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The Challenge of Cross-Cultural Quality of Life Assessment

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Abstract

As a result of an increased international cooperation in the health cure field, the demand for cross-culturally applicable, patient-oriented instruments to assess the need for and to evaluate the outcome of medical interventions has also grown. However, basic problems exist in assessing health related quality of life - one of the most prominent outcomes - across cultures. Conceptually it is unclear to which extent the quality of life construct is transferable from one cultural context to another. Methodologically, the ways to assess the construct have to be sensitive to different cultures and practically, application of quality of life measures may be difficult. The current paper addresses these issues, presenting the current state of the art in cross-cultural development of health-related quality of life assessment instruments as well as a critical review thereof, using examples from internationally active working groups in terms of the translation, psychometric testing and norming of questionnaires such as the SF-36, the NMP or the WHOQOL.

1. Introduction

Within the past 20 years, the field of quality of life research has received increasing attention from the medical community. A recent development within this expanding field is the increase in the demands for international quality of life research in terms of conceptual clarifications, methodological approaches available and practical applications in the international health field (Berzon et al. 1993).

The interest in quality of life research concerns the description of function and well-being of populations with and without medical conditions (epidemiological perspective), its use as an outcome criterion for interventions (clinical perspective) and its contribution to decision making in the health care field (political perspective). These objectives are not only of relevance at a national level, also international efforts are directed at these goals.

The term international has different meanings: politically it refers to a nation, geographically it refers to country, anthropologically it refers to culture, sociologically it refers to society and psychologically it refers to the identity of its members. All of these meanings are reflected in the notion of language which makes it one of the key issues in working with quality of life assessments internationally.

For the following discussion it might be helpful to distinguish between the terms „international“ and „cross-cultural“. Usually the term „international“ is used to refer to phenomena concerning more than one nation or culture with a possible extension to cultural groups within one nation. In its focus on quality of life research, the term „international“ denotes primarily activities of different countries in the quality of life field (i.e. studies from different countries concerning specific conditions). Cross-cultural quality of life research in contrast denotes an additional collaborative and comparitive effort in the quality of life field (i.e. using the same instrument to assess quality of life in a specific condition across cultures). Thus, the use of quality of life tools in different cultures as well as their comparison across cultures is a challenge for researchers.

While anthropology has focussed on quality of life indicators across cultures and nations, this research mainly concerns the so-called objective indicators of quality of life (such as gros national product, infant mortality, life years). Subjective indicators of quality of life have only recently been included in sociological surveys on well-being of citizens of e.g. the United States (Campbell et al. 1981) or Germany (Glatzer und Zapf 1984). These surveys focus on quality of life not primarily in terms of health but in terms of satisfaction with different life domains including the material, financial as well as political aspects of well-being. Health related quality of life in contrast directly focusses on dimensions of function and well-being that are relevant for a person’s judgement of his or her health status. Especially as concerns chronically ill patients, this perspective is directly linked to concept of disease.

From a cross-cultural perspective it is necessary to realize that illness is a patient’s perspective of and response to disease, the meaning of which is largely determined by cultural schemata. As Hutchinson (1996) points out these meanings of disease are most clearly noticeable in so called folk-illnesses. These include conditions like susto (depressive anxiety, often experienced

by Latin Americans), koro (the fear of penis withdrawal into the body, described in China), windigo (cannibalistic obsession, seen in native Americans), high blood (a conception of health as depending on an equilibrium between too much and too little blood) as well as heart distress (often voiced by Iranian women under specific distressing life conditions). Other examples for the cultural bases of illnesses as referred to by Hutchinson (1996) include the tribe of the Mano in Liberia who do not consider Malaria a disease because so many suffer from it or the perception of measles, mumps and whooping cough as inherent conditions of normal growing up in rural Greece. Most known are conceptions of disease as function of a

balance of different forces (e.g. between hot and cold in Mexico or between Ying and Yang in China) or as an activity of supernatural forces (as viewed by the Abron of the Ivory Cost) or of enemies (as viewed by the Doubans of Melanesia).

If disease, as anthropological research suggests, is so very much culture-bound, how could quality of life be culture free? The basic scepticism, especially of Anthropology, is captured in the following citation: „Although some researchers may desire a scale or similar instruments for global assessments of cultures, permitting comparison of the „nature“ of one culture with that of another, no such scale exists. In fact, given the multiplicity of variables or domains comprising a culture, that goal is unrealistic, both theoretically and methodologically“ (Johnson 1986, p. 511).
In reviewing attempts at measuring health-related quality of life cross-nationally, Guarnaccia (1996) points out that „researchers start with an underdevelopped notion of culture and its impact on quality of life assessment. In focusing on particular ethnic populations, there is a lack of attention to inter- and intracultural diversity among study populations. Inadequate approaches are applied to the adaption and translation of quality of life instruments“ (Guarnaccia 1996, p. 523). Thus it seems that the call for construction of measures of quality of life that should be sensitive to language and dialect, customs, beliefs and traditions as well as education and socio-economic status of respondents has remained unheard.

Given the rising interest in international quality of life research and in cross-culturally applicable measures, both for research in a given country as well as in terms of comparisons across countries, the following questions are essential:

1. Is quality of life a relevant concept in a given nature/culture?
2. Do nations/cultural groups share an identical set of concepts about quality of life?
3. Can quality of life concepts be assessed with quality of life instruments?
4. Is quality of life measurable across nations/cultures with the same instrument?
5. Can quality of life data be compared across nations/cultures?
6. Do cross-cultural quality of life results provide a sound basis for decision making in the health care field?

Brislin et al. (1973) have pointed out early that in translating measures from one culture to another the aspect of semantic equivalence (i.e. comparable meaning), content equivalence (i.e. the relevance of questions across cultures), technical equivalence (the types of question

used), and criterion equivalence, (the functioning of the questionnaire in the respective culture) are of importance.In order to approach these key issues, a set of basic criteria to judge the equivalence of instrument versions across cultures, as provided by Hui and Triandis (1985) is necessary. These criteria include functional equivalence, which concerns the adequacy of translations, scale equivalence, which concerns the comparability of response scales, operational equivalence, which concerns the standardization of psychometric testing procedures and metric equivalence concerning the order of scale values across a continnuum.

2. Approaches to cross-cultural instrument development

In developing a cross-nationally usable measure, three goals can be distinguished: The first would be to develop an instrument which is universally applicable across all cultures. The more modest second goal would include the development of a core instrument, which might be universally applicable but which contains specific add-on national modules. The last option pertains to the development of a series of national instruments, which are specific to each culture. So far, the efforts in existing research on cross-cultural instruments focusses on the first aim with the question whether instruments are universally applicable across cultures. Different working groups have assembled, mostly related to a specific instrument which have been active in cross-cultural development. The first group historically active in the field is the European group for quality of life and health measurement group (EGQLHM) working with the Nottingham Health Profile (NHP). Along the guidelines of the instrument's authors, the group provided translation and psychometric testing of the Nottingham Health Profile in several languages (EGQLHM Group 1992). The second group to join efforts in the endeavour was the European Organization for Research and Treatment of Cancer (EORTC), which began to develop the EORTC quality of life Questionnaire in 1986 (Aaronson et al. 1996). In 1991, the International Quality of Life Assessment Project Group (IQOLA) was founded, which works with the SF-36 Health Survey (Aaronson et al. 1992). In parallel, the European Quality of Life Project Group developed, which contributed to the development of the EUROQOL Questionnaire (Kind 1996). The World Health Organization quality of life (WHOQOL) Group followed around the same time with the simultaneous effort at developing a quality of life instrument from different cultures (WHOQOL 1994). Although the Sickness Impact Profile (SIP, Bergner et al 1981) has been a widely used instrument to assess health-related quality of life, international efforts to work with the SIP were only

begun in 1994. In parallel the Functional Assessment of Cancer Treatment (FACT) Group began its work in translating and testing the FACT Questionnaire (Cella & Bonomi 1996).

Developments of national versions of other questionnaires are also present, however not tied to an internationally functioning group of experts continuously exchanging on and working with the instrument. Thus, without using the efforts of international groups, language versions of various mostly disease specific instruments focussing only one of the quality of life domains are available such as the Functional Living Index Cancer Flic (Schipper et al 1996). In a recent review Anderson et al (1993) described the Beck Depression Inventory (available in Chinese, Canadian, French, German, Dutch, Swedish, Turkish, Korean and Finnish), the McGill Pain Questionnaire (existing in Dutch, Finnish, Norwegian, German, Italian, Arabic, French French, Canadian French, Swedish, Hungarian and Israeli) or the Center for Epidemiologic Studies Depression Scales, available from U.S. citizens of different origin as well as for Greek, French, Japanese and Yugoslavian persons or the Zung Self-Rating Depression Scale, which is available in Finnish, Dutch, Hmong, Japanese as well as Austrian, Chechoslovakian, French, German, Arabic, Italian, Polish, Swedish and Spanish. In contrast to these dimension specific instruments, which however have a longer history in development, the generic quality of life instruments have only recently been subjected to the process of translation, psychometric testing and norming. One exception is the adaptation of the Cantrill Self-Anchoring Striving Scale (Cantrill 1964), which is a very easy and easily internationally usable ladder scale with rungs, the top rung representing the best possible and the bottom rung representing the worst possible description of a feeling state. The scale is flexible, can be offered with different types of questions at different time points and has been used in general population studies in over 40 western and non-western countries involving over 20.000 interviews. In spite of its frequent use for the purpose, the scale does not in the essential sense represent a quality of life instrument, because it is not multi-dimensional in nature, but rather representing a method of questioning, which uses patient-defined endpoints. In terms of generic measures, also General Health Questionnaire is available in French, Italian, Spanish, Norwegian, Dutch, Japanese, Chinese and Yoruba, and the Psychological General Well-Being Index is available in Swedish, Norwegian, German and English and has been used in a clinical trial for hypertension in Austria, Denmark, Finland, France, Holland and Italy. Three approaches can be distinguished in cross-culturally developping an instrument (Bullinger et al. 1996). The first concerns the sequential approach, which refers to transfering an existing questionnaire from one culture to another. This approach was used

with the SF-36 Health Survey (Ware 1996), the Functional Assessment of Cancer Treatment (FACT, Cella & Bonomi 1996) questionnaire and with the Nottingham Health Profile (NHP, Hunt et al. 1981). The second constitutes the parallel approach, which includes assembling an instrument based on existing scales from different countries, which e.g. was used by the European Organization for Research and Treatment of Cancer quality of life Working Group (EORTC-QLQ-C30 Aaronson et al. 1996). The last is the simultaneous approach, which involves the cooperative cross-cultural development of a questionnaire, which so far was only used by the World Health Organization quality of life Working Group (WHO-QOL 1994). Each of these approaches includes as basic steps in the developing process the translation of the questionnaire, its psychometric testing and the norming process. The following overview will be centered on the approaches of the international working group mentioned above. Comparisons between instruments are to be made on the ground of issues in translation, in psychometric testing and in norming (Chwalow 1995).

2.1 Translation

The aspect of translation has been most intensely been dealt with in recent as well as older literature (Sartorius & Kuyken 1994, Guillemin et al. 1993). From cross-cultural and comparative sociological research as well as from cross-cultural psychiatry and educational psychology, theoretical foundations and methodological approaches to translating instruments from one culture to another have been suggested. Here, each working group has developed its own procedures for translation, which are essentially based upon a forward translation. However, the number of translators necessary as well as the use of back translations is debated. While e.g. in the Nottingham Health Profile Group strong emphasis is placed upon discussing forward translations in a focus group of health care professionals and patients suffering from the condition under question, the use of back translators was emphasized in the translation of the SF-36 Health Survey. In the FACT Group, the issue of translation was strongly emphasized by including in addition to several translators from each country a group of experts in the field, which were asked to review the translations, and a linguist who revised the translations. In the WHOQOL Group, translations were even more complicated by the fact that they were to be performed from a wide variety of original languages back into English, a process, which also was surveyed by quality ratings of translations, as was the case in the IQOLA SF-36 Group. In the EORTC Group the translations issue was pragmatically solved by obtaining different translations, which were then to be reviewed by the national

coordinators in each country. The FACT relies on double translation methodology, the use of an expert advisory committee pilot testing and thorough linguist revision of the translations.

In reviewing different approaches to translation, Acquadro et al. (1996) stress the need to include at least two forward translations with a comparative discussion and is sceptical about the use of back translations, which often are hampered by potential inferior quality of translations, which then unruly affects judgement of the forward translations. Most important is the international harmonization of translations into different countries by getting together a group of bilingual persons from different countries, which are able to interact and critically review each other's translations. While the basic philosophy of most guidelines for translation focussed upon the adequacy of the translation from the original into the target language, Guyatt (1993) questions the attempt to transpose the measure from one country to another as closely as possible, arguing that during translation inconsistencies and unlogical formulations as well as culturally untransferable expressions can occur, which should be the basis for reformulation of the question (also for the original) rather than adaption in the target language. In spite of the differences of the translation approaches, most authors agree that the use of two forward translators is absolutely mandatory, the use of a back translator is discussable, the use of focus groups to evaluate the applicability of the translated questionnaire in a specific country is recommendable.

2.2 Psychometric testing

Basically, psychometric testing relies on methods and procedures from psychometric theory. This includes item descriptive statistics, measures of reliability, validity and sensitivity. The international working groups, however, differ in the procedures employed for psychometric testing. The SF-36 IQOLA Group e.g. gives specific importance on the item discriminant validity and on the item response theory as a means to distinguish patterns of item responses across cultures. In addition, emphasis is placed on the perfomance of the questionnaire in terms of known group differences that is testing whether the SF-36 is able to differentiate between patients differing in the degree of disease severity. In psychometric testing, the FACT Group uses item analysis on the basis of the Rasch model, structural equation models and multivariate statistics to replicate the factor structure of the measure across countries. The WHOQOL Project and also the SF-36 Group employ structural equation models to test the measurement model of the questionnaire across countries. In the WHOQOL Work involving

data of over 4500 persons from 15 countries the model is first fitted for the global data set and then replicated in each country (Powers et al in preparation). In addition, item scale correlations as well as item descriptive statistics are used to test whether items are applicable across cultures. In the EORTC Group, item and scale statistics were used to decide, whether specific items followed the measurement model in one country as compared to another.

2.3 Norming

Of all the international working groups on quality of life assessment only the IQOLA Group had the opportunity to rely on population based data to assess the quality of life of the general population. So far, data from seven countries are available, these include the U.S., Great Britain, Germany, the Netherlands, Sweden, Denmark and Italy. More IQOLA member countries are in the process of collecting national norms (Denmark, France e.g.). A comparison of the measurement model of the SF-36 dimensional structure across countries showed that western countries are highly similar in these models. In addition, comparisons of scale values of SF-36 sub-scores across countries shows a similarity in rating with only slight differences in country profiles. This, however, only applies to industrialized western countries. The similarity of the SF-36 structure as well as convergent scale values across cultures suggests that identical weighing systems can be used. The normative data of the SF-36 can be employed in each country to obtain age and gender specific reference groups for clinical quality of life data, which can be expressed as deviation from the respective age and gender specific norm.

Other working groups such as the NHP Group were able to collect a convenience sample of the general population, which could be traced back using available census data. Thus e.g. the NHP in Germany was used within a sample of over 500 inhabitants of a north German city, which can now be used as reference data for clinical groups (Kohlmann et al. 1996).

2.4 State of the art in international instrument testing

An overview of information regarding the state of international work with generic and specific instruments shows that most widely-known instruments have undergone translation. Testing has been completed in some instruments but norming still has to be carried out (see tab. 1). The languages in which instruments are available so far include mainly European languages (north, south, west, but not east), South American (with exception of Spanish),

Asian, Arabic or African languages are definitely underrepresented. However, international adaptation work is also performed outside the respective working groups, and activities are quickly developing but do not necessarily publish their research. It is therefore necessary to caution the use of instruments which are not accompanied by a detailed work report. To achieve high quality of life instruments, international review committees and clearing houses for international quality of life assessment have been founded (in Boston e.g. the Medical Outcomes Trust which after strict review approves instruments for international use after sufficient translation, testing and - if possible - norming).

3. Problems in cross-cultural quality of life assessment

Focussing on the essential questions of quality of life research, the current state of the art suggests the following conclusions:

The question of the quality of life concept across nations or cultures has explicitly been addressed only by the WHOQOL Group. By formulating a common frame-work of dimensions and directions to formulate quality of life questions within an international expert group and having the items developed in each culture, the group attempted to highten as much as possible the chance for nationally or culturally specific items to evolve. The process resulted in the development of different national forms, in which, due to the process chosen, the possibility of producing a culturally relevant questionnaire was substantial.

The second question concerns the identical set of concepts shared by nations/cultural groups. Again, the WHOQOL Group is the only one having addressed this question. By giving each culture the chance to produce national items, the development of national questionnaires was enhanced. However, when analyzing the common data pool, an overlap of nationally produced items across cultures was noticeable. This overlap was so strong that national items did not significantly increase the explained variance of the questionnaire. Thus it seems possible that different nations and cultural groups share an identical set of concepts about quality of life.

The third question concerns the different forms in which assessment of quality of life is performed. None of the international working groups has addressed this question so far, because all had worked with quality of life instruments in the form of questionnaires or interviews. It is not clear, whether other forms of communication might better be able to grasp the cultural connotation and responses to quality of life (e.g. pictures, colours etc.).

The forth question concerning the measurability of quality of life across nations and cultures with the same instrument has been addressed by almost all of the international working groups referred to above. In fact, the use of specific instruments across cultures in the production of psychometric data there was a possibility to compare the performance of the questionnaire. The notion that quality of life is measurable across nations and cultures with the same instrument can be psychometrically supported, although it might be possible that culturally specific connotations to quality of life are not grasped. Item analysis as well as structural equation models employed in almost all international working groups show that there is a high similarity at least between western industrialized countries in quality of life concepts. Specifically the IQOLA Project found that the psychometric properties of the SF-36 were acceptable in each culture, that there is considerable overlap between western countries in the dimensional structure of the SF-36 and that in norming studies the scale scores of the SF-36 questionnaire do only slightly differ. Likewise, the WHOQOL Project showed that items constructed by different cultures were similar, national items did not contribute significantly to the instrument's quality, and structural equation modelling did not show substantial differences in the relationship of dimensions across cultures. This lends support to the notion that quality of life in fact is a cultural universal.

The fifth question concerning the comparability of quality of life data across cultures can in part be answered with the preceding one. However, comparisons are hampered by the question whether the response scales are cross-culturally comparable. This has explicitly been addressed in several international working group. With the SF-36, a Thurstone scaling exercise was performed to identify the relative distance of descriptors in the answer scale across countries. It was found that such differences at least in western countries were minimal (Ware 1996). Similarly, the WHOQOL Project employed a procedure to assess the relative distance between answer response scales across countries and chose descriptors which in each country best reflect the distance. Provided thus that the comparibility of answer scores as well as the cross-cultural applicability has been tested, quality of life data can be compared across nations and cultures.

The last question concerns cross-cultural quality of life results as a basis of decision making. This question has not been addressed sufficiently in international quality of life research. There has been reluctance to compare quality of life data across countries in terms of an epidemiological analysis. Interestingly, this is different from comparative sociological research in so-called objective indicators of quality of life across countries. Should that comparison, which is essentially possible by the data collected so far in the international

working groups (especially those who had the possibility to collect norm data), suggest that there are differences in quality of life, which do not depend on age, gender, educational status or employment or excerpts to basic conditions of living and health care, such data have great substantial political relevance.

4. Discussion

In trying to answer the essential questions posed above, the following set of problems has to be kept in mind. One of the main problems concerns to possible ethnocentrism of this instruments and approaches used. All of the measures developed so far depart from the notion of verbal expressions of inner feelings and experiences. The main focus of existing questionnaires has been critically perceived as a white Anglo-Saxon middle-class outlook on quality of life so far it is prevailing and is even noticeable in a WHOQOL-Questionnaire.

A second problem is the possible normativity of the quality of life concept. There is a concern that quality of life dimensions are not value-neutral but act as standards according to which the individual in the society is expected to live up. In addition, biases in assessment may occur in terms of the choice of convenient samples for quality of life assessment and in terms of the very mode of questioning employed.

Finally, ethical consequences in cross-cultural quality of life research have to be kept in mind, which concern the freedom of personal information as well as the abuse potential of quality of life information collected within specific cultures and are ready to be included in clinical studies (Bernhard et al 1996, Matthias et al 1994, Cella et al 1993).

To sum up, international efforts to assess quality of life cross-culturally do exist. The developed instruments have passed the translation phase and mostly are in a testing phase and need to be reviewed for their cross-cultural performance. First results with instruments for which cross-cultural testing (and in part norming) was possible an (?) suggests (?) cross-cultural applicability of the instruments.

In conducting such research transparency of underlying concept is mandatory as is modesty in using specific measurement approaches. Correctness in applying instruments and analyzing

data is one of the methodological prerequisites for cross-cultural research and responsability for the results also after their publication should be taken by the researchers.

Quality of life research has a descriptive as well as a prescriptive aspect, which suggests that independent of race, gender, age, social status, occupation and mental or physical health, well-being and function as perceived by the person as is a human concern. Efforts to scientifically study and to politically improve the quality of life of its members should be a moral imperative in each society. However, not all societies have the possibility to address the quality of life of their citizens in a similar manner, especially countries in which the living conditions may need improvement. Provided, however, that the quality of life of citizens is a major concern in a society, quality of life data may give information about the respective status of populations, may thus suggest plans to improve the quality of life status of these populations by specific interventions, can be used to measure the effects of such interventions and can contribute to minimizing the gap between the „developed“ and the „developing“ world.

In conclusion, quality of life seems a universal human concept as concerns its relevant dimensions, which is not to say that the intensity of endorsement of these dimensions is similar across countries. Different individual behaviors, societal conditions and cultural regulations may apply, but these concern the means rather than the results of pursuing well-being. Specific behaviors which are instrumental in obtaining positive quality of life may vary culturally, such as engaging in religious services, engaging in specific activities or engaging in specific social behaviors. Although cultures do differ in their basic conditions provided to strive at a favorable quality of life, the person’s subjective perception is not a linear reflection of these conditions. This does not imply that improvement of societal conditions is irrelevant, but it draws attention to the fact, that human perception (which is also a function of access to societal goods, information and education) may be the most important common denominator in quality of life research.

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