptation process rather than developing a new measure. Adapting questionnaires into country- or region-specifics dialects and into a cultural context and lifestyle is defined as a “cross-cultural adaptation” process.<sup>5,8</sup>

Today, the translation and cultural adaptation of instruments is an internationally recognized method. Translation consists of obtaining a version that is semantically equivalent to the original. Cross-cultural adaptation is necessary when the instrument is intended for use on a target population that is culturally different from that of the original version. This could require either the alteration or removal of items from the original scale.<sup>8</sup>

For instance in Turkey, just as in other countries, there is an increasing interest for HRQoL studies. Most of them were done for cross-cultural adaptation process of a questionnaire from a different cultural origin and for determining the validity and reliability of its Turkish version. In the adaptation of some measurements from western countries to those from Turkey, it is important to reflect the significant cultural differences. Otherwise, some problems can emerge in equivalence process in which attempts to produce equivalency between the source and target based on content.

There are many forms of equivalence least commonly mentioned in the HRQoL literature. Semantic, experiential, and conceptual equivalences are some of them.<sup>9</sup>

**Semantic Equivalence** refers to the correct translations between items and concepts; it is also referred to as functional equivalence.<sup>10</sup> The objective of a translated

questionnaire is to produce the same responses from the patient that the original would, which will ultimately lead to the obtaining of comparable data.<sup>11</sup> Therefore, it is important to assess whether the words mean the same thing, whether there are multiple meanings to a given item, and whether there are grammatical difficulties in the translation.<sup>10</sup>

In the adaptation process of HRQoL questionnaires into Turkish, problems relevant to semantic equivalence can occur. For example, in the adaptation of the Myocardial Infarction Dimensional Assessment Scale (MIDAS) into Turkish items 20, 29, 30 and 34 led to some difficulties.<sup>12</sup> Therefore, the statements for these items were restructured through similar recommendations. The items 20's statement was changed from the original scale "Have you had any worries about death?" to "Have you ever experienced the fear of death?", since it was more appropriate for MI patients to be "afraid" of dying rather than being "worried" about "death". "Have you ever been worried about your diet?" from item 29 of the original scale was changed to "Have you ever paid attention to your eating habits?" "Have you ever been worried about your cholesterol?" from item 30 of the original scale was changed to "Have you ever paid attention to your cholesterol?" "Did you feel cold?" from item 34 of the original scale was changed to "Have you ever felt colder after taking your medication?", since it involved the drug instead of the temperature of the weather.

In **Experiential Equivalence**, questions seek to capture the experiences of daily life; however, often in a different country or culture, a given task may simply not often be experienced (even if it is translatable). The questionnaire item would have to be replaced by a similar item that is in fact experienced in the target culture.<sup>9</sup> An example might be the item "bowling or playing golf" that represents moderately strenuous physical activity in the SF-36 questionnaire. In the Turkish version this item is replaced with "walking", because golf and bowling aren't usual sports activities in Turkish

society.<sup>13</sup> Similarly, leisure activity items like “going to parties, movies, the theater or concerts” can also be meaningless for the ones who live in villages because life style and leisure activities differ between the urban and rural areas.<sup>14</sup>

Reliability and validity studies on the Psoriasis Life Stress Inventory (PLSI) to assess QoL in Psoriasis patients set a good example for considering the cultural differences in producing experiential equivalences.<sup>14</sup> During these studies it was recognized that some of the items were not suitable for Turkish cultural norms. Items on avoidance of sunbathing and going to swimming pools or communal baths were being utilized as generally not relevant to Turkish traditions. Especially in rural areas, these activities were commonly seen as improper for both males and females for religious-cultural reasons. Such items on drinking and smoking were evaluated as not usually relevant to women, especially in rural areas, so it was seen as meaningless to ask to what extent psoriasis resulted from excessive smoking or drinking. Therefore, İnanır et al developed a new quality of life instrument for patients with psoriasis addressing the psychosocial difficulties in an Islamic community.<sup>14</sup>

**Conceptual Equivalence** refers to the question whether a given domain has the same importance across different cultures and religions.<sup>10</sup> Often words hold a different conceptual meaning between cultures. The concept of a nuclear family and extended family are common examples in this context. For instance, the meaning of “seeing your family as much as you would like” would differ between cultures with different concepts of what defines “family”-nuclear versus extended family.<sup>9</sup> Unlike in Western societies, the extended family is quite common in Turkey. In addition, it is important for a traditional Turkish family to look after their parents when they are ill or elderly. Therefore, the large majorities of the elderly live with their children, and usually do not work inside or outside the home.<sup>15</sup> Measuring the usual daily activities,

items like “can you prepare your own meals”, “can you go shopping for groceries or clothes” or “can you do your housework” might be meaningless because such activities are performed by younger family members.

Also, the concept of “quality of life” in itself has different meanings according to religious beliefs. In Islamic societies, the Quran and Hadith are the main guidance for Muslims in their activities in daily life. These references are adopted by a great majority of Turkish people who are strongly influenced by Islamic convictions. Hence, the Quran and Hadith (prophetic sayings) may play an important role for these people, especially in the perceptions of disease and health. In the meaning of a Hadith “there is no illness that Allah has created, except that He also has created its treatment”.<sup>16</sup> This statement provides hope for the treatment of illnesses among Muslims. Nevertheless, illnesses are a form of test or trial for Muslims. The Quran points out; “O you who have believed, seek help through patience and prayer. Indeed, Allah is with the patient... And We will surely test you with something of fear and hunger and a loss of wealth and lives and fruits, but give good tidings to the patient, who, when disaster strikes them, say, ‘indeed we belong to Allah, and indeed to Him we will return’ ”.<sup>17</sup>

In the highlight of this verse, despite low QoL, some patients may not complain about their situation and consent to the fate. This attitude can influence the results of a QoL measurement. For instance, even if his or her illness is serious, the patient may answer the items of “how satisfied are you with your health?”, “how satisfied are you with yourself?”, “how satisfied are you with your ability to perform your daily living activities?” by thanking God for everything. Hence, such items should be evaluated regarding the beliefs of the patient.

## Conclusion

As a conclusion, we should underline that the discrepancies in socioeconomic status, health care systems, and health perceptions, religious and traditional beliefs need to be considered in cross-cultural adaptation of HRQoL measurements. Especially in the adaptation from western/developed countries originated measures to eastern developing countries, it is important to reflect the significant cultural differences.

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