



Modelling Health Related Quality of Life for the AQoL-6D

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Preface/Synopsis

The present research paper was written in March 2006 but by error was not published. At the time of its writing the instrument was called the AQoL 2, but has since been relabelled to more clearly distinguish the differences between the various AQoL instruments.

The present paper presents details of the procedures used for developing the descriptive system for the AQoL-6D, and, in particular, the modelling which led to the final instrument structure. This was very extensive and detailed and is not fully produced here. Rather, the overall approach to the modelling is described and details provided for the analysis behind the construction of the most complex dimension, viz, the social dimension. Similarly work was carried out for each of the other dimensions.

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Modelling Health Related Quality of Life for the AQoL-6D

1 Introduction

The paper presents an account of the Structural equation modelling used to develop the AQoL 2 model from the data collected in the AQoL Construction Survey.

2 Questionnaire development

The aim of the AQoL Mark 2 Construction Questionnaire Survey was to provide a bank of items which would provide the basis for extensive analysis to develop a new version of the AQoL Mark 1 Health Related Quality of Life instrument. There were two major objectives guiding the development of the AQoL Mark 2 Construction Questionnaire. First it was desirable that the AQoL Mark 2 have elements of continuity from the AQoL Mark 1 to allow for some level of comparison between the results. Secondly, the new questionnaire was intended to improve the sensitivity of the AQoL Mark 1, particularly in measuring health states of healthier people, with the intention of facilitating the use of the instrument in health promotion. Thirdly, the new instrument was intended to extend the domain of Health related quality of life covered by the AQoL to allow for extension of the concept of “health” to cover domains likely to be added to the concerns of health promoters over the next decade.

This development was undertaken in three phases: literature review, consultations and focus groups with key informants, pre-testing and piloting.

2.1 Review of literature and QoL questions

An extensive review was undertaken on the literature and, in particular, the questions used in the measurement of health related quality of life. This work built on foundations laid in previous stages of the AQoL. The first was the AQoL validation study, a survey of three samples of Victorian adults: population, hospital inpatients and outpatients. In this survey, each informant completed the AQoL Mark 1 questionnaire and five other instruments (SF-36, EQ5d, 15D, WHOQoL and HUI2/3). The validation survey provided a basis for the comparative analysis of a large number of items, which guided the selection and testing of items for the AQoL mark 2. The second resource was the large bank of items developed for the AQoL mark 1. These items were reviewed and many tested for inclusion in the AQoL Mark 2.

2.2 Consultations, focus groups and expert review

The brief for the development of AQoL mark 2 specified that it was to address the needs of health promoters, and in particular be sensitive to measurements of quality of life affecting aged persons, those of NESB and adolescents. Interviews were conducted with researchers working in the areas of aging, youth health and ethnic health.

Because of the significance of the health promotion objectives of the AQoL Mark 2, it was decided to conduct group discussions. After initial interviews with key stakeholders from the health promotion area, several potential informants were identified. These informants included potential users of the AQoL Mark 2, either as researchers who might be expected to utilize the instrument, or policy or management people who would use the resulting analysis. Three broad questions were canvassed:

- What is the current role of quality of life measurement in health promotion.
- How is quality of life is conceptualized by practitioners and researchers working in health promotion?
- In revising the Assessment of Quality of Life instrument, where should we focus our attention?
- Over the next five to ten years, what are broad changes and developments are likely to occur in Health Promotion that we should try to anticipate in revising our Quality of life instrument?

2.2.1 More detailed discussion of focus groups

In June, 1998, two focus groups were held with a number of key practitioners in the Health promotion area. The Focus Groups were an early step in the process of identifying issues that would structure the development of a bank of items from which the AQoL could be modified to provide a quality of life instrument for health promotion. The plan for the development of the Mark II AQoL instrument specifies that item development will commence with extensive consultation with practitioners. Areas of practice that have been identified include health promotion generally, and specifically issues in adolescent and NESB health. The AQoL Steering Committee includes experts from these areas whose advice is sought on the best procedure to follow in the consultation process.

For the general area of Health Promotion, VicHealth was approached to nominate health promotion practitioners who might be expected to have an interest in the application of quality of life measurement in the field. The nominated persons were invited to participate in two focus groups held at Melbourne University in June, 1998.

The first area considered by groups was: what is the current role of quality of life measurement in health promotion. Specifically:

- How extensively is quality of life measurement used currently?
- What are the main current applications of quality of life instruments?
- What are the major issues at the moment for quality of life measurement in Health Promotion?

The next area considered was conceptualization of quality of life measurement in health promotion:

-
- How is quality of life conceptualized by practitioners and researchers working in health promotion? In most current applications of quality of life assessment, informants are ill and undergoing some form of treatment: poor health states are compared with good health states. Will this model require revision for applications in Health Promotion, eg where healthy people encouraged not to become ill; or healthy people are encouraged to get even healthier?

What needs fixing? In revising the Assessment of Quality of Life instrument, where should the research team focus our attention? Specifically:

- What are the main shortcomings in quality of life measurement that most urgently need attention?
- Which of these short-comings would be most amenable to improvement in a revised AQoL?

The initial responses to these issues show that quality of life measurement is rarely used in health promotion. At present, outcomes are more likely to be measured in terms of knowledge gain or lifestyle change. Informants could see a major advantage in the possibility of quality of life measure that would provide a common metric enabling different health interventions to be compared, but many were sceptical about the possibility of developing such a measure.

There was some concern among practitioners that at present quality of life measurement tools have a more clinical application. Moreover, there are problems as a result of the program logic underlying much health promotion activity. Many health promotion interventions work by initially increasing the recipient's level of concern about a health issue in anticipation of changing behaviour and ultimately improving quality of life. A lengthy time scale would be required to see many health promotion outcomes translated into changes in quality of life.

Some participants anticipated an increase in the importance of less material elements in health: for example psychic satisfaction, spirituality, sexual fulfilment, and that these elements may feature more prominently in conceptions of quality of life in future. Another issue was the increasing awareness of subcultural differences in health-related attitudes and behaviours and the impact this was having on work in health promotion. Finally, future trends anticipated in health promotion practice (eg increasing focus on social capital and empowerment, sensitivity to social settings) appear to be moving away from individual level objectives towards collective ones. These issues have many implications for the design of a quality of life instrument, particularly in the matter of individualistic vs. collective conceptions of health.

2.3 Development of Pilot version of Questionnaire

The results of the Focus Groups were compared with results from the literature review and, after extensive discussion within the AQoL research team, a pilot version of the questionnaire was designed. This included 112 items and covered the following six domains:

1. social (including work, family and intimate relationships)
2. independent living
3. mental health
4. illness (including pain)
5. values and beliefs
6. Sensory

The Pilot Questionnaire was sent out for review by experts in the field of Quality of Life measurement, and extensively pre-tested in face-to-face interviews, which were carefully

observed and followed by de-briefing of informants to detect areas of ambiguity or misunderstanding.

2.4 Sample Selection

The construction survey was administered to three samples:

- 316 randomly selected members of the Victorian adult population over 18 years
- 96 inpatients from one Melbourne Metropolitan Hospital
- 206 outpatients attending the outpatients department in the Melbourne Metropolitan Hospital

2.4.1 Adult Population Sample

Sample error estimates suggested that responses from 1000 individuals would provide an optimal trade off between field cost and precisions of estimates. Allowing for a response rate of 66% required 1500 units to be selected in the sample.

All Victorian postcodes were stratified by population size and social economic status using the SEIFA indicator. The number to be included in the sample was determined by the postcode population.

A different approach was taken for the 235 postcodes with populations too small to warrant inclusion of a single person in the sample. Using the cumulative frequency of the populations of these small postcodes, a random start sampling interval approach was used to select 44 postcodes from which one sample member was chosen.

As a result of these two procedures, a sample of 1514 members was selected from a total of 436 postcodes, with the number sample members from each post-code varying between 1 and 18.

A computer readable telephone directory was used to select the required number of telephone services from each postcode. After sending a preliminary letter explaining the study to the registered subscriber, a telephone interview was used to collect information about the number of subscribers and, after randomizing by first name, one "in-scope" individual was selected from each telephone service. (Information about the number of subscribers was subsequently used to weight the data to offset the over-representation of telephones servicing one person, as against those used by many people. Similarly information was collected about the number of director listings for each subscriber for allow for weighting down of subscribers whose multiple listings increased their chance of selection).

The sample as selected, and after weighting for differential numbers of subscribers per telephone service should give a two stage unclustered sample design stratified by the following:

- post code location and population size
- for small postcode areas: socio-economic status (use of SEIFA index in the selection of very small postcode areas)

The primary sampling unit is the telephone service, and the secondary sampling stage is the selection of one person from among those who regularly use the service.

The errors to which the sample is prone include

- non-response or refusal from the telephone subscriber

-
- non-response or refusal from the selected person
 - errors in postcode population estimates
 - errors resulting from mapping of SEIFA census data aggregated to 1996 postcode boundaries on to boundaries contemporary with the study
 - errors resulting from the exclusion of telephone services not included in the machine readable telephone directory.

A mail questionnaire was posted to the selected person.

2.4.2 Inpatient sample

Inpatients were opportunistically selected from four wards in one Melbourne metropolitan hospital. Patients were initially approached by clinical staff with a letter requesting the patient's participation. Researchers, who worked in the hospital over a four week period, approached all inpatients for whom permission was granted by clinical staff, and who were available in the ward at the time of interviewer visit. Informants required sufficient English language to complete the questionnaire either in writing or orally: translations or interpretation was not available. The informants represent a "time slice" sample of inpatients who were well enough to complete the questionnaire, either unaided or with the assistance of an interviewer. Interviewers reported no refusals from among 96 in-scope patients.

2.4.3 Outpatient sample

Patients in the waiting room of the emergency department of the same hospital were approached by interviewers, presented with a short letter explaining the study and requested to fill out the questionnaire while waiting for attention: 206 complied.

2.5 Field procedures for population sample

The field stage of the population survey consisted of the following steps:

- initial letter to selected telephone subscriber, introducing the study and explaining the procedure.
- telephone call further to explain the study and to select informant from household. 5 telephone calls were made at different times and days before the number was abandoned. This step frequently required additional subsequent calls to secure agreement from the selected person.)
- despatch of the questionnaire by post in nearly all cases. Interviews were for in pre-test and some pilot informants, and where interviewer assistance was requested)
- up to two reminder letters or phone calls in cases of non-response to despatched questionnaires.

Telephone interviews for selection of informants were conducted by project research staff in the pilot stage, and by three experienced research assistants who were extensively trained for the main stages of the project. The procedure for telephone selection was highly systematized and rigorously adhered to by staff.

A qualified and extensively experienced Social Worker was retained in the role of counsellor for any respondents who might have encountered health or personal difficulties as a result of completing the questionnaire. the social worker was available "on call" to answer queries or deal with problems raised by any informants who were disturbed, worried or upset as a result of

completing the construction questionnaire. The Social Worker was instructed to refer any such callers to an appropriate agency. No calls were received.

2.5.1 Response rates

Table 1 Fieldwork summary: population sample

| | | |
|--|------|------|
| a. initially selected | 1514 | |
| b. not used for study | 489 | |
| c. effective target sample | | 1025 |
| out of scope cases | | |
| d. business telephone service | 14 | |
| e. no contact after 5 calls | 117 | |
| f. number disconnected | 169 | |
| g. total out of scope | | 300 |
| h. in scope sample | | 725 |
| i. refusals by answerer | 229 | |
| j. refusals by selected person (aged/infirm) | 44 | |
| k. refusal by selected person (language) | 45 | |
| l. refusal by selected person (other) | 4 | |
| m. total refusals | | 322 |
| n. questionnaires issued | | 403 |
| o. questionnaires not returned | | 87 |
| p. questionnaires returned | | 316 |

Note:

316 returned questionnaires include 38 from informants replacing those where the original telephone subscriber had removed.

Table 2 Response Rates: population sample

| | |
|-----------------------------------|-----|
| base: target sample (p/c) | 31% |
| base: in-scope sample (p/h) | 44% |
| base: questionnaires issued (p/n) | 78% |

The field procedures used for the population survey ensured that, once a questionnaire was issued, the selected person was highly likely to respond: 78% complying. On the other hand, the high rate of refusal by the “answerer” (that is to say the telephone subscriber initially selected from the telephone directory) was of concern.

One source of difficulty was errors in the machine readable telephone directory. Of the 1025 letters sent to telephone subscribers, 118 were returned undelivered. Many other letters were found not to have been delivered, although not returned. Some errors were due to the original subscriber having removed. Many errors were due to the omission of flat or unit numbers from the directory for multiple dwellings at a single address. This meant that, during the initial telephone interview, “answerers” were asked to respond to questions about the names and numbers of users of their telephone service from an unknown “cold” caller. Procedures were subsequently modified so that in such cases, the telephone interviewer offered to send a preliminary letter to establish the credibility of the study.

Probably the major reason for the difficulty in securing participation was the sheer bulk of the questionnaire: with 112 quality of life items, each with two questions, plus background

information questions. This is an unavoidable problem confronting any survey researcher requiring answers to a large number of items during the construction stage of any questionnaire. A trade off is required between the large questionnaire desirable for instrument construction and the need for a short questionnaire to reduce respondent burden and facilitate high response rates.

2.6 Data Processing

To randomize order effects, questions were randomly sorted into 8 different sequences which were incorporated into eight different versions of the questionnaire. These eight versions were randomly allocated among informants.

Upon receipt, questionnaires were visually checked, and some instances, where pages appeared to have been skipped, informants were requested to re-complete.

Data from the completed questionnaires was double entered, and all inconsistencies checked and re-entered. All items were range checked and many logical checks were carried out. SPSS/data entry was used during key punching.

2.6.1 Missing Data

Missing information on individual items was well within acceptable boundaries, with the exception of three questions about intimate relationships. These items were subject to EM estimation using the SPSS Missing Values procedure, so that answers to all the questions in the social dimension were used to estimate values on intimacy questions for those who had not answered.

3. Analysis

Initially, all frequency distributions and missing values were checked to identify items that might lack sufficient variance or have no “head room” or “foot room”. Such items were felt to be unlikely to detect change in health states.

Another aspect checked at this stage was differences in response between the population, outpatient and inpatient samples. Lack of discrimination was seen as a matter of concern for most variables, but not in the case of items where, *on prima facie* grounds, hospital status might be considered less likely to affect response: for example social items. Similarly, items were omitted where responses on the associated scale items (about the effect of the health state on quality of life) suggested the differences in levels of response to the item was not associated with different levels of concern in terms of quality of life.

These considerations were generally used to rank items, rather than discard them at this preliminary stage of the analysis.

3.1 The modelling approach

The remainder of the analysis was a search for structure among the items, so that selection of a small number of items for the AQoL mark 2 instrument could adequately represent a wide range of health states.

This process used two structural equation programs: for dimensions with fewer than 20 items, the EQS program was used. For other dimensions, the LISREL program was applied. In each case, canonical correlations were used to reflect the ordinal nature of the data from the items. For purposes of validation, in the case of one dimension both programs were used and, due to differences in the algorithms, results were found to differ slightly.

The structural equation analysis was conducted in two stages: to begin with, analysis was conducted domain by domain: for example, all the Social items were examined, then all the Independent Living items and so forth. As a result of this analysis a few items were identified that strongly supported a scale within each domain. The next step was to combine each domain, as specified in the first part of the analysis, into an overall model, with each dimension (Social/Sensory etc.) loading onto an overall measure of health related quality of life.

In this paper we proposed to describe in detail the process used to develop one dimension: the social dimension. This dimension presented the most difficult task at a substantive level requiring consideration of relationships across a broad range of levels: intimates, family members, friends and community. Additionally, because of the extreme sensitivity attaching to questions about sexual relationships, items about intimate relationships suffered from high levels of non-response which required special treatment if unacceptably large numbers of cases were not to be discarded.

3.2 Modelling the Social Dimension

There were 25 items intended to measure the social dimension included in the Construction Questionnaire. These are shown in Table 3.

Table 3 Questions anticipated to cover social domain included in the construction questionnaire

| Questions and responses (bold = ultimately selected, underlined = seriously considered AQOLXX = based on item from AQOL mark one) | Number of Response codes: (all qns include the response: "this qn not relevant to me") |
|--|--|
| Q1. My relationships with my family, friends and the people with whom I spend most of the day (eg people where I work, neighbours) make me: | 5. very happy ... very unhappy |
| Q2- My relationships with my family make me: | 5. very happy ... very unhappy |
| <u>Q3. My relationships with my friends make me:</u> | 5. very happy ... very unhappy |
| Q4. My relationships with the people with whom I spend most of the day (e.g. people where I work, neighbours) make me: | 5. very happy ... very unhappy |
| Q5. My close and intimate relationships (including any sexual relationships) make me: | 5. very happy ... very unhappy |
| Q6. I feel that I can rely on the support of my family and friends | 5. always ... never |
| Q7. Because of my health, my relationships (e.g. with my friends, partner or parents) generally: AQOL 7 | 4. always ...seldom close&warm |
| Q8. My relationships generally (e.g. with my friends, partner or parents): | 4. always ...seldom close&warm |
| Q9. My relationships generally (e.g. with my friends, partner or parents): | 4. always-never cold & hostile (code values reflected prior to analysis) |
| Q10. My relationships with my friends: | 4. always ...seldom close&warm |
| Q11. My relationships with my partner or wife or husband: | 4. always ...seldom close&warm |
| Q12. My relationships with other members of my family generally: | 4. always ...seldom close&warm |
| Q13. My relationships with other people with whom I spend the day (e.g. people at work, neighbours): | 4. always ...seldom close&warm |
| Q14. Thinking about my relationship with other people: AQOL8 | 4. I have plenty of friends I am socially isolated. |
| Q15. Thinking about my health and my relationship with my family: AQOL9 | 4. my role in my family is unaffected by my health ... I cannot carry out any pa of my family role. |
| Q16. Thinking about my health and my role in my community (eg local church or other organization) | 4. my role in the community is unaffected by my health ... I cannot carry out any part of my community role, |
| Q17. Thinking about the number of friends I have: | 4. generally happy ... very unhappy |
| Q18. Thinking about how often I feel lonely: | 5. never ... all the time |
| Q19. Thinking about my relationships with friends, partner or parents: | 5. very close ... not at all close |
| Q20. My relationships with my friends, partner or parents are: | 4. always satisfying ... never satisfying |
| Q21. Thinking about my ability to share in family life: | 4 able to fully participate ... unable to participate at all |
| Q22. Thinking about my social life, e.g. visiting friends, participating in sporting or cultural events, going out to dances, dinner or films: | 6 full satisfying social life ... no social life |
| 'Q23. Thinking about my relationship with people outside my family | 5. I get along very well ... I do not get on well |
| Q24. To what extent am I satisfied with my sexual relationship(s) | 4. very satisfied ... very dissatisfied |
| Q25. Thinking about my sexual relationship(s)? | 4. great sexual relationships ... my sexual relationships are poor. |

Note: the following questions explicitly included a "not relevant applicable to me: response in addition to the responses shown in the table: Question numbers 1 to 4, 8-13, 16, 24, 25.

3.3 Dealing with missing values in the social dimension

As mentioned previously, the problem of “internal missing data” was most severe on several questions intended to measure the Social Domain. The special measures used to deal with this problem are described in this section. These measures permitted us to impute responses in the case of a few items with high levels of non-response. The alternative of omitting the problematic items was rejected on substantive grounds the AQoL Mark 2 was expressly intended to capture this aspect of the social domain, an area conspicuously missing from the AQoL Mark 1.

3.3.1 Expectation Maximization method for estimation of missing values

The EM process within SPSS for dealing with missing values is a form of SEM, which uses a process similar to estimation by regression, but using latent variables constructed from those items for which responses are available. In effect, this is an estimation which attempts to deal with errors on the predictor, as well as on the predicted, variables.

It operates iteratively, using a maximum likelihood algorithm. The maximum number of iterations and minimum lambda can be specified if desired.

The user has the option to specify which variables are used in the estimation.

We consider first the sexual and intimate relationship items (Q1, 24 and 25). We used the following items to predict values for non respondents on the grounds that these items deal with warm relationships, or those with partners or other intimate relationships: accordingly, we use the following to predict missing values on these three sexual items:

- Q5 close and intimate relationships
- Q7 Because of health relationships – close and warm
- Q8 relationships generally – close and warm
- Q10 relationships w friends – close and warm
- Q11 relationships with partner etc – close and warm
- Q12 relationships with other family members – close and warm
- Q14 relationships with other people – lonely
- Q15 relationship w family & health
- Q16 health and role in community
- Q17 n friends
- Q18 how often feel lonely
- Q19 relationship with friends, partner or parents
- Q21 ability to share in family life (t<-5)
- Q22 social life, visiting friends etc. (t<-6)
- Q24 TWE satisfied w sexual relationships
- Q25 Thinking about sexual relationships: great to poor.

With respect to Q16 (health and role in community), we have argued that the comparison of responders and non-responders suggests those who do not answer appear to have less utility from non-familial relationships, (as well as less utility on a few family questions that include friends or “other” family members). Accordingly, the following items were used in the estimation of missing values:

- Q4 people with whom spend day make me happy
- Q8 relationships generally
- Q10 relationships w friends

-
- Q12 relationships with other family members
 - Q13 people with whom spend day – close and warm
 - Q17 n friends
 - Q19 relationship with friends, partner or parents
 - Q22 social life, visiting friends etc.
 - Q23 relationships with people outside family

There were six questions where the proportion of non responses was large enough to require special consideration (> 5%). These questions were all ones where a “not relevant to me” response attracted many informants. Two of the four questions were about sexual and/or intimate relationships. (In the remaining 21 questions, not considered here, the maximum proportion missing was 3.4%.)

- Q1 My relationships with my family, friends and the people with whom I spend most of the day (eg people where I work, neighbours) make me:
- very happy
 - generally happy
 - neither happy nor unhappy
 - generally unhappy
 - very unhappy
 - this question is not relevant to me. (Missing, N= 14, 2.3%)

31 missing cases in total, 5% of all respondents

- Q5 My close and intimate relationships (including any sexual relationships) make me:
- very happy
 - generally happy
 - neither happy nor unhappy
 - generally unhappy
 - very unhappy
 - this question is not relevant to me (Missing, N= 84, 13.6%) .

93 missing case, 15% of all respondents.

Q9R (Coding reflected)

111 missing cases, 18.0%

- Q16 Thinking about my health and my role in my community (eg local church or other organization):
- my role in the community is unaffected by my health
 - there are some parts of my community role I cannot carry out
 - there are many parts of my community role I cannot carry out
 - I cannot carry out any part of my community role. AqoIQ9adapted
 - this question is not relevant to me. (Missing, N= 195, 31.6%)

206 missing cases 33.3% of all respondents

- Q24 To what extent am I satisfied with my sexual relationship(s)?
- I am very satisfied
 - I am satisfied overall
 - I am dissatisfied overall
 - I am very dissatisfied

-
- this question is not relevant to me (Missing, N= 187, 30.3%)

203 missing cases, 32.8% of all respondents

Q25 Thinking about my sexual relationship(s)?

- I have great sexual relationships
 my sexual relationships are good
 my sexual relationships are fair
 my sexual relationships are poor
 this question is not relevant to me. (Missing, N= 204, 33.0%) ItemB q9.1.

218 missing cases, 35.3% of all respondents.

It is possible to compare the responses to other questions between those who respond and do not respond to any particular questions. This analysis was undertaken for the four questions with higher proportions of missing informants. Taking the responses to all questions as scales, the mean values on any question can be compared between those responding and not responding to any particular question. A t-test for difference of means is used to check if there are significant differences between respondents and non-respondents. A negative t value shows the missing informants have significantly higher mean (=lower utility) than those not missing.

3.3.1.1 Qn 1 Relationships with family

Q1 My relationships with my family, friends and the people with whom I spend most of the day (eg people where I work, neighbours) make me: ... very happy etc.

There are 31 missing cases, 5% of respondents.

Qns where means of respondents and non respondents on Q1 is significantly different:

Q7 Because of my health, my relationships (e.g. with my friends, partner or parents) generally: ... are very close and warm etc.. (t = -2.4)

Q13 My relationships with other people with whom I spend the day (e.g. people at work, neighbours): ... are always close and warm, etc. (t = -2.8)

Q15 Thinking about my health and my relationship with my family: ... my role in the family is unaffected by my health etc. (t = +2.1 note: greater utility for missing cases)

Q22 Thinking about my social life, e.g. visiting friends, participating in sporting or cultural events, going out to dances, dinner or films: ... I have a full, satisfying social life. etc. (t = -2.7)

Q23 Thinking about my relationship with people outside my family: ... I get along very well with other people etc. (t = -2.0)

These patterns of difference are consistent with the missing response on Q1, if we take question 1 to refer primarily to non-family relationships (people where I work etc). Those who fail to answer Q1 generally derive significantly lower utility from non-family relationships (Qns 13,22 and 23). In contrast, those who did not answer Q1 report significantly higher utility in the question focussing expressly on familial relationships Q15.

We believe there is evidence that those missing on Q1 are not substantively different in most respects than those who do answer Q1, with the exception of differences that would be expected for those with lower utility from non-familial relationships. In the instances where their responses to other questions do differ significantly, there is a plausible substantive explanation.

Accordingly we use the ME estimation method to replace missing values.

3.3.1.2 Q5 Close and intimate relationships

Q5 (My close and intimate relationships make me ... very happy ...) attracted a high rate of non-response: 15%. Those who are missing on this question have significantly lower utility than those answering on many items in the Social Domain. They have lower utility ($t = -2.0$ to $t = -4$) on Qns 7, 8, 10, 11, 14, 15, 17, 18, and 19 covering relationships with family, partner, friends, other people as well as feelings of loneliness. They have far lower utility ($t = -4$ to $t = -21.4$) than respondents to Q5 on Qns 16, 21, 22 and 24 covering community, family life, full social life and sexual relationships. (the failure to see a significant difference in the case of Q25 (sexual relationships) is due to the small N of informants who fail to miss Q5 but respond to Q25: 7 in total.

- Q7 Because of health relationships – close and warm
- Q8 relationships generally – close and warm
- Q10 relationships w friends – close and warm
- Q11 relationships with partner etc – close and warm
- Q14 relationships with other people – lonely
- Q15 relationship w family & health
- Q16 health and role in community ($t < -4$)
- Q17 n friends
- Q18 how often feel lonely
- Q19 relationship with friends, partner or parents
- Q21 ability to share in family life ($t < -4$)
- Q22 social life, visiting friends etc. ($t < -5$)

Again, those missing on this question appear to have a consistently low utility on other social questions, a response that is consistent with their not answering Q5.

ME estimation of missing values using the remaining social questions would appear to be appropriate in the case of Q5.

3.3.1.3 Q16 Health and Role in Community

There are 206 cases missing, most ticking “does not apply”. These informants have significantly lower utility on the follow Social Items:

- Q4 people with whom spend day make me happy
- Q8 relationships generally
- Q10 relationships w friends
- Q12 relationships with other family members
- Q13 people with whom spend day – close and warm
- Q17 n friends
- Q19 relationship with friends, partner or parents
- Q22 social life, visiting friends etc.
- Q23 relationships with people outside family

This groups appear to have low utility on extra familial relationships, but average utility on family relationships. Given that this pattern is consistent across all social items, the ME procedure for missing values appears appropriate.

3.3.1.4 Q24 To what extent satisfied w sexual relationship

There are 203 missing cases on this item, nearly all in the “not relevant to me” category.

This group of informants has significantly lower than average utility on the following items:

- Q7 Because of health relationships – close and warm
- Q8 relationships generally – close and warm
- Q11 relationships with partner etc – close and warm ($t < -12$)
- Q12 relationships with other family members – close and warm
- Q14 relationships with other people – lonely
- Q15 relationship w family & health
- Q16 health and role in community ($T < -5$)
- Q18 how often feel lonely
- Q19 relationship with friends, partner or parents
- Q21 ability to share in family life ($t < -5$)
- Q22 social life, visiting friends etc. ($t < -6$)
- Q25 thinking about sexual relationships ($t = -2.5$, $N = 14$)

3.3.1.5 Q25 Thinking about sexual relationships great to poor

With 218 missing cases, this is the questions with the highest incidence of non response.

Non respondents on this question have far lower utility on a small number of items than do those who respond to this qn.

- Q11 relationships with partner etc – close and warm ($t < -11$)
- Q14 relationships with other people – lonely
- Q15 relationship w family & health ($t < -4$)
- Q16 health and role in community ($t < -6$)
- Q21 ability to share in family life ($t < -6$)
- Q22 social life, visiting friends etc. ($t < -6$)

Only 29 non respondents to Q25 fail to respond to the other sex item (Q24) but their utility is slightly but not significantly lower: 2.0 for respondents, and 1.8 for non respondents.

3.4 Social Dimension: structural modelling

There were four steps in the development of the model and selection of a small number of items to measure the Social Dimension of health related quality of life, from among the 25 questions included in the Construction Survey. The objective was to reduce the items to a manageable number (say three or four), while retaining a strong substantive coverage of the major aspects of the Social Dimension. A further issue was to deal with several items which had major measurement problems, for example, higher than acceptable levels of missing data, or poor distributional characteristics.

The steps in the process were as follows:

1. A LISREL model was constructed with all 25 items assumed to be measuring a single underlying construct. This model was examined carefully, and additional paths added to it so as to improve the fit: All paths added to the model were correlations between the items, net of the underlying latent characteristic.
2. The correlated errors found by LISREL were used to search for any structure among the items: that is to say for “subset” of variables that could be shown to be measuring specific aspects of the social dimension: for instance sexuality. Several variables were excluded at this stage (e.g. three sex variables reduced to one with acceptable missing data and a subset of variables covering “participation” were dropped from the analysis).
3. The remaining items were analyzed using EQS to determine Raykov’s composite scale reliability, within each sub-dimension. This assisted in identifying redundant items and, together with a consideration of distributional characteristics and level of missing data, guided selection of the final set of items. Raykov’s composite scale reliability overcomes shortcomings in Cronbach’s Alpha which underestimates the coefficient when items are not Tau equivalent, that is to say, when they are differentially related to the underlying construct. (Raykov 1997)

3.4.1 Step 1 Lisrel Analysis: 25 item congeneric model.

The LISREL program was used to develop a congeneric model, where the 25 social items were assumed to be manifestations of a single latent characteristic: a social dimension of health related quality of life.

The choice of LISREL was determined by its capacity to analyze large numbers of variables measured at the categorical or ordinal level. After reflecting one item (Q9) so that a low code value indicated high quality of life, SPSS Missing Values procedure was used to make EM estimates of missing values, and the resulting data rounded to zero decimal places. All 25 items (including those with unsatisfactorily high levels of missing data) were included in this first stage of the analysis.

The PRELIS program was used to generate matrix of polychoric correlations, which were then fitted to a simple congeneric model. (25 measures of a single latent construct) Considering the large number of items, and the range of substantive content (ranging across relationships in the domains of family, friendship, work, community and sex) the fit of the initial model is remarkably good: CFI 0.97, (ideally > 0.95) RMSEA =0.086 (ideally < 0.05).

Table 4 Lambda values from congeneric model with 25 manifest variables

| | | | | | | | | | |
|-------|------|--------|------|-------|------|-------|------|-------|------|
| nq001 | 0.92 | nq006 | 0.77 | nq011 | 0.91 | nq016 | 0.80 | nq021 | 0.88 |
| nq002 | 0.92 | nq007 | 0.88 | nq012 | 0.90 | nq017 | 0.81 | nq022 | 0.78 |
| nq003 | 0.91 | nq008 | 0.96 | nq013 | 0.88 | nq018 | 0.82 | nq023 | 0.64 |
| nq004 | 0.87 | nq009r | 0.68 | nq014 | 0.87 | nq019 | 0.87 | nq024 | 0.93 |
| nq005 | 0.91 | nq010 | 0.90 | nq015 | 0.79 | nq020 | 0.86 | nq025 | 0.87 |

Using LISREL, an exploratory principal components analysis was undertaken (making only ordinal assumptions about the data). This analysis supports the general conclusions from the congeneric model. The 25 items appear to share a great deal of common variance. The first component explains 47% of the total variance, the second component explains a further 12%. This suggests that, as intended, the items do, in the main, measure a underlying single construct.

3.5 Step 2: Examination of correlated errors and search for substructure

The next step was to examine “correlated errors”: correlations between individual items that are net of the single latent characteristic. No correlated errors are initially included in the model, but they identified by the program and are added, one at a time, during the process of development. As would be expected with 25 items, many of which were intentionally redundant, there were many substantial correlated errors.

In developing models, Joreskog recommends an iterative process of examination of the largest correlated error, followed by its inclusion in the model, followed by examination of the next largest correlated error and so on. Some correlated errors are readily understood in substantive terms, others are more difficult to explain. Joreskog recommends that only those correlated errors which “make sense” should be included in revisions to the model.

A brief description of this process as applied in the development of the SOCIAL dimension follows.

3.51 Q8 and Q11

Q8 (relationships with friends partner or parents-close and warm) and Q11 (relationships with partner wife or husband-close and warm) were reported as having the largest correlated error. Including the correlated error in the model, substantially reduced the lambda loading to the two variables (.96 to .88 and .92 to .84 respectively). Because “close and warm” familial and social relationships are, *a priori* at the core of the concept of the social domain of health related quality of life, the correlated error term was not included in the model.

3.5.2 Sex

Paired correlations between three variables about sex were reported at various stages of the review of correlated errors. Q24 (extent satisfied with sexual relationship) and Q25 (R has great - poor sexual relationships) were the second correlated errors recognized by LISREL and, in later steps, correlations were found between each of these and Q5 (close and intimate relationships – including sexual relationship make R happy). This network of correlated errors suggested a sub structure covering sexual behaviour, and the three variables were modelled onto a latent variable “SEX” which in turn loaded onto the higher order SOCIAL construct. See figure SOC4a

An exploratory maximum likelihood Principal Factor Analysis (making only ordinal assumptions about the data) resulted in 4 factors. One factor had high loadings uniquely from the three questions asking about sex and intimate relationships. This shows that the structure hypothesized from the analysis of correlated errors is replicated in an exploratory factor analysis, generally a far less sensitive procedure.

We use the existence of the SEX component of the SOCIAL dimension to justify the selection of a single item covering sexual relationships. Q5 has a slightly lower gamma value (path from the SEX latent variable to Q5) than either of Q24 or Q25 (0.87 vs 0.94 and 0.91 respectively). However with 15% missing data (13.6% in the “doesn’t apply to me” category, Q5 is far more likely to be answered than Q24 or Q25 (with 32.8% and 35.3% missing respectively).

3.6 Q9 and Q23

LISREL suggested that correlated errors should be modelled between Q9 (relationships generally) and Q23 (relationships with people outside family). This suggests there might possibly be a factor of relationships in general, but it is curious that Q8 (relationships generally, close and warm) does not become part of this cluster. This path was not modelled.

3.6.1 Participation

A cluster of correlated errors emerged between the following items:

- 15. health and relationship with family – role unaffected/cannot carry out
- 16. health and role in community – role unaffected/cannot carry out
- 21. ability to share in family life – fully able/unable to participate

In the initial congeneric model the Lambda values for the first two of the three items were lower than average (.79 & .80) suggesting that they are less closely related to the latent concept than other items.

A cluster of high correlated errors was found involving each pair of the three variables, suggesting that they defined some type of substructure. As all three items focus on role and participation in various social contexts, it is reasonable to define this substructure as “participation”.

A model with the three items loading on to a lower order latent variable (PARTICIPATION) was tested, and found to fit well. The Gamma value between PARTICIPATION and SOCIAL is, however, low (0.65) which suggests that participation items are less strongly related than others to the SOCIAL dimension, and should be considered for exclusion from the dimension. (See SOC4A.PTH).

There is further evidence from the Principal Components analysis to support exclusion of these items. In comparison with all other items, items 15, 16 and 21 have the lowest correlations with the first principal component: (0.21, 0.17 and 0.33 respectively). This suggests that of all items, these are least closely associated with the single underlying construct: social health related quality of life.

3.6.2 Items excluded from the substructure

The following items are not included in the substructure, and should be considered for exclusion

4. relationships with people with whom I spend most of day – happy
(A substantial correlated error was found between this and item 11, but not included in model because of lack of substantive interpretation.)

6. can rely on support of family and friends – always-never
(Lambda is low – 0.76)

7. because of health relationships with friends, partner or parents – close and warm

8. relationships generally – close and warm

9R. relationships generally – never cold and hostile
(Lambda is low 0.77)

19. relationships with friends partner or parents – very/not at all close -

20. relationships with friends, partner or parents – always/never satisfying

23. relationships with people outside family – do/do not get along well
(Lambda is low 0.68)

3.7 Step 3 Selecting items within each sub dimension - reliability

3.7.1 Subscale Friends

Table 5 Relationships, friends variables

| Model | CFI | RMSEA | Reliability Index a. | Lambdas | Ref |
|------------------|------|-----------|----------------------|---|---------------------------|
| All 7 vars | .994 | .253 | .930 | V18 = .576 V22 = .531 | socl1.eqs |
| drop V18 and V22 | .999 | .0835 | .935 | V14 = .644 | socl1x1.eqs |
| drop V14 | 1.0 | .031 | .932 | V3 = .804 V10=.868 V13=.760 V17=.721 | socl1x2.eqs |
| drop V17 | 1.0 | insuff DF | .924 | V3 = .767 v10=.899 v13=.766 | socl1x3.eqs (warnings) |

a. square the reliability index to get the reliability coefficient

The three preferred items are:

NQ003 'Q3-Soc Relatns w friends make me '/happy-unhappy

NQ010 'Q10-Soc Relnshps w my friends'/always-seldom close&warm

NQ013 'Q13-Soc Relnshps w oths I spend day with'/always-seldom close&warm

The distributional characteristics of the three variables are shown in the following tables and figures. Question 3 has a lower standard deviation than the others, but is less badly skewed and has better discrimination at the healthy end of the scale. The kurtosis on Q3 is also closer to normal.

Table 6 Summary Statistics, questions 3, 10, 13

| | | NQ003 Q3-Soc Relatns w friends make me | NQ010 Q10-Soc Relnshps w my friends | NQ013 Q13-Soc Relnshps w oths I spend day with |
|------------------------|---------|--|--|--|
| N | Valid | 603 | 615 | 615 |
| | Missing | 15 | 3 | 3 |
| Mean | | 1.7363 | 1.8683 | 2.1577 |
| Std. Error of Mean | | 2.411E-02 | 3.360E-02 | 3.938E-02 |
| Median | | 2.0000 | 2.0000 | 2.0000 |
| Mode | | 2.00 | 2.00 | 2.00 |
| Std. Deviation | | .5921 | .8333 | .9767 |
| Variance | | .3506 | .6944 | .9539 |
| Skewness | | .538 | 1.268 | 1.258 |
| Std. Error of Skewness | | .100 | .099 | .099 |
| Kurtosis | | 1.799 | 2.569 | 1.649 |
| Std. Error of Kurtosis | | .199 | .197 | .197 |
| Range | | 4.00 | 4.00 | 4.00 |
| Minimum | | 1.00 | 1.00 | 1.00 |
| Maximum | | 5.00 | 5.00 | 5.00 |
| Sum | | 1047.00 | 1149.00 | 1327.00 |

Figure 1 Frequency distribution: social relations with friends

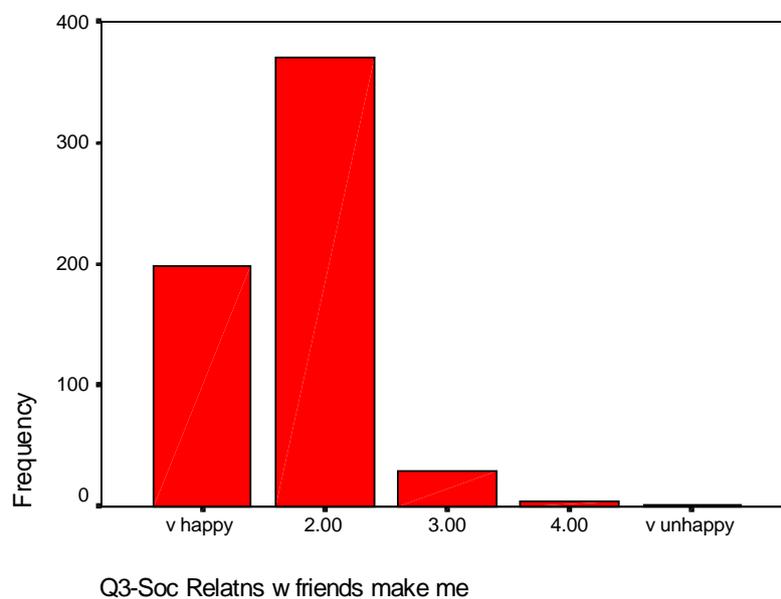


Figure 2 Frequency distribution: social relations, question 10

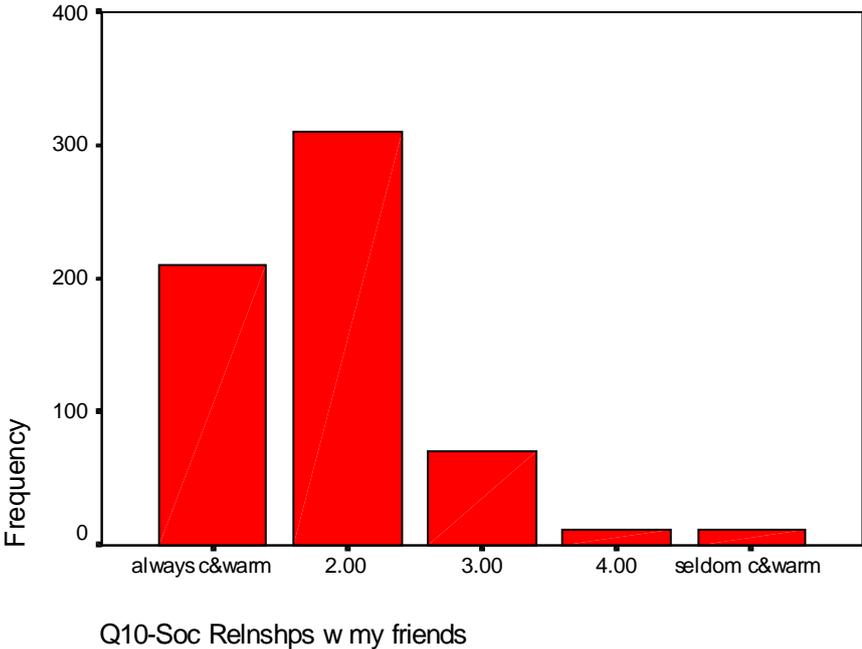
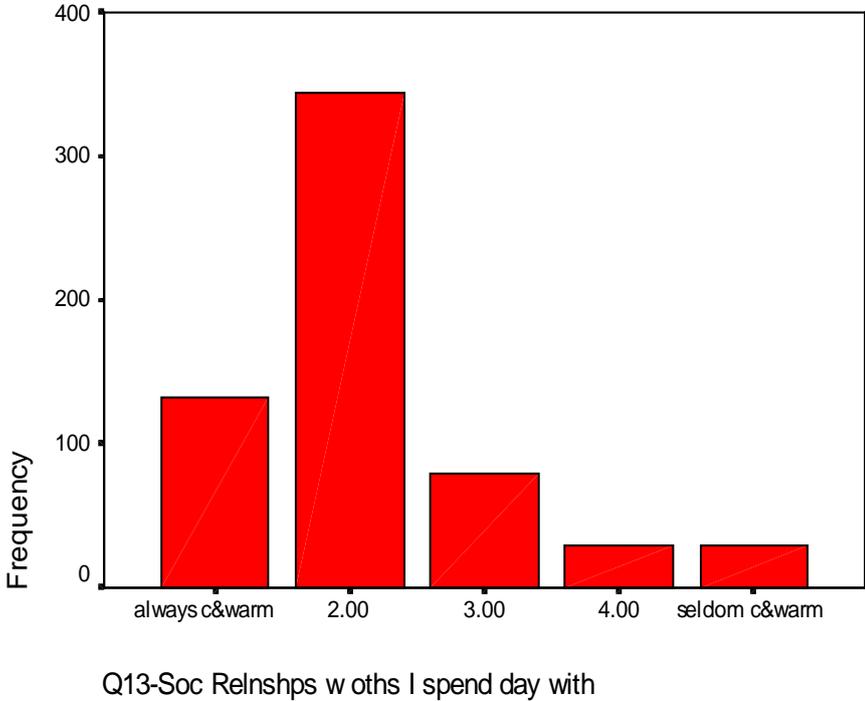


Figure 3 Frequency distribution: social relationships, question 13



3.7.2 Subscale: Sex

The sex subscale model has three variables and is precisely identified, i.e. zero degrees of freedom for the congeneric model. It follows that fix indices are not available, but item selection can still be based on lambdas and composite scale reliability. These figures are shown in the following table:

Standardized Lambda loadings for sex variables:

NQ005 'Q5-Soc Close & intimate reltns make me /very happy-very unhappy :0.751
 NQ024 'Q24-Soc TWE am I satsfd w sexl relnshp'/very sat-very dissatisfied: 0.916
 NQ025 'Q25-Soc Thnkg abt my sexl relnshps'/great-poor: .0.926

Composite Scale Reliability: 0.949

Table 7 Summary statistics: social relationships, questions 5, 24, 25

| | | NQ005 Q5-Soc Close & intimate reltns make me | NQ024 Q24-Soc TWE am I satsfd w sexl relnshp | NQ025 Q25-Soc Thnkg abt my sexl relnshps |
|------------------------|---------|--|---|---|
| N | Valid | 525 | 415 | 400 |
| | Missing | 93 | 203 | 218 |
| Mean | | 1.8076 | 1.9976 | 2.3475 |
| Std. Error of Mean | | 3.625E-02 | 4.059E-02 | 4.871E-02 |
| Median | | 2.0000 | 2.0000 | 2.0000 |
| Mode | | 2.00 | 2.00 | 2.00 |
| Std. Deviation | | .8307 | .8268 | .9742 |
| Variance | | .6900 | .6836 | .9491 |
| Skewness | | 1.435 | .726 | .304 |
| Std. Error of Skewness | | .107 | .120 | .122 |
| Kurtosis | | 2.993 | .233 | -.876 |
| Std. Error of Kurtosis | | .213 | .239 | .243 |
| Range | | 4.00 | 3.00 | 3.00 |
| Minimum | | 1.00 | 1.00 | 1.00 |
| Maximum | | 5.00 | 4.00 | 4.00 |
| Sum | | 949.00 | 829.00 | 939.00 |

Although Q5 has a lower lambda, and poorer skewness and kurtosis than the other items, its comparatively low level of missing data makes it an obvious choice as a single indicator of the sexual sub-domain of social elements in health related quality of life.

The level of missing data might further be reduced by considering the response categories. On the major sex items it was important to include a “not relevant to me” response to allow for persons not having sexual relationships. Although the same response category was included in Q5 about intimate relationship, it is probably not essential. Whereas large proportions of people, especially ill people do not have sexual relationships, every person who is not a total social isolate will have one relationship that is more intimate than others. Of the 15% of informants who

do not answer this item, 13.6% chose the “doesn’t apply” response. If this response were removed, it is highly likely that the rate of missing data would fall substantially.

Figure 4 Frequency distribution: intimate relationships, question 5

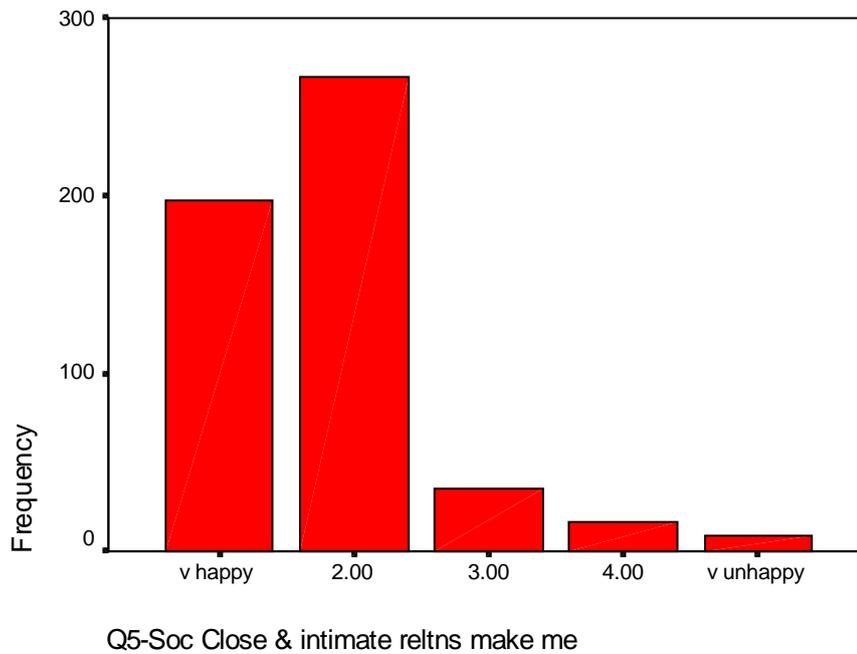


Figure 5 Frequency distribution: sexual relationships, question 24

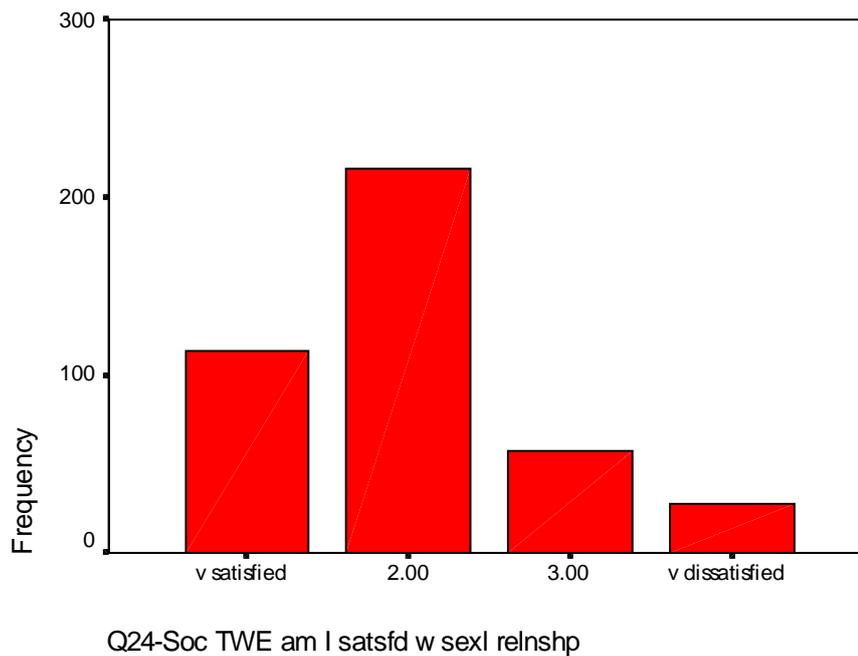
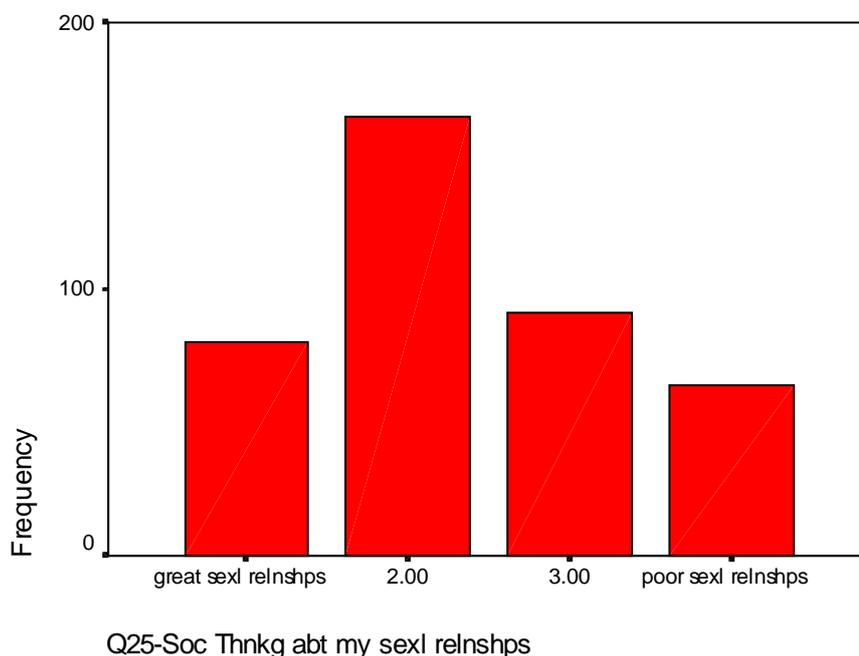


Figure 6 Frequency distribution: social relationships, question 25



4 Family

4.1 Family

Four questions were identified as relating specifically to family through a cluster of correlated errors. When fitted as a single congeneric model, the fit was very good as shown in table 8. The omission of V11 on the grounds of lower lambda was consistent with the specific focus of this item on partner wife or husband.

Its omission had minimal effect on the reliability index, and left Q2 (relationships with family) as the single strongest lead item among the three. An examination of the distributional characteristics shows that Q2 deviates more than some items from normality: e.g. higher kurtosis and skewness. However Q2 has an acceptable standard deviation acceptable level of missing data.

Table 8 Relationships, family variables

| Model | CFI | RMSEA | Reliability Index a. | Lambdas | Ref |
|------------|-----|-------|----------------------|--|------------|
| All 4 vars | 1.0 | .054 | .945 | V1 = .802 V2 = .846 V11 = .754 V12 = .880 | socl3.eqs |
| drop V11 | 1.0 | | .944 | V1 = .757 V2 = .913 V12 = .887 | socl3x1eqs |

Table 9 Summary statistics, family question 1, 2, 12

| | | NQ001 Q1-Soc Relatns w family,friends, people | NQ002 Q2-Soc Relatns w family make me | NQ012 Q12-Soc Relnshps w oth fam membrs genrly |
|------------------------|---------|---|---|---|
| N | Valid | 587 | 604 | 614 |
| | Missing | 31 | 14 | 4 |
| Mean | | 1.7888 | 1.6407 | 1.7932 |
| Std. Error of Mean | | 2.573E-02 | 3.060E-02 | 3.422E-02 |
| Median | | 2.0000 | 2.0000 | 2.0000 |
| Mode | | 2.00 | 1.00 | 2.00 |
| Std. Deviation | | .6235 | .7520 | .8479 |
| Variance | | .3887 | .5656 | .7190 |
| Skewness | | .734 | 1.520 | 1.358 |
| Std. Error of Skewness | | .101 | .099 | .099 |
| Kurtosis | | 2.502 | 3.621 | 2.541 |
| Std. Error of Kurtosis | | .201 | .199 | .197 |
| Range | | 4.00 | 4.00 | 4.00 |
| Minimum | | 1.00 | 1.00 | 1.00 |
| Maximum | | 5.00 | 5.00 | 5.00 |
| Sum | | 1050.00 | 991.00 | 1101.00 |

Figure 7 Frequency distribution: social relations, family, question 1

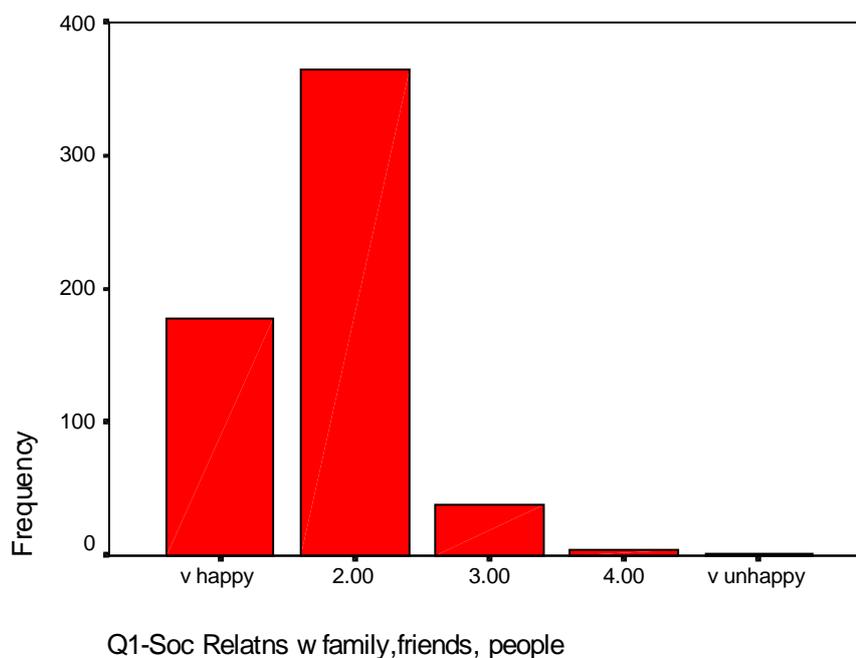


Figure 8 Frequency distribution: social relationships, question 2

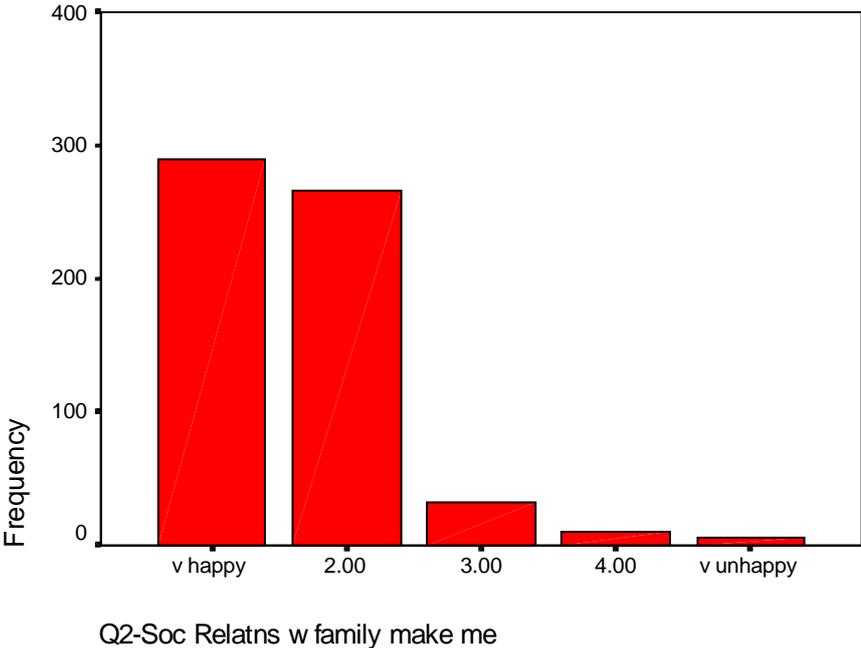
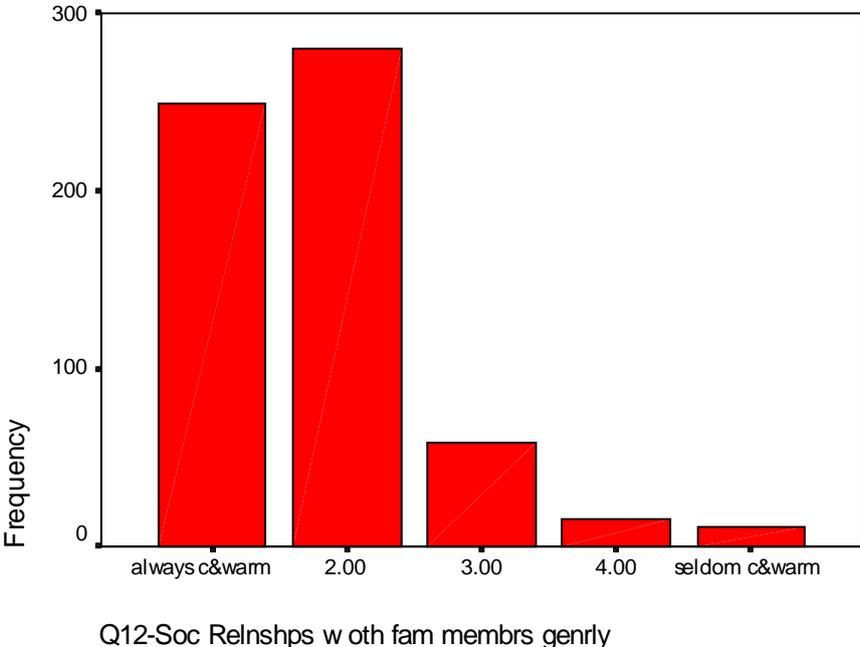


Figure 9 Frequency distribution: social relationships, question 12



4.1.1 Participation Sub Dimension

The participation sub domain was suggested for exclusion from the instrument on the grounds that it is less closely related to the underlying primary latent construct SOCIAL than are the other sub domains. However, within the boundaries of the construct itself, the three items form a satisfactory scale, with an acceptable reliability and substantial lambdas.

Table 10 Relationships, sub domains

| Model | CFI | RMSEA | Reliability Index a. | Lambdas | Ref |
|------------|-----|------------------------------|----------------------|--|-----------|
| All 3 vars | 1.0 | insuff DF exactly identified | 0.948 | V15 = .852 V16 = .887 V21 = .856 | socl4.eqs |

4.1.2 Non Sub-dimension items

| | |
|--------|--|
| NQ004 | 'Q4-Soc Relatns w pple spnd day make me '/very happy-very unhappy |
| NQ006 | 'Q6-Soc Rely on support of family & friends'/always-never |
| NQ007 | 'Q7-Soc Bcse health relatnshps w f p parnts: '/always-seldom close&warm |
| NQ008 | 'Q8-Soc Relnshps generally w f p parents: '/always-seldom close&warm |
| NQ009R | 'Q9R-Soc Rshps gnrlly w f p p: (1=HLTH)'/never-always cold & hostile |
| NQ019 | 'Q19-Soc Thnkg abt relnshp w f p parnts'/very-not at all close |
| NQ020 | 'Q20-Soc Relnshps w frnds partnr parnts are'/always-never satisfying |
| NQ021 | 'Q21-Soc Thnkg abt abilty share in fam life'/ |
| NQ022 | 'Q22-Soc Thnkg abt socl life eg visit friends'/ |
| NQ023 | 'Q23-Soc Thnkg about relnshp w pple exc famly'/get along – do not get along well |

There were eight items that did not appear readily to form part of a substructure. The items could, of course, still be closely related to the social dimension: their failure to form part of a substructure simply indicates relationships among them are more totally accounted for by the single latent variable SOCIAL than is the case with items forming sub-dimensions. It is possible, however that there is redundancy among them: that is some items might account equally well for the variance in the latent variable.

An examination of the substantive content of the items suggest this may well be the case. Most of the questions in this group cover several types of social relationships (eg “friends, partner, parents”). For this reason, in examining these items, we include the subdimensional items within the analysis. This is to avoid possible double counting between individual items and other items within the substructures defined by FRIENDS, SEX or FAMILY. However, only the three items preliminarily select for each subdimension are included, and the PARTICIPATION subdimension is excluded.

4.2 Content of AQoL 2 Questionnaire

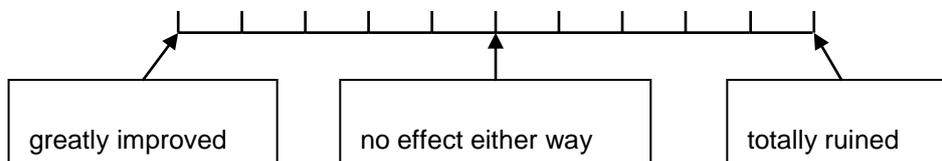
Dimension 1: Social Dimension

Q1 My close and intimate relationships (including any sexual relationships) make me:

- very happy
- generally happy
- neither happy nor unhappy
- generally unhappy
- very unhappy

Scale Question to follow each question:

How does this affect my quality of life?



Q2 Thinking about my health and my relationship with my family:

- my role in the family is unaffected by my health
- there are some parts of my family role I cannot carry out
- there are many parts of my family role I cannot carry out
- I cannot carry out any part of my family role.

Q3 Thinking about my health and my role in my community (that is to say neighbourhood, sporting, work, church or cultural groups):

- my role in the community is unaffected by my health
- there are some parts of my community role I cannot carry out
- there are many parts of my community role I cannot carry out
- I cannot carry out any part of my community role.

Q4 How much help do I need with household tasks: eg preparing food, cleaning the house or gardening.)

- I can do all these tasks very quickly and efficiently without any help
- I can do these tasks relatively easily without help
- I can do these tasks only very slowly without help
- I cannot do most of these tasks unless I have help
- I can do none of these tasks by myself.

-
- Q5 Thinking about how easy or difficult it is for me to get around by myself outside my house (eg shopping, visiting):
- getting around is enjoyable and easy
 - I have no difficulty getting around outside my house
 - a little difficulty
 - moderate difficulty
 - a lot of difficulty
 - I cannot get around unless somebody is there to help me.
- Q6 Thinking about your mobility, including using any aids or equipment such as wheelchairs, frames, sticks:
- I am very mobile
 - I have no difficulty with mobility
 - I have some difficulty with mobility (for example, going uphill)
 - I have difficulty with mobility, I can go short distances only
 - I have a lot of difficulty with mobility. I need someone to help me
 - I am bedridden.
- Q7 Thinking about washing myself, toileting, dressing, eating or looking after my appearance:
- these tasks are very easy for me
 - I have no real difficulty in carrying out these tasks
 - I find some of these tasks difficult, but I manage to do them on my own
 - many of these tasks are difficult, and I need help to do them
 - I cannot do these tasks by myself at all.

Dimension 3: Mental Health

- Q8 How often did I feel in despair over the last seven days?
- never
 - occasionally
 - sometimes
 - often
 - all the time.
- Q9 And still thinking about the last seven days: how often did I feel worried:
- never
 - occasionally
 - sometimes
 - often
 - all the time.

Q10 How often do I feel sad?

- never
- rarely
- some of the time
- usually
- nearly all the time.

Q11 When I think about whether I am calm and tranquil or agitated, I am:

- always calm and tranquil
- usually calm and tranquil
- sometimes calm and tranquil, sometimes agitated
- usually agitated
- always agitated.

Dimension 4: Coping

Q12 Thinking about how much energy I have to do the things I want to do, I am:

- always full of energy
- usually full of energy
- occasionally energetic
- usually tired and lacking energy
- always tired and lacking energy.

Q13 How often do I feel in control of my life?

- always
- mostly
- sometimes
- only occasionally
- never.

Q14 How much do I feel I can cope with life's problems?

- completely
- mostly
- partly
- very little
- not at all.

Dimension 5 Pain

Q15 Thinking about how often I experience **serious pain**. I experience it:

- very rarely
- less than once a week
- three to four times a week
- most of the time.

Q16 How much pain or discomfort do I experience:

- none at all
- I have moderate pain
- I suffer from severe pain
- I suffer unbearable pain.

Q17 How often does pain interfere with my usual activities?

- never
- rarely
- sometimes
- often
- always.

Dimension 6: Sensory Perception

Q18 Thinking about my vision (using my glasses or contact lenses if needed):

- I have excellent sight
- I see normally
- I have some difficulty focusing on things, or I do not see them sharply, eg. small print, a newspaper or seeing objects in the distance.
- I have a lot of difficulty seeing things. My vision is blurred. I can see just enough to get by with.
- I only see general shapes. I need a guide to move around
- I am completely blind.

Q19 Thinking about my hearing (using my hearing aid if needed):

- I have excellent hearing
- I hear normally
- I have some difficulty hearing or I do not hear clearly. I have trouble hearing softly-spoken people or when there is background noise.
- I have difficulty hearing things clearly. Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
- I hear very little indeed. I cannot fully understand loud voices speaking directly to me.
- I am completely deaf.

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- Q20 When I communicate with others, e.g. by talking, listening, writing or signing:
- I have no trouble speaking to them or understanding what they are saying
 - I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
 - I am understood only by people who know me well. I have great trouble understanding what others are saying to me.
 - I cannot adequately communicate with others.

References

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