Chapter 13

Conclusions, Implications, and Recommendations

The multi-faceted work described in this report reflects a 5-year concentration on quality of life (QOL) in nursing homes. The study was larger and more detailed than previous work on nursing-home QOL. It has yielded a number of tools and approaches, as well as suggested hypotheses and areas that might be fruitful for further research. At this writing, ideals about the "good nursing home" are undergoing considerable upheaval as the culture change movement proposes dramatically different ways to design and organize care in nursing homes and assisted living settings are serving some people who would formerly have been in nursing homes (Lustbader, 2000; Weiner & Ronch, 2003). Also, some people with nursing home levels of need are receiving care in Assisted Living settings where by design they are likely to have more autonomy and privacy than do nursing-home residents, and such innovations are expected to improve QOL. They may also increase the expectations of frail older people in group residential settings. It will be important to be able to measure QOL to track the effects of such changes.

Summary of Findings

Major findings from this project are listed below:

1. It is feasible to collect information directly from nursing home residents about their own QOL. Even residents with substantial cognitive confusion can complete QOL interviews. On average, we were able to collect first-hand data from 60% of residents in a nursing home.

2. The 11 QOL domains that we identified (comfort, security, functional competence, relationships, enjoyment, meaningful activity, dignity, individuality, privacy, autonomy, and spiritual well-being) could be tapped in 54 questions. These QOL domains are

independent but relate to a latent QOL multidimensional construct. The scales had adequate scale properties in 2 large field tests.

3. Family members and staff members were poor proxies for residents themselves. When we had multiple sources of reporting, family and staff reports were statistically significantly associated with resident reports but correlations on scales were rarely better than 0.3. Family members were somewhat more congruent with residents than staff.

4. QOL average domain scores for facilities are capable of differentiating one facility from another. At both Wave 1 and Wave 2, we were able to discern patterns whereby some nursing homes fell several standard deviations above or below the mean on multiple QOL domains.

5. Although QOL varies across facilities, we also see variation across residents.   Resident ADL, cognitive status, and sensory impairment are predictors of better QOL. We were able to show that personality of the resident has a small independent effect on resident QOL after controlling for functional status.   Length of stay made no difference in QOL.

6. During Wave 1, facility-wide observation of resident and staff interactions identified several observable phenomena that were associated with better or worse resident QOL. When we streamlined the number of observation occasions and the number of items observed in Wave 2, we no longer found associations between our observations and resident reported QOL. At both Waves, the results of the observations distinguished facilities from each other, suggesting some promise for observational protocols as an auxiliary way of assessing facility QOL, especially as it related to those who cannot be interviewed.

7. QOL measures could be satisfactorily conducted by staff members and surveyors under research conditions. No systematic differences in accuracy, concordance between research interviewers, or attitudes to the process could be attributed to whether the staff assessor was a nurse, on the one hand, or a member of the social work or activities staff, on the other.

8. No strong pattern emerged to connect off-site indicator data from OSCAR and MDS to QOL.

9. We collected copious data describing facility structure and process but found no clear associations between these findings and QOL. We observed an enormous range in the way only 40 nursing homes arrange their nursing services, activities, and a myriad of other functions that could have an impact on the QOL domains. This variation has implications for measurement of any new indicators. Records for activities, room changes, in-service education, care planning, and other kinds of archival data varied also in both level of detail and format.

10. We developed new approaches to measuring physical environments that had high inter-rater reliability and did not require specialized knowledge or subjective judgments. We found many problems with physical environments in the 40 Wave 1 nursing homes. Private rooms are associated with better QOL. We have begun a cluster analysis approach that is promising in that the clusters seem associated with QOL. Our new approach to environmental assessment pinpoints the environment for each individual resident, enabling use of more powerful hierarchical analysis to examine the effects of the nested environments of rooms, units, and facilities.

Implications

This report demonstrates the feasibility of collecting information from nursing home residents about their quality of life (QOL). Given that QOL data is collected directly from residents, such contact provides an opportunity to collect other salient information at the same time on relevant topics like affect and satisfaction. This information can be used for a variety of purposes including quality assessment and assurance, consumer information, and quality improvement. It can also be employed as a building block in a payment system that re-enforces better quality by paying more for it.

Underlying this work is the growing appreciation that QOL and satisfaction are major issues of concern to current and potential users of long-term care. The historical preoccupation with technical elements of quality of care, focused largely around nursing care issues, needs to be tempered with more attention to this important area. Plans to revise the MDS 3.0 reflect recognition of this shift in priorities.

The measure developed (in both its full form and subsequent shorter versions) was able to distinguish among NHs. Although resident characteristics explained the majority of the explained variance, the proportion accounted for by facilities was sufficient to permit discrimination and to serve as the basis for rewarding desired behavior in this area. It would be useful to field these measures in new and larger samples of nursing homes. In their further development, they also need to be tested for cross-cultural relevance.

Making QOL measurement in the nursing home context fully operational probably requires a more comprehensive list of domains that those assessed in this project. Salient elements, such as functioning, health, cognition, and affect, were specifically eliminated from this study under the terms of the contract, but measures of these domains should be included in

final efforts to field a QOL battery. M. Powell Lawton, an early pioneer in defining QOL (and

an original collaborator on this project until his death), exhorts researchers to recognize that

QOL must represent both subjective and objective aspect of quality (Lawton, 2001). On the

other hand, Lawton summarized a desirable subjective multidimensional QOL construct with

great attention to the domains studied here.   Aggregating "investigators' top-10 lists" from

previous research, Lawton proposed 11 human needs that must be satisfied in nursing homes to

create a better QOL: autonomy, privacy, dignity, social interaction, meaningful activity,

individuality, enjoyment versus aversive stimulation, safety and security, spiritual well-being,

clarity of structure and functional competence. He argues that each of these 11 needs is

universal and each "can be served or frustrated by caregivers; and may be represented by its

fulfillment for each individual and by its capacity to be fulfilled by the facility (Lawton, 2001,

p.147)."

Our work shows that the data derived from proxy reports is not sufficiently comparable to

the reports of residents themselves to allow ready substitution at the individual level, although

the mean values of the proxy respondent groups were closer to the means of the residents and

could therefore be used to develop NH level information. The poor performance of proxies

suggests that whenever a resident can be interviewed directly, proxies should not be used in lieu

of resident self-report.

Determining QOL for those who cannot express themselves verbally, even in short and

simple interviews remains a problem. Many residents with substantial dementia according to the

MDS could complete usable QOL responses; we, therefore, recommend against any MDS-based

screening prior to conducting QOL interviews. That being said, many people who are unable to

respond lack a voice, and in some instances we cannot really infer their QOL from any non-

verbal clues. One could rely on those who can respond to serve as the sentinels for those who cannot, but such a policy is uncomfortable. More work is needed to identify ways to give the resident who cannot communicate a better voice. The observational efforts at the facility level were designed to observe phenomena that have face validity for being associated with a better or worse QOL for the residents observed, particularly residents with dementia. At the same time, this study shows the dangers of arbitrarily excluding resident respondents on the basis of their cognitive performance. Although the level of participation declined with more severe cognitive impairment, even some severely impaired residents were able to participate meaningfully.

Substantial efforts went into developing a QOL tool that was psychometrically sound. As a result it had reasonable internal reliability, especially for a measure of amorphous constructs. The level of reliability was maintained in the shorter versions, which did not capture as many domains. Various tests showed that there was good inter-rater reliability and that the questionnaire could be used to good effect by both nursing home staff and surveyors. Although the performance of both types of staff under artificial test conditions may be better than in actual practice, when other factors may influence their performance, these findings are encouraging.

Whereas the QOL appears to have sufficient reliability to make it a viable tool, the issue of validity is much harder to address. There is some evidence that conceptually related domains appear to be better correlated with each other than those expected to be less related, but in the absence of an independent gold standard for QOL there is no specific way to demonstrate validity. The sample of nursing homes was designed to provide some variation, but again there was no way to create an independent measure along which to array the homes. Subsequent work might well examine how well the measure discriminates among homes believed by some independent criterion to represent better and worse QOL. For example, facilities that are making

an active effort to create a social and physical environment designed to enhance QOL might be compared to more typical facilities. During this project, we struggled with the problems, however, of using facility reputation for good QOL as a source of validation of QOL measures, and for using expert raters. There is no reason to think such criterion measures should have greater weight than the measures derived from residents themselves.

Another line of investigation might explore more carefully the correlates of better QOL scores. While the easily accessible structural measures drawn from interviews and that OSCAR did not demonstrate a strong correlation, more subtle or simply other measures than more directly reflect ambiance and personal attention might be more useful. It is intriguing that the number of activities staff was a stronger correlate with QOL than was the amount of nursing staff (professional, nonprofessional or both). More attention might be usefully devoted to understanding the implications of this observation. The strongest relationship between environmental factors and QOL was the presence of single rooms, but much more work remains to be done in exploring the effects of environment. Future work might also look at interactions and the possibility that QOL is influenced by a specific confluence of resident characteristics within specific environments.

We are also eager to see longitudinal work undertaken with QOL measures to determine their sensitivity to change. If they are to be used in before-after tests of quality improvement efforts, they will need to demonstrate that sensitivity.

The QOL score has been largely handled as a series of domain measures, but work with a variety of constituencies suggests that the values applied to the individual domains are quite similar. Hence a simple summative summary score might be more easily understood by many users. More work could be done on the advantages of creating and using such a score. There are

always tradeoffs, of course, between the detail involved in sub-scores and the efficiency of a single scale. For some purposes, the separate domains may be more conceptually useful, but in many instances a single score would likely encourage wider use of the construct. We caution again that the longer measures contain much information that might be useful for QI purposes. Similarly, short screeners, such as we developed as potential instruments for the MDS (the QOL-14 and the QOL-MD-14) and our 11-item list of summary statements in our QOL battery (which itself forms a scale and which we used to validate our domains) are examples of brief approaches.

Whether using a single score or domain score, issues arise about how various aspects of QOL should be weighted. In our developmental work, for example, we weighted all domains equally, but we recognize that such a stance is arbitrary. Once we recognize that different weighting schemes are feasible, the question arises as to whose values should inform the weighting and how, if at all, weightings can be keyed to individual preferences.

QOL measurement in nursing homes is in its infancy compared to the many decades of work on functional status and quality of care. Some individuals raise concerns about pursuing QOL too vigorously because they believe that many of the factors influencing QOL are out of facility control. They argue that if most QOL is influenced by health conditions and social circumstances, and even somewhat by personality, there is little room left for care to affect outcomes. We view such negativism as short-sighted. The very observation of variation across facilities suggests that positive efforts can affect QOL. It is well known that nursing home life can affect QOL negatively, and remedying these negative effects should itself produce positive effects. With greater knowledge and precision, professionals may be able to identify residents at

higher risk of poor QOL because of certain physical or sensory impairments or because of social isolation and lack of family. It would then be feasible to target efforts to those individuals.

Systematically collecting and reporting information on QOL is itself likely to have a profound positive effect in NH care. Using the score in more deliberate ways to report on facility performance and even to encourage better QOL outcomes by linking payment to performance would likely have an even more profound effect. The question always arises about when is an instrument ready for broad application. Almost any tool can be improved. Undoubtedly this measure will evolve over time but the fundamental building blocks are in place. It is certainly as good as many such instruments in common use. The needs for emphasizing these vital aspects of nursing home care outcomes argue strongly for active implementation, even while additional refinements are pursued.

References

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