

Appendixes

The Characteristics of Nursing Home Residents with Dementia

At the start of this assessment, OTA looked for a large database on nursing home residents that might be used to determine what proportion have dementia, how nursing home residents with dementia differ from other residents, and whether residents with dementia require more staff time or cost more to care for than other residents. In 1984, the New York State Case Mix Reimbursement Project collected detailed information on 3,427 residents in 52 New York State nursing homes as a basis for a new Medicaid reimbursement system, RUG-II. OTA contracted with Rensselaer Polytechnic Institute for retrospective analysis of that data.

The nursing homes included in the study had been selected to be representative of nursing homes in New York State in terms of location, size, type of ownership, levels of care, and staffing. A 10-page questionnaire, the Patient Assessment Instrument (PAI), was used to collect information on resident characteristics. Relative resource use by different residents was determined on the basis of a time and motion study that measured the amount of time spent by staff with each resident during a 24-hour period.

The PAI recorded residents' diagnoses using ICD-9 codes—i.e., numbers assigned to specific diagnoses in an international coding system. There is no ICD-9 code for dementia. Rather, the dementia syndrome is associated with many different ICD-9 codes (see ch. 1). Analysis of the database using the ICD-9 codes most likely to indicate dementia showed that 41 percent of all nursing home residents had one or more diagnoses associated with dementia (including primary, secondary, and tertiary diagnoses).

In general, residents with one or more diagnoses associated with dementia had greater impairment in activities of daily living (ADLs) (eating, dressing, bathing, toileting, bladder control, bowel control, and personal hygiene) and behavior (wandering, verbal abuse, physical aggression, and regressive or inappropriate behavior) than residents with no such diagnoses. However, residents with diagnoses associated with dementia varied greatly in ADLs and the behavioral characteristics measured by the PAI. Some had no self-care deficits, for example.

OTA and Rensselaer assumed that part of the reason for this variation was differences in severity of

dementia; that is, residents with mild dementia were assumed to have different characteristics from those with severe dementia. Since the PAI does not include any measure of cognitive ability, severity of dementia cannot be ascertained directly from the data. However, a rough index of severity was constructed retrospectively by Rensselaer, in consultation with OTA. The five PAI items used to develop the index of severity are listed in table A-1, along with the resident descriptors and score values for each descriptor. A score value of 0 indicates that these descriptors are generally not characteristic of or specific to dementia. Higher score values are assumed to indicate increasing severity of dementia.

Residents were given a total score between 0 and 15 based on their scores on each of the five PAI items. Overall, 6 percent of residents with one or more diagnoses associated with dementia had a severity score of 0 (defined as "none"); 34 percent had scores between 1 and 5 (defined as "low"); 32 percent had scores between 6 and 10 (defined as "middle"); and 29 percent had scores between 11 and 15 (defined as "high").

Tables A-2 through A-11 show the proportion of residents with impairment in each of seven ADLs and four behavioral problem categories, according to whether they had any diagnoses associated with dementia and, if so, the severity of dementia. (Percentages have been rounded and may not total 100 percent.) The data demonstrate that as the severity of dementia increases (as measured by the index of severity), impairment in ADLs and behavioral problems also increase.

The New York State RUG-H system groups nursing home residents into 16 categories that differ in terms of clinical characteristics and use of resources. In general, residents with diagnoses associated with dementia were found in categories with higher disability more often than other residents. Further, residents with diagnoses associated with dementia had 5.6 percent greater resource use overall than other residents.

It should be noted, however, that these figures represent actual, not ideal resource use. In particular, residents with diagnoses associated with dementia were cared for in nursing homes that treat all kinds of patients, not special care facilities for persons with dementia. It is not known whether resource use is greater or less for dementia patients in special care facilities.

The index of severity used in this analysis is far from ideal for several reasons. First, it was developed retrospectively. Second, the five PAI items used to de-

velop it require a subjective judgment by the interviewer; no standard tests were used to derive the response given. Finally, many of the descriptors used to develop the index of severity could apply to some persons who do not have dementia.

These problems point to the need, emphasized throughout this report, to include measures of cognitive ability in surveys of elderly and long-term care populations. While the reliability and validity of such measures are far from perfect, they do address the central features in dementia and are therefore more likely to accurately reflect severity of dementia than measures of other patient characteristics.

Both Texas and Massachusetts are or will soon be collecting data on nursing home residents to develop State Medicaid reimbursement systems. In Texas, the Mini-Mental State Exam (MMSE) (see ch. 8) is being used to measure residents' cognitive abilities. It is not known whether a measure of cognitive abilities will be included in the Massachusetts study (1).

Appendix A References

1. Cornelius, E., project officer, Health Care Financing Administration, Baltimore, MD, personal communication, Nov. 10, 1986.

Table A-1.— Resident Descriptors Used To Develop the Index of Severity

Questionnaire item	Score value
<i>Expressive communication:</i>	
1. Speaks and is generally understood	0
2. Speaks, but is understood with difficulty	0
3. Uses only structured sign language, writing, or yes or no responses,	0
4. Uses only gestures, grunts, or primitive symbols to communicate. This includes a special cueing system developed with the patients (e.g., aphasiac)	1
5. Cannot convey needs (e.g., comatose)	2
6. Cannot determine	0
<i>Receptive communication/comprehension:</i>	
1. Generally understands oral communication	0
2. Has limited comprehension or oral communication; needs repetition or simplified explanations	1
3. Depends on lip reading, written material, or structured sign language	0
4. Understands only primitive gestures, facial expressions, simple pictograms, and/or recognizes environmental cues	2
5. Unable to understand or no indication by patient (e.g., comatose)	3
6. Cannot determine	0
<i>Learning ability:</i>	
1. Listens, retains, and comprehends directions or teaching instructions. Knows what to do and when.	0
2. Difficulties retaining or comprehending instructions. Needs clues or continuous reminding	1
3. Cannot comprehend and retain instructions. Must be shown every time.	2
4. Cannot comprehend and retain instructions, No instructions given	3
5. Cannot determine	0
<i>#motivation:</i>	
1. High—initiates activity, keeps appointments, willing to tolerate discomfort/pain to achieve goals	0
2. Moderate—will work toward goals but needs to external support and urging.	0
3. Minimal—passive, participates in activities when told to when it is required. Activities may be performed in a slow, mediocre or inaccurate fashion	1
4. Poor—resists activity, feels someone else should do everything	2
5. None—due to organic causes.	3
6. Cannot determine	0
<i>Refusal to care for oneself:</i>	
1. Performs routine activities (e.g., ADLs) to the extent physically capable	0
2. Performs routine activities (e.g., ADLs) but not to the extent physically capable. Activities are performed incompletely or are of mediocre quality.	0
3. Resists assistance by others in performing routine activities (e.g, ADLS), though needs assistance from others	0
4. Refuses to perform routine activities (e.g., ADLs), of which physically capable. Staff must perform the activities	0
5. Unable mentally to perform routine activities (e. g, ADLs) regardless of willingness.	4

SOURCE W J , Foley, "Dementia Among Nursing Home Patients Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U S Congress, Washington, DC, 1986

Table A-2.—Eating: Proportion of Nursing Home Residents by Eating Ability

Level of impairment	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Independent—generally feeds self without supervision or physical assistance. May use adaptive equipment.	29%	13%	61	26	3	1
2. Minimal supervision and/or physical assistance—requires intermittent verbal encouragement or guidance and/or physical assistance with minor parts of feeding, such as cutting food, buttering bread and opening milk carton, setting up equipment.	45	37	35	56	38	14
3. Continuous supervision—requires constant one-on-one guidance, teaching and encouragement. May occasionally need help with eating.	11	20	2	12	33	17
4. Hand-fed—totally fed by hand. This includes syringe feeding.	13	27	1	6	22	61
5. Tube or parenteral feeding.	3	3	—	—	3	7

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W. J. Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A.3.—Dressing: Proportion of Nursing Home Residents by Dressing Ability

Level of impairment	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Independent—uses no supervision or physical assistance. This includes obtaining clothes and managing buttons, socks and shoes.	18%	6%	38%	10%	10%	—
2. Minimal supervision and/or physical assistance—a person does not have to be constantly present to insure the patient dresses self. May need verbal directing and motivating for the proper arrangement and retrieval of clothing or speed in dressing, and/or putting on artificial limb.	21	11	35	24	1	—
3. Continuous supervision—requires a person to be present to guide, teach, and motivate patient during the entire task, (e.g., needs physical assistance with difficult parts of dressing, such as fasteners).	7	6	11	14	4	—
4. Continuous physical assistance—patient participates in task, but needs constant help with major parts of dressing (e.g., putting blouse/shirt over shoulders).	15	12	10	22	10	2
5. Total assistance—has to be completely dressed by another person; resident does not participate.	35	61	6	30	81	87
6. Patient generally wears a bed gown (60% or more of the time).	4	4	—	1	4	11

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W.J., Foley, "Dementia Among Nursing Home Patients Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-4.—Bathing: Proportion of Nursing Home Residents by Bathing Ability

Level of impairment	One or more dementia diagnoses					
	No dementia diagnosis	All levels of severity	None	Low	Middle	High
1. Independent—requires no supervision or support. May use special equipment and water may be drawn for the patient.	3%	1%	7%	1%	—	—
2. Minimal supervision and/or physical assistance—requires intermittent checking and observing. May require physical assistance for minor parts of the task, transferring in and out of bath and bathing back.	23	9	45	18	1	—
3. Continuous supervision—requires constant one-on-one observation, motivation and aidance.	9	6	16	12	3	—
4. Continuous physical assistance—patient participates but requires constant help with most parts of bathing.	21	14	20	29	9	1
5. Total assistance—patient does not participate. Patient is bathed in bath, shower, or bed by another person.	44	70	12	41	87	99

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W.J., Foley, "Dementia Among Nursing Home Patients" Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-5.—Toileting: Proportion of Nursing Home Residents by Toileting Ability

Level of impairment	One or more dementia diagnoses					
	No dementia diagnosis	All levels of severity	None	Low	Middle	High
1. Independent—can toilet self without supervision or physical assistance. May require special equipment, such as a raised toilet or grab bars.	34%	18%	73%	36%	5%	—
2. Minimal supervision and/or physical assistance—requires intermittent observing and guidance for safety or encouragement reasons, May require physical assistance for minor parts of task, such as clothes adjustment and washing hands.	13	8	15	16	5	1
3. Continuous supervision—requires constant one-to-one guidance and teaching.	2	2	1	3	2	—
4. Continuous physical assistance—patient participates but requires constant help with major parts of the task or task will not be completed (e.g., maintaining balance, transferring, wiping and cleaning).	13	10	6	15	13	1
5. Total assistance—patient does not participate at all; another person assists with all aspects of toileting procedures.	10	12	2	7	18	12
6. Incontinent—taken to toilet on a regular scheduled basis,	16	26	2	16	34	35
7. Incontinent—does not use the toilet	13	25	—	8	23	52

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W.J., Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-6.—Bladder Control: Proportion of Nursing Home Residents by Bladder Control Ability

Level of impairment	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Continent—full control or rarely incontinent (i.e., less than once per week).	50%	24%	83%	47%	10%	1%
2. Occasionally incontinent—lacks bladder control at night and/or 1-3 times per week during the daytime.	11	10	12	17	10	3
3. Frequently or totally incontinent—4 or more times per week during the daytime.	29	58	5	32	74	81
4. Indwelling catheter—self care, no assistance needed.	—	—	—	—	—	1
5. Indwelling catheter—not self care, needs assistance.	7	7	—	3	6	14
6. External (or intermittent) catheter.	2	1	—	2	1	1

NOTE Because of rounding, figures may not add to 100%.

SOURCE W J , Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-11 Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-7.— Bowel Control: Proportion of Nursing Home Residents by Bowel Control Ability

Level of impairment	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Continent—full control or rarely incontinent (i.e., less than once per week).	59%	30%	90%	58%	14%	2
2. Occasionally incontinent—one time or less per week loses control. Is generally aware of the urge to move bowels and maintain control	11	12	4	13	18	5
3. Frequently or totally incontinent—two or more times per week loses. Is generally unaware of urge to move bowels,	29	57	2	28	67	92
4. Ostomy—self care, no assistance needed.	—	—	1	—	—	—
5. Ostomy—not self care, assistance needed.	1	1	2	1	1	1

NOTE Because of rounding, figures may not add to 100%.

SOURCE W J , Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-8.—Personal Hygiene: Proportion of Nursing Home Residents by Personal Hygiene Skills

Level of impairment	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Independent—generally responsible for and receives no supervision or assistance with personal grooming.	18%	4%	28%	6%	—	—
2. Minimal supervision and/or physical assistance—requires intermittent verbal cueing or observation; and/or requires assistance with difficult parts of grooming.	24	12	54	26	1	—
3. Requires constant one-on-one observation, guidance and encouragement with all or most of personal grooming.	7	7	6	16	4	—
4. Continuous assistance—participates in personal grooming but needs constant physical assistance to complete grooming adequately or at all.	16	12	9	24	11	1
5. Total assistance—does not participate; another person performs all or most aspects of personal hygiene.	35	65	4	29	83	100

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W J , Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-9.—Wandering: Proportion of Nursing Home Residents Who Wander

Extent of wandering behavior	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Does not wander.	95%	84%	95%	83%	77%	89%
2. Wanders with no clear direction in usual environment. May wander into another resident's room.	3	11	4	11	15	8
3. Unless supervised or restrained, wanders throughout the facility. Can find way back.	1	2	—	2	2	1
4. Takes every opportunity to wander away from unit. Cannot find way back.	1	3	—	2	5	2
5. Unless supervised or restrained, wanders outside the facility with no clear direction.	0	1	1	1	1	1

NOTE: Because of rounding, figures may not add to 1000/.

SOURCE: W. J., Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1985.

Table A-10.-Verbal Abuse: Proportion of Nursing Home Residents Who Are Verbally Abusive

Extent of verbal abuse	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. No verbal abuse or disruption.	73%	57%	76%	53%	50%	66%
2. Occasional verbal abuse or disruption (i.e., three times or less per month).	11	11	12	15	11	6
3. Predictable verbal disruption during specific care routines only (e.g., bathing). Four or more times per month.	7	13	6	14	14	11
4. Short-lived verbal disruption during the day and/or night for no appropriate reason (e.g., not just during care routines). Four or more times per month.	3	5	—	6	6	3
5. Recurring verbal disruption during the day and/or night for no appropriate reason. At least four times per month, but not daily.	3	6	4	5	7	6
6. Daily recurring verbal disruption during the day and/or night for no appropriate reason.	3	9	2	7	12	9

NOTE: Because of rounding, figures may not add to 100%.

SOURCE: W. J., Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-11.—Physical Aggression: Proportion of Nursing Home Residents Who Exhibit Physical Aggression

Extent of physical aggression	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. No physical aggression.	87%	68%	96%	72%	61%	65%
2. Occasional minor physical aggression (i.e., three times or less per month). Minor aggression refers to physical acts that cannot cause potential physical injury to self or others, but are disruptive).	5	9	2	10	10	9
3. Predictable physical aggression during specific care routines only (e.g., bathing) or as a reaction to normal stimuli (e.g., bumped into). May strike or fight.	5	15	1	11	19	19
4. Occasional extreme physical aggression (i.e., three times or less per month) to the point of potential physical injury to self or others (e.g., throws or pokes with sharp objects).	1	2	—	3	2	1
5. Recurring aggression for no rational reason (e.g., not just during specific care routines). At least four times per month, but not daily.	1	4	—	4	5	4
6. Daily recurring aggression for no rational reason (e.g., not just during specific care routines or reaction to normal stimuli).	1	3	—	2	3	3

NOTE: Because of rounding, figures may not add to 1000/.

SOURCE" W. J., Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.

Table A-12.—Regressive or Inappropriate Behavior: Proportion of Nursing Home Residents Who Exhibit Regressive or Inappropriate Behavior

Extent of regressive or inappropriate behavior	No dementia diagnosis	One or more dementia diagnoses				
		All levels of severity	None	Low	Middle	High
1. Does not exhibit regressive or inappropriate behavior.	76%	51 %	92%	60%	42%	41%
2. Exhibits nondisruptive regressive behavior, such as rocking.	14	23	5	18	28	28
3. Occasionally (i.e., three times or less per month) exhibits inappropriate behavior (e.g., smears feces, throws food, makes sexual advances).	5	7	—	7	9	8
4. Frequently (i.e., four times or more per month, not daily) exhibits disruptive and inappropriate behavior, such as frequently dressing and undressing self, smearing feces, throwing food, stealing, sexually displaying oneself to others.	3	9	2	9	10	9
5. Daily exhibits disruptive and inappropriate behavior.	3	10	1	7	12	15

NOTE: Because of rounding, figures may not add to 1000/.

SOURCE" W J , Foley, "Dementia Among Nursing Home Patients: Defining the Condition, Characteristics of the Demented, and Dementia on the RUG-II Classification System," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1986.