

Quality of life for people with intellectual disabilities in China: a cross-culture perspectives study

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Abstract

Background The concept of quality of life (QOL) is explained on the basis of traditional Chinese culture and contemporary social and cultural trends.

Method The importance of internationally recognized QOL domains and indicators was determined for three respondent groups: consumers, parents of the consumers, and teachers and rehabilitation professionals working with the clients.

Results Principal component analysis confirmed seven factors influencing QOL for people with intellectual disabilities (ID) in China. These seven components are conceptually equivalent to the eight domains found in the international QOL literature.

Conclusion The concept of QOL has become one of the most sensitive issues in present Chinese society and peoples' lives, and an important theoretical framework for the education and rehabilitation for people with ID in several ways: curriculum development, service delivery models, education and rehabilitation practices, and employment models.

Keywords China, people with intellectual disabilities, quality of life, quality of life measurement

Introduction

Over the decade, the concept of quality of life (QOL) has gained increasing attention in the field of special education and social services for people with intellectual disabilities (ID) in China. Several studies (e.g. Xu 2002, 2003, 2004) have focused on the conceptualization and measurement of QOL and its application within the Chinese society. As a continuous effort, the present study further explored this concept from the perspective of individuals with ID, their family members, and professionals in the context of Chinese traditional culture and Chinese contemporary social and cultural trends. In Chinese traditional culture, there is a widespread belief of life happiness consisting of four core elements: FU, LU, SHOU and XI. FU means well-being and good fortune, as opposed to misfortune. LU originally refers to office salary in feudal China; now it stands for stable physical and financial wellbeing. SHOU refers to long life (health and longevity). XI implies happiness. For the long history, Chinese put these four words together, representing a description and expectation for a happy life. This belief coincides with the QOL concept. In Chinese contemporary society, there is an emerging trend on advocacy for people with ID to focus on enhancing their independence and productivity which reflects the important aspects of QOL concept. The shift of service delivery model from process-focused to outcome-oriented indicates the

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needs of embracing a more comprehensive framework to guide the reform of education and social service system at both policy-making and practice levels (Xu 2002). Herewith, it is of significance to examine how the internationally recognized QOL core domains and indicators can be integrated into Chinese systems from Chinese traditional culture perspective and in terms of Chinese contemporary social and cultural trends concerning people with ID (Schalock & Verdugo 2002). The general purpose of the present study is to continue to study the QOL concept from contemporary social, cultural and economical Chinese perspectives, and to begin a systematic inquiry about its etic (universal) and emic (culturebound) properties in Chinese context. As discussed later, based on these and other related findings, the QOL concept is becoming a key principle and theoretic basis for reforming contemporary Chinese special education and rehabilitation practices.

Method

Participants

Participants were recruited from four cities in the different regions of China: Beijing, Harbin, Ningbo, and Chengdu. There were 87 consumers (46 males and 41 females; 62 were younger than 20 years old, 21 were between 20 and 30, and 4 above 30). All consumers were within the moderate range of ID. Of the 87, 73 lived with their family, 11 lived in welfare centres, and 3 lived in supported accommodations. Of the 87, 5 were employed in regular jobs, 11 in sheltered workshops, 3 in supported employment, and 7 in occupation centres. The remainder were unemployed. Fifty-eight parents (52% of whom were mothers) constituted the parent respondent group. The professional group was composed of 210 teachers or rehabilitation personnel who were in active contact with the consumers.

Measure

The survey instrument used was the *Cross-Cultural Survey of Quality of Life Indicators* that includes 4-point Likert scale ratings on the importance and use of 24 core QOL indicators (Verdugo & Schalock 2001). There are three forms of the survey: consum-

ers, parents and professionals [see Jenaro *et al.* (this volume) for more details about the Survey]. The data presented in this article relate only to the importance ratings.

Procedure

We first translated the English version of the Survey into Chinese. In order to guarantee that the content and meaning of the Chinese questionnaire was consistent with the English version, back-translation technology was used (Brislin 2000). In that process six bilingual experts were invited to translate the Chinese version to English, ensuring the core domains and indicators used in Mainland China were consistent with those used in other studies (see Jenaro, this volume). The 'back-translated' version was then compared with the original survey to examine the consistency. The Chinese version of the Survey, which was explained in detail to all respondents, was administered individually by one of the authors. Any questions asked by a respondent were answered with additional examples given if necessary. Data from the three respondent groups was combined for statistical analysis since at this point, we are more interested in general trends rather than potential respondent group differences. SPSS 10.0 (SPSS 2000) was used for all analyses.

Results

Principal component analysis

The value of Kaiser-Meyer-Olkin Measure Test was 875.946 ($P < 0.01$, KMO = 0.781), indicating that factor analysis (principal component analysis) was appropriate. On the basis of the principal component analysis of the importance ratings, seven factors emerged, with a total variance explained of 67.3% (see Table 1). Two of the original eight factors (personal development and physical well-being) were highly correlated ($r = 0.74$, $P < 0.01$) and thus loaded onto one component (# 1 in Table 1). This finding might be caused by Chinese social-economical status, cultural differences, or some other emic factor(s) that we are currently attempting to understand better. Discussions among a group of Chinese researchers in the field concluded that the seven components extracted from the analysis are equivalent to the eight

Table 1 Principal component analysis (factor analysis)

Component	Initial eigenvalues			Load square extracted from sum		
	Sum of square	Mean square %	Cumulative %	Sum of square	Mean square %	Cumulative %
1	7.154	29.810	29.810	7.154	29.810	29.810
2	2.252	9.385	39.195	2.252	9.385	39.195
3	1.728	7.202	46.396	1.728	7.202	46.396
4	1.427	5.947	52.343	1.427	5.947	52.343
5	1.282	5.340	57.684	1.282	5.340	57.684
6	1.180	4.916	62.600	1.180	4.916	62.600
7	1.118	4.659	67.259	1.118	4.659	67.259

domains found in the international QOL literature (Schalock & Verdugo 2002).

Domain ratings of importance

Importance raw scores (as assessed on the Survey) were summed across respondent groups and items within each of the eight core domains. The domain's importance to the three respondent groups was ranked based on these scores. In descending order (rank # 1 = most important), the rankings were: 1 = physical well-being, 2 = rights, 3 = material well-being, 4 = emotional well-being, 5 = personal development, 6 = social inclusion, 7 = interpersonal relations, and 8 = self-determination.

Discussion

Before 1987, there was no scientific definition of ID in China. In 1987, the State Department of China issued the definition and standard of ID (the term mental retardation is more commonly used in China), which was consistent with the international definition, namely, the 1983 8th AAMR mental retardation definition (Grossman 1983). From then on, this definition has been used. The 1992 9th AAMR mental retardation definition (Luckasson *et al.* 1992) did influence research in China, especially the relationship between one's environment and people with ID and the focus on the state of individual functioning. When the 2002 AAMR definition (Luckasson *et al.* 2002) was introduced to China, Chinese edu-

cators did comparative study and analysis on the new definition. They thought that this 2002 AAMR definition with its emphasis on individualized supports systems was closely related to the QOL concept. In addition, the 2002 AAMR System has influenced our thinking because of its emphasis on social context, the potential of persons with ID, and that the concept of QOL is the same for all persons. Thus, the concept is a re-enhancement for understanding ID. The significance is to provide a key theoretical basis for people with ID and to include contemporary society in the process of changes and development. Thus, a set of QOL values and the evaluation system for people with ID are consistent with normal human groups. Data from the current study provide an empirical basis for that theoretical development.

In the early 1980s, the education for children with ID in China adopted curricula from the general schools. However, the general school curriculum could not meet or satisfy the individualized education needs of children with ID and thus Chinese educators started to study and try to adopt a developmental functioning curriculum. The QOL concept had a great impact on the development of this new curriculum. As the QOL research was developing in depth, the QOL-oriented curriculum attached importance to the willingness and need of children. The key factors in previous curricula were oriented to social needs and subject development. The QOL-based curriculum should help children with ID realize their own life ideals, help them develop a positive self-concept and improved interpersonal relations, enhance their community inclusion and focus on

their happiness and achievement. To accomplish this, the curriculum emphasizes the consistency and harmony between the individual and their environment. The core domains validated in this study along with the relative importance of those domains will assist in the further development and application of a QOL-based curriculum.

Currently, the QOL concept is also making an active influence on special education and rehabilitation in China. Special education for children with ID began in the 1980s. At that time, the traditional separate special education schools were developed, followed by the present Chinese special education multi-development system that focuses on having students with special needs 'studying in regular class'. After the QOL concept was introduced to Chinese special education, Chinese educator began to study how to improve QOL for people with ID through the supports paradigm. On this basis, the supported education theory and practice model for people with ID in contemporary China was established. Supported education possesses these characteristics: the dynamic pluralistic education placement for children with ID established to substitute the former single placement model, the individualized curriculum constituted to substitute the former subject-oriented curriculum, the community functional teaching model founded to substitute the classroom-teaching model, the children-centred learning strategy developed to substitute the teacher-centred teaching strategy, the active parents involvement was recommended to substitute the positive parents co-ordination, and the multi-evaluation system was established to substitute the grade- and knowledge-oriented evaluation model. We are at present attempting to develop a multi-subjects education-rehabilitation model to substitute for the single education model.

The QOL concept has also influenced the employment and career development for people with ID. As suggested in the present data, a QOL rehabilitation model requires that the independence, productivity and community inclusion model for people with ID be improved, the employment and career development for people with ID be emphasized, and the supported employment and supported life model for adults with ID be implemented. In the former planned economy, sheltered employment was established for people with disability in China. The social welfare factories administered by government offered

opportunities for people with disabilities, especially for people with hearing impairment and with physical disabilities, and for a few people with ID. However, with the establishment of the Chinese market economy system, the former welfare-based employment model encountered fundamental difficulties. To solve this difficulty, and under the premise that adults with ID increasingly need a quality of life, the supported employment model for people with ID is becoming recognized. The vocational education model in accordance with supported education, community life and other related issues are developing from theory to practice. In 2002, China started the Rehabilitation Center Project for adults with ID. We used the QOL theory in this project as the key concept, including using the currently used Survey to assess the process and results of the project.

Conclusion

In conclusion, this study introduced further the QOL concept from an international perspective into Chinese Education and Rehabilitation for people with ID. From the perspective of Chinese traditional culture and contemporary society, we use the concept of QOL and its core indicator system to analyze the present attitudes of Chinese people with ID, including their parents and professionals working with them. Three conclusions result from the current study. First, the results showed that seven principal components of QOL are consistent with the eight core domains based on the international QOL literature and thus confirm the concept's etic properties. Second, the study found that although there are some differences in ratings, all three respondent groups share the relative ranking of the domains' importance. Third, the concept of QOL is significantly influencing the social life, employment, and life development of persons with ID in China in a number of ways: curriculum development, education and rehabilitation models, and employment approaches.

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