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WHOQOL-OLD Project: method and focus group results in Brazil

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ABSTRACT

Background

Exploring the conditions that allow satisfactory quality of life in old age is an issue of scientific and social relevance.

Objectives

To describe a quality of life assessment method for the elderly and present the results from focus groups conducted among old people in good health and ill health, as well as their caregivers.

Methods

The methodology used in the WHOQOL-OLD project is the same as utilized in the development of other WHOQOL modules. Five focus groups were conducted in Brazil. The sampling procedure was done according to convenience. Eighteen old people and five caregivers took part in the focus groups. All the focus groups followed a pre-established methodology.

Results

A tendency towards making an association between quality of life and wellbeing and feeling well was observed. The responses spontaneously included the 6 domains proposed in WHOQOL-100, thus corroborating the multidimensional nature of this construction. Nineteen out of the 24 original facets of this instrument were cited as relevant, and the five facets not spontaneously remembered were not concentrated in a single domain. When questioned about the importance of each of the 24 facets of WHOQOL-100, the groups considered all of them to be relevant. However, suggestions for modifications to five facets were made. Additional items were also examined and considered relevant for assessing quality of life among the elderly, by both the old people and the caregivers.

Conclusions

The results corroborate the hypothesis that old people constitute a particular group and, as such, they have relevant specific characteristics. Thus, an appropriate instrument for assessing quality of life among the elderly needs to consider such matters.

Keywords

Aged. Quality of life. Focus groups. Caregivers. Old people's health.

INTRODUCTION

The aging of the population is a relatively new phenomenon all around the world. According to data from the World Health Organization (WHO), life expectancy for the whole world, which today is 66 years, will become 73 years by 2025.[5] In Brazil, the prospect for the year 2030 is that there will be a population of around 25 million old people.[10] Preliminary data from the latest demographic census[7] (IBGE, 2000) show that around 10 million people among the Brazilian population are over 65 years old.

Within this reality, there is a need for specific studies among advanced age groups by healthcare professionals.

Investigations of the conditions that allow good quality of life in old age, and also the variations that this age gives rise to, have taken on great scientific and social importance. Attempting to answer the apparent contradiction that exists between old age and wellbeing, or even the association between old age and disease, may contribute towards understanding the aging process and the limits and attainability of human development. In addition to this, such investigations will give the possibility of creating alternatives for interventions aimed at promoting wellbeing among the elderly.

From the beginning of the 1990s, the WHO observed that quality of life measurements took on particular importance in health assessments, both from the individual and social perspectives.[9] There are several scales for assessing quality of life. However, they differ in relation to their underlying conceptual aspects and the importance given to subjectivity, to the detriment of objectivity in choosing responses to the items investigated. They also differ regarding the nature and weight of each domain for assessing quality of life as a resource for generating concepts pertinent to the population in question, for subsequent verification via a psychometric focus.[6,3,11] Because of such particular aspects, the importance of utilizing qualitative methods has been highlighted.

The World Health Organization Quality of Life Group (WHOQOL Group) has developed a scale within a cross-cultural perspective for measuring quality of life among adults. The subjective character of quality of life (encompassing both positive and negative aspects) and its multidimensional nature have been considered fundamental characteristics. There is now interest within the WHOQOL Group in developing an instrument for evaluating quality of life among elderly adults. Such interest is justified by the fact that it is not possible to assume that instruments that are suitable for assessing the field of physical health among young adults, for example, are the same or appropriate for populations of elderly adults. Specific matters probably need to be addressed for each age group. In addition to this, the magnitude of the aging phenomenon, together with the scarcity of instruments for evaluating such questions, strengthens such interest.

The present study forms part of a wider project that involves 16 other centers: Scotland (coordinating center), England, Germany, Spain, Denmark, France, Czech Republic, Hungary, Finland, Canada, Australia, United States, Israel, Japan, Sweden, China and also the European office of the WHO, as well as the Brazilian center of WHO's Quality of Life Group.

The WHOQOL-OLD project has two main objectives:

To develop an instrument for assessing quality of life among elderly adults (WHOQOL-OLD), from the starting point of quality of life measurements for younger adults (WHOQOL-100), recently published in its original version (WHOQOL Group,[12] 1998) and also in the form of the Brazilian version.[4]

To utilize WHOQOL-OLD in an innovatory cross-cultural project that will compare the aging that takes place with good health and ill health.

For this, the methodology and action strategy for the project will follow a series of clearly defined steps that have already been utilized in the development of other modules within WHOQOL. In summary, these steps include: 1) review of the WHOQOL instrument; 2) conducting of focus groups; 3) pilot module for WHOQOL-OLD; 4) collection of data for the pilot; 5) analysis of the pilot data; 6) module for the field test; 7) production of a questionnaire for evaluating "Attitudes in relation to aging"; 8) field test; 9) analysis of the data from the field test (testing the possibility for an abbreviated version of WHOQOL-OLD); 10) publication and dissemination of the results.

The involvement of each center, through working with this method and applying it in the different languages of the participating countries, will allow wide-ranging development of WHOQOL for elderly adults.

Thus, the present article has the objective of describing the method for conducting focus groups on quality of life among the elderly in Brazil, and the results from this.

METHODS

Five focus groups were conducted in Brazil, and these followed an internationally standardized methodology (WHOQOL Group, 1995). In addition to this, four professionals who were particularly involved in caring for the elderly were interviewed individually. Thus, the groups furnished concepts from distinct angles regarding various aspects of quality of life among the elderly. The five focus groups were composed as follows: healthy old people aged 60-80 years, sick old people aged 60-80 years, healthy old people aged over 80 years, sick old people aged over 80 years, and caregivers.

Subjects

The sampling of subjects was done according to convenience, while following selection criteria that encompassed different subpopulations of the elderly. The healthy old people in both age groups were recruited from a community choir for the elderly that is part of a university extension project. On the other hand, the sick old people aged 60-80 years were selected during their internment in a university general hospital. The sick old people aged over 80 years were recruited from an old people's home that serves as a training area for medical students. The group of caregivers was made up of individuals connected with the old people's home or recommended by it. The criterion for choosing the recruitment locations was their ease of access resulting from their link with university services.

Thus, 18 elderly people and five caregivers participated in the focus groups, as shown in Table 1. The criterion of the individual's subjective opinion of his or her health was utilized as the means for classifying this person as healthy or sick. This choice was based especially on the subjective principle that the WHO quality of life assessment instruments are based on. The elderly people was asked directly whether they considered themselves to be healthy or sick, just before conducting the focus groups, and their responses defined which group they would be allocated to.

Table 1 – Description of the characteristics of focus group participants.

Groups	N	Women	Average age (min. and max.)	Average length of education	Average number of children	Origin
60-80 in good health	5	4	68 (65-71)	13.3	2.3	Old people's choir
60-80 in ill-health	4	1	71 (63-77)	3.7	6	Hospital
80+ in good health	3	1	84.6 (80-90)	13.6	3.6	Old people's choir
80+ in ill-health	6	6	87.8 (80-94)	6.1	4.1	Old people's home
Caregivers	5	5	55 (39-78)	14.4	-	Old people's home

Procedures for conducting the focus groups

All the groups observed the pre-established methodology described in the following:

Ethical aspects: the project was examined and approved by the Ethics Committee of Hospital de Clínicas de Porto Alegre. All the participants involved in the study were adequately informed and agreed in advance to take part in it. Even when informed of the possibility of interruption during the group, none of them gave up or refused to participate.

Location: the places where the focus groups were conducted were comfortable, calm and silent. Two groups were conducted in an old people's home, one in a classroom at the university hospital during the patients' internment and the two with the participants in the old people's choir in a classroom close to where the choir meets.

Coordination: this was done by a professional with experience of conducting groups, accompanied by an assistant. The latter was responsible for tape-recording the group discussions and typing the content of what the participants were expressing, in a computer at that location.

Recordings: at the end of each group discussion there was a computerized record of the content of the group discussion and a complete audio record, from the beginning to the end of each group. The tape-recorder was switched on right at the start of the group discussion and was only switched off after all participants had left the location. Such observation allowed the recording of any manifestation that might have been made after the formal termination of the group discussion.

Duration: the average duration of the group discussions was 120 minutes. This length of time allowed all the themes to be adequately dealt with, but without causing fatigue, loss of attention or dispersion of the participants.

Description of the activities during the group discussion: to begin with, the coordinator used open questions to put forward the concept, i.e. what can improve or worsen quality of life and what is most important for it. This stage of the discussion lasted 20 minutes on average. Following this, the group read and examined the definition of each domain and each of the items in WHOQOL-100,[4] guided by the coordinator. The relevance of these domains for the participants' lives and the suitability of the formulation of the questions (such as clarity, vocabulary and conciseness) were investigated. This stage of developing the group discussion lasted around 60 minutes. The third stage of conducting the groups was dedicated to suggestions of other topics considered relevant for quality of life that were not dealt with in the original questionnaire original. The objective of this stage was to generate new items that could be added to those already understood by the participants as being relevant. The best way of formulating questions on such items was also examined with the elderly participants.

RESULTS

The group discussions ran their course in an atmosphere of amicable and calm cooperation. The participants showed satisfaction about being able to discuss specific aspects of quality of life for their age groups. They expressed their contentment in seeing that their experiences would be taken into account and that there was interest in studying old people. There had been a certain apprehensiveness among the researchers that the elderly people, especially those aged over 80 years, would not be willing or be in a condition to participate in an activity that required a high level of concentration and abstraction for around two hours, which was not borne out. The old people kept up their interest and participation throughout the group discussions.

A summary of the contributions that emerged from the focus groups is presented in Tables 2 to 4.

Table 2 – Summary of focus group discussions – responses to general questions on quality of life: positive and negative aspects.

Focus groups	Definition of quality of life	What is important for quality of life?	What harms your wellbeing?	What would improve your quality of life?
60-80 in ill-health	Wellbeing, money, feeling well.	Health, giving social support to others.	Not being allowed to help, health problems.	Stable financial conditions, work, being active.

60-80 in good health	Having happiness in life, love and friendship.	Having voluntary activities, religion, health, good relationships with the family, an activity, support from others, activities with other old people, learning, reading and eating well.	Lack of work opportunities, politics, lack of respect towards the elderly, lack of attention to the health and education systems, lack of sense of humor.	
80+ in ill-health	Independence, the head working well, freedom and health.	Health (especially mental), motivation, contact with the children and grandchildren, eating well, money.	Illness, pain, anxiety.	Eating well, walks, friendship, prayers, being capable of helping others and obtaining gratitude, health, being in a good physical condition, having the possibility of sharing feelings.
80+ in good health	Health, spirituality, having good living conditions.	Participating in some social organization, feeling happy.	Lack of interest, marital problems, not having a good relationship with the family.	Having the desire to do things.
Caregivers	Living well (without illnesses), having intellectual activities, expectations for the future, being respected.		Lack of attention and love, difficulties in keeping up with technological advances.	Being valued, preparation of the young for dealing with old age, love and contact from the family, motivation for learning.

The responses to the general questions presented in Table 2 came from open questions related to the definition and positive and negative aspects of quality of life. The idea that quality of life consists of a multidimensional construction became evident from the heterogeneity of the various matters contained in the responses. There was a tendency to make an association between quality of life and wellbeing or feeling well. Aspects of quality of life considered important by all the groups of elderly people were also highlighted, such as health, sociability, social support, physical activity, the possibility of giving support and the feeling of usefulness. Some groups indicated religious belief, stable financial conditions and good living conditions as important factors in quality of life.

The responses spontaneously covered all the six domains proposed in WHOQOL-100, thus demonstrating that they are generically appropriate for investigating the quality of life among the elderly. Of the 24 original facets of this instrument, 19 were cited as being relevant to the interviewees' quality of life. The items "sleep and rest" (physical domain), "body image and appearance" (psychological domain), "sexual activity" (social relationship domain), "transportation" (environmental domain) and "dependence on medication or treatment" (level of independence domain) were not spontaneously remembered by the old people. Thus, these unremembered facets were not centered on a single domain.

Table 3 summarizes the comments of the different groups of old people and their caregivers with regard to the facets of WHOQOL-100 that gave rise to suggestions or criticisms, both in their definition and the manner of asking about them.

Table 3 – Revision of the items in WHOQOL-100. Synthesis of the comments from the old people and caregivers' focus groups.

Groups	Domain 1: Physical	Domain 2: Psychological	Domain 3: Level of independence	Domain 4: Social relationships	Domain 5: Environment	Domain 6: Spirituality, religious belief and personal beliefs
60-80 in ill-health		Body image and appearance: it was suggested that the elderly should accept the changes in body image secondary to aging.	Dependence on medication or treatment: medication was regarded as a factor for improvement in quality of life.			
60-80 in good health	Energy and fatigue: it was suggested that the point to which the physical limitations can be tolerated should be evaluated. Sleep and rest: it was emphasized that the need for sleep diminishes among the elderly.	Memory and concentration: some participants indicated that this item is no longer relevant.	Dependence on medication or treatment: medication was regarded as a factor for improvement in quality of life.			
80+ in ill-health	Pain and discomfort: it was indicated that the tolerance of pain is greater among the elderly.		Capacity for work: this was not considered so important for the elderly. The possibility for recreation is more relevant than work.	Sexual activity: there were divergences in relation to the relevance of this item for the elderly.		
80+ in good health	Pain and discomfort: it was suggested that the importance that pain takes on in individuals' lives should	Negative feelings: it was suggested that the term depression is too specific and does not substitute for negative	Dependence on medication or treatment: the predominant opinion was that taking medications worsens the quality of life.	Sexual activity: the group did not reach a consensus regarding the importance of this item.	Transportation: this item was not considered important for the elderly.	

	be evaluated.	feelings.				
Caregivers	Energy and fatigue: it was suggested that this item is even more important among the elderly than among the young.	Body image and appearance: it was suggested that physical signs like wrinkles are not as important as eyesight problems, for example.	Dependence on medication or treatment: there is an impression that medications have a positive connotation for the elderly. Capacity for work: it was indicated that difficulty in working affects men more than women.	Sexual activity: it was observed that the question assumes that there is sexual activity, which is not always true among the elderly.	Physical environment: there was a special observation regarding noise.	Spirituality/religion/personal beliefs: it was observed that some old people begin to give more importance to religion in their old age, especially when they have some serious illness.

When questioned about the importance of each of the 24 facets of WHOQOL-100, the groups considered them all to be relevant. However, five facets merited modification for application to the elderly: a) body image and appearance; b) capacity for work; c) negative feelings; d) sexual activity; and e) dependence on medication or treatment. In the facet body image and appearance, there were two fundamental differences in relation to the original formulation of WHOQOL-100 for adults: an emphasis on the acceptance of the modifications resulting from the age and giving value to good bodily functioning to the detriment of its appearance. With regard to the facet capacity for work, the old people's emphasis was on taking advantage of the time through useful or enjoyable activities. The hypothesis was raised that this facet would be more pertinent to men than to women. In the facet negative feelings, the emphasis on depression as a negative feeling, to the detriment of other feelings that were also negative and could be present, was considered excessive. The facet sexual activity was the most polemical and generated most controversy. Some participants considered this to be irrelevant for old people, while others considered it to be very relevant. It was suggested that the question should be formulated in such a way as to not presuppose that sexual acts were necessarily taking place, but that activities such as caressing and physical contact (kisses and hugs) should also be considered. The facet dependence on medication or treatment was criticized because dependence on medication or treatment could be seen both as a factor in the worsening of quality of life, due to the diminution of autonomy, and also as an improvement through the beneficial effect that some medication and/or treatment provide.

The proposals for additional items were examined (Table 4). All the items proposed were considered to be relevant for evaluating the quality of life among the elderly, both by the old people interviewed and by the caregivers.

Table 4 – Additional items proposed that were considered relevant by the focus groups.

Sensory function (e.g. eyesight, hearing);
Communication: opportunity to talk to other people;
Memory; capacity to think, concentrate and make decisions;
Relationships – with friends and family;
Opportunity for social contact (going out and meeting people);
Housing situation;
Feeling of social isolation;
Financial matters;
Work satisfaction: paid or voluntary work;
Facing up to losses: friends or members of the family;
Significant life events (e.g. retirement or becoming a grandparent);
Importance of eating well/having a good appetite;
Opportunity for leisure activities/recreation;
Importance of having achievements recognized.

DISCUSSION

According to Neri,[8] it was only in the 1990s that old age "with disease" ceased to be regarded as synonymous with old age as a whole, both by science and culture. Recent epidemiological trends, such as the growth in the numbers of healthy old people, are forcing a change in the theoretical presupposition that old age is synonymous with disease.

Thus, the development of strategies for ascertaining how old people perceive their own aging has fundamental importance for enabling the development of instruments that are capable of quantifying this process in a valid manner. The present work describes a specific qualitative investigation method. This method constitutes the first step in the development of a cross-cultural instrument for assessing quality of life among the elderly. The role of qualitative research as an exploratory tool and a preparation for a subsequent quantitative stage is thus highlighted. The utilization of focus group discussions regarding matters relating to quality of life among the elderly has the objective of adding the experience and concepts of the population to be investigated, to the concepts that have come from the "experts". Thus, an opportunity for verifying the pertinence of the items proposed and adding other not previously listed is created.

According to Browne et al,[2] each population of elderly people will give particular value to certain domains. Nonetheless, old people have questions that can be generalized but differ from those of the general adult population. Bowling,[1] with an interest in asking old people what they deemed important in determining quality of life, interviewed a population from a community of different ages, with and without illnesses. This author found that the elderly only differed from the other age groups in attributing lesser importance to physical work activities and greater weight to health than younger people did.

In the present study, the perception of the need for additional items that was observed in the focus groups corroborates the hypothesis that the elderly constitute a particular group and, as such, present relevant specific characteristics.

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