

**Residents' Perceptions of their Quality of Life in
Detroit
Nursing Facilities**

Final Report to the Detroit Area Agency on Aging 1-A

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Background

In June 2009 the Centers for Medicare and Medicaid Services (CMS) significantly revised its direction to state nursing facility survey staff about the conduct of facility inspections.¹ These revisions, based on recommendations from the 2008 CMS/Pioneer Network Environment Symposium, reflect the heightened priority recently accorded person centered care and resident quality of life (QoL) in nursing facilities.

While the federal Nursing Home Reform Act of 1987 charged nursing facilities with responsibility to assure both resident quality of care and resident quality of life, most of the wide variety of report cards, surveys and clinical indicators developed by federal and state governments, trade associations, and researchers have focused on quality of *care*, i.e., the assessment of objective treatments and their clinical results. Though a number of instruments that assess satisfaction have been developed by the long term care industry², fewer psychometrically validated instruments measure the QoL of nursing facility residents in a manner consistent with the issues of concern in this population.³ Of these, still fewer assess QoL by eliciting responses directly from the patient/resident.^{4,5} Since QoL assessment is based upon the person's own experiences, values, and perceptions, direct elicitation of the individual's response - rather than the perceptions of family or caregivers - is considered to be the gold-standard.⁶ Proponents of person centered long-term care hold that including QoL measurement alongside measurements of clinical status and outcomes, such the various scales and quality indicators derived from the Minimum Data Set (MDS 2.0⁷), is essential to provide a truly holistic view of residents and their lives within the facility. Such information holds promise both at the individual level, to define more clearly the positive and negative aspects of a person's life within a given facility, and at a summary level, to assist facility administrators and policymakers to gauge the overall QoL at the facility level or within a geographic area. Ideally, both individual and summary QoL data can identify both the positive aspects of life within the facility and needed changes in everyday practice that could improve life for a given individual or the overall QoL within the facility. As many quality of life issues revolve around relationships, autonomy, and respect, measuring QoL also allows facilities the opportunity to improve care experiences without increasing overall operating costs.

¹ Centers of Medicare & Medicaid Services "Guidance to Surveyors; S&C 09-31" 2009.

² Castle N, Lowe TJ, Lucas JA, Robinson JP, Crystal S. "Use of Resident Satisfaction Surveys in New Jersey Nursing Homes and Assisted Living Facilities."

³ Kane, Rosalie. Definition, Measurements, and Correlates of Quality of Life in Nursing Homes: Toward a Reasonable Practice, Research, and Policy Agenda. *The Gerontologist*. 2003;SI II: 28-36.

⁴ Harper GJ. Assessing older adults who cannot communicate. In: Kane RL, Kane RA, eds. *Assessing Older Persons: Measures, Meaning, and Practical Applications*. New York: Oxford University Press; 2000: 483-515.

⁵ Logsdon R, Gibbons L, McCurry S, Terri L. Quality of life in Alzheimer's disease: patient and caregiver reports. *J Mental Health Aging*. 1999;5:21-32.

⁶ Kane RA, et al. Quality of Life Measures for Nursing Home Residents. *J Gerontology*. 2003;58A:240-248.

⁷ Centers for Medicare and Medicaid Services. "MDS 2.0 for Nursing Homes." From: http://www.cms.hhs.gov/nursinghomequalityinits/20_NHQIMDS20.asp. Accessed on 1/12/2010.

In 2008, the Detroit Area Agency on Aging (DAAA) undertook a wide-ranging systematic review of nursing facilities located within its planning and service area. The goal of this effort was to improve the quality of institutional long-term care by strengthening the financial stability of providers, increasing work force retention and improving resident care outcomes. These issues were tackled from many angles, including legislative forums, participation by local grass roots organizations and provider input. To incorporate the nursing home resident's voice into this effort, DAAA contracted with the University Of Michigan Institute of Gerontology (UM) to design and deploy a QoL survey.

Reflecting Michigan's ongoing economic struggles and the widespread poverty of its citizens, a negative image of Detroit has become pervasive in the mainstream media^{8,9}. This image has cast a deep pall over all service sectors, including nursing facilities. Fueling the negative perception is recent research suggesting that urban facilities with high Medicaid census typically are not providing quality care to their residents. Facilities with a high percentage of African-American residents are more likely to have a higher number of survey deficiencies, lower staffing ratios and tend to be less financially viable, leading to poor quality of care^{10,11,12}. Other research has suggested that facilities that are more reliant on Medicaid funds have less financial flexibility and are less able to provide quality care.^{6,13} Long term care facilities located in Detroit rely heavily on Medicaid funding, deriving, on average, 87.5% of their funding from this state-run program. They also predominantly serve an "urban" resident mix, with an average population across Detroit facilities that is 79% African-American. Thus, it might be expected that most Detroit nursing home residents would be unhappy, judge their quality of life as poor, and feel that their needs were not being met. Indeed, a previous study conducted on behalf of DAAA in 2004 stated that clinical management of the population mix found in Detroit nursing facilities was a major problem and was inconsistent with high quality care¹⁴. The UM research team was tasked to discover whether residents' perceptions supported this bleak picture.

DAAA asked UM to build on previous work to develop and field test the QoL instrument, called the POSM NF (Participant Outcomes and Status Measures for Nursing Facility Residents). A number of practical considerations prompted this decision. First, an existing QoL instrument, the POSM Home and Community Based Services (POSM

⁸ Zumbun, J. America's Fastest-Dying Cities. Forbes. From: http://www.forbes.com/2008/08/04/economy-ohio-michigan-biz_cx_jz_0805dying.html?partner=email; accessed on August 12, 2009.

⁹ Okrent, Daniel. "Detroit: the Death – and Possible Life – of a Great City." From: <http://www.time.com/time/nation/article/0,8599,1925796,00.html>; accessed on November 20, 2009.

¹⁰ Smith, DB, et al. Racial Disparities in Access to Long-Term Care: The Illusive Pursuit of Equity. J Health Politics, Policy and Law. 2008;33:861-881.

¹¹ Mor, V, et al. Driven to Tiers: Socioeconomic and Racial Disparities in Quality of Nursing Home Care. Millbank Quarterly. 2004;82:227-256.

¹² Smith DB, et al. Separate and Unequal: Racial Segregation And Disparities In Quality Across US Nursing Homes. Health Affairs. 2007;26:1448-1458.

¹³ Weech-Maldonado, R. The Relationship Between Quality of Care and Financial Performance in Nursing Homes. J Health Care Finance. 2003;29:48-60.

¹⁴ Douglass, R, et al. The Least Among Us: An Analysis of Medicaid-Intensive Nursing Homes and the Patients That They Serve. November, 2004 for: Detroit Area Agency on Aging.

HCBS), had been designed by UM with support from the same funder, the Michigan Department of Community Health. The POSM HCBS had been developed with extensive stakeholder input, had undergone multiple rounds of testing, and was in routine use across the state. The ability to compare QoL of persons receiving long term services and supports across care settings was very attractive to DAAA. Second, the design of the POSM NF focused only on domains not already measured by the MDS 2.0 Resident Assessment Instrument which is used, by federal mandate, in virtually all nursing facilities in the nation. The brevity of POSM NF enabled more interviews to be conducted for the modest budget allotted to this effort. Third, computerization of the tool could be easily accomplished by the same vendor that had provided software for the POSM HCBS, allowing for quick turnaround of interview data. Finally, use of POSM NF enabled DAAA to take part in an international effort by interRAI, an international research collaborative,¹⁵ to create a standardized subjective QoL instrument that could support cross-national comparisons. The opportunity to have a benchmark against which to interpret the outcomes of the Detroit survey effort was also very attractive.

Overview of the Survey Instrument

POSM NF is a 52 item interviewer-administered instrument consisting of ten domains: Availability of Paid Care/Supports; Relationships with Support Workers; Activities and Community Integration; Personal Relationships; Dignity/Respect; Autonomy; Privacy; Security; Comfort; Environment/Meals. Domains comprise four to eight items each. One item, “I would recommend this facility to others”, is used as a measure of overall satisfaction with the institution.

POSM NF provides scores at the item level, the domain level, and an overall summary score. Each item is scored on a 5 point Likert scale which ranges from “strongly disagree” to “strongly agree.” Each domain score is computed as an average of all individual items completed within the given domain. If more than half of all items in a domain are completed, the average of the items completed by the respondent within that domain is computed and imputed as the score for the missed items. If less than half of all the items in a domain are completed, the sample mean for that domain is computed and imputed as the score for the missed items. All domain scores are then totaled and multiplied by 2 to obtain the summary (or total) score, which ranges from 20-100, with 20 indicating the lowest possible quality of life in a nursing facility and 100 indicating the highest possible quality of life.

Methods

Outreach to Facilities and Residents

The DAAA planning and service area contains 37 nursing facilities. Small facilities (those with 120 beds or less) predominate (16 of 37) as do for-profit facilities (32 of 37) operated by corporations (30 of 37). The average number of total staff hours per resident per day was 1.39 at the time of the survey and the average overall Nursing Home

¹⁵ www.interrai.org

Compare rating was 2.35 (out of 5 possible stars).¹⁶ Each of the facilities was contacted by the DAAA project manager via mail with telephone follow-up to solicit its participation as a data collection site.

DAAA hired 17 individuals to administer the survey. All interviewers took part in a day-long training. Within a facility, “eligible” residents were those individuals who had resided within the facility for at least 90 days and had a score of 3 or lower on the MDS 2.0 Cognitive Performance Scale; this cut-off was chosen to identify individuals who were reasonably capable of understanding and answering the questions posed in the survey. Randomization was achieved by acquiring the full birth date of all residents who met the CPS threshold; residents whose date of birth ended in a 0, 1 4, or 5 were identified and approached consecutively for participation in the survey until ten percent of the eligible residents in the facility had been contacted.

Originally, the project team planned to interview residents on weekends, when there were likely to be fewer scheduling conflicts due to therapy or other resident activities; however, many of the facility administrators requested that they be onsite while the interviews were being conducted. Because aid from the nursing home administrator was needed to identify eligible residents, interviews were conducted during normal business hours.

Residents were approached no more than twice in an effort to complete the survey. All participants were interviewed in a quiet, private place and were assured that their responses would be kept confidential. Only residents willing and able to sign an informed consent form were interviewed.

Characteristics of the Sample

Of 37 facilities within the service area, 32 agreed to participate. Facility characteristics of participating nursing homes are shown in Table 3.

¹⁶ From: <http://www.medicare.gov/NHCompare/Include/DataSection/Questions/HomeSelect.asp>. Accessed on January 26, 2009.

Table 3: Characteristics of Detroit Facilities and Participating Facilities

	All		Sample	
	N	%	n	%
Number of Facilities	37	100%	32	86.5%
Size (beds)				
small (0-119)	16	43.2%	14	43.8%
medium (120-149)	10	27.0%	9	28.1%
large (150+)	11	29.7%	9	28.1%
CMS Star Rating				
1	10	27.0%	7	21.9%
2	13	35.1%	12	37.5%
3	6	16.2%	5	15.6%
4	7	18.9%	7	21.9%
5	1	2.7%	1	3.1%
Profit Status				
For Profit	32	86.5%	28	87.5%
Non-Profit	5	13.5%	4	12.5%
	All		Sample	
Owner Status	N	%	n	%
Corporation	30	81.1%	26	81.3%
Individual	4	10.8%	4	12.5%
Partnership	1	2.7%	1	3.1%
Church	2	5.4%	1	3.1%

No statistically significant differences were found between all facilities within the service area and those participating in the survey including number of beds, Nursing Home Compare star rating and Medicaid funding percentage.

316 residents were approached to participate in the survey. Five residents were unable to complete the interview and 48 residents declined to participate resulting in a total of 263 completed interviews. On average the survey took approximately 22 minutes to complete (range 0-45 minutes) and over 90% of interviews were completed in one visit. The respondent sample was 57% female and 85% African-American. The average age of participants was 54 years (range 12-85); 18 participants did not provide their age. The gender mix of the sample was not found to be statistically significantly different from the eligible nursing facility population (long-term stayers with a CPS score of ≤ 3). However, the sample was younger (p -value < 0.0001) with a higher proportion of African-Americans (p -value = 0.04). A comparison of the general nursing facility population in Detroit and survey participants is shown on Table 4.

Table 4: Comparison of Detroit Nursing Facility Population and POSM NF Participant Sample

	All		Sample	
	N	%	n	%
Total number	13810	100%	311	100.0%
Gender				
Male	6064	43.9%	135	43.4%
Female	7739	56.0%	176	56.6%
Race				
American Indian/Alaskan	20	0.1%	1	0.3%
Asian	47	0.3%	1	0.3%
African American	10654	77.1%	263	84.6%
Hispanic	110	0.8%	1	0.3%
White	2912	21.1%	45	14.5%
Age Group				
0~17	77	0.6%	6	1.9%
18~24	96	0.7%	2	0.6%
25~34	527	3.8%	23	7.4%
35~44	1736	12.6%	64	20.6%
45~54	2344	17.0%	64	20.6%
55~64	3117	22.6%	63	20.3%
65~74	4344	31.5%	70	22.5%
75~84	1512	10.9%	18	5.8%
85~94	57	0.4%	1	0.3%

Findings

Psychometric properties of the survey instrument

As measured by Spearman's correlation coefficients, only 12 of the 52 items had a correlation greater than 0.50. Most item correlation occurred in the Relationships with Support Workers, Personal Relationships and Environment/Food domains. Generally, domains appeared to be consistent as measured by Cronbach's alpha. Aside from the Comfort and Dignity/Respect domains which had alphas of 0.37 and 0.48, respectively, the remaining eight domains had Cronbach's alphas from .63 to .84.

Table 1: Item Correlations

Item	Item	Correlation
B1	B6	0.51
B2	B3	0.54
D4	D5	0.68
E2	H5	0.57
G4	G5	0.51
H2	H5	0.53
J3	J4	0.69
J3	J6	0.54
J4	J5	0.52
J4	J6	0.65
J4	J7	0.59
J5	J7	0.51

Table 2: Domain Cronbach's Alphas

DPOSM: Domain	Alpha
Availability of Paid Care/Supports	0.81
Relationship with Support Workers	0.66
Activities and Community Integration	0.67
Personal Relationships	0.68
Dignity/Respect	0.48
Autonomy	0.76
Privacy	0.72
Security	0.63
Comfort	0.37
Environment/Meals	0.84

Survey results

We first considered each of the ten domains separately.

Availability of Paid Care/Supports

Overall, respondents are happy with the care and services they are receiving. They indicated that their services were what they needed and were helping them to live their lives the way they want. Across the domain, at least 58% agreed with all items (range = 58-65% “agree” or “strongly agree”).

Relationships with Support Workers

Respondents were less positive about this dimension of their lives. They were closely split on items relating to selecting workers who assist them, directing the work of paid supports and being involved in decisions about their own care. Almost 48% indicated that they could not replace a worker when they wanted (“disagree” or “strongly disagree”) as compared to 39% saying they could (“agree” and “strongly agree”); 10% were neutral. They were, however, positive about workers respecting their likes and dislikes, workers having enough time for them, not being ignored by workers and being assisted by workers when needed.

Activities and Community Integration

Though residents were mostly positive about the activities they could participate in and their integration within the community, they were closely split regarding doing activities that were important to them – 40% indicated they could not do activities that were important to them (“disagree” and “strongly disagree”) and 46% indicated they could do activities that were important to them (“agree” and “strongly agree”).

Personal Relationships

Most respondents indicated that they have people who wanted to do things with them (77%) and that they had people they could count on outside of the facility’s support staff (90%). However, 35% of residents indicated that they did not have people they could chat with and 37% felt that they did not belong to a group that valued them. Furthermore, 55% of residents indicated that they did not have opportunities for romance or affection and 61% indicated that they did not have opportunities for a sex life.

Dignity and Respect

Respondents were overwhelmingly positive when asked about this issue. Over 80% responded positively on all questions regarding dignity and respect, including respect from care providers, respect from friends and family, and not being taken advantage of by facility staff. The vast majority (86%) indicated that they can express their opinions without fear of consequences.

Autonomy

Respondents were split when asked about spending time with a pet if they wished (54% “disagreed” or “strongly disagreed” while 32% “agreed” or “strongly agreed”) and their ability to go somewhere on the “spur of the moment” (52% “disagreed” or “strongly disagreed”; 40% “agreed” or “strongly agreed”). For most other aspects of autonomy,

respondents were strongly positive (“agree” or “strongly agree”). For example, 86% said they decide how to spend their time, 83% decide how their money is spent and 63% decide who comes into their room. 56% of respondents indicated they were living “where I want” as compared to 44% who were not living where they wanted.

Privacy

Residents consistently reported that their privacy was respected by facility staff and administration. When asked whether they could have a private conversation, 83% of residents agreed or strongly agreed, 80% of residents agreed or strongly agreed that their personal information is kept private, and 87% of residents agreed or strongly agreed that their privacy is respected during care procedures.

Security

Residents were overwhelmingly positive about their personal security. No more than 19% indicated on any given question that they did not feel secure (range = 2-19%). For example, 90% of respondents “agreed” or “strongly agreed” when asked whether they feel secure around the person providing their support. Less than 2% of respondents indicated that they did not feel safe around their family and friends.

Comfort

Responses to most questions in the comfort domain were strongly positive. The only question that resulted in split responses was the question “I am bothered by the noise here”. 27% of respondents indicated that they were bothered by the noise within the facility (“agree” or “strongly agree”) as compared to 58% who were not bothered (“disagree” or “strongly disagree”).

Environment/Meals

Residents were split in regard to food and meals in the facilities. Strong agreement existed when they were asked about enjoying mealtimes, getting enough food to eat and enough variety in foods. However, respondents were closely split when questioned about getting their favorite foods (44% “disagreed” or “strongly disagreed”; 38% “agreed” or “strongly agreed”), and liking the food provided by the facility (49% “agreed” or “strongly agreed”; 29% “disagreed” or “strongly disagreed”).

Overall Satisfaction and Total QoL Score

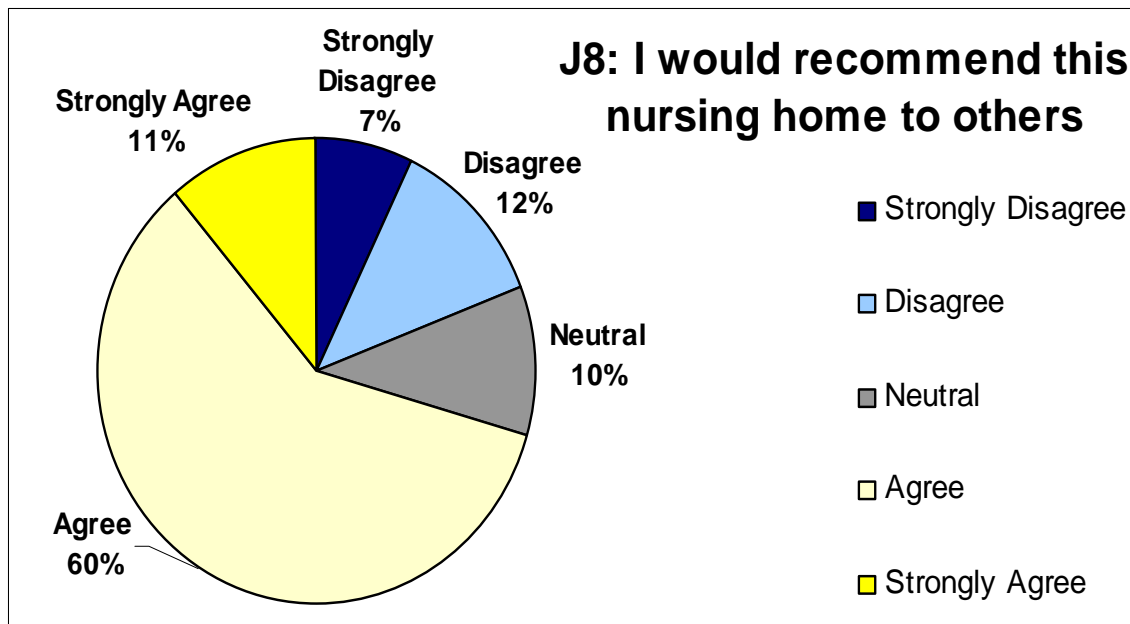
The average total score was 69.9 (range = 37.5 – 100). The total score did not vary significantly based on gender (p-value = 0.46), race or ethnicity (p-value = 0.20), age (p-value = 0.36) or facility characteristics.

Overall satisfaction is considered a key component of QoL in nursing facilities.¹⁷ Responses on the final question (“I would recommend this nursing home to others”) were used as a proxy for overall satisfaction. Those who responded “strongly agree” or “agree” were considered to be satisfied whereas those who responded “neutral”, “disagree” or “strongly disagree” were considered to be unsatisfied., Over 70% of the respondents

¹⁷ Castle, NG, et al. Use of Resident Satisfaction Surveys in New Jersey Nursing Homes and Assisted Living Facilities. *J Applied Gerontology*. 2004; 23: 156-171.

indicated that they were satisfied; of these, 11% “strongly agreed” with the statement recommending the facility to others.

Graph 1: Distribution of “I would recommend this nursing home to others” responses



This measure of satisfaction did not vary significantly regardless of any facility characteristics tested including size of facility (small, medium, large), for-profit/non-profit status, type of owner (church, individual, corporation or partner) star rating, percent of funding coming from Medicaid, or the racial make-up of the facility.

Activities and Community Integration, Personal Relationships and Environment/Meals domains were positively correlated with living where a resident wants. Though facility characteristics were not predictive of a resident’s overall satisfaction, two facility characteristics did predict whether a resident was living where he or she wanted: overall Nursing Home Compare star rating and for-profit status.

Differences among “positive” and “negative” respondents

To better understand what specific issues were most strongly related to overall satisfaction, and to identify possible steps that might be taken to improve satisfaction, UM analyzed responses from those who would recommend their current facility (“positives”) against those who would not recommend their current facility (“negatives”).

The strongest item correlations among the positives were workers having enough time for residents, residents not being ignored by workers, eating when a resident wants, enjoyment of mealtimes, liking the food and access to favorite foods (all p-values <0.0001). On a domain level, issues that appeared to drive overall satisfaction were Availability of Paid Care/Support (p-value = 0.001), Personal Relationships (p-value =

0.001), Autonomy (p-value = 0.002), Security (p-value = 0.047) and Environment/Meals (p-value = 0.001).

When analyzing the responses of the positives as compared to the negatives, significant differences emerged. Negatives had a fairly negative impression of their relationships with support staff. For example, only 32% had a positive response (“agree” or “strongly agree”) when asked about directing workers, only 27% indicated they could replace a worker when they wanted and only 40% indicated that workers had enough time for them. In contrast, 48% of positives indicated that they directed workers, 44% indicated they could replace a worker if they wanted and 74% agreed when asked about workers having enough time for them (all items, p-values ≤ 0.0001).

When asked about activities and community integration in the facility, a substantially smaller portion of negatives indicated that these played an important role in people’s lives (54%) as compared to positives (73%) (p-value = 0.0282). The same group also indicated that they do not belong to a group that values them (49% “disagreed” or “strongly disagreed” as compared to 62% of positives who “agreed” or “strongly agreed”).

A large difference appeared between the positives and negatives when asked about expressing opinions without fear of consequences. The positives overwhelmingly agreed (92% “agreed” or “strongly agreed”) that they could express their opinions without fear of consequences; only 72% of negatives agreed (p-value = 0.0006).

Another area in which large differences were found is in the Autonomy domain. Only 47% of negatives agreed when questioned about controlling who comes into their room as compared to 70% of positives (p-value = 0.0003). Furthermore, when asked about spending time with a pet and going where they want on the “spur of the moment,” similarly large differences appeared: 38% of positives indicated they could spend time with a pet if they wished as compared to 17% of negatives (p-value = 0.0063); 46% of positives agreed that they could go where they want on the “spur of the moment” as compared to 24% of negatives (p-value = 0.0218).

Positives were more likely to indicate they were living where they want than negatives (68% of positives “agreed” or “strongly agreed” as compared to 29% of negatives; p-value = < 0.0001). Satisfaction and living where a person wanted were found to be strongly, positively correlated (p-value = < 0.0001).

In terms of feeling safe and secure, regardless of recommendation status, most respondents indicated that they felt safe when around family and friends (97% of positives “agreed” or “strongly agreed”; 94% of negatives “agreed” or “strongly agreed”; differences insignificant). The groups disagreed, however, when asked about feeling safe around people who provide their care (97% of positives agreed; only 76% of negatives agreed; p-value < 0.0001), getting help right away if they need it (79% of positives agreed; 46% of negative agreed; p-value < 0.0001) and feeling that their possessions are safe (82% of positives agreed; 53% of negatives agreed; p-value < 0.0001).

Large differences exist between the positive and negative groups about comfort and food related items. Only 50% of negatives indicated that they get a good night's sleep as compared to 80% of positives (p-value <0.0001). Even larger disagreements exist when discussing most food related issues. For example, positives overwhelmingly indicated that they enjoy mealtime (77% "agreed" or "strongly agreed"); negatives did not (40% "disagreed" or "strongly disagreed", 26% were neutral and only 30% "agreed" or "strongly agreed") (all p-values <0.0001).

Discussion

Based on these results, most residents of nursing homes in Detroit are quite satisfied with their current nursing home experience and report a good quality of life. Respondents who were positive about their overall nursing facility experience tended to be positive about many aspects of this experience. Conversely, those who were negative about their overall experience tended to be negative about many aspects. Facility characteristics, Medicaid funding or racial-make up of the facility were not correlated with overall QoL scores.

When compared to the research on quality of care in urban facilities serving a Medicaid population, these findings are certainly good news; but are they too good to believe? Given that there was a very low rate of refusal to participate, that survey respondents were interviewed in private, and that the vast majority (86%) indicated that they could express their opinions without fear of consequences, we have no reason to suspect that the responses provided were dishonest or coerced. Moreover, because younger residents are over-represented in the sample, and younger people typically have lower scores on quality of life surveys the findings may actually under-represent the average resident's perceived QoL. While it is possible that some respondents wanted to present themselves in the most favorable light, the response patterns do not support the presence of social desirability bias, given the low correlations among most items. Last, while it is possible that respondents did not understand the questions they were asked, the interview sample represented individuals without substantial cognitive impairments, an indication that they were capable of understanding. Thus, we conclude that these survey results accurately reflect the perceptions of the residents interviewed, and are a reliable baseline against which to compare future QoL surveys. These results are also consistent with findings from much social indicator research that finds low correlations between perceived QoL and material wealth, economic prosperity of the region, and other "objective" measures of societal quality.

Another area of interest is those who were negative about their facility, nearly a third of the sample. Clearly, for many nursing home residents, there is still substantial room for improvement in their QoL. Whether this group's perceptions are amenable to change is not known. Given the current economic climate, which is particularly bad in Michigan and even worse in Detroit, any proposals to improve QoL are unlikely to be adopted unless they are cost neutral or, if possible, cost saving. Some of the results point toward effective, inexpensive ways to improve quality, however. For instance, though respondents were very positive when questioned about workers respecting their likes and

dislikes, workers having enough time for them, and not being ignored by workers, they were less positive regarding selecting workers that assist them, directing the work of workers and being involved in decisions about their own care. Thus, it appears that one obvious way to improve resident QoL is to include individuals in their own care decisions. This concept is fully supported by the culture change movement and materials on person-centered planning are abundant.

Residents were closely split (46% agreed, 40% did not) regarding whether they could participate in activities that are important to them. Again, this suggests an increased emphasis on person-centered planning, to discover what activities are considered "important" to the individual resident, instead of relying on scheduled group activities. This is an issue highlighted in the recent CMS guidance¹⁸. CMS strongly encourages nursing facility staff to seek information from residents regarding their interests and preferences so that residents can accomplish the things they would like to while in the facility. In this survey, only 46% of respondents indicated that they could participate in activities that are important to them as compared to 40% indicating that they could not. By communicating with residents to determine their interests, nursing facilities may be able to increase the variety of activities available to residents in accordance with resident wishes thereby improving QoL.

In addition to expressing a need for more meaningful activities, 35% of residents indicated that they did not have people they could chat with (as compared to 58% who said they did). A facility might address this problem by establishing a volunteer visitor program with a local community or church group. Inviting local volunteers into the facility to visit with residents could help to improve residents' QoL while also providing benefit to the volunteers¹⁹ at very little, if any, cost.

Another survey finding that may have a no-cost resolution is noise. 17% of all respondents and 33% of all negatives indicated that they do not get a good night's sleep in the facility. Simple changes like training staff to maintain quiet during sleeping hours and reducing noise from televisions, carts and cleaning equipment in hallways and common areas are cost-neutral ways to combat disturbances that may have a negative impact on a resident's ability to obtain a good night's sleep and therefore improve their QoL.

Additional ways to improve residents' QoL at a low cost include improving or changing meal-time environments by allowing people to select their meal-time companions, and emphasizing respectful speech, e.g., ensuring that residents are called by the name they prefer. Simple changes like these may come at low cost or effort but may have a highly positive impact on residents' QoL.

In addition to addressing or improving facility-specific issues, system-wide concerns also need to be addressed. Research indicates that staff stability within a facility has an impact

¹⁸ Centers of Medicare & Medicaid Services "Guidance to Surveyors; S&C 09-31" 2009; pg. 10.

¹⁹ Damianakis, T, et al. Volunteers' Experiences Visiting the Cognitively Impaired in Nursing Homes: A Friendly Visiting Program. *Canadian Journal on Aging*. 2007: 26: 343-356.

on the quality of care residents receive²⁰. Furthermore, nursing staff commitment to remain in their jobs has been shown to increase residents' satisfaction with their staff relationships and their QoL. By finding ways to encourage health care professionals and direct care workers to make a long-term commitment to providing care in a given nursing facility, quality of care will improve as well as QoL²¹.

Limitations

Because of the challenge and time commitment associated with interviewing people who have substantial cognitive limitations, residents with a Cognitive Performance Scale score of 4 or more were not included in this study. Their perceptions may or may not be different from those of the individuals interviewed.

Residents who chose to participate in the survey were on average younger than the resident population eligible for the study (53 versus 65); this renders the results less generalizable.

One concern regarding the answers obtained is that they may have been given out of fear. Though this is an issue to consider, over 85% of respondents indicated that they could express opinions without fear of consequences; thus, we assume that respondents did provide honest, truthful answers to the interviewers also.

Because this is the first QoL survey ever done in Detroit facilities, it is not possible to know how stable the findings are. It is also probable that across facilities, there are wide differences in resident perception that cannot be accounted for in a city-wide sample. Further, because the POSM instrument has been deployed only in Detroit, we cannot say whether these results are cause for celebration or concern. When additional data becomes available, comparisons between facilities and geographic areas will be undertaken.

An obvious limitation to this study in its current form is the lack of accompanying data from the MDS. Linking these data can be expected to improve our understanding of the interplay among functional, health, mental health, or demographic characteristics and QoL. This activity was outside the scope of work for the present study.

Conclusion

This survey was commissioned to discover what long-stay nursing facility residents in Detroit had to say about their QoL in nursing facilities. The fact that these results clearly contrast with other research findings on quality of care in urban facilities should serve as a reminder that quality, like beauty, has no one gold standard. Residents have provided a wealth of information that can serve as a change agenda for downstream DAAA quality initiatives, as well as action by facility resident councils, administrators, and advocates.

²⁰ Mor, V, et al. Drive to Tiers: Socioeconomic and Racial Disparities in Quality of Nursing Home Care. *Millbank Quarterly*. 2004;82:227-256.

²¹ Bishop, C, et al. Nursing Assistants' Job Commitment: Effect of Nursing Home Organizational Factors and Impact on Resident Well-Being. *The Gerontologist*. 2008; 48 (Special Issue I): 36-45.

These findings can also serve as a yardstick to measure the outcomes of future interventions aimed at improving specific aspects of QoL among nursing facility residents in Detroit.

It would seem then, that one of the recommendations for future action should be, “do more research.” Here lies a perplexing paradox: how to balance the need for scientific objectivity with the need to learn about the specific preferences of each person interviewed. Standard survey techniques employed here, such as using an unbiased third party as the interviewer, reading items as written without interpretation, employing a standard Likert scale response set, and guaranteeing respondent anonymity are prerequisites for ensuring objectivity and reliability of survey level QoL data. However, this scientific approach necessarily stifles any further conversation about specific issues important to a given individual, conversations that are at the very core of the person-centered planning approach.

What, then, is the utility of undertaking future QoL surveys? It seems unlikely that there is an unbiased way for nursing facility staff to administer an objective survey that also enables exploration of individual preferences. Thus, nursing facility administrators would do well to encourage ongoing conversations with individual residents about these issues and to take concrete action to address preferences and needs on an individualized basis. To gauge whether such efforts are successful, administrators also need to support a formal follow-up survey that will pass the scientific sniff test. Only if both these conditions are met can we achieve what the authors believe is the core mission of this quality of life research effort: to find out and to act on what would make life better for the individuals we have interviewed.