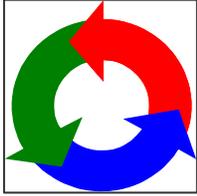


Appendix S

QOL Scales Scoring Document

Note: Approved for dissemination by CMS on December 21, 2001.



*Measures, Indicators, & Improvement of Quality of Life
in Nursing Homes*

**Quality of Life Scales for
Nursing Home Residents**

Study Director, Rosalie A. Kane

**CMS Project Officer: Mary Pratt
CMS Co-Project Officer: Karen Schoeneman**

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**These measures were developed and tested as part of the CMS project,
Measures, Indicators and Improvement of Quality of Life in Nursing Homes
conducted under Master Contract #500-96-0008 between CMS and the
University of Minnesota.**

**For further information, contact Rosalie Kane at Division of Health Services
Research & Policy, School of Public Health, University of Minnesota, 420
Delaware St., SE, Box 197, D-527 Mayo Building, Minneapolis, MN 55455.
Phone 612.624.5171, Fax 612.624.5434, or email: kanex002@tc.umn.edu**

Quality of Life Scales for Nursing Homes

Background

In 1998, the Center for Medicare and Medicaid Services (CMS) awarded the University of Minnesota School of Public Health a contract to conduct a study called *Measurement, Indicators and Improvement of the Quality of Life in Nursing Homes*. One of the main purposes of this project was to develop and test measures of quality of life (QOL) of older nursing home residents, emphasizing psychological and social aspects of QOL. The goal was to obtain information on QOL from as many nursing home residents over age 65 as possible, including those with cognitive impairment.

The measures provided here should be based on data collected from interviews with nursing home residents where residents are asked the actual questions that comprise the scales. Although it is possible to interview care personnel or family members about an individual resident to obtain proxy reports of a residents' QOL, we recommend against this strategy because our study showed that staff and family answer the questions differently from the residents for whom they were reporting.

The QOL items were administered to residents as part of a larger interview, which contained more candidate items on QOL than were eventually incorporated into scales, as well as some additional questions. The shortened scales presented here are relatively independent of each other, have acceptable levels of internal reliability and test-retest reliability, and have been shown to have good validity. The scale development was performed with a sample of 1988 residents in 40 nursing homes in 5 states, about 1300 of whom were able to complete all or most of the scales.

The properties of and results of analyses with these measures are described in technical manuscripts now in progress. Thus, information about scale reliability, test-retest reliability, and validity is not included here. Those wishing to use the tools can contact investigators at the University of Minnesota as described on the cover page of this document.

Domains of Quality of Life

The scales presented here assess 11 domains of QOL. As of today, no attempt has been made to combine them into a single score. In addition, the scales are not meant to tap the entire construct of QOL. The measures should be used in conjunction with other established measures of functional status, self-rated health and affect measures, which also tap components of QOL.

The domains for which measures were developed and the generation of items for the scale was guided by a thorough review of literature, discussion with experts, and focus groups with residents. Additionally, the study explicitly included domains of quality of life that nursing homes are expected to optimize under current federal regulations. The quality of life outcomes are defined in the box below.

Domains and Their Definitions

Physical comfort. Residents are free from pain, uncomfortable symptoms, and other physical discomforts. They perceive that their pain and discomfort are noticed and addressed by staff.

Functional competence. Within the limits of their physical and cognitive abilities, residents are as independent as they wish to be.

Privacy. Residents have bodily privacy, can keep personal information confidential, can be alone as desired, and can be with others in private.

Autonomy. Residents take initiative and make choices for their lives and care.

Dignity. Residents perceive their dignity is intact and respected. They do not feel belittled, devalued, or humiliated.

Meaningful activity. Residents engage in discretionary behavior that results in self-affirming competence or active pleasure in the doing of or watching of an activity.

Food enjoyment. Residents enjoy meals and food.

Individuality. Residents express their preferences, pursue their past and current interests, maintain a sense of their own identity, and perceive they are known as individuals.

Relationships. Residents engage in meaningful person-to-person social interchange with other residents, with staff, and/or with family and friends who live outside the nursing home.

Safety, security & order. Residents feel secure and confident about their personal safety, are able to move about freely, believe that their possessions are secure, and believe that the staff has good intentions. They know and understand the rules, expectations, and routines of the facility.

Spiritual well-being. Residents' needs and concerns for religion, prayer, meditation, spirituality, and moral values are met.

Using the Scales

Various users will develop their own practices for applying the scales. Below are some guidelines and caveats that emerged from our fieldwork, which are based on two waves of data collection involving interviews with approximately 3500 residents in 100 nursing homes. The second wave of data collection is scheduled to be completed by December 2001.

Whom to interview. All older nursing home residents other than those who are comatose or in a vegetative state should be approached to participate. In our study, the interview on quality of life was attempted if the resident could sustain a simple conversation. Once begun, data collection was discontinued if the resident could not respond meaningfully (that is, with other than no response, don't know, or non-sequiters) to 4 of the first 6 questions asked. The intent was to include residents with a wide range of characteristics in terms of functional status, cognition, sensory impairment, and length of time since admission, and to limit pre-emptive exclusions to a few obvious situations.

Sample size for facility-level estimates. If there is an intent to use the measures to generate average QOL scores for a facility, an adequate sample of completed interviews is necessary. Our preliminary work suggests that if an alpha error is set at 5% and power is set at 80%, a random sample of 17 responding residents per facility is sufficient to calculate a reasonable facility estimate for all domains (7-17). For an alpha of 1% and

power of 90%, a sample of 25 residents was sufficient for all domains but one (the range was from 14 to 32 subjects depending on the domain). These estimates may be revised downwards based on analyses conducted in a new sample of 60 additional facilities in 5 states.

Context and confidentiality. It is important to establish a comfortable and, as much as possible, private context in which to conduct the interview, and to pace the questions so that residents can take their time to consider their responses. In our field test, interviews were conducted by study personnel, and residents were assured that their responses were confidential and would not be communicated to nursing home personnel. A test is presently underway to see whether responses would differ if interviews were conducted by nursing home staff.

Training. Interviewers completed extensive training on how to administer scales. They were taught to repeat the response categories frequently during the interview. Training emphasized how to establish good rapport without biasing the results, guessing, or abandoning the response categories. Large-print cards with the response categories were shown to those whose eyesight permitted their use. Interviewers were also taught to give the resident enough time to think about each answer, which often meant that residents made extensive comments about the topic while thinking of their answer. Interviewers were taught to recognize this process as important to collecting valid answers, but to return to the questions and the response categories, asking residents to answer taking all they had been saying into account. If necessary, the interviews were divided into more than one sitting to avoid fatiguing residents or to fit into their schedule. The entire interview ranged from 40 to 90 minutes. The quality of life scales were a shorter component of that interview, taking about ½ the time, about 20 to 45 minutes.

Question order. In the University of Minnesota QOL study, the domains were measured in the order presented below. Pre-testing suggested that the comfort scale was a good one to begin with because it is easily comprehended and not threatening. Order effects have not yet been tested.

Likert Versus Dichotomous Responses. All but 3 questions used for the scales are preferably answered in a 4 point Likert format: “often,” “sometimes,” “rarely,” “never.” If residents were unable to respond in that format after multiple attempts, the question was repeated and residents were asked whether their response would be “mostly yes” or “mostly no.” Some residents use the dichotomous response only occasionally and others do so for the whole interview. Interviewers were instructed to attempt the Likert-type response option wherever possible. For residents who ordinarily could respond to Likert-type response options, three tries were made before the interviewer allowed the use of the dichotomous response option.

Developing a Score. To maximize the number of residents providing quality of life data, we blended the two modes of response: Likert-type and dichotomous. We empirically derived a formula for combining these responses, where all “mostly yes” responses were re-scaled to 3.8 and all “mostly no” responses rescaled to 1.5. A higher

score on a domain meant a better quality of life on that domain. This scoring solution is based on Wave 1 data; it may be modified after Wave 2 data are analyzed.

Missing items. To create a score for a domain at least 75% of questions must be answered with either a Likert response or a dichotomous yes-no response. When that condition was met, missing items (that is, items where the respondents refused to answer, did not know, or where no answer was present) were imputed at the average of that respondent score for all the items he or she completed for the domain.

Lead questions. The following question could be used as a lead in to the quality of life scales: *“I am going to ask you some questions about the quality of life here at (name of nursing home). We are asking these questions so that we can see how well we are providing service to our residents (or whatever the reason for the study). There are no right or wrong answers to my questions and the whole discussion concerns what life is like for you here at (name of nursing home).”*

Each set of domain items contained its own lead-in statement, which is reproduced in the scales below.

Quality of Life Scales

Comfort Scale: *The first questions are about how comfortable you are and the help you get to make you more comfortable.*

CMF		Often	Some- Times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	How often are you too cold here?	1	2	3	4	1.5	3.8	0	0
2	How often are you so long in the same position that it hurts?	1	2	3	4	1.5	3.8	0	0
3	How often are you in physical pain?	1	2	3	4	1.5	3.8	0	0
4	How often are you bothered by noise when you are in your room?	1	2	3	4	1.5	3.8	0	0
5	How often are you bothered by noise in other parts of the nursing home, for example, in the dining room?	1	2	3	4	1.5	3.8	0	0
6	Do you get a good night’s sleep here?	4	3	2	1	3.8	1.5	0	0

4 out of the 6 questions must be answered in first 6 columns to construct the scale. 2 DK/NR responses may be imputed to domain score average. Score Range: 24-6. A higher score is more positive.

Functional Competence Scale: *The next questions are about how easy it is for you to do things for yourself as much as you want.*

FC		Often	Some-Times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/REF
1	Is it easy for you to get around in your room by yourself?	4	3	2	1	3.8	1.5	0	0
2	Can you easily reach the things that you need?	4	3	2	1	3.8	1.5	0	0
3	If you are anywhere in the nursing home and need a bathroom, can you get to one quickly?	4	3	2	1	3.8	1.5	0	0
4	Can you easily reach your toilet articles and things that you want to use in your bathroom?	4	3	2	1	3.8	1.5	0	0
5	Do you do as much to take care of your own things and your room as you can and want?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: Score range 20-5. A higher score is more positive.

Privacy Scale: *The next questions are about privacy or lack of privacy.*

PRI		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/REF
1	Can you find a place to be alone if you wish?	4	3	2	1	3.8	1.5	0	0
2	Can you make a private phone call?	4	3	2	1	3.8	1.5	0	0
3	When you have a visitor, can you find a place to visit in private?	4	3	2	1	3.8	1.5	0	0
4	Can you be together in private with another resident (other than your roommate)?	4	3	2	1	3.8	1.5	0	0
5	Do the people who work here knock and wait for a reply before entering your room?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score range 20-5. A higher score is more positive.

Dignity Scale: *The next questions concern respect for your dignity.*

DIG		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do staff here treat you politely?	4	3	2	1	3.8	1.5	0	0
2	Do you feel that you are treated with respect here?	4	3	2	1	3.8	1.5	0	0
3	Do staff here handle you gently while giving you care?	4	3	2	1	3.8	1.5	0	0
4	Do staff here respect your modesty?	4	3	2	1	3.8	1.5	0	0
5	Do staff take time to listen to you when you have something to say?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 20-5. A higher score is more positive.

Meaningful Activity Scale: *Now we have some questions about how you spend your time.*

MA		As much as You want?	Too Much?	Too Little?		Mostly Yes	Mostly No	DK	NR/ REF		
1	Do you get outdoors:	4	1	1	Do you get outdoors as much as you want?	3.8	1.5	0	0		
				Every day	Several times a week	About once a week	Less than once a week	Less than once a month	DK	NR/ REF	
2	About how often do you get outdoors?			4	3.25	2.50	1.75	1	0	0	
3	Do you enjoy the organized activities here at the nursing home?			Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
				4	3	2	1	3.8	1.5	0	0
4	Outside of religious activities, do you have enjoyable things to do at the nursing home during the weekend?			4	3	2	1	3.8	1.5	0	0
5	Despite your health condition, do you give help to others, such as other residents, your family, people at this nursing home, or the outside community?			4	3	2	1	3.8	1.5	0	0
6	Do the days here seem too long to you?			1	2	3	4	1.5	3.8	0	0

4 out of the 6 questions must be answered in first 6 columns to construct the scale. 2 DK/NR responses may be imputed to domain score average. Score Range: 24-6. A higher score is more positive.

Relationship Scale: *The next questions are about your relationships here at (name of the facility).*

REL		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Is it easy to make friends at this nursing home?	4	3	2	1	3.8	1.5	0	0
2	Do you consider that <u>any</u> other resident here is your <u>close</u> friend	4			No 1			0	0
3	In the last month, have people who worked here stopped just to have a friendly conversation with you?	Often 4	Some- times 3	Rarely 2	Never 1	Mostly Yes 3.8	Mostly No 1.5	DK 0	NR/ REF 0
4	Do you consider any staff member to be your friend?	4	3	2	1	3.8	1.5	0	0
5	Do you think that (name of the facility) tries to make this an easy and pleasant place for families and friends of residents to visit?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale.. 1 DK/NR response may be imputed to domain score average. Score Range: 20-5. A higher score is more positive.

Autonomy Scale: *The next questions are about the choice and control that you have.*

AUT		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Can you go to bed at the time you want?	4	3	2	1	3.8	1.5	0	0
2	Can you get up in the morning at the time you want?	4	3	2	1	3.8	1.5	0	0
3	Can you decide what clothes to wear?	4	3	2	1	3.8	1.5	0	0
4	Have you been successful in making changes in things that you do not like?	4	3	2	1	3.8	1.5	0	0

3 out of the 4 questions must be answered in the first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 16-4 . A higher score is more positive.

Food Enjoyment Scale: *The next three questions are about your eating experiences at (name of nursing home).*

ENJ		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you like the food at (name of the facility)?	4	3	2	1	3.8	1.5	0	0
2	Do you enjoy mealtimes at (name of the facility)?	4	3	2	1	3.8	1.5	0	0
3	Can you get your favorite foods at (name of the facility)?	4	3	2	1	3.8	1.5	0	0

All questions must be answered in first 6 columns to construct the scale. No imputing is allowed. Score Range: 12 to 3. A higher score is more positive.

Spiritual Well-being Scale: *The next questions ask about your spiritual life here at (name of the nursing home).*

SWB		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you participate in religious activities here?	4	3	2	1	3.8	1.5	0	0
2	Do the religious activities here have personal meaning for you?	4	3	2	1	3.8	1.5	0	0
3	Do you feel your life as a whole has meaning?	4	3	2	1	3.8	1.5	0	0
4	Do you feel at peace?	4	3	2	1	3.8	1.5	0	0

3 out of the 4 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 16 to 4. A higher score is more positive.

Security Scale. *The next set of questions asks about how safe and secure you feel at (name of the facility).*

SEC		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you feel that your possessions are safe at this nursing home?	4	3	2	1	3.8	1.5	0	0
2	Do your clothes get lost or damaged in the laundry?	4	3	2	1	3.8	1.5	0	0
3	Do you feel confident that you can get help when you need it?	4	3	2	1	3.8	1.5	0	0
4	If you do not feel well, can you get a nurse or doctor quickly?	4	3	2	1	3.8	1.5	0	0
5	Do you ever feel afraid because of the way your or some other resident is treated?	1	2	3	4	1.5	3.8	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 20 to 5. Higher score is more positive.

Individuality Scale. *The next questions are about your individual preferences for your life.*

IND		Often	Some- times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Taking all staff together, nurses, aides and others, does the staff know about your interests and what you like?	4	3	2	1	3.8	1.5	0	0
2	Do staff members know you as a <u>person</u> ?	4	3	2	1	3.8	1.5	0	0
3	Are the people working here interested in your experiences and the things you have done in your life?	4	3	2	1	3.8	1.5	0	0
4	Do staff here take your preferences seriously?	4	3	2	1	3.8	1.5	0	0
5	Do residents here know you as a <u>person</u> ?	4	3	2	1	3.8	1.5	0	0
6	Are your personal wishes and interests respected here?	4	3	2	1	3.8	1.5	0	0

4 out of the 6 questions must be answered to construct the scale. 2 DK/NR responses may be imputed to scale average. Score Range: 24 to 6. Higher score is more positive.

Summary Items: *The next twelve questions sum up what we have discussed so far. They ask for overall ratings of the quality of your life .(Instructions to interviewer: Try to use the “excellent/poor” format. If the resident cannot use the four-item scale, go to the “yes/no” format.)*

How would you rate the quality of your life here with respect to:

SUM		Excellent	Good	Fair	Poor		Yes	No	DK	NR/ REF
CMF	Feeling physically comfortable?	4	3	2	1	Do you feel physically comfortable?	3.8	1.5	0	0
FC	Doing as much for yourself as you want?	4	3	2	1	Can you do as much for yourself as you want?	3.8	1.5	0	0
PRI	Having the privacy that you want?	4	3	2	1	Do you have the privacy you want?	3.8	1.5	0	0
AUT	Having choice and control in your daily life?	4	3	2	1	Do you have choices in your everyday life?	3.8	1.5	0	0
DIG	Feeling that your dignity is respected?	4	3	2	1	Is your dignity respected?	3.8	1.5	0	0
MA	Having interesting things to see and do?	4	3	2	1	Do you have interesting things to see and so?	3.8	1.5	0	0
ENJ	Enjoying your food and meals?	4	3	2	1	Do you enjoy food and meals?	3.8	1.5	0	0
IND	Following your own interests and preferences?	4	3	2	1	Are you able to follow your own interests and preferences?	3.8	1.5	0	0
REL	Having good friendships and relationships?	4	3	2	1	Do you have good friendships and relationships?	3.8	1.5	0	0
SEC	Feeling safe and secure?	4	3	2	1	Do you feel secure and safe?	3.8	1.5	0	0
SWB	Meeting your spiritual and religious needs?	4	3	2	1	Can you meet your spiritual and religious needs?	3.8	1.5	0	0
QOL	Your life as a whole?	4	3	2	1	Is your life as a whole good?	3.8	1.5	0	0

Note: These items were not summed to create a scale but used as individual criterion measures for the separate domain scales. Further work is being done to examine how much each domain contributes to overall QOL.

Investigators at the University of Minnesota are still analyzing these QOL measures. We would appreciate your sharing any comments and experiences with using these measures.