Focus Group Discussions with Older Adults and Carers for Development of Pilot WHOQOL-Old Measure

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Focus group discussions were conducted within a multicentre study WHOQOL-Old ("The measurement of quality of life in older adults and its relationship to healthy ageing"). The main objective of the WHOQOL-Old Programme is to develop a module for the assessment of quality of life in older adults. This development occurs through the adaptation of the WHO measure of quality of life, the WHOQOL and in focus groups. For this purpose, a series of focus groups were run with older adults and professional carers, discussing different facets of QoL and WHOQOL-100 measure. Older adults aged 60–93 years and carers took part in focus groups. The following most common factors impacting the quality of life of older people were identified: health, financial problems, family relations, communication.

Key words: quality of life, older adults, carers, WHO, WHOQOL-100

INTRODUCTION

Focus group discussions were conducted within a multicentre study WHOQOL-Old. The main objective of the WHOQOL-Old Programme is to develop a module for the assessment of quality of life (QoL) in older adults. This development occurs through the adaptation of the WHO measure of QoL, the WHOQOL-100. The WHOQOL-100 matches the WHO definition of health, involves a comprehensive and subjective assessments of QoL and have been developed collaboratively according to a standardised protocol in a number of states worldwide (1–3). The WHOQOL-100 covers the younger adults' overall QoL and general health, as well as QoL domains referring to physical health, psychological state, social relationships and environment. The WHOQOL-100 seeks subjective judgements by asking individuals to rate the occurrence, frequency or intensity, concern or worry about, and satisfaction with each of the 24 facets. The psychometric properties of the WHOQOL-100 were investigated using relevant data extracted from the international pilot testing. These data were based on a sample of 4802 respondents from one of 15 field study centres worldwide. The mean age was 43.4 years, with a standard deviation of 16 years. On the basis of these data, all facets of the WHOQOL-100 demonstrated good internal consistency, with Cronbach's alphas ranging from 0.65 (for physical environment) to 0.93 (for working capacity) (4). As a result, each national WHOQOL instrument is sensitive to the culture in which it is applied while maintaining cross-cultural comparability (4–7).

Questionnaires for the assessment of QoL have been developed on adult and young population, with little or no representation of aged subjects, and are now inadequate for the older adults (8–10). Research of views, opinions and needs of older people includes a variety of questioning techniques such as interviews, focus group discussions and questionnaires (11–13). For developing a questionnaire on QoL for older people, it was recommended to use focus groups method (1, 3, 14, 15). In the course of discussions all the "domains" have to be identified by older people themselves. Focus groups are a specific instrument that focuses on the problems associated with ageing and the elderly and is used in scientific research for finding out the gaps not covered by the existing measures. According to Morgan (14), focus groups enable to gather a huge amount of situational information in a shot period of time. The data collected are free of the influence of the researcher. In this case the results of a focus group are based not on the researcher's own assumptions con-

cerning inclusion relevant items. Focus groups were used in this study to identify the main factors that affect QoL, to help in compiling a questionnaire for a survey by identifying the areas and items for it.

Focus group discussions are indicated as one of the most acceptable methods of providing information on the needs of the elderly (11–13, 16, 17). It gives the possibility to explore how the elderly live in a real situation and what is acceptable to them. It is vital that these people are given the chance to set the agenda, and that it is not imposed upon them. All too often so-called experts (using the expert methods) make assumptions as to what the elderly need. The true experts of the needs and QoL to enable them to live as they want are the elderly themselves.

Literature data identified a number of important methodological issues concerning the elderly as participants in focus groups (17, 18). These issues are related to a decline in sensory (vision, hearing) and communication abilities associated with advancing age. These issues should be taken into account while implementing a focus group discussion. In conclusion, focus groups are a method for gathering research data; they are focused on the research topic, involve use people in group discussion, have a moderator to guide the discussion, provide data of a qualitative nature (11, 13). Focus group discussions with different groups of participants help identify common problems and opinions and in research studies are used as a self-contained method acting as the principal source of data. Focus groups allow to identificate the main problems more successfully than questionnaires and interviews (11, 13, 18).

The aim of our study was to determine the main factors impacting the QoL of the elderly. For this purpose, the method of a series of focus group discussions with older adults, and professional carers was used.

SUBJECTS AND METHODS

Participatants of the in focus groups were selected according to the guidelines provided by the WHOQOL-Old co-ordinating centre. Inclusion criteria: participants should consent to take part in the study; fit the age requirements. Exclusion criteria (determined in advance with the assistance of group convenors): terminal illnesses (*e.g.*, cancer); dementia or other significant cognitive impairments.

For all groups socio-demographic data (age, education, current living circumstances/level of support received) were collected, as well as information on the health status defined from answers of the participants to the following question: "Do you consider yourself to be generally healthy or unhealthy?". Eighteen older adults took part in four separate focus group sessions. The groups were structured according to the age criteria (Table 1).

Table 1. **Composition of focus groups of older adults by age and gender**

Status	Age (number of persons)	Gender
"Healthy" – Group 1	60–79 (5)	All female
"Healthy" – Group 2	80–90+ (4)	Female (3) / Male (1)
"Unhealthy" – Group 3	60–79 (5)	Female (4) / Male (1)
"Unhealthy" – Group 4	80–90+ (4)	Female (3) / Male (1)

Data on self-reported problems related to general health and daily activities were collected. All older people in groups 1 and 2 reported to be "healthy". In the "young healthy" group there were less frail, more active and more mobile older people. Subjectively "healthy" older adults as usual indicated 1–2 problems of general health. Three participants in the "unhealthy" group 4 had serious physical disabilities, 1 female used a wheelchair part of the day. The majority of "unhealthy" older adults reported having a long-standing illness that limited their lifestyle, multiple impairments such as impaired sight or hearing, chronic condition such as osteoarthritis, cardiovascular diseases, etc. The most frequent problem experienced by "unhealthy" people aged 80 and over was pain followed by mobility problems. However, intense medical and social care was required by only a minority of those aged 80 and over who had chronic, multiple conditions.

All participants in the carers' focus group were female aged 32–54 years, working full-time as professional carers with a long working experience (7–15 years).

Focus groups were conducted following a standardized protocol provided by the WHOQOL-Old coordinating centre. A letter outlining the WHOQOL-Old study and requesting access to older adults was distributed to two older adults' organizations in Vilnius. On receiving verbal consent to participate an invitation letter and other necessary information was distributed. Two moderators participated in each focus group session. The participants were well motivated to speak about their quality of life. Nobody was forced to reply if he/she did not want. The flow of discussion was influenced neither by the conformity nor polarization of views. Informed consent forms were signed before a focus group session. Refreshments were offered. Each discussion group las-

ted approximately 1.5 hours. The discussions were tape-recorded. Data were collected by rotating the items across all focus groups and covered free-form discussion of QoL (identification of important for participants items/areas), discussion of WHOQOL-100 – review of facets, a list of additional items/areas for consideration.

Permission to conduct the focus groups research was obtained from Lithuanian Bioethics Committee.

RESULTS

Open Quality of Life discussions. All discussions in older adults' focus groups were run in a free manner, allowing participants to comment on their feels and personal experiences. All participants felt grateful for the opportunity to discuss their QoL and briefly described the problems they experience, many of them spoke of health, adequate medical help, medicines, finances, family and friends. Health was the top priority issue. According to their opinion, even small changes in the health state usually have a considerable impact on OoL.

All participants acknowledged that health affected their personal life and their abilities to communicate and to keep social contacts. A significant problem mentioned by most participants in all groups was getting adequate medical help and medicines. Older people identified a variety of problems in the provision of medical care: increasing costs of medicines, changes in reimbursement policy and in the structure of care-giving institutions, etc. A few participants were openly distressed about the impact the changes of health care system were exerting on their lives. Their most common worrying problems were health, finances and the quality of family relations. All aspects of safety were considered to be the area of high importance for more "healthy" elderly. More "healthy" older adults tended to relate their personal experiences and QoL with political issues and the reform process in Lithuania. According to the participants, many different factors such as living environment, loneliness, participation in different outdoor activities, different activities for promoting health, learning and other may have an impact on the QoL (Table 2). All older adults stressed the importance of being valued and respected by the family. Only the first group of "healthy" older people actively participated in working life (unpaid). Feeling part of society, satisfaction with the ability to perform some work and tasks had a positive impact on their QoL.

The carers raised many significant items concerning the forms of psychological support and the problems of elderly care (Table 3). These included: older people receive no regular visits of community nurses; older people don't receive adequate information on the aging issues; carers need appropriate training in different kinds of support. In order to improve the QoL of older adults, the carers identified the main strategies such as devices, education, care provision at home, etc. They stressed the importance of education of older people and the problems of acceptance of old age. Two carers expressed concerns about the difficulty in getting care at home and different problems following discharge from hospital in a weakened state. They pointed out that there could be more support from community, stressed the shortage of the continuity of care and of the allocated finances. Costs for privately provided care are too high for most of the elderly, and there are only few private agencies for care in Lithuania.

Table 2. **Older adults' opinion on the factors influencing their quality of life**

Negative effect	Positive effect
• impaired mobility	• physical and mental activity and independence
• ill-health, pain	• finances
• insufficient pension cover for most older people	• medical care, medicines
• low level of social protection	• improved living conditions (according to personal desires)
• low level of health protection	• lifelong learning, promotion of skills
• lack of medicines	• preserved memory
• unstable social-economic situation	• preserved working ability
• lack of personal contacts with friends, loneliness and isolation	• variety of personal contacts
• living environment doesn't meet personal requirements	• feelings of self-esteem accomplishment, self-confidence
• unsafe environment	• to be valued and respected by family
• unavailable equipment and aids	• happy and healthy family life
• bad communication among family members	• physical activity for promoting good health
	• individual abilities to cope up
	• contentment that he/she had a good life

Table 3. **Carers' opinion on the factors influencing the quality of life of older adults**

Factors enhancing the quality of life of the elderly	Factors worsening the quality of life of the elderly
• Financial resources	• Low income is the main factor influencing ability to buy food, medicines, pay for private care services
• Psychological factors (respect, attention and other.)	• Lack of support at home in terms of advice, practical help, professional services (home nursing, home care)
• Individual needs supported	• Need for support to make life easier at home
• Efforts to health promotion illness prevention	• Bad family relations
• Health information and education about strategies to promote healthy aging	• Lack of cooperation between health care providers
• Improvement of delivery of health services and medical care	• Areas of declining ability • Problems in getting personal mobility aids

Review of WHOQOL-100 facets. All items and facets of WHOQOL-100 were considered absolutely relevant for older adults, nevertheless, the priority of different facets was pointed out to differ significantly. A few problems were identified: lack of specificity (sexual activity, transportation), complicated situation is not covered by offered questions (social support and services, medical care). Older people lack awareness and information of the various types of social support and service provision available to them. As the participants indicated, the questions on medical care are extremely actual, a lot of information relating and need inclusion of supplementary questions dealing with the quality of medical care. An ardent discussion developed on the items of sexual activity in the groups of carers and "healthy" older adults. The participants indicated that questions about sexuality do not cover the range of sexual feelling in old age and should be amended.

Additional items. Older adults discussed the following additional items important to them and not included in WHOQOL-100: family communications, perceptions of death, the impact of negative discrimination, freedom of choice. The most frequently discussed items were: living situation – most participants indicated that personal requests have to be considered when providing living conditions; coping up – issues related to coping up were raised by both "healthy" and "unhealthy" elderly. Older patients mentioned that they used a variety of tactics to cope up with the problems related to aging. One of the older participants said she felt shocked of becoming increasingly dependent. The others were better adapted: "*I've accepted my illness*". "*There are many elderly that are in a much worse situation...*". The participants stressed the importance of education on ageing to avoid the distress of infirmities of old age. Older people did not seem to grief over lost abilities, they preferred acceptance of losses. The participants approved a positive grandmother's role coinciding with a traditional image and with respect of the ancestors' traditions. The carers mentioned the importance of good nutrition. Older adults indicated other factors influencing the QoL in old age: prophylaxis, heredity, active ageing. The participants suggested new items to be included: provision of details of age-related discrimination (in community, in family, in health care, etc.); estimation of individual needs and control over their satisfaction; evaluation of lifelong goals. In this respect, a few "healthy" older adults and carers mentioned purpose, efforts and the sense of gratification or satisfaction.

Prioritization of issues. Participants considered the most important factors influencing quality of life to be health, importance to remain physically and mentally active, finances and good family relations. Carers and older adults prioritized the issues differently, but the financial issues were highly significant for all. Shortage of finances was considered as an important aspect strongly affecting other issues of QoL as it regulates the ability to pay for meals, medicines and leisure time activities. Nevertheless, the carers placed on the first place and stressed the importance of the psychological factors and the feeling of disaster experienced due to being dependent and disabled. The carers raised the issue of educating the elderly about the aging process. Transportation as a need of older people was not ranked as a priority. Deterioration of the physical environment was not a matter of concern for most of the participants. The older people highly valued their abilities to participate in social activities, but had no knowledge on service provision and lacked an adequate understanding of the natural aging process. Older people reported using a variety of individual tactics to help them in coping up with difficult situations. Most seemed to feel that the tactics they employed were rather effective.

DISCUSSION

The findings showed that in general the situation of the elderly is complicated due to socio-economic trans-

formations, poor finances and rearrangement of the health care system. They feel lonely, offended and impoverished. The results of the study are likely to be indicative of the needs and problems of the older adults, as they showed a good consistency of questionnaire answers in all the three groups targeted. A good agreement between the results of the focus group and the information gathered by other methods (literature survey, published data of medical help and social care providers) is evident (7, 9, 12, 16).

All focus groups were focused on topics and were having a discussion guided by two moderators. The most common factors influencing the QoL of older people were identified. All participants briefly described the greatest problems they experience, many of them spoke of health, financial problems, family relations, communication. Overall, the focus group participants were shown to have serious problems in terms of getting the health care and support they needed. Carers and few older adults stressed the problem of acceptance of old age. Older participants as well as carers pointed out a lack of organizations providing medical information, advice and support at home. Participants raised the issue of finances as a key to maintaining many other aspects of quality of life strongly influencing choices and abilities to meet needs. Older adults stressed the importance of being valued and respected by family. The image of a stable supportive family is traditional for native Lithuanians. All focus groups considered the items and facets of WHOQOL-100 absolutely relevant to older adults, similarly as in other countries (5, 7, 19). Nevertheless, the priority of different facets of WHOQOL-100 for older adults was pointed out to be greatly different. All additional issues were noted to be actual for older adults and should be included into WHOQOL-Old measures of higher importance. These are perception of death, living situation, discrimination, education, coping up.

This series of focus groups gave a picture of the problems of older adults in Lithuania. In most cases the incomes could not cover the living demands, thus restricting the choice of food, raising problems in getting the adequate medical care and resources to support independent living. Drawn together, the results of all focus groups allow a preliminary conclusion on different factors that influence the QoL. Society should be constantly aware of the current needs of older people and on the level of unmet needs. The results indicate that the level of unmet needs has a significant implication for the QoL. Our information concerning the situation is not sufficient to get a full picture of the needs of older people and their QoL. However, the good consistency of answers in all focus groups is indicative of the main factors.

The findings provided a group of the major factors that impact the QoL of older people in Lithuania in the present period of reforms and restructurization. Many of the issues raised reflect the structural reform and transformation of the medical care system. Older people were confused about the services offered. Other researchers (12, 17) also found confusion and lack of knowledge among older people in other countries concerning services. The results have important implications as to the formal sources of support provided to elderly people. Needs and preferences, the use of health and social care may be very different for the next generation of older people. Focus group discussions give an indication of the QoL and needs of older people only at the time of the study.

Discussions on sexuality questions showed that this item is important. However, older people's own attitudes towards the role and value of sex in later life remain relatively unexplored (20). As Gott has reported (20), the stereotype of the "asexual older person" has little empirical grounding and is influenced by cultural and religious traditions.

The focus group investigation provided results that enable to answer the question about the main factors influencing the QoL of older adults. These factors were identified and the information generated by the focus groups was effective in compiling a questionnaire for older people. The data showed that health status is a reasonable indicator of global QoL of older adults. A similar conclusion was made by Covinsky et al. (9), therefore assumptions about the overall QoL of individuals should not be based only on their health state measurements. The importance of a *subjective* assessment of the QoL by individuals themselves has also been acknowledged (15, 16, 21). A number of studies have demonstrated that physicians' ratings of the QoL of their patients with chronic illnesses are significantly lower than the patients' self-rated QoL (6, 8). As highlighted by findings of a low correlation between the self-rated and functional QoL, physical assessments alone are inadequate as indicators of QoL. These findings reveal the discrepancy between the exogenous and endogenous assessments of QoL. Although health-related QoL in older people is generally assessed by measuring specific domains of health status, such as activities of daily living or pain, the association between health-status measures and patients' perception of their QoL is not clear and will be investigated in future.

The total of the data will be used to identify gaps in the current version of the WHOQOL on younger adults. The findings of the focus group studies suggest that WHOQOL-100 does not cover all items important for older adults and will be used to

develop a WHOQOL-Old questionnaire. The coordinating group of the WHOQOL-Old project conducts a cross-cultural comparison of data and item generation.

The results of the focus group studies have been sent to the Steering Group of the programme WHOQOL-OLD. In partnership with all participating centers, the Steering Group will agree a set of core facets and definitions of facets for the pilot older adult's module. The use of focus group discussions in different participating countries will ensure the cultural sensitivity and relevance of the language and concepts included in each centre-specific version of the future QoL measure, which will be used for an intercultural survey that aimed to compare the QoL of older adults in different countries.

CONCLUSIONS

1. The most common factors that influence the quality of life of the elderly were identified to be as follows: health, mobility, finances, family relations, communication, acceptance of old age, living environment, discrimination, health education. These results will be used for a cross-cultural comparison of data within the project WHOWOL-Old and for compiling a new pilot questionnoire for older adults.

2. WHOQOL-100 should be modified and together with additional items cover all items important for older adults.

ACKNOWLEDGEMENTS

The author acknowledges Dr. V. Valeikienė for assistance in conducting the focus groups.

Received 28 April 2003
Accepted 29 May 2002

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E. Čeremnych

FOKUSUOTOS GRUPINĖS DISKUSIJOS SU PAGYVENUSIAIS ŽMONĖMIS IR SLAUGYTOJAIS VYKDANT PSO WHOQOL-100 PROGRAMOS I ETAPĄ

S a n t r a u k a

Straipsnyje pateikta tarptautinio multicentrinio tyrimo WHOQOL-OLD („Pagyvenusių žmonių gyvenimo kokybės įvertinimas ir jo ryšio su sveiku senėjimu tyrimas“) pirmojo etapo (fokusuotos grupinės diskusijos) medžiaga. Šio tyrimo tikslas – sukurti gyvenimo kokybės klausimyną, kuris padėtų įvertinti pagyvenusių žmonių gyvenimo kokybę. Tam tikslui I etape pagal specialią metodiką (fokusuotos grupinės diskusijos) vykdoma pagyvenusių žmonių ir slaugytojų apklausa, aptariant įvairius gyvenimo kokybės aspektus ir PSO klausimyną WHOQOL-100. Tyrime dalyvavo 60–93 metų asmenys, gyvenantys Vilniaus mieste, ir slaugytojos. Didžiausią įtaką gyvenimo kokybei turintys veiksniai: sveikatos problemos, pinigų stoka, santykiai su šeimos nariais, nepakankamas bendravimas.

Raktažodžiai: gyvenimo kokybė, pagyvenusieji žmonės, slaugytojai, PSO, WHOQOL-100