

Original Paper

QOL Assessment for Aged Persons with Intellectual Disabilities

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Abstract

A QOL Questionnaire was created for aged persons with intellectual disabilities utilizing R. L. Schalock's QOL Questionnaire. Thirty-nine people living in an institution were then asked to fill out the Questionnaire. At the same time they were given M. P. Lawton's revised edition of the PGC Morale Scale which measures subjective happiness for aged persons. A strong relationships was found between QOL and the satisfaction with their occupations, various activities and exchanges with families. We believe that combining these two assessments allows a more thorough examination of each subject resulting in better individual programs.

1. Objectives

There are many different types of QOL Assessments. Mainly, these assessments are subjective measures and are often used as checklists for evaluating institutions. There have been calls by society citing the need for QOL Assessments for aged persons that could be reflected in policy. Although there have been some studies, and the care manual for aged persons with intellectual disabilities by Aigo-Kyokai has been published, this is only the beginning in the research of QOL itself and QOL Assessments for aged persons with intellectual disabilities.

We believed that the QOL for aged persons and the QOL for aged persons with intellectual disabilities are basically the same, but there are some problems in evaluating the latter group. It is very important to evaluate their satisfaction with life, but because the persons may have difficulty understanding language or expressing themselves, it is very difficult to evaluate their subjective QOL. If we want a person to understand the question, we should make the question as straightforward as possible. But because of differences in circumstances such as living in an institution or living at home, or the degree of their disabilities, one type of question may not be suitable for all individuals. We think that QOL assessments for a person with intellectual disabilities and assessments for those without intellectual disabilities, can have the same structure, but various types of questions are needed depending on their degree of disability or varying life style.

This study focused on persons who have little difficulty in understanding language or expressing themselves, and who live in an institution where many aged persons with intellectual disabilities live.

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2. Methods

Questions were selected from R. L. Schalock's QOL Questionnaire for Mental Retardation (1993) that were appropriate for aged persons living in Japanese institutions for the intellectually disabled. In addition, the "Check list for a comfortable institution life" by the Association of Institutions for the physically disabled and WHO/QOL-26 were consulted to create a tentative QOL assessment tool for aged persons with intellectual disabilities. This questionnaire contained 10 questions on satisfaction, 5 questions on productivity/activities, 5 questions on community integration, 5 questions on future life, 5 questions on human rights and 10 questions on independence. Although there are no questions on future life and human rights in Schalock's QOL questionnaire, they were included in our questionnaire, because those responding were aged persons living in institutions. Each question uses a three point system to score the answers; 3 points for a positive answer, 1 point for a negative answer, 2 points for a moderate answer. It was felt that this questionnaire did not adequately measure the subjective QOL of aged persons, so M. P. Lawton's revised edition of the PGC Morale Scale, which measures the subjective satisfaction of aged persons, was included for a more thorough assessment of the subjective QOL of aged persons.

Eight institutions in Okayama Prefecture were asked to use these two assessment tools. Each institution was asked to select 5 people who were over fifty years of age and had little difficulty understanding language and expressing themselves. The staff at each institution interviewed each subject to get answers to the questionnaire. Staff members were told that, if the person had any difficulty understanding the question, meaning should be explained to ensure understanding. If there was a question that the person had difficulty answering, the staff member was advised to answer the question using their own judgment while making a note of the fact.

3. Results

Responses were received from thirty-nine persons (20 males, 19 females) from five institutions, that were reliable enough to analyze. The ages of the subjects was as follows; twenty-seven people in their fifties, eleven people in their sixties and one person in his seventies (seventy-two).

① Results of the QOL Questionnaire responses

First, each score was calculated and the points were totaled to get an overall picture of the results. They scored 908 points out of a possible 1170 points (if everyone responded with three points) on the section on

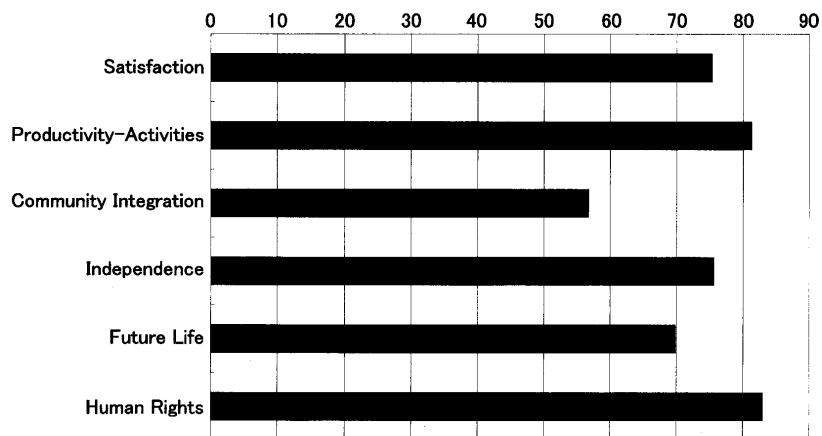


Fig. 1 Results of QOL Questionnaire in 7 Facilities

satisfaction. This is a total score of 77.6%. There were different numbers of questions in each section and the results are shown in Figure 1. Both Community Integration and Future Life scores were lower than the other sections. The overall average score for each person was 91 ± 10.68 out of a possible 120 points. The total points of each section are shown in Figures 2-7.

Satisfaction; Most of the answers were positive. People felt they were an important part of the family and were shown respect.

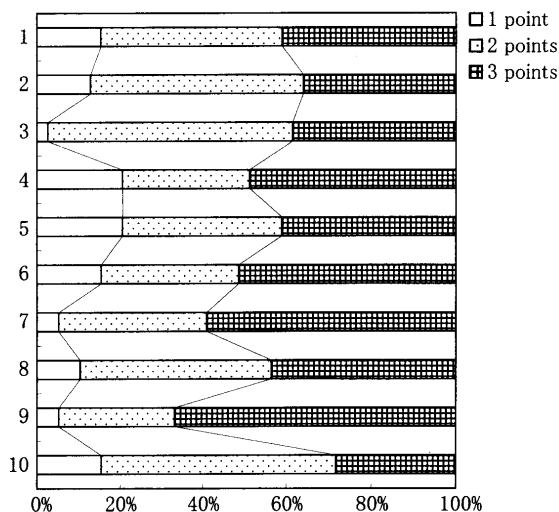


Fig. 2 Results of Questions on "Satisfaction"

Productivity/Activities; The people felt they were given an explanation about the activities they would be doing, and that the activities were worthwhile, but only a few people could make decisions about activities by themselves.

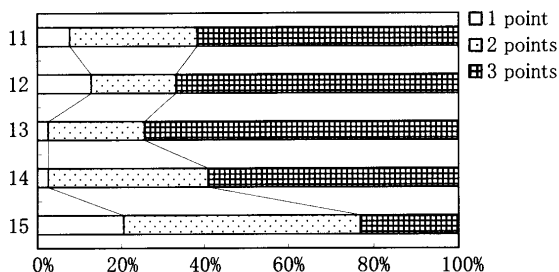


Fig. 3 Results of Questions on "Productivity-Activities"

Community Integration; There was a significant difference from the other sections. No one gave a three-point answer. For the question, "Do you have friends over to visit your home?", no one answered "Fairly often". Also only a few people participated in recreational activities such as community events, sports and cultural activities in the community.

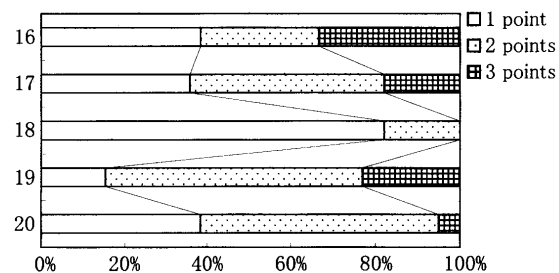


Fig. 4 Results of Questions on "Community Integration"

Independence; It is characteristic to trust parents and guardians but we had to decide if the answers given were true or not, and if the questions were clear, because the answers in this section were spread out over a wide range. In general, most of the respondents felt their lives were planned for them.

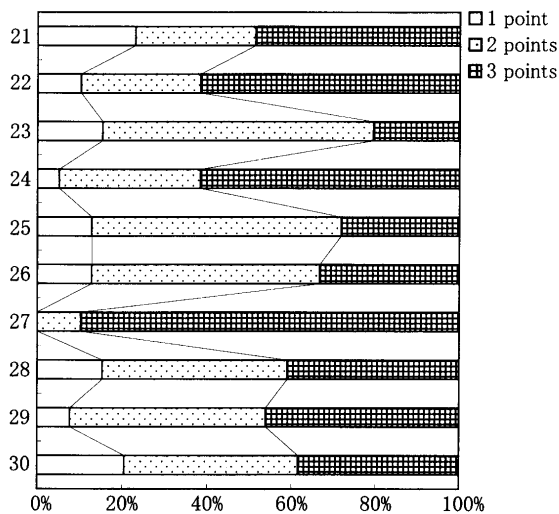


Fig. 5 Results of Questions on "Independence"

Future life; There were some positive answers concerning their present life, but very few wanted to live with just aged people in the future. This question is not directly related to QOL but we found that many people wanted to give their opinion about their own future. More than sixty percent of the respondents were anxious about their future life. Because this section was added by us, we thought some of the questions would result in a wide variety of answers which would be difficult to translate into numbers.

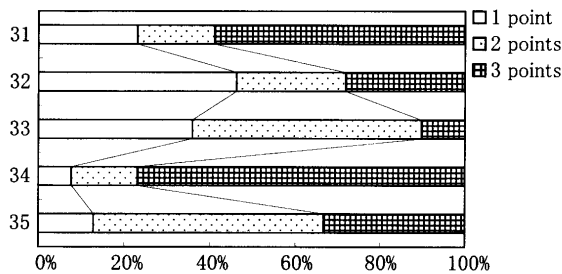


Fig. 6 Results of Questions on "Future Life"

Human Rights; Eighty percent of the responses indicated that those responding felt they were maintaining their human rights. But it should be remembered that there were some negative answers in this section. An examination of the correlation between the total score in each section and the overall total score for each person, showed a strong correlation ($p < 0.05$) between the overall total and the totals in the satisfaction, productivity/activities, human rights, and independence sections ($p < 0.1$).

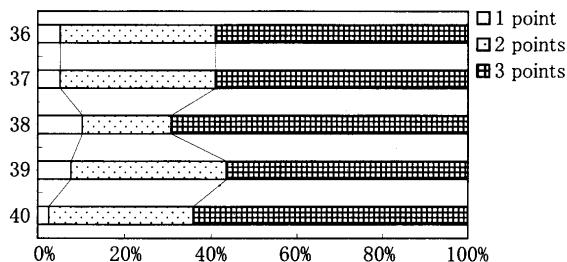


Fig. 7 Results of Questions on "Human Rights"

② Results of the PGC Morale Scale

It is said that “morale” is one side of “subjective happiness”. M. P. Lawton who created this scale, said “morale is high” when the following are true.

1. Basic Self Satisfaction. A person feels that he has accomplished something in life and that he is a valuable and adequate person.
2. Personal Space of their own. Throughout their lives, they have had the desire to give and be given things by others or the environment.
3. Acceptance of the fact that there are things you cannot change, for example your own age.

M. P. Lawton organized the PGC Morale Scale into seventeen items in three categories, “Psychological comfort”, “Attitude toward aging”, and “Loneliness”. There are two to four choices and a one point answer indicates high morale.

This PGC Morale Scale was given to the subjects in this study and thirty-seven responses were received with an average score of 10.67 ± 3.30 (see Figure 8). For the question, “Do you think your life is getting worse as you age?”, 81.0 percent of the people responded no. For the question, “Do you think it is not worthwhile to continue living?”, 91.8 percent of the people felt it was worthwhile to continue living. For the question, “Are you satisfied with your life?”, 83.8 percent of the people said yes. These responses indicated a feeling of optimism. On the other hand, for the question, “Do you feel lonely?”, 51.4 percent of the people answered that they sometimes felt lonely. For the question, “Are you satisfied that your family or friends come to see you?”, 40.5 percent said they were satisfied. For the question, “Do you think being old is better than you thought it would be when you were young?”, 35.2 percent of the people felt it was better. For the question, “When you are worried about something, do you get flustered?”, 51.4 percent said yes. Feelings of loneliness and anxiety can be seen.

③ Relationship between the QOL Questionnaire and the PGC Morale Scale

Although we looked for a correlation between the individual personal scores of the PGC Morale Scale and the overall total scores and item scores for the QOL Questionnaire, no significant correlations were found. A strong correlation was found between the total scores of each section and the morale scale. Also, there was a correlation ($p < 0.05$) among satisfaction, productivity and independence ($p < 0.1$). However, a

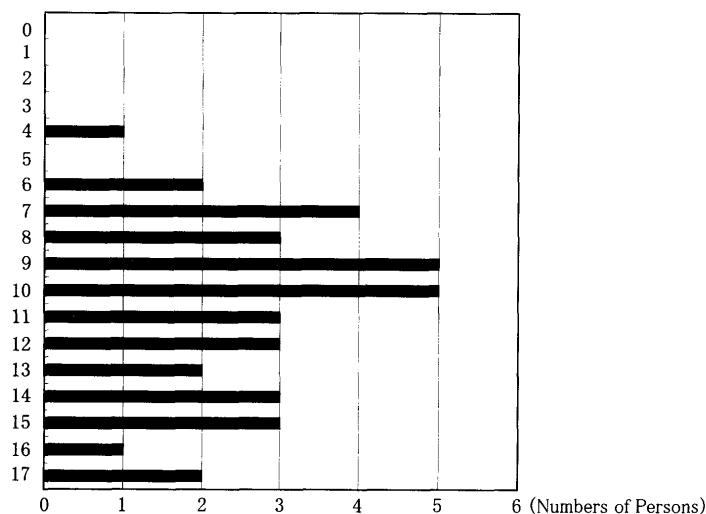


Fig. 8 Results of PGC Morale Scale (Number of Persons with Each Total Score)

tendency for a reverse correlation was found in social integration. No correlations were found in future life and human rights.

④The opinions of the staff member who joined this study

It was difficult to make the subjects understand the meaning of the questions. In particular, three institutions said that the sections regarding satisfaction and human rights on the QOL Questionnaire were the most difficult to understand.

4. Discussion

①Validity of QOL Questionnaire

In this study, each subject was interviewed directly by one or two staff members. The interpretation and free translation of the questions were left up to the staff member. No large differences in scoring were seen between institutions and there was a probability that the meaning of the questions was understood by the respondents and that they were able to analyze the answers. Looking at these results, persons with intellectual disabilities realizing their age can be seen.

In this study, subjects were selected who were able to process the questionnaire easily. If the QOL Questionnaire is expanded, the manual may also have to be expanded to include such items as the average of more than two staff member interviews (separately), and sample sentences for easier understanding. If the answers are not reliable, other staff members may be called on to assist the person in answering. If a person with severe disabilities has difficulty understanding the questions, R. L. Schalock's suggestion of having a family member or guardians answer the questions, may be tried. It is important when revising the questionnaire that questions which prove difficult to understand because they are abstract, should be eliminated. When the questions are examined for revision, questions may have to be separated into those that are important for personal background information and those that could be eliminated. The results of this QOL Questionnaire show the characteristics of people with intellectual disabilities living in institutions, but not those of an aged person. This questionnaire may be tried on different generations to see if there are any differences in the results and to get more data about the Questionnaire.

②The QOL for aged persons with intellectual disabilities revealed by the results from the QOL Questionnaire

According to the relationship between the QOL Questionnaire and the PGC Morale Scale, fulfillment in their productivity, activities and exchanges with their families are large elements in the subjective happiness and desire for self decision making. But in elderly people, there was also the impression that many people do not want to change their life style, as would be necessary to reverse the correlation of the morale scale and community integration. Many of them do not want to live with just aged persons. The staff who participated in this study felt that, even if there are problems in the respondents' life style, they would have difficulty accepting a more comfortable life and would also find it difficult to accept getting ill. Of course some of the questions were difficult to answer because of a lack of experience or information. Therefore, they must be given more information, opportunities to experience many things, as well as opportunities to make choices. On the other hand, the elements for subjective happiness are different for each person. In some cases where the objective QOL score is low, we must look carefully at the person's subjective QOL.

In this study, both the QOL Questionnaire and the PGC Morale Scale were used, which enabled us to compare conditions for the objective QOL and find the factors for the QOL Questionnaire. For example, the death of family members or friends is a fact which cannot be avoided when one gets old. This may seem to lower the objective QOL, but when people are able to accept the fact, their subjective QOL increases. It

is important to support their loneliness and anxiety by encouraging personal relationships. It is possible to find patterns in the QOL of aged persons, but we must look at the person carefully, and not only improve their environment and services, but also improve the personal programs that are a part of the subjective QOL.

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Appendix

QUALITY OF LIFE QUESTIONNAIRE

No: _____ Gender: Male Female _____
 Evaluator: _____ Test Date: _____
 Birth Date: _____ Age: _____
 Institution Entry Date: _____

RESULTS

Scale	Self- Reported	Examiner Reported			
Satisfaction					
Productivity/ Activities					
Independence					
Community Integration					
Future Life					
Human Rights					
TOTAL SCORE					

ADMINISTRATION OF QOL QUESTIONNAIRE

1. Respondents:

A: Qualifications

More than fifty years of age.

Has appropriate receptive and expressive language ability.

B: Five individuals selected and interviewed individually.

2. Instructions for respondents:

The following instructions are explained to respondents.

I want you to think about where you live, work, and have fun, and the family, friends, and staff that you know. Together, let's answer some questions that express how you feel about these things. If you like, you can check the choices given for each item; if you like, I can check them for you after reading and discussing each of the three alternatives for each item. Please try to answer each of the items and we will take as much time as you need. There are no right or wrong answers. We want only to know how you feel about where you live, work, and have fun, and the family, friends, and staff that you know. Do you have any questions?

3. Instructions for examiners:

If the respondent consents, proceed to administer the 40 items. When reading the items, pay close attention to the exact wording. You may paraphrase items and repeat them as often as necessary to ensure the respondent's understanding of the item content. If the respondents have difficulty answering, the examiner should answer the question from the choices, using the examiner's judgment while making a note in the appropriate column.

4. About the PGC Morale Scale:

Administration is the same as for the QOL Questionnaire.

Choose one answer from each set of choices.

If the respondent has difficulty answering, the examiner may exercise judgement to choose the answer. Column is divided into two parts, self reported and examiner reported.

(A)SATISFACTION		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
1.	Overall, would you say that life :	Brings out the best in you?	Treats you like everybody else?	Doesn't give you a chance?		
2.	How much fun and enjoyment do you get out of life?	Lots	Some	Not much		
3.	Are most of the things that happen to you:	Rewarding	Acceptable	Disappointing		
4.	How satisfied are you with your current home or living arrangement?	Very satisfied	Somewhat satisfied	Unsatisfied or very unsatisfied		
5.	Do you have more or fewer problems than other people?	Fewer problems	The same number of problems as others	More problems than others		
6.	How many times per month do you feel lonely?	Seldom, never more than once or twice	Occasionally, at least 5 or 6 times a month	Frequently, at least once or twice a week		
7.	Do you ever feel out of place in social situations?	Seldom or never	Sometimes	Usually or always		
8.	Compared to others, are you better off, about the same or less well off?	Better	About the same	Worse		
9.	How successful do you think you are, compared to others?	Probably more successful than the average person	About as successful as the average person	Less successful than the average person		
10.	Do you have anyone you can talk to when you are troubled?	Many	About one	No one		

(B)PRODUCTIVITY/ ACTIVITIES		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
11.	How well did your educational or training program prepare you for what you are doing now?	Very well	Somewhat	Not at all well		
12.	Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?	Yes, definitely	Probably	I'm not sure, or definitely not		
13.	How good do you feel you are at your job?	Very good, and others tell me I am good	I'm good, but no one tells me	I'm having trouble on my job		
14.	How satisfied are you with the skills and experience you have gained or are gaining from your job?	Very satisfied	Somewhat satisfied	Not satisfied		
15.	How did you decide to do the job or other daily activities you do now?	I chose it because of pay, benefits, or interests	Only thing available or that I could find	Someone else decided for me		

(C)COMMUNITY INTEGRATION		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
16.	Do you worry about what people expect of you?	Sometimes, but not all the time	Seldom	Never or all the time		
17.	How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?	3-4 times per week	1-2 times per week	Never or all the time		
18.	Do you have friends over to visit your home?	Fairly often	Sometimes	Rarely or never		
19.	How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?	3-4 per month	1-2 per months	Less than 1 per month		
20.	Do you participate actively in those recreational activities?	Usually, most of the time	Frequently, about half the time	Seldom or never		

(D)INDEPENDENCE		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
21.	Who decides how you spend your money?	I do	I do, with assistance from others	Someone else decides		
22.	How do you use health care facilities (doctor, dentist, etc.)?	Almost always on my own	Usually accompanied by someone, or someone else has made the appointment	Never on my own		
23.	How much control do you have over things you do every day, like going to bed, eating, and what you do for fun?	Complete	Some	Little		
24.	Is there a limit on belongings such as clothes, accessories, make up, and personal items?	No limit	Somewhat limited	Very limited		
25.	Can you have luxury items such as tobacco, liquor, coffee and others?	Any time	Most of the time	Never		
26.	When can friends visit your home?	As often as I like or fairly often	Any day, as long as someone else approves or is there	Only on certain days		
27.	Do you trust your parents or guardians?	Yes	Fairly	No		
28.	Do you look forward to having contact with family members. For example, phone calls, letters and visits?	Yes	Sometimes	No		
29.	Are there people living with you who sometimes hurt you, pester you, scare you, or make you angry?	No	Yes, and those problems occur once a month or once a week	Yes, and those problems occur every day or more than once a day		
30.	Overall, would you say that your life is:	Free	Somewhat planned for you	Cannot usually do what you want		

(E)FUTURE LIFE		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
31.	Would you like to continue staying at this institution?	Yes	Don't care	No		
32.	Would you like to live with other aged persons in the future?	Yes	Don't care	No		
33.	Would you like to live in the community some day?	Yes	Don't care	No		
34.	Would you like for someone to hear your opinions about your hopes for the future?	Yes	Don't care	No		
35.	Are you anxious about your future?	Yes	Somewhat	No		

(F)HUMAN RIGHTS		ANSWER ALTERNATIVES			Self-reported	examiner reported
		3points	2points	1point		
36.	Are you free to practice your own religion or beliefs?	Yes	Somewhat	Never		
37.	Does the staff listen to you and your opinions?	Listen well	Listen sometimes	Never listen		
38.	Do staff members direct or command you?	Never	Sometimes	All the time		
39.	Do you feel your human rights are being violated?	Never	Sometimes	All the time		
40.	Do you feel the staff protect your human rights?	Yes	Fair	Never		

PGC MORALE SCALE

Questions	Choices	Self-Reported	Examiner reported
1. Do you think your life is getting worse with aging?	a)yes <u>b)no</u>		
2. Do you think you are as vigorous as last year?	<u>a)yes</u> b)no		
3. Do you feel lonely?	<u>a)no</u> <u>b)not much</u> c)sometimes d)yes		
4. Are you Irritated by small things recently?	a)yes <u>b)no</u>		
5. Are you satisfied with friends and family's visits?	<u>a)satisfied</u> b)see more		
6. Do you feel worthless in the process of aging?	a)yes <u>b)no</u>		
7. Do you have difficulty sleeping when nervous?	a)yes <u>b)no</u>		
8. Is aging better than you thought it would be when you were younger?	<u>a)better</u> b)same c)worse		
9. Do you feel that it is not necessary to live?	a)yes <u>b)not much</u> <u>c)no</u>		
10. Are you as happy as when you were young?	<u>a)yes</u> b)no		
11. Do you feel a lot of sadness?	a)yes <u>b)no</u>		
12. Do you have a lot of concerns?	a)yes <u>b)no</u>		
13. Do you get angry easily?	a)yes <u>b)no</u>		
14. Is living a very difficult thing?	a)yes <u>b)no</u>		
15. Are you satisfied with your present life?	a)yes <u>b)no</u>		
16. Do you think about things too seriously?	<u>a)yes</u> b)no		
17. Do you get flustered easily when concerned?	a)yes <u>b)no</u>		

(When you choose an answer which is underlined, you get one point. Then add to get the total points. That becomes your morale score.)