

Nursing Homes

Law Reviews
FURBA 87⁹

Brookings - Persons w/ Disabilities, Dec. 13 1995

Peter Leibold, CHA

HCFA Report

★ Quality of Care in Teaching Nursing Homes: Findings and Implications

Peter Shaughnessy, Ph.D. Andrea Kramer, David Hille,
John Steiner

★ Development & Testing of Nursing Home Quality Indicators
Zimmerman, Karen, Arling Clark, Collins, Ross, 1988

NextCard	2.9% APR	VISA	MEDIA KIT	FORTUNE 5 HUNDRED
TIME	Search	GO		

TIME NATION/TIME SPECIAL INVESTIGATION OCTOBER 27, 1997 VOL. 150 NO. 17

FATAL NEGLECT

IN POSSIBLY THOUSANDS OF CASES, NURSING-HOME RESIDENTS ARE DYING FROM A LACK OF FOOD AND WATER AND THE MOST BASIC LEVEL OF HYGIENE

BY MARK THOMPSON

Once she moved into Creekside Care Convalescent Hospital, it didn't take Bessie Seday long to realize that the promises made to her by the nursing home before she arrived had evaporated. "I couldn't get anybody's attention, starting on the fourth day," recalls the bed-bound 84-year-old. "You'd have your call light on for hours, but nobody came." What made her waiting more desolate was the near total deprivation of sunlight during her four months at Creekside. "It was a dungeon," she says. "I really would have liked to see the sunshine, but they never put us outside." Things only got worse when the sun set, and the staff ignored calls for help or pain-killers. "The screaming is what got to me the worst, the screaming when the lights went out," she says. "I couldn't fall asleep until 1 or 2 in the morning with all that screaming going on."

Jeffery Aaronson-- Network Aspen for TIME



Elder Care: At many nursing homes the treatment is neglect

Bessie's daughter Ann used to visit her mother in the home, some 50 miles northeast of San Francisco, and find her lying immobile in a filthy bed. "She was not turned and kept clean and dry, which led to the bedsores," Ann recalls. A bedsore on Bessie's left hip turned into a gaping wound that would not heal, despite repeated whirlpool baths. Creekside nurse Patricia Lloyd knew why: the special washing machine for cleaning dirty bedpans had broken down. "So we washed bedpans in the whirlpool," she says, "and then we'd put patients with big bedsores, like Bessie Seday, in there." Fixing Bessie's wound required repeated surgery, including the removal of her left buttock and part of her pelvis. "They were washing her," says Lesley Clement, her attorney, "in a damn cesspool."

Mark Richards-- Contact for TIME



GUMSHOES: Investigators Von Packard and Dina Rasor behind the stack of death certificates that mobilized the feds

Bessie, who now lives with her daughter, was lucky to get out alive. A TIME investigation has found that senior citizens in nursing homes are at far greater risk of death from neglect than their loved ones imagine. Owing to the work of lawyers, investigators and politicians who have begun examining the causes of thousands of nursing-home deaths across the U.S., the grim details are emerging of an extensive, blood-chilling and for-profit pattern of neglect. In Chicago last week a 73-count indictment was returned against a hospice operator charged with bilking Medicare and others of \$28 million for services to

the terminally ill that were never delivered. In Detroit a nursing home that was part of a chain whose owner was convicted of Medicaid fraud 17 years ago was cited again last year for bad hygiene, inattention to frail residents and incompetent staff. In Texas attorney general Dan Morales has filed 50 lawsuits against nursing homes this year for neglect and failure to medicate.

In California a team of lawyers specializing in fraud has begun to investigate what's killing people in the state's 1,400 nursing homes. In Washington, Senator Charles Grassley of Iowa, chairman of the Senate's Special Committee on Aging, last week dispatched three investigators from the General Accounting Office to California to pore over data, confer with state officials and visit suspect nursing homes. One of their first stops was Creekside (now operating as Vacaville Rehabilitation and Care Center), which denied the investigators access to medical records--until they returned with a subpoena. Grassley calls the California data "troubling" and says the situation "requires immediate attention."

Palo Alto attorney Von Packard has studied the death certificates of all Californians who died in nursing homes from 1986 through 1993. More than 7% of them succumbed, at least in part, to utter neglect--lack of food or water, untreated bedsores or other generally preventable ailments. If the rest of America's 1.6 million nursing-home residents are dying of questionable causes at the same rate as in California, it means that every year about 35,000 Americans are dying prematurely, or in unnecessary pain, or both. The investigations bear out something many Americans have suspected all along: in a recent survey published in the Journal of the American Geriatrics Society, 30% of those polled said they would rather perish than live in a nursing home. Packard, who has spent nearly two years tracking the data, says, "We believe thousands would have lived significantly longer had they been taken care of."



Neglectful caregivers are preying not only on elderly residents but also on American taxpayers. More than \$45 billion in government funds, mostly from Medicare and Medicaid, is pumped into nursing homes annually, an amount that comes to nearly 60% of the national tab for such eldercare. In order to pocket a larger slice of the federal stipend, many nursing homes--largely for-profit enterprises--provide a minimal level of care, if that.

Mark Richards-- Contact for TIME



NIGHTMARE: Seday's four months in Creekside Care Convalescent Hospital included screams at night, no sunlight by day

Packard and his investigators, referred to as "hearse chasers" by some in the nursing-home trade, have begun contacting relatives of deceased patients whose California death certificates cite malnutrition, dehydration and other signs of neglect. They're often shocked to learn what killed their loved ones. "They don't know their parents died of malnutrition," says Dina Rasor, an investigator working for Packard, "until we tell them." Even more telling, the causes of death on California death certificates are often listed by doctors affiliated with the nursing home involved, suggesting that Packard's list may well understate the number of deaths in which neglect played a role. Packard and his investigators are gathering death certificates for five more states, which they decline to name.

Death comes to the elderly in many ways, including heart and lung failure, chronic disease and plain bad luck. But David Hoffman, an assistant U.S. attorney in Philadelphia, thought he spied something else at work last year, when he saw festering bedsores eating away the flesh of three residents in a local nursing home. He knew the home had been pocketing government money the residents were given to ensure good care, and he saw the bedsores as proof that they weren't getting it. He investigated and later sued Geriatric and Medical Companies Inc., which operated the Tucker House nursing home. The nursing-home company settled the case for \$600,000, sent condolences to the families of the three residents and--perhaps most important--set off probes by law firms around the country seeking similar evidence of poor care and the resulting fraud. Their plan: to present evidence of widespread fraud to the Justice Department in the hope that the government will take the lead in the case and share in any damages awarded.

The idea of using death certificates to try to prove fraud was born at the Creekside facility. Shortly after Rhoda Johnson moved into Room 52 of the nursing home in 1992, her daughter Ila Swan became concerned about her care. Swan, a 57-year-old former telephone worker, says her anxiety grew when she saw a woman in Room 51, across the hall, try to climb out of bed after her calls for a nurse went unanswered for an hour. According to the woman's roommate, as the woman struggled to get out of the bed, she toppled and struck her head on the tile floor. She lay there for 20 minutes, her cries for help going unanswered by the staff as a pool of blood grew around her. She died a short time later. Swan visited the county records office to review the woman's death certificate and those of others who had died while residing at Creekside and other nearby nursing homes. She was startled to find 10 questionable causes of death listed on the first 30 she reviewed. "They'd listed malnutrition, dehydration, bedsores and urinary-tract infections as causes of death," Swan says.

"These nursing homes were killing people."

Soon Razor and investigator Robert Bauman heard of Swan's work. Intrigued, they began working with Packard to obtain records listing the cause and place of death for every Californian who died from 1986 to 1993. More than 300,000 had died in nursing homes.

What happened next surprised Razor and Bauman most. Nearly 22,000 of the nursing-home deaths were attributed to lack of food or water, infections or internal obstructions--all preventable, at least in theory. Packard and his investigators didn't add deaths to their list if the deceased suffered from other ailments that exacerbated those four causes. So people who died of both cancer and malnutrition, for example, were not counted.

7.3%

Many nursing homes have become dangerous places largely because they are understaffed--and underregulated. The Federal Government doesn't dictate staffing levels, and state efforts at regulating quality are meager. With 2 of every 3 dollars spent by nursing homes going to payrolls, the most tempting way to increase profits is to cut personnel.

Generally, the nursing-home industry likes to settle lawsuits quietly and often hands over money only in exchange for silence. But that didn't happen at Creekside, where lawsuits alleging neglect have recently been getting into the public record. Four former residents of Creekside have won more than \$2 million in settlements after alleging poor care. An additional four suits are pending. In fact, Packard's California death list contains the names of dozens of people who died there.

Creekside, which opened in 1989, is a handsome place, its fieldstone-walled foyer graced by a big aquarium. Its brochure boasted of private patios and a recreation director who "understands the subtle limitations of age." It promised "all the comforts of home" plus "state-of-the-art nursing equipment" for its 120 residents.

Court records and interviews tell a different story. "The whole place was a fiasco," says nurse Patricia Lloyd, who moved away from California after she testified against Creekside, where she had worked for four years, until 1995. "Everybody was sick; everybody was having problems." Did such care lead to premature deaths among Creekside residents? "Absolutely," Lloyd says firmly and quickly. "I'm 100% sure. People would come in, they'd get depressed, stop eating and start falling. Then they'd get tied down to a chair, and they'd rapidly decline and die. That was something that was pretty common at Creekside."

Feeding was always a problem, says Suzanne Cologgi, a former Creekside nurse's aide. "The staff would give up really quickly, so the patient wouldn't get enough food," Cologgi says. "Because there wasn't enough staff, a lot of people went without eating or sat in dirty diapers." Many times Cologgi would have 20 minutes to feed seven residents, all of whom depended on her to spoon every bit of food into their mouth. "Sometimes you'd need 30 minutes for one," she recalls. "Full trays would go back untouched."

Patients who ate poorly were supposed to get 240-calorie liquid supplements to help them gain weight. "We didn't even pass them out, even though we signed [forms indicating] that they got them," Lloyd says. "Sometimes, patients who could talk would ask for them, and get them, but the patients who couldn't talk didn't--and they were the ones who

really needed them." Medical charts, Lloyd says, were routinely falsified.

State inspectors told similar tales in their regular reports on Creekside. In early 1993 restraints were being used on 62 of 112 Creekside residents, some without consent. The family of a severely impaired woman at Creekside in 1992 had chosen a relative to make decisions regarding her care. Yet a state inspector found that the patient herself had signed consent forms allowing tranquilizers and physical restraints to be used on her. Such drugs were administered for "purposes of discipline or convenience" of Creekside's staff, a state report said.

There were pitiful examples of Creekside residents not getting enough to eat. A female resident sat in the dining room picking occasionally at her food for 25 minutes but didn't eat. Another resident complained that his food card--which specified that he disliked broccoli--was routinely ignored. "We don't look at the cards," a kitchen worker told him. A state inspection came upon a Dickensian scene: Creekside's cook violating federal regulations by adding water to pureed meat. "We usually use water," she said, "to thin the pureed meat." During another inspection, of nine residents supposedly playing a game, seven were doing nothing, one was participating, and "one resident was eating Play-Doh." In February 1993 inspectors found up to 35 residents parked in wheelchairs in common areas of the nursing home "for long periods of time (i.e., four hours or more) with no apparent meaningful activities."

When the laundry room's hot-water heater broke for a week, the staff washed bedding in cold water, which failed to do the job. Bedding and gowns "have yellow or brown stains and/or urine or fecal odors," the state reported. Towels were so rare that nurse's aides would wet and soap one end to wash residents and use the other half to dry them. Sheets were used for diapers.

Creekside attorney James Geary says Creekside was unexceptional. "It was probably no better, and no worse," he says, "than any other nursing home." Except that Creekside is paying for its lack of care. Bessie Seday, for example, collected a \$862,500 settlement last December stemming from the infected bedsores she contracted while living at Creekside.

Rhoda Johnson, Ila Swan's mother, lived at Creekside nearly two years, until July 1993. Her family alleged in a lawsuit that the nursing home essentially abandoned Johnson: she was often left lying in her own waste, hungry, cold, unfed and unturned. One day she complained to Swan that her hip hurt. With her sons' help, Swan lifted her mother out of the bed, pulled up her nightgown and collapsed in sobs. "She had this bedsore on her hip that was so deep," her daughter recalls, "that I could see the hip socket and leg bone moving inside the hole." Her bottom was bruised and caked with dried feces, which Swan peeled off with her fingers amid her tears. "I never had looked under the covers," she says. "I didn't think I had to." Johnson, now 98 and living in a Utah nursing home, doesn't talk much about her experience. "Creekside was mean to me," she says. "They didn't give me a drink, they yelled at me, they hurt me." She received a \$775,000 settlement in May 1996.

Creekside owner Richard Schachten, who trained and spent his early years as an undertaker, disputes any suggestion that neglect was endemic. "The quality of care was very good," says Schachten, who sold the business in 1995. "I have not paid one dime in fines, there's never been an admission of guilt, and the facility's license was never revoked or

suspended."

Implicit in Schachten's defense is the presumption that the government keeps a keen eye on nursing homes. A decade ago, Congress passed a major nursing-home reform bill, which did help to cut down on the use of physical restraints and tranquilizers. But in 1995 a quarter of the nation's nursing homes failed even to assess each patient's needs or develop individual care plans, federal records show. Even more failed to ensure sanitary food, and about 1 in 5 didn't provide proper treatment for bedsores.

That year the Federal Government got the power to punish nursing homes in ways other than denying them federal funds. The government can now levy fines, deny payments for new patients to nursing homes and mandate training for their staffs. Yet the government seems mighty miserly when it comes to holding nursing homes accountable.

In the past year nearly 10,000 of the 15,000 nursing homes inspected by the states had violations, and many were forwarded to federal officials with proposed punishments. But fines or other penalties were imposed in only 2% of the cases. State inspectors recommended to U.S. authorities that 5,458 nursing homes--1 in every 3--be barred from collecting money for new patients. Washington cut that figure to 156. The states urged Washington to order special training for the staffs in 3,039 nursing homes; Washington ordered such training for only 103. And state inspectors urged Washington to fine 2,935 nursing homes for violations. The Federal Government fined only 228 (and those that paid without appealing had to pay only 65% of the fine).

Officials of the Health Care Financing Administration, a section of the Department of Health and Human Services that enforces federal nursing-home rules, were unable to justify to TIME the gap between recommended penalties and those that were ultimately exacted. The officials say nursing homes "have a right" to correct problems before penalties are imposed. But a former government inspector disagrees. "Congress said to impose these penalties, and they're not," says Charles Bailey, a lawyer who left the HCFA this year after spending nearly seven years trying to punish bad nursing homes.

California fined nursing homes \$2.4 million last year but has collected only \$500,000 (the state gives nursing homes a 50% discount on fines that are not appealed).

And then there are the maggots. In 1994 a nurse at the Fairfield Health Care Center in Fairfield, Calif., found about 40 maggots in a bedsore on the left heel of an 87-year-old man. State inspectors recommended a \$24,000 fine, but the nursing home appealed, saying the wriggling larvae didn't constitute evidence of poor care. Besides, the nursing home argued, maggots are good for eating away dead tissue inside a wound. The state hearing officer agreed with the nursing home and threw out the fine.

Brenda Klutz, deputy director of licensing for California's health department, calls that decision "very distressing and emotional," but she doesn't call it wrong. In fact, she echoes the nursing home's argument. "In an era of alternative medicine, maggots are being used for debridement of dead tissue," she says. "The fact that these sorts of eggs and maggots can hatch in a 24-hour period may not even mean that there was improper wound care." With regulators like that, the elderly in nursing homes may

have more to fear than either the maggots or the nursing-home operators.

--With reporting by James L. Graff /Chicago and S.C. Gwynne /Austin

[BOX]

How to CHOOSE a Nursing Home That Actually Cares

Making the decision to move a parent into a nursing home is painful. Finding the right place can be just as trying. Here are some tips to help guide you.

--Consult the state's survey of inspections. Each state conducts inspections about once a year and issues a survey of its findings that should be available at all nursing homes. Even a good home may be cited for deficiencies, but they should be minor and promptly fixed. Bad signs: problems affecting residents' health, or an inability to produce the most recent surveys.

Federal law requires each state to have an ombudsman's office with information on all nursing homes. To contact your ombudsman, call the National Citizens' Coalition for Nursing Home Reform in Washington at (202) 332-2275.

--Make an unannounced visit to prospective nursing homes. Look, listen--and smell. Wander hallways, speak to residents and staff, get a sense if both enjoy being there. A nursing home that won't let you visit unannounced may well have something to hide. Look for clean, well-groomed residents. Discreetly try to assess oral hygiene. Listen for the staff's tone in dealing with residents. Make sure that nurses and aides mingle with residents and don't view their charges as widgets on an assembly line. While most nursing homes occasionally smell of urine and feces, there should be no persistent stench or overwhelming scent of air fresheners.

--Keep your eyes open. Watch the call lights that residents use to summon help. See how long it takes for help to arrive; more than five minutes is too long. Look for obstacles or puddles left in corridors that could endanger frail residents with failing vision. Visit during a meal: assess the food, and check that those who can't feed themselves are helped. Keep your eyes peeled for residents in restraints; the more you see the more leery you should be.

--Once you've picked a home, visit frequently. Residents with an attentive family and regular visits tend to receive better treatment than those who are essentially abandoned. --M.T.

time-webmaster@pathfinder.com

Good Info on OBRA 87 enforcement implementation

HCFA	Medicare	Medicaid	Help	Feedback	Search	FAQs
------	----------	----------	------	----------	--------	------

implementation

Report on Peer Review Organizations (PRO)

Over the last several years, HCFA has re-engineered the PRO program to better meet the goal of improving the health status of Medicare beneficiaries. The focus of the PRO program has shifted from a balance between utilization review, DRG validation and quality of care review (including beneficiary complaints) to almost total immersion in quality improvement projects through the Health Care Quality Improvement Program (HCQIP). This shift is in line with the Agency's strategic goal of improving the health status of Medicare beneficiaries by promoting the delivery of high quality, effective and efficient health services.

The HCQIP relies on provider-based quality improvement, a data-driven external monitoring system based on quality indicators, and sharing of comparative data and best practices with providers to stimulate improvement. PROs conduct a wide variety of quality improvement projects that focus on important clinical and non-clinical topics that have the potential to improve care provided to many Medicare beneficiaries. The scopes of these projects vary in size depending on the study purpose and design. For example, there are "national" projects, such as the Cooperative Cardiovascular Project, focusing on improving care provided to Medicare patients suffering heart attacks, which involve most of the hospitals in the country that treat Medicare patients. Individual PROs also design and structure "local" projects in which they involve work collaboratively with specific providers and managed care plans in their areas. Working together as partners, the PROs and providers/plans utilize Continuous Quality Improvement techniques to measurably improve processes and outcomes of care rather than relying on the prior system of medical record review which sought to identify individual instances of poor quality of care, followed by the sanctioning of poor performers.

Under Federal budget rules, the PRO program is defined as "mandatory" rather than "discretionary" because, like Medicare benefits, PRO costs are financed directly from the trust funds and are not subject to the annual appropriations process. PRO Trust Fund outlays in Fiscal Year (FY) 1996 totaled 190 million dollars which is the same amount that was spent in 1995.

In FY 1996, HCFA administered 53 PRO contracts, one per State, the District of Columbia, the Virgin Islands, and Puerto Rico. Four contracts were competed and awarded in FY 1996. Of the remaining 49 contracts, 48 were noncompetitively renewed and one was extended while a potential conflict of interest was resolved. Each contract is reimbursed through a cost plus fixed fee type contract.

Survey and Certification of Medicare and Medicaid Facilities

The Survey and Certification program is designed to ensure that providers and suppliers comply with Federal health, safety, and program standards. HCFA administers agreements with State survey agencies to conduct onsite facility inspections to certify facilities for participation in the Medicare and Medicaid programs. Only certified providers and suppliers are eligible to receive Medicare payments or payments from the Medicaid program that is funded through the Medicaid appropriation. A companion Medicaid State certification program is funded through the Medicaid appropriation. In FY 1996, State surveyors conducted 24,092 facility inspections (including 17,227 in nursing homes) and cited 19,460 facilities for deficiencies. Currently there are more than 57,000 certified facilities.

Nursing Home Compliance and Enforcement

Nursing home reforms, mandated by the Omnibus Budget Reconciliation Act of 1987

(OBRA 87) and implemented in 1990, significantly elevated standards for nursing home care. Among the provisions implemented in 1990 are requirements for higher standards of care for residents, improvements in the quality of residents' daily lives, more beneficiary focused/outcome oriented

improvements in the quality of residents' daily lives, more beneficiary focused/outcome oriented surveys, and better training of nurse aides. The enforcement aspects of OBRA 87, implemented in 1995, define alternative sanctions for nursing homes that do not meet the revised standards.

In July of 1995, HCFA implemented the enforcement portion of OBRA 87 nursing home reforms. This regulation, which identifies alternative sanctions, was the most controversial portion of the reforms and was implemented only after lengthy consultation with all parties involved in nursing home reform. Prior to the implementation of the 1987 enforcement legislation, the only adverse actions available for HCFA and the States to impose against nursing homes that were out of compliance with the requirements were termination of the provider agreement, denial of participation for prospective providers, and denial of payment for new admissions. The revised enforcement procedures provide HCFA and the States with a variety of remedies to encourage prompt compliance from providers that do not meet the OBRA requirements. These remedies were developed as intermediate or alternative steps that HCFA or the State could implement prior to (and possibly in lieu of) termination of the nursing home from the Medicare and/or Medicaid programs.

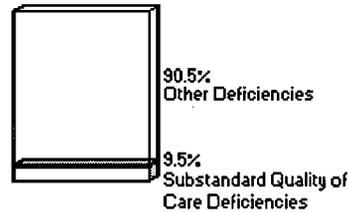
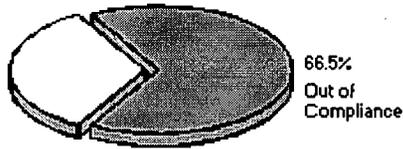
Consistent with OBRA '87, ten alternatives to termination were described in regulation and accompanied by guidelines for their imposition. In addition to termination of the provider agreement, the following remedies were identified:

- State monitoring
- Directed plan of correction
- Temporary management
- Denial of payment for new admissions
- Denial of payment for all admissions
- Directed inservice training
- Civil money penalties
- HCFA approved alternative State remedies
- Transfer of residents with closure of the facility
- Transfer only of Medicaid and Medicare residents

Compliance Data for Nursing Homes

July 1, 1995 to June 30, 1996

Substantial Compliance
33.5%

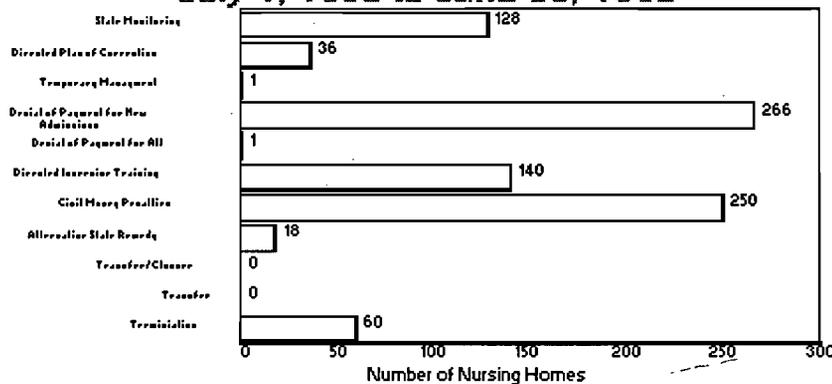


~~2/3~~ 2/3 out of 3
10% really bad

During the first year of implementation of the OBRA '87 enforcement provisions, 17,227 standard surveys of nursing homes were conducted by the State survey agencies. Of these surveys, 66.5 percent found situations which were out of compliance with the requirements. Nationally, 9.5 percent of the surveys cited deficiencies that constitute substandard quality of care, i.e., deficient practice(s) of a higher level acuity under the regulatory requirements covering quality of care, quality of life, and resident behavior and facility practices. The majority of the noncompliant surveys (98.9 percent) allowed the nursing home an opportunity to correct deficiencies prior to the imposition of remedies if an acceptable Plan of Correction (PoC) was provided by the facility. An acceptable PoC must state how the corrective action will be accomplished for those residents affected by the deficient practice, how the facility will identify other residents having the potential to be affected by the same deficient practice, what measures or systemic changes will be implemented to ensure the deficient practice will not recur, and how the facility will monitor the corrective action and its continued effectiveness. The remaining noncompliant facilities (1.1 percent) were subjected to immediate remedies based upon deficiencies which constituted immediate jeopardy to the health and safety of the residents, and/or were nursing homes considered as poor performing facilities based upon current survey results and previous survey history. Subsequent reevaluation of the noncompliant nursing homes, conducted mostly by revisits to the facilities, determined that 61.9 percent of the resurveys constituted substantial compliance. Consequently, of the total standard surveys conducted, approximately 88 percent were in substantial compliance as of the original survey or the first revisit.

Imposed Remedies

July 1, 1995 to June 30, 1996



Overall, 899 remedies were imposed in 591 nursing homes (.03 percent). With the exception of transfer and transfer with facility closure, all remedies were utilized. Denial of payment for new admissions and

termination continue to be statutorily mandated remedies under the new enforcement procedures when a provider remains out of compliance for 3 months or 6 months, respectively. Of the remedies available, 266 denials of payment for new admissions were imposed and 60 providers were terminated during the first year of implementation of the new enforcement procedures for nursing homes.



[Return to Table of Contents](#)

OR



[Go to next page](#)

Last Updated 06/09/97

	Medicare	Medicaid	Help	Feedback	Search	FAQs
---	--------------------------	--------------------------	----------------------	--------------------------	------------------------	----------------------

Center for the Study of Aging

RAND

Labor and Population Program

Research Brief

RAND Study

May 1996

Government Policy and the Cost and Quality of Nursing Homes

The long-term convalescent health-care industry in the United States faces three well-documented problems: (1) many indigent patients cannot gain access to nursing homes; (2) the quality of nursing home care is often suspect; and (3) the cost of this care is considerable and continues to increase at a worrisome pace.

The Medicaid program, which helps indigent patients gain access to nursing home care by directly reimbursing the homes, is the dominant purchaser of nursing home services in the United States.^[1] Nursing home administrators argue that the Medicaid program can induce them to admit more Medicaid patients and provide higher quality if the program pays a higher rate of return on Medicaid patient care. RAND investigated this issue and found that increasing the rate of return on Medicaid patients would induce nursing homes to admit more Medicaid patients, but it would not induce them to increase quality.

Regulation and Nursing Home Behavior

The business of nursing homes is to provide patients with a package of commodities such as medical care, room and board, and social activities. Some of these services are devoted to rehabilitation and others toward lifestyle maintenance. Together these components constitute the quality of care provided to patients.

Nursing homes care for two types of patients: those who finance their care privately and those whose care is paid for through the Medicaid program. However, the sum of private-pay and Medicaid patients cannot exceed a level determined by regulation. A nursing home's capacity is regulated by the Certificate of Need (CON) cost-containment program. The program attempts to control total industry expenditures by limiting the supply of nursing home beds. CON requires that before an existing home can be expanded or a new one built, the government must certify that the proposed facility is indeed "needed." Thus the program effectively limits the capacity of existing nursing homes and new entries into the market.

It can be assumed that nursing homes provide private-pay and Medicaid patients with the same level of quality. This assumption follows from the legal restrictions that homes cannot discriminate in the provision of service based on source of payment, and that most nursing home services, such as nursing care, social services, and dietary services are jointly produced for both types of patients and exhibit economies of joint production. Thus, it is both legally and technically difficult to improve the level of services provided to private-pay patients without also improving them for Medicaid patients.

Homes charge private-pay patients what the market will bear; thus, private-pay demand is a function of price and quality. In contrast, homes receive a set Medicaid reimbursement rate for the care of Medicaid patients, and thus Medicaid demand depends only on quality, since Medicaid patients pay zero out-of-pocket expenses.

Because private-pay patients pay a positive price and nursing homes must supply the same level of quality to both types of patients, it can be assumed that quality must be above the minimum level at which Medicaid patients (who pay zero) prefer nursing home care to independent living. It follows, then, that there is considerable demand among Medicaid patients for nursing home care; and the study found that there are indeed long lists of Medicaid patients in hospitals waiting for nursing home openings. Most nursing homes operate well above 90 percent capacity; and in the New York State sample examined in this study, most homes had well over 95 percent capacity.^[2]

In sum, the Medicaid program has created a "secondary market" for nursing home care, and CON restricts supply so that there is excess Medicaid demand. Homes charge private-pay patients what the market will bear and receive the Medicaid reimbursement rate for the care of Medicaid patients. The homes use price and quality to maximize profits as they compete for private-pay patients, knowing that they can always fill excess capacity with Medicaid patients at the Medicaid reimbursement rate.

Effects of Policy Actions on Nursing Home Costs and Quality

The study team used econometric modeling to examine a sample of 455 nursing homes in New York State. Since higher quality is produced primarily through labor-intensive activities such as personal contact with patients by employees and highly personalized physical and psychological therapy, policies designed to improve quality are relatively expensive. The modeling showed, for example, that a policy that increases quality 1.3 percent will increase cost by 10 percent. In contrast, cost-containment policies can achieve large savings without producing a large deterioration in quality.

The researchers examined the effects of two critical policies in the nursing home industry: competition and the return allowed on Medicaid patients. With respect to competition, the appropriate market to analyze is the private-pay market, since homes do not compete for Medicaid patients. The analysis showed that increases in competition are associated with higher levels of quality, since this is the way that nursing homes seek to attract more private-pay patients. However, restricting competition would have the effect of reducing costs, because the homes would not have to provide expensive quality improvements to attract patients away from competitors. In sum, increasing competition to promote quality would lead to more costly care, while restricting competition achieves considerable savings without a large sacrifice in quality.

In examining the second policy question, whether the government could purchase increased access to nursing homes for the poor and higher quality as well, the researchers found that there is a quality-access trade-off. Increasing the rate of reimbursement for Medicaid patients would induce nursing homes to admit more Medicaid patients, but it would not lead to higher quality of care, because improving quality is very expensive and is targeted toward the private-pay market.

[1] Of the \$75 billion spent on nursing home care in 1994, approximately 65 percent was in the form of government expenditures (federal, state, and local), with Medicaid accounting for over 80 percent of the government's share.

[2] Homes cannot operate at 100 percent capacity for several reasons: (1) they must hold beds open a certain number of days for patients who have temporarily entered hospitals for treatment of acute illnesses; (2) there are always a few days between the discharge of a patient and the admission of a new patient; and (3) homes may hold beds open longer for preferred patients (e.g., a Jewish home may wait longer for a Jewish patient who must remain hospitalized a few days longer than a non-Jewish patient).

RAND research briefs summarize research that has been more fully documented elsewhere. This research brief describes work conducted in RAND's Labor and Population Program as part of the Center for the Study of Aging, and at the University of Colorado, Boulder, supported by a grant from the National Institute on Aging. The methodology and findings of this work are documented in Paul J. Gertler, "Subsidies, Quality, and the Regulation of Nursing Homes," *Journal of Public Economics*, Vol. 38, 1989, pp. 33-52, and in Paul J. Gertler and Donald M. Waldman, "Quality-Adjusted Cost Functions and Policy Evaluation in the Nursing Home Industry," *Journal of Political Economy*, Vol. 100, No. 6, 1992, pp. 1232-1256. Abstracts of RAND documents may be viewed on the World Wide Web. RAND is a nonprofit institution that helps improve public policy through research and analysis; its publications do not necessarily reflect the opinions or policies of its research sponsors.

RB-5012

Copyright © 1996 RAND

All rights reserved. Permission is given to duplicate this on-line document for personal use only, as long as it is unaltered and complete. Copies may not be duplicated for commercial purposes.

Published 1996 by RAND

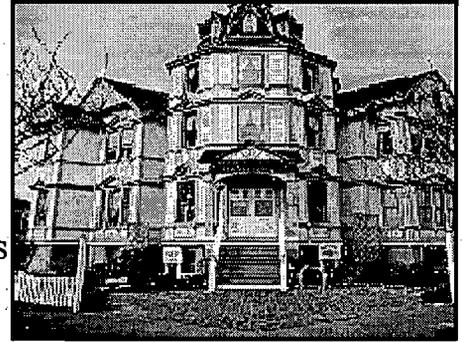
This Research Brief is also available in hard copy.

RAND's Home Page

Elder Abuse in Institutions

What kinds of elder abuse occur in institutions?

The great majority of reported acts are physical abuse. Other types of elder abuse that have been reported in institutions include sexual abuse, monetary abuse, or acts where an employees perform work routines improperly, e.g. cutting off a bandage with a sharp instrument. Sometimes, patient abuse can cause irreparable damage, as in a case where a punch by a nurse's aid resulted in permanent blindness for the elderly resident.



Abuse can be subtle or covert, including harassing elderly residents or controlling them with drugs or restraints. Restricting the personal choices of residents (e.g. in regard to bathing or feeding times, or what to wear) can also be abusive. Sometimes residents are placed in isolation, especially if they are aggressive or hard to care for.

Who abuses elders in nursing homes and why?

In the United States, nurses' aides (equivalent to nursing assistants in Canada) are the most frequent abusers. This is likely because they are the largest group of employees working in institutions for the elderly. Male workers, although outnumbered by females, are more likely to be overtly abusive, such as assaulting residents physically.

Oftentimes staff are overworked and underpaid. In addition, residents can be aggressive or difficult to manage. In institutions, routines are seen as important, and residents who do not cooperate may cause frustration in workers, who react with anger.

What can be done about it?

Elders need to understand what elder abuse is, and to be informed of their basic rights. Such knowledge protects against the risk of abuse. It can also be useful to educate staff about elder abuse, particularly covert abuse, which they often do not consider to be harmful. Staff need to know that elder abuse is a crime and that offenders can be punished.

In addition, workers should be trained in conflict resolution, so that violent responses to difficult situations can be reduced. When residents object to procedures (like being forced to take a shower), staff should be encouraged to seek alternatives, such as providing a bath instead, or a different time to shower. In many cases, staff themselves feel powerless and the pressures of the job are overwhelming.

Finally, as with any crime, the presence of witnesses tends to deter potential offenders, and to increase the chances of successful prosecution. It is important that managers of institutions and families of residents keep this in mind. Residents who are visited

regularly by vigilant family members are less likely to become victims of elder abuse.



PAGE BACK

Home



This site was funded and is owned by the Sudbury Elder Abuse Committee, Sudbury, Ontario, Canada. It was authored by Beverley Bourget, Social Planning Council Sudbury Region. Technical development, DESIGN and HTML SOURCE courtesy of Internet Education Resources.



Access to Justice Network
Publications

Subjects Directories Events Forums
Information Services Learning Resources
Legislative Materials Library Catalogues
Mailing Lists Site Map What's New

Feedback Search

ACJNetTM

Français

Text Menu Bar

Publication of Alberta Family and Social Services - Office for the Prevention of Family Violence - 1990

Elder Abuse

What is It? What to Do About It?

Table of Contents

- What Is It?
 - Who Is Affected?
 - Who Are The Abusers?
 - Why Does It Happen?
 - What To Do About It
 - Resources
-

What Is It?

Elder abuse is any deliberate action or lack of action which causes harm to an elderly person. It can take many forms.

Physical Abuse

Physical abuse includes any kind of physical assault, such as slapping, pushing, kicking, punching, or injuring with an object or weapon. It also includes deliberate exposure to severe weather, inappropriate use of medication and unnecessary physical restraint.

Sexual Abuse

Sexual abuse includes any forced sexual activity.

Psychological Abuse

Psychological abuse includes humiliation, isolation, intimidation, threats, and inappropriate control of activities. Removal of decision making power when the elderly person is still competent to make his/her own decision is also considered to be psychological abuse.

Financial Abuse

Financial abuse includes the misuse of the elderly person's funds or property through fraud, trickery or force.

Neglect

Neglect is any lack of action required to meet the needs of an elderly person. It includes inadequate provision of food, clothing, shelter, required medication or other kinds of health and personal care, as well as social companionship.



Who Is Affected?

Any elderly person may become the victim of abuse. Males and females of any income level, any cultural or ethnic group, persons in good health or persons incapacitated in some way may be abused by someone close to them.

A recent national survey on elder abuse indicates that 4% or approximately 100,000 elderly persons living in private dwellings in Canada have recently suffered one or more forms of abuse or neglect.



Who Are The Abusers?

The abusers can be anyone, but they are most commonly family members with whom the abused person is living. In a small Alberta study conducted in 1985, over half the elderly people reported to have been abused were living with the persons who abused them.



Why Does It Happen?

There is no one simple answer to this question. Many factors seem to contribute to abuse

There is no one simple answer to this question. Many factors seem to contribute to abuse and each case has its own unique mix of factors.

Abusive Style of Interaction

In some families, the members have a way of relating to each other that is generally hostile and non-nurturing. The adult children may have been abused by their parents, and having learned to interact in such a manner, carry it on into the next generation. Or there may be some unresolved family conflicts which foster abuse.

The family may have a history of wife abuse which carries on into old age. Or in some cases, the roles may become reversed if the former abusing partner becomes incapacitated and his wife seizes the opportunity to retaliate.

Dependency

In some cases, the elderly person becomes dependent to some degree on family members for assistance. Such dependency can tax the resources, both material and psychological, of family members and set the stage for abuse.

Conversely, some persons who abuse are in some way dependent on the persons they are abusing. The most common cases are those in which a son or daughter is dependent on an elderly parent for shelter and/or finances.

Stress

Stress caused by too many demands and too few resources can contribute to abuse.

Intoxication

Intoxication allows some people to be abusive by breaking down their inhibitions.

Lack of Knowledge

Ignorance about the aging process and the needs of elderly people sometimes results in harm to the psychological and/or physical well being of elders.

Societal Attitudes

Our society emphasizes competence, vigor, self reliance and physical beauty characterized by smooth skin and slim bodies. When these characteristics start to fade as people age, the value of the people themselves lessens in the eyes of many. Little respect is given to persons who are seen as useless and unattractive. It is much easier to abuse people who are not respected.

Rarely will any one of these factors on its own lead to abuse. Usually a combination of circumstances is involved.



What To Do About It

Elderly people who are being abused find it very difficult to tell anyone. They are usually ashamed and sometimes afraid. If at all possible, though, they should tell someone they trust. **NO ONE SHOULD HAVE TO LIVE WITH ABUSE.**

In some cases, it may be impossible for the abused persons to tell anyone. They may be isolated or incapacitated. In such cases, friends, relatives or care-giving professionals need to be aware of the possibility of abuse.

Some signs to look for:

- Discrepancies between a person's standard of living and his/her financial assets, or a depletion of assets, without adequate explanation.
- Malnourishment and inadequate physical care.
- Physical injuries, such as bruises, burn marks, welts, rope burns, tufts of hair missing, broken bones, none of which can be adequately explained.
- Withdrawn, apathetic or fearful behaviour, particularly around certain persons.
- Medical needs not attended to.

If the abused person is in imminent danger, the police should be called. Assault is as much a crime within families as it is on the street.

If abuse is only suspected, further investigation should be conducted by appropriate persons. Professionals who might be consulted are doctors, social workers, community health or home care nurses, psychologists and lawyers. Investigation of abuse must be undertaken carefully so that the situation is not aggravated.

Part of the investigation could include talking with the elderly person to determine the accuracy of the suspicions. If abuse is confirmed, it may be that he or she prefers to stay in the situation rather than choose any alternatives that seem available. Giving information and discussing all alternatives can be helpful. Unless the person who is being abused is unable to care for him or herself or make personal decisions because of some disability, he or she has the right to choose where and how to live. In other cases, the Public Guardian may be able to assist.

It may be appropriate to offer assistance to the suspected abuser. Counseling and support services may help alleviate the factors contributing to the abuse. Relief care of the elderly person may assist in reducing stress.



Resources

For Information and Support Services

- Local Health Units
- Senior Citizens Centres
- Family and Community Support Services or local social services agencies
- Alberta Family and Social Services District Offices
- Alberta Mental Health Clinics
- Offices of the Public Guardian

- Calgary
Kerby Centre
1133 - 7th Avenue SW
Calgary T2P 1B2
265-0661

- Edmonton
Elderly Adult Resource Services
24 hours phone service
439-3100

For Information Only:

The Office for the Prevention of Family Violence
10030 - 107 Street Edmonton T5J 3E4
422-5916

[Subjects](#) | [Directories](#) | [Events](#) | [Forums](#) | [Information Services](#) | [Learning Resources](#) |
[Legislative Materials](#) | [Library Catalogues](#) | [Mailing Lists](#) |
[Site Map](#) | [What's New](#)

[Up](#)

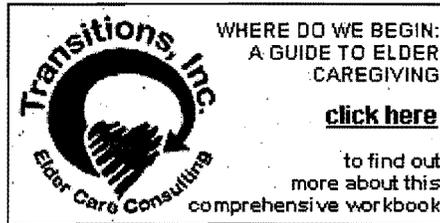
[Search](#)

[Feedback](#)

[Français](#)



careguide
www.careguide.net



Click Here To Visit The CareGuide Bookstore

NURSING HOME RESIDENT'S BILL OF RIGHTS

Under federal regulations, all nursing homes must have written policies that describe the rights of residents. The nursing home is required by law to make this policy statement - the "Nursing Home Resident's Bill of Rights" - available to any resident who requests it. The following outlines the issues that should be covered in the bill of rights.

1. The Right To Be Informed Of Your Rights And The Policies Of The Home

The nursing home must have written policies about your rights and responsibilities as a resident. You must sign a statement saying that you have received and understood these rights and the rules of the home when you are admitted.

2. The Right To Be Informed About The Facility's Services And Charges

Every resident has the right to be fully informed of the services available in the facility and of the charges related to those services. This includes charges for services not covered under Medicare or Medicaid and charges that are not covered by the facility's basic rate.

3. The Right To Be Informed About Your Medical Condition

Every resident has the right to be fully informed of his/her medical condition, unless the physician notes in the medical record that it is not in the patient's interest to be told.

4. The Right To Participate In The Plan Of Care

Every resident must be given the opportunity to participate in the planning of his/her medical treatment. This includes the right to refuse treatment.

5. The Right To Choose Your Own Physician

Every resident has the right to choose his/her own physician and pharmacy. Residents do not have to use the nursing home's physician or pharmacy.

6. The Right To Manage Your Own Personal Finances

You can either manage your own funds or authorize someone else to manage them for you. If you authorize the home to handle your funds, you have the right to:

- Know where your funds are and the account number
- Receive a written accounting statement every 3 months
- Receive a receipt for any funds spent
- Have access to your funds within 7 banking days

7. The Right To Privacy, Dignity And Respect

Every resident has the right to be treated with consideration, respect, and with full recognition of his/her dignity and individuality, including privacy in treatment and in care for his/her personal needs.

8. The Right To Use Your Own Clothing And Possessions

Every resident may retain and use his/her personal clothing and possessions as space permits, unless to

do so would infringe upon rights of other patients, or constitute a hazard to safety.

9. The Right To Be Free From Abuse And Restraints

Every resident has the right to be free from mental and physical abuse, and free from chemical and physical restraints except as authorized in writing by a physician for a specified and limited period of time, or when necessary to protect the patient from injury to him/herself or to others.

10. The Right To Voice Grievance Without Retaliation

Every resident should be encouraged and assisted to exercise his/her right to voice grievances and recommend changes in policies and services to facility staff and/or outside representatives of his/her choice without fear of coercion, discrimination, or reprisal.

11. The Right To Be Discharged Or Transferred Only For Medical Reasons

Residents may only be discharged or transferred for medical reasons, or for his/her welfare or that of other residents. You must be provided with 30-days advance written notice of the transfer or discharge. The law gives you the right to appeal your discharge or transfer.

12. Your Rights Of Access

- Residents may receive any visitor of their choosing and may refuse a visitor permission to enter their room or may end a visit at any time
- Residents have the right to immediate access by family and reasonable access to others
- Visiting hours of at least 8 hours must be posted in a public place
- Members of community organizations and legal services may enter any nursing home during visiting hours
- Communication between the resident and visitor are confidential
- Visitors may talk to all residents and offer them personal, social, and legal services
- Visitors may help residents claim their rights and benefits through individual assistance, counseling, organizational activity, legal action, or other forms or representation.

[Elder Care Search](#) | [Bookstore](#) | [Elder Care FAQs](#) | [List Your Facility](#)

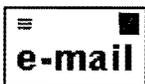
Tell Your Provider You Found Them On CareGuide!



**Interested In Being Included
in CareGuide? [Click here](#)**



**Help Us Serve You Better.
[Fill Out Our On-Line Survey](#)**



Questions or Comments? E-mail us at care@careguide.net or call 415-474-1278.

Copyright © 1996 - 98 CareGuide LLC



overview of a panel on quality
more detailed things follow

Improving Quality of Life for Nursing Home Residents: The Challenge & The Opportunities

Symposium & Workshop
July 11-12, 1996

Health Care Financing Administration
Health Standards and Quality Bureau
Center for Long Term Care
Baltimore, Maryland

EXECUTIVE SUMMARY

The Health Care Financing Administration (HCFA) held a public symposium July 11, 1996, followed by a workshop July 12 to focus attention on ways to improve quality of life for nursing home residents. The symposium, organized by HCFA's Center for Long Term Care in the Health Standards and Quality Bureau (HSQB), sought recommendations from prominent researchers, representatives of stakeholder groups, and the public for improving quality of life and improving federal and state measurement of quality of life in each nursing home.

More than 300 people attended the public symposium, which was held at HCFA's Baltimore headquarters. HCFA invited six prominent long term care researchers to present papers for discussion in answer to the questions posed above. The experts drew on their leading edge research in quality of life, and on their collective professional experience.

The six experts included:

Gwen Uman, R.N., Ph.D.
Partner
Vital Research

Rosalie Kane, D.S.W., Professor
Institute for Health Services Research
School of Public Health
University of Minnesota

Catherine Hawes, Ph.D.
Senior Policy Analyst
Research Triangle Institute

David Gustafson, Ph.D., Founder
Center for Health Systems Research & Analysis
University of Wisconsin - Madison

Michele Teitelbaum, Ph.D.
Senior Associate
Abt Associates, Inc.

Robert Rubinstein, Ph.D.
Director of Research
Philadelphia Geriatric Center

Panels composed of representatives of various stakeholders involved with nursing homes commented on the researchers' presentations. These responders included academicians, nursing home industry representatives, state surveyors, consumer advocates, long-term care ombudsmen, and professional groups. Comments were also invited from the audience.

Approximately 40 stakeholders were invited to attend a second-day workshop session with the researchers and HCFA staff to evaluate the recommendations received at the symposium and to suggest projects for HCFA to undertake in response to the recommendations.

Conference Objectives

HSQB Director Richard Besdine, M.D., opened the conference, highlighting the need for a "systematic quantifiable approach" to identify and improve the "pleasures" of cognitively and physically impaired populations in long-term care institutions. He called on conference participants to "highlight the research base" of quality of life variables to address the divergent needs of residents.

Dr. Besdine underscored the point that HCFA had organized the conference to hear the voices of the various stakeholders concerned with improving nursing home life for residents, and that HCFA sought to forge a partnership with those stakeholders in developing practical, cost-effective steps to meet that goal.

Dr. Besdine articulated three questions for the conference to address:

- What are the elements that influence quality of life for nursing home residents, and what is the relationship of quality of life to a number of variables among nursing home residents such as their cognitive status, length of stay, age, chronic disease burden, gender, and ethnicity?
- How can HCFA cost effectively use its limited financial resources for training surveyor personnel and for data collection to improve quality of life for nursing home residents?
- What are the most reliable and informative ways to measure the performance of nursing homes to ensure that they enhance quality of life for nursing home residents?

The Program

Jeff Finn, Executive Director of the Setting Priorities for Retirement Years (SPRY) Foundation, moderated the opening day program. In his remarks to conference participants, he noted past difficulties in health professionals reaching a consensus on how to define and measure quality of life in the nursing home setting. Nonetheless, he said, "Whenever possible, the individual resident should serve as the ultimate guide in directing nursing home staff to improve his or her quality of life."

The July 11 symposium comprised a series of four panels of presenters and responders. In addition, participants viewed three excerpts from an award-winning Canadian video production entitled *Not My Home* (video courtesy of Deveaux Babin Productions) that depicted various aspects of nursing home life and the views of residents, their families and nursing home staff. Finally, members of the audience were afforded two opportunities to voice their opinions on points made during the four panels and to advance their own suggestions for improving nursing home residents' quality of life.

While some speakers identified specific indicators associated with enhancing or threatening quality of life, others described surveys used to measure resident satisfaction in long-term care facilities. One expert highlighted new research that will soon enable more precise measurements of well-being in the cognitively impaired, and one spoke of issues surrounding the impact of a resident's impending death on not only that resident, but on other residents and staff.

Some of the panelists focused on the need for enhanced surveyor training, and the importance of information dissemination to various publics about quality of life indicators in nursing homes as a means of heightening awareness of the issues among consumers, nursing home advocates and the industry. Several speakers voiced the need for nursing homes to focus more attention on the needs of individual

residents. Such an action would require facilities to become acquainted with the life and history of the resident prior to entering the institution so that homes could develop a more responsive and personalized care plan and schedule for each resident. (Appendix A contains a more detailed summary of presentations and responses from day one of the symposium.)

In addition, there were comments from various audience members that quality of life for residents was in part dependent on:

- Adequate staff to carry out resident care;
- Enhanced training for aides and other staff on the importance of quality of life issues for residents; and
- Improving the quality of life for the workers themselves in the facility.

At the day two workshop, HCFA invited representatives of stakeholder groups (nursing home industry, surveyors, researchers, consumers, ombudsmen, state agencies, and HCFA staff) to consider three key questions. The participants were assigned to one of three work groups to develop recommendations as to specific actions that HCFA could take to answer the questions.

The first question focused on the diverse populations and the diverse viewpoints of today's nursing home residents. To that end, HCFA asked how to best define quality of life for these different people. The first question also asked respondents to make recommendations on ways to help nursing home surveyors to assess acceptable performance by facilities.

The second question asked participants to make recommendations on how existing measures for quality within nursing homes could be strengthened and applied to quality of life indicators. In addition, HCFA asked whether the current Minimum Data Set (MDS) could be modified to capture additional quality of life information. HCFA also asked participants for their ideas on offsite indicators that would help surveyors focus their onsite reviews of facilities.

The third question asked participants to define appropriate roles for HCFA as it sought to improve quality of life for nursing home residents. In short, should HCFA move beyond its traditional role of being solely a "regulatory" agency? If so, what are the dimensions of that role?

Center for Long Term Care staff presented workshop participants with the following framework for consideration of these three questions: Not only is the nature of long-term care changing, but also the resident population is changing. The expectations for care are also changing rapidly. What was expected and accepted years ago is no longer suitable. The challenge is to devise a means of meeting the changing and greater demand for services by residents at a time when there are fewer resources devoted to ensuring that attention is paid to improving residents' quality of life.

In answering the three questions posed by HCFA's Center for Long-Term Care, various discussion group participants proposed a series of short and long-range options for HCFA. Those individual suggestions which are detailed below, fall under six major topics:

- Defining Quality of Life;
- Changes in the Survey Process/Regulations;
- Training;
- Information Sharing;
- Research; and
- Additional Issues of Concern.

Defining Quality of Life

The subgroup which had discussed the special populations question reported that while quality of life can be defined in the nursing home setting, such an effort will take time and constant vigilance on the part of various stakeholders, all of whom must look to the individual resident for direction. It is less

valuable to attempt to categorize residents into subgroups (such as cognitively impaired, relatively young, belonging to various cultural backgrounds, etc.) and attempt to define best practices for the subgroups than it is to consider each resident individually and to determine what would suit that resident best.

Defining quality of life for an individual will come through a combination of means: through interviews with the resident when possible; through regular observation of the resident; through facilities developing an individual biography of each resident that includes milestones of the person's life prior to coming to the facility; and through use of measures that are currently part of the MDS. This information, in turn, should then be used to continually monitor the resident's plan of care, modifying it to accommodate changing circumstances. Participants recommended that nursing homes develop a system that clearly shows the connection between identified quality of life issues for the individual resident and the specific activities within a resident's plan of care.

As one workshop participant noted, "What's important is what gives them pleasure." Another participant added: "The central responsibility is to know each individual who lives [in the nursing home]."

Various individuals made the following specific suggestions for topics that need further discussion:

- Aspects of a nursing home's environment, such as paging systems, noise level, and layout, that may have a negative impact on residents' quality of life;
- Facility routines, procedures, and policies that may negatively affect residents by producing an institutionalized atmosphere;
- Costs-benefits of encouraging private resident rooms in new construction;
- Ways facilities can acquire more help with low or no cost such as use of volunteers;
- Attaching nursing staff to the residents, not the unit so they go along to help the residents in programs;
- Giving all staff (not just clinical) 20 minutes a day to visit one assigned resident and be their advocate;
- Impacts of the common practice of rotating nursing staff to different living units;
- Issues surrounding dying residents, including the impact of the facility environment and policies on these residents, their families, other residents and staff;
- Negative emotional impact on residents caused by the ending of their physical therapy and possible ways to alleviate this problem; and
- Widespread desire of cognitively intact residents to be around other residents who are on a similar cognitive level and segregated from disruptive residents.

Participants urged that all workgroups formed to work on quality of life projects include representation from an array of stakeholders including consumers and nurse aides.

Changes in Rules/Regulations/Survey Process

One theme that emerged both from workshop participants and from audience members during the first day's symposium was that some of today's nursing home regulations and safety codes may hinder nursing homes from providing a home-like environment that could improve the residents' quality of life. For example, one individual urged HCFA to reconsider its current hospice payment regulations that often make it necessary for a dying resident to move to a "hospice" bed in another wing away from familiar staff. Another participant acknowledged the inherent tension regulators face in trying to create a safe environment while working to recognize residents' needs for dignity, privacy and personal autonomy.

There was also widespread rejection by workshop participants, including the industry, of a consultative role for surveyors, although some wanted to allow surveyors to share best practices information with facilities during surveys.

Given those concerns, the following suggestions for consideration were made by individual participants:

- Reconsider life safety code requirements that may now be outdated and that may conflict with facilities providing residents a good quality of life;
- Refocus enforcement budgets on improvement of marginal facilities;
- Develop a survey procedure to ask simple, closed-ended interview questions of some residents who are now considered non-interviewable;
- Consider conducting surveys on weekends or at night, based on concerns to investigate;
- Have survey agencies send a questionnaire to families after a resident's admission and later. In this matter, however, special attention must be paid to ensuring confidentiality in questionnaire responses to negate the possibility of reprisals against residents. One participant noted that a family's responses to a questionnaire often differed from the resident's. In addition, while some participants said that consumer satisfaction was important to measure, others cautioned that some facilities would use poorly constructed resident and family satisfaction surveys that were designed to produce positive answers as marketing tools;
- Give States more leeway in making changes to the survey process to suit their needs, subject to HCFA's review and approval;
- Direct surveyors to look at a nursing home's management philosophy and values relative to staff turnover. This suggestion was based on the assumption that quality of life is affected by resident-staff ratio, staff satisfaction and staff turnover. One workshop participant noted that in some instances, staff turnover is healthy for a facility; and
- Use current research results to design a questionnaire to interview residents about satisfaction. Questionnaire results could be delivered to surveyors in advance of the on-site survey. Workshop participants disagreed on who should conduct the resident interviews -- the facility or an outside, impartial entity.

Training

Given the complexity of defining quality of life for residents, some workshop participants emphasized the importance of enhanced training of surveyors and other stakeholders in measuring this dimension of nursing home life for residents. The following individual suggestions were made for HCFA to:

- Develop advanced training courses for surveyors that would place special emphasis on interviewing techniques, especially aimed at talking with residents who have communication or cognitive impairments;
- Create a series of case studies for surveyors to improve their understanding of how to investigate quality of life issues and how to make decisions about adequacy of facility compliance with quality of life regulations;
- Improve training courses that emphasize modeling for professional caregivers, including certified nurse assistants;
- Create a video on quality of life issues for nurse aide training.

Information Sharing

Sharing information about quality of life was deemed a critical area for attention and action if HCFA wants to improve quality of life among residents. Some participants detailed several ways in which HCFA could share information among various stakeholders in the nursing home arena.

For example, there was a recommendation that that HCFA mirror the partnership model of information dissemination that the Agency so successfully used to promote a significant reduction in the use of resident restraints. To that end, HCFA was urged to pick a "best practice" within a nursing home that could improve residents' quality of life, to forge a partnership with industry and consumer advocates, and to give the practice national prominence in hopes of improving that aspect of care.

There was also a recommendation from one of the workshop subgroups that HCFA, in collaboration with stakeholders and States, should solicit good ideas from facilities on ways to promote quality of life among residents. Under the plan, HCFA would sponsor recognition of good ideas through an annual "Nifty Innovations Award." Using informal terminology like this makes a statement that HCFA is not looking just for authoritative best practices that have been developed by experts, but also good ideas that are developed by nursing home staff and used with good results. An expert panel comprising HCFA and stakeholder representatives would evaluate the ideas submitted. One workshop participant remarked that it is critical that the innovations be "nifty" to residents, not just to long-term care professionals. To highlight the importance of the issue, HCFA would publicize the awards at a public ceremony. The winning ideas would be disseminated through various means, including a HCFA-sponsored newsletter, through provider and consumer publications, and possibly the internet.

As part of this information sharing process, HCFA was urged by the subgroup to develop an information clearinghouse of innovations and good ideas on promoting quality of life among residents. Among the information would be examples of nursing homes in the country where residents are satisfied with quality of life and case studies for professionals to use in training programs.

Among other ideas put forth by various workshop participants, HCFA was advised to develop a means for public disclosure of facility performance on quality of life and quality of care indicators. This was deemed part of the process to help consumers choose the "right" nursing home and to enable residents and their families to knowledgeably monitor ongoing nursing home performance. The disclosed information might include OSCAR data, long-term care ombudsman information, and facility-specific reports based on the MDS. Several participants also said that resident's families should be tapped as a data source for the public disclosure files by seeking their input through mail surveys.

In disseminating that information, a participant urged HCFA to put nursing home information on personal computers in facilities and let the residents have access to these computers and be trained in their use.

Research

Although workshop participants identified some specific actions that could be taken with respect to training of staff and surveyors and to the dissemination of information to improve quality of life for residents, they also voiced a clear need for additional research that needs to be undertaken to ensure that any quality of life indicators that are developed are meaningful to residents. Among the research topics proposed by various individuals:

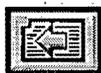
- To determine differences in perceptions among staff and residents, conduct a study in which residents who are capable either complete their own MDS or view the one completed by staff;
- Make an immediate commitment to fully automating the MDS and providing feedback reports to consumers and providers;
- Implement pilot projects to determine factors associated with pleasurable outcomes for residents with Alzheimers and other related dementias;
- Initiate studies to probe the correlation and differences between resident and family satisfaction rates;

- Conduct more research on the impact of death and dying on residents in nursing facilities;
- Develop and validate quality of life indicators based on the MDS;
- Develop a systematic method for face-to-face data collection that acknowledges different sub-populations of residents. Workshop participants differed on the need to place residents into subgroups, some reasoning that each resident should be evaluated solely as an individual;
- Look at other sources of data besides the MDS. Study whether there are any currently available data that could be indicators. Such indicators of quality of life may include:
 - Staffing levels for various staff categories, such as activities;
 - Staff turnover;
 - Satisfaction of staff;
 - Resident/family participation in care; and
 - Unnecessary hospitalizations of terminally ill residents.

Additional Issues of Concern

Beyond addressing the specific issues raised in the key questions articulated by HCFA, various individuals discussed a central challenge faced by all those interested in improving the life of nursing home residents: how can they work in partnership to raise the visibility of this important issue? More specifically, what steps can be taken to create an environment in which facilities want to improve the quality of life for their residents in response to customer needs, external and internal reports and surveys, and their own need for continual quality improvement? How can current information already gathered in research studies about what is important to residents encourage facilities to go beyond the minimum quality of life requirements? And lastly, how can residents and families be educated to be alert consumers who can actively participate in planning their optimum care and monitoring facility performance?

Although answering those questions will take time, participants lauded HCFA for convening the symposium and focusing the attention of diverse interests on the topic.



[Return to Sharing Innovations in Quality Page](#)

Last Updated 09/25/97

HCFA	Medicare	Medicaid	Help	Feedback	Search	FAQs
-------------	----------	----------	------	----------	--------	------

HCFA	Medicare	Medicaid	Help	Feedback	Search	FAQs
-------------	-----------------	-----------------	-------------	-----------------	---------------	-------------

Quality of Life in Nursing Homes: What are Potential Indicators on the Nursing Home Resident Assessment Instrument (RAI)?

PANEL 2

Presenter:

Catherine Hawes, Ph.D., Senior Policy Analyst, Research Triangle Institute

Dr. Hawes was the principal investigator of the HCFA contract that led to the development of the Resident Assessment Instrument (RAI) for nursing homes which HCFA has adopted. This instrument includes the Minimum Data Set (MDS) screening tool as well as the Resident Assessment Protocols (RAPs). She was a member of the Institute of Medicine Committee on Nursing Home Regulation which produced a report on recommendations for ways to improve nursing home regulation in 1986 that eventually became part of the Ombudsmen Reconciliation Act of 1987 (OBRA 87). She has studied quality of life issues in a variety of residential settings, including nursing homes, assisted living facilities, and is currently working with Rosalie Kane as a members of an advisory committee at the Picker Institute to develop quality of life and consumer satisfaction measure for home care.

Response Panel:

Kathleen M. Cantaben, RN, MPA
Consultant to the Center for Health Systems Research and Analysis
University of Wisconsin

Charlene Harrington, Ph.D.
Department of Social and Behavioral Sciences
University of California - San Francisco

Mary K. Ousley, RN
Representative of the American Health Care Association
Corporate Director of Clinical Services, Horizon/CMS Healthcare Corp.

Quality of Life in Nursing Homes: What are Potential Indicators on the Nursing Home Resident Assessment Instrument (RAI)? Catherine Hawes, Ph.D.

In her presentation, Dr. Hawes discussed the use of the Resident Assessment Instrument (RAI) to identify indicators of quality of life for residents in nursing homes. She acknowledged that although the RAI was primarily designed as an instrument for assessing residents' care needs and has been used to measure quality of care, this does not preclude its potential utility for measuring quality of life. The RAI contains many potentially useful indicators of quality of life. While these indicators may be limited, there are three distinct advantages for using the RAI: the widespread availability, reliability and utility of the data.

Dr. Hawes stressed that her intentions for the RAI-based indicators is for them to be used as proxies of what might be investigated further during a facility site visit and in interviews with or observations of residents. It is not her intention that they be perceived as a full range measure of what might be considered quality of life.

Using a conceptualization developed by David Zimmerman of the University of Wisconsin, she proposed a three tier approach for the use of RAI-based quality of life indicators. The first tier would

proposed a three tier approach for the use of RAI-based quality of life indicators. The first tier would include the "high probability" indicators of a problem in quality of life. For example, social engagement, a tested and validated measure that appears to capture important aspects of quality of life for nursing home residents, would be a tier one indicator. In addition, there are individual items or combinations of RAI items that may indicate a quality of life problem for residents. These include:

1. Participation in the assessment and decisions about care planning;
2. Prevalence of physical restraints;
3. Behavior management;
4. Distressed mood;
5. Activities; and
6. Maximizing functional independence and minimizing the effects of impairment.

Tier two indicators include those that may indicate a potential problem in quality of life. Items in this category, such as respect for residents' privacy and dignity, autonomy and residents' feelings about their lives in the facility are not directly measured by the RAI. However, the following items could be investigated as potential manifestations of lack of privacy and dignity:

1. Unsettled relationships;
2. Autonomy and end-of-life decisions, e.g. advance directives; and
3. Distressed mood and behaviors.

The final tier includes indicators for residents with special risks for quality of life problems. Examples of the quality of life problem, descriptions and the specific MDS item(s) for this tier are:

1. Potential social isolation;
2. Little social engagement (none of the above is checked for sense of initiative and involvement);
3. Severe communication deficit (rarely or never understood);
4. Severe pain ; and
5. Potential for treatment that violates privacy and dignity (residents who receive assistance in toileting, bathing and/or receive treatments such as pressure ulcer and, residents who are incontinent).

In conclusion, Dr. Hawes recommended further research be funded to test the suggested three tiers of indicators for reliability and validity through using more direct measures of quality of life that are obtained through direct observation and interview with residents.

Response Summaries

Kathleen M. Cantaben, RN, MPA

Kathleen Cantaben, is one of the expert survey consultants to HCFA's current contract with the University of Wisconsin. As such, she has been involved in the development, pilot testing, and training for the current 1995 Survey Process, and is now part of a team monitoring implementation of the new survey in 8 States. She is also with the New York State Department of Health. Ms. Cantaben stated that she believes currently there exists a tremendous amount of information available in MDS data. However, this information has to be looked at cautiously, she added. In the survey process, the RAI is examined, yet it is not an audit. The validity is really dependent upon the training of the nurses and staff filling out

yet it is not an audit. The validity is really dependent upon the training of the nurses and staff filling out the paperwork. When turnover rates are high, the Minimum Data Set (MDS) may be completed by many individuals. In Ms. Cantaben's view, quality of life is like trying to hold on to Jell-O. She also said that surveyors know quality of life when they see it and when they don't see it. But trying to prove it, or articulate it back in an intelligent manner can be difficult.

During a survey, a sample of residents must be selected. Perhaps the RAI and indicators can identify groups of people to focus on. One possible indicator might be to look at people not involved in their care plan. Depression combined with restraints and no knowledge about a care plan might explain why someone is acting out. If this information can be aggregated it might point to potential problems. At the same time, we must build on what a facility does that works well and work from that perspective. While this information can serve many useful purposes it must first be tested by validation studies. Once the quality indicators are selected, they can help to identify residents to survey and potentially define certain populations that are at risk for poor quality of life.

Charlene Harrington, Ph.D.

Dr. Harrington was a member of the Institute of Medicine (IoM) Committee on Nursing Home Regulation that produced the 1986 report that was largely incorporated into OBRA 87 and the 1996 IoM panel that conducted a large scale study of nurse staffing. She has long been involved in a variety of long term care research projects including a current HCFA study to determine if any QoL indicators exists in HCFA's OSCAR database.

Dr. Harrington felt that the quality of life (QOL) concept was difficult to define. Nevertheless, she observed that QOL is not only an essential component but sometimes literally a matter of life and death. While collecting and analyzing data of QOL is a positive idea, Dr. Harrington expressed concern about the one-third of nursing homes being cited for failure to complete comprehensive assessments on residents. She said there appears to be inadequate training for completing assessments and care plans. Research shows a positive relationship between higher ratios of registered nurses and improved outcomes: thus the Institute of Medicine recently recommended increased staffing in nursing homes. In addition to staffing levels, turnover rates for nursing assistants and directors of nursing is too high to permit continuity of care and ultimately foster QOL in these facilities. Furthermore, insufficient time is spent on direct care, she said. Data from the Health Care Institute of America (HCIA) and Arthur Andersen found that nursing homes are only spending 36 percent of their operating expenses on direct nursing care.

Summarizing, Dr. Harrington suggested that in order to provide quality-of-life indicators, we must ensure that there is a basis of quality of care and sufficient staff resources to achieve these ends.

Mary K. Ousley, RN, Corporate Director of Clinical Services for Horizon/CMS Healthcare Corporation

Speaking on behalf of the American Health Care Association, Mary Ousley suggested that Dr. Hawes' paper could be improved by recognizing that facility professionals also recognize the need for quality of life in addition to residents, their families and resident advocates. She said the nursing home industry should be recognized for how far it has come in the past 15 years. She suggested that nursing homes would support customer defined measures of satisfaction, such as what really makes the resident happy. However, getting the answer to the question means answering the problem of satisfying whom. Moreover, she noted that satisfaction ratings are highly subjective. Information about the Minimum Data Set (MDS) is widespread and requires no additional resources to provide baseline data, she said. One should be able to tie performance to facility staff.

Ms. Ousley also said she supports the idea of developing quality-of-life indicators, but with caveats. First, she said additional research is needed to demonstrate whether the indicators really measure quality of life. Second, any follow-up procedures must also be tested to provide structure and process. She noted that it will be difficult to aggregate the information to reflect individual needs and overall quality. Ms. Ousley expressed concern whether quality of life could be measured within the survey environment. For example, she said that one might assume that if 10 out of 15 residents are not involved in their care plan,

then it is a problem. However, perhaps the resident doesn't want to be involved or is just not able to be involved. Looking at the MDS may force people into boxes that detract from the individual's quality of life.



[Return to Sharing Innovations in Quality Page](#)

Last Updated September 25, 1997

HCFA	Medicare	Medicaid	Help	Feedback	Search	FAQs
-------------	-----------------	-----------------	-------------	-----------------	---------------	-------------

	Medicare	Medicaid	Help	Feedback	Search	FAQs
---	----------	----------	------	----------	--------	------

Quality of Life in Nursing Homes from a Consumer Research Perspective

Assuring Quality of Life in Nursing Homes: Regulatory Strategies

PANEL I

Presenters:

Gwen Uman, RN, Ph.D., Vital Research

Dr. Uman is a gerontological nurse practitioner who has extensive clinical research experience as well as 14 years of specialized business experience in the area of research methodology and psychometrics for education, health care, and consumer research. Vital Research has developed a unique behavioral approach to the measurement of consumer satisfaction that has been successfully applied in a variety of industries, including health care. Using a consumer research approach to the study of quality of life in nursing facility residents has been one focus of Dr. Uman's research.

Rosalie Kane, DSW, University of Minnesota

Dr. Kane has extensive research experience in the field of long-term care, specifically the areas of autonomy, quality assurance, and quality of life issues. She was a member of the Institute of Medicine Committee on Nursing Home Regulation which produced a report on recommendations for ways to improve nursing home regulation in 1986 that eventually became part of the Ombudsmen Reconciliation Act of 1987 (OBRA 87). Currently, she is the director of a large longitudinal study to evaluate the effectiveness of a model of assisted living facilities compared to nursing homes in Oregon, for which she had developed measures of personal autonomy, control, and social well-being.

Response Panel:

Margaret Gerteis, Ph.D.
Director, Communication and Education
Picker Institute

Theodora Marcot, MS, RN.
Owner of Healthy Seniors

Faith Mullen, Esq.
Senior Policy Analyst
Public Policy Institute
American Association of Retired Persons

Michael Tripple
Assistant Director, Minnesota Department of Health
Representative of the Association of Health Facility Survey Agencies

Cat Selman, BS, ACC
Vice President
National Association of Activity Professionals

**Quality of Life in Nursing Homes from a Consumer Research Perspective
Gwen Uman, Ph.D.**

Gwen Uman, Ph.D.

In her presentation, Dr. Gwen Uman described some of the issues and benefits of using a consumer research approach for the evaluation of Quality of Life (QoL) in nursing homes and offered recommendations for further study. Dr. Uman advocates the consumer research approach for evaluating QoL in nursing homes because it elevates all residents, regardless of their cognitive capacity, from subordinate positions to important positions: a person who has something meaningful to say. Further, this approach incorporates the resident's family into the concept of customer and applies importance to the different perspective a family brings to the evaluation of QoL, but does not elevate their status above that of the resident.

A consumer research approach in nursing homes has three goals:

1. To listen, understand, and respond to the voice of the resident and family;
2. To include residents from the highest to the lowest cognitive levels possible in the measurement of satisfaction; and
3. To quantify and systematize measurement of resident and family satisfaction.

The first goal can only be achieved by eliciting the responses of residents and family members to questions such as, what do you want?, what do you like and dislike here?, what would you change? Dr. Uman used a qualitative approach in her research which involved residents and families from three facilities in Southern California. Six over-arching consumer requirements emerged from the analysis of these participant's responses: autonomy and choice, safety and security, resident-staff communication, food and environment, companionship, and help and assistance.

In order to achieve the second and third goals, a systematic, standard measure must be developed which can be administered to all residents and identifies a facility's ability to meet or exceed the customers' requirements (autonomy & choice; safety & security; resident-staff communication: food & environment; companionship; help & assistance) must be developed. Dr. Uman described the process used in her research to address these goals. The process she described used, whenever possible, the concrete examples provided during qualitative interview, the residents' own words, to create a set of structured, closed-ended, behaviorally oriented questions that could be answered "yes or "no." For example, one question is, "Do the people who work here smile at you?" The logic behind this approach is to present residents and family members with behaviorally-oriented observable indicators of what they say they want (consumer requirements), and ask them whether they are getting them. The advantages to this approach are:

1. Results of the measurement process are more actionable because they are tied to observable events that a facility can change;
2. Personal opinion is removed, thus minimizing stereotyping and bias that is intrinsic when consumers and providers are of different ethnic groups or social classes; and
3. It is easier for cognitively impaired residents to give a dichotomous answer than a scaled answer.

Figure 1 displays the products of operationalizing consumer requirements in nursing homes. The Screening Interview Schedule (SIS) has five questions and the Resident Satisfaction Interview (RSI) has 42 questions. Resident and Family Importance tools are supplemental and are used to confirm that the identified requirements remain salient.

Measurement

Resident	Family
Interviews by External Interviewers	Surveys Distributed by Mail
Screening	Family Satisfaction

Screening Resident Satisfaction Resident Importance	Family Satisfaction Family Importance
--	--

Fig. 1 Measurement Component

Dr. Uman shared findings from her field research which demonstrated that 79% of residents with a wide range of abilities and cognitive levels were willing and able to report on the quality of their daily experience using a set of structured, closed-ended, behaviorally-oriented, "yes" and "no" response questions.

In the final section of her presentation Dr. Uman reviewed 10 recommendations for additional studies to further refine and validate her research. The following provides a brief description of these recommendations:

1. A qualitative study of newly admitted NH residents and their families would be useful to identify any higher level consumer requirements that become dampened by prolonged institutional living.
2. Design a study to validate the accuracy or fairness of resident's responses to the behaviorally oriented structured interview.
3. Conduct a study using 100 NHs to determine the range of satisfaction scores across NHs and whether scores discriminate between NHs (residents and families as the unit of analysis).
4. Examine within-NH test-retest reliability at baseline, six months and one year.
5. Conduct a correlational study of consumer-generated satisfaction data with practical and available off-site variables potentially related to Quality of Life.
6. Conduct a study to examine the influence of facility staff interviewers on critical scores.
7. Facilities that decide to contract for external measurement of consumer satisfaction might be allowed to submit their findings over time to be reviewed by surveyors in advance of the survey.
8. Resident selection should be stratified by Cognitive Performance Scale (CPS) level.
9. Train surveyors in interviewing methods for the nursing facility population: techniques that sensitize surveyors to communication problems and other disabilities.
10. To the extent possible, HCFA should offer support and shaping of Quality Assurance (QA) team functions within nursing facilities such as: how to interpret quality of life indicators and how to prioritize indicators.

In closing she outlined her vision for a Quality of Life system which is cyclic and pivots around the improvement process to achieve excellence.

Assuring Quality of Life in Nursing Homes: Regulatory Strategies
Rosalie Kane, DSW.

In her paper Dr. Kane argues that quality of life is rarely acceptable for most nursing home residents in any given facility, even when the facility meets all OBRA standards. Therefore, serious attention to quality of life requires approaches to system change, not merely better measurements and more defensible quality of life monitoring by survey agencies (though the latter is also important.) Quality of life is viewed as distinct from quality of care and from physical health and functional outcomes; without construing and measuring quality of life separately (as opposed to seeing it as an aggregate multidimensional measure of well-being), the separate "quality of life" condition makes little sense.,

The paper presents seven conceptual questions that should guide regulatory policy related to quality of life:

1. How much reduction in quality of life is tolerable in exchange for the care provided in a nursing home?
2. Can examples be found in the United States where the quality of life in certified, licensed nursing homes is acceptable for the majority of its residents? (Answer: a qualified "yes").
3. Can quality of life be defined validly and measured accurately enough to confidently separate facilities that offer an acceptable quality of life from those that are sub-standard?
4. What steps can be taken to correct quality of life problems once identified?
5. What is the role of the regulatory agency in bringing about correction?
6. How is quality of life correlated positively and negatively with other values and goals reinforced in the regulatory system?, and

system?, and

7. What is the relationship between regulation and personal autonomy?

In response to Question 7, the paper suggests that protective regulations usually limit (sometimes necessarily) the autonomy of those being protected, but 4 exceptions were identified where regulation can enhance autonomy, namely: a) regulations requiring disclosure; b) regulations requiring meaningful participation of consumers; c) regulations curbing autonomy-reducing practices; and d) regulations requiring environments that meet the minimum specifications for autonomy.

Based on review of research and scholarship on nursing home life, the following components of quality of life were emphasized for cognitively intact residents: continuity with preferred lifestyles; meaningful relationships and activities; control over daily life; and perceived dignity and self-esteem. For cognitively impaired residents, quality of life should be judged by intuitively obvious observable evidence of positive or negative affect, from which quality of life is inferred. The following points were made about measurement of quality of life:

1. Quality of life measures should lean more towards measuring outcomes than staff behavior thought to be associated with outcomes, emphasizing the components mentioned above.
2. Satisfaction with aspects of life and care should be measured by weighting satisfaction against the importance of those items to the individual resident.
3. Even on the face of it, the MDS is an inadequate screener for quality of life.
4. Methodological work is needed to minimize positive response biases in quality of life measures. Some ideas about how to overcome the bias are presented in the paper.
5. Empirical and conceptual work is needed to determine the level of tolerance of problems that should be allowed before a deficiency is noted on the quality of life condition (e.g., proportion of residents reporting a poor quality of life).
6. The National Institute on Aging Alzheimer's special care unit demonstration should be examined to look for measures that are suited to observing quality of life for persons with dementia.
7. More systematic and detailed strategies for social service review is needed; social services could be the point of accountability for maintenance of quality of life.
8. For corrective action purposes, develop a repository of practical examples of successful strategies that nursing homes have used that are associated with quality of life for subgroups of residents. Attention should be paid to staffing and environmental strategies.

Related to the current survey process, experiment with the following:

- Selecting much larger samples of residents for quality of life interviews;
- Conducting much of the quality of life survey in the evenings and on weekends;
- Emphasizing newly admitted residents in the quality of life samples; and
- Adding more social workers and older consumer activists to the survey teams.

Develop enhanced surveyor training around quality of life, including generating more case examples of what would constitute deficiencies of different levels. This training should assist surveyors with distinguishing between routines that facilities view as coping efficiently with regulations and actual regulatory requirements. Instruct surveyors in how to explore the quality of life implications of the way the facility handles negative reactions to environmental constraints that are permitted by regulation, including double rooms.

Dr. Kane recommended these long-range strategies:

- Review existing regulations to make sure that none impinge unnecessarily on resident autonomy or quality of life.
- Immediately implement the IOM Committee recommendation to study the costs and benefits of singly occupied rooms in nursing homes with a view to requiring some proportion of singly occupied rooms in all new construction or substantial renovation. The study should examine the construction and operating costs associated with a convention that requires that all rooms be capable of either single or double use as in hotel rooms.
- Monitor closely developments in assisted living in states that regulate the environments and service structure towards privacy, choice, and normal lifestyles. Refrain from imposing federal regulations that would require that these entities meet all OBRA standards.
- Encourage development and testing of private consumer guides and rating systems for nursing homes.

Response Summaries

Response Summaries

Margaret Gerteis, Ph.D.

From her perspective as a representative of the Picker Institute, a non-profit organization that researches quality of care from the patient's perspective, Dr. Gerteis noted the similarities between Gwen Uman's research and that of the Institute's for example; 1) stressing the patient's perspective, 2) basing research on specific occurrences that patients say matter and, 3) grouping the patient's responses into domains that can be linked to QoL improvement efforts. However, Dr. Gerteis noted that the Picker Institute has been reluctant to take on assessments of long-term care residents for reasons that both Dr. Uman and Dr. Rosalie Kane suggest. First, the task of compiling accurate data is labor intensive and requires onsite interviews. Second, there are difficulties assessing cognitively impaired individuals, not just with the data accuracy but also with the specificity in details provided.

Despite these drawbacks, Dr. Gerteis said she was persuaded by Dr. Uman and now believes several of the methodological problems in assessing quality have been resolved. In spite of this she stressed that an important question remains which is "How can such data best be used?" She commented further that as an investigative tool, the data may pinpoint where problems lie or which groups are at highest risk for poor care. Alternatively, the information might be used for external reporting to compare institutions for accreditation or consumer choice. This use, however, is more problematic since adjustments would need to be made for case mix or other differences. The most promising use of the data, according to Dr. Gerteis, is to target and prioritize improvements for internal use particularly for groups of patients.

Theodora Marcot, MS, RN

Ms. Marcot, a gerontological nurse, provides care management services for older adults facing transitions in their lives. In that role, she assists seniors and their families in finding ways to remain as independent as possible, whether at home, in assisted living or in nursing homes. Ms. Marcot posed the question of how we define quality of life (QoL) as opposed to quality of care. She suggested that the most important task for a nursing home in assuring a greater quality of life for residents is to find out who the person was before he/she came into the facility and to maintain as much of that individual's preferences as possible.

Unfortunately, present assessment tools measure functional abilities or disabilities to comply with licensing regulations -- quality assurance measures. Likewise, she noted that staff are not trained to identify personal factors that might lead to a greater quality of life. Assuring quality of care is a more mechanical measure of how an institution and its staff can meet the physical needs of its residents. Assuring quality of life requires determining what is important to maintain the personal autonomy and desires of each individual, and planning to meet those individual preferences.

In terms of obtaining reliable information, Ms. Marcot said she believes that we need to explore systems for assessing persons as individuals beyond their activities of daily living and develop methods to meet individual preferences within facilities. She said quality of life is not a measure of how quickly staff respond to physical needs but how well an institution recognizes and respects a person's individual preferences. Ms. Marcot agreed strongly with Dr. Kane's belief that HCFA should commission a study of costs and benefits of single occupancy rooms. As Dr. Kane stated, "The result of shared occupancy is a lack of opportunity to modify living space, control time, choose intimate associates, pursue interests and experience privacy, all of which seem related to quality of life." In conclusion, Ms. Marcot questioned whether or not the quality of life for residents in an institution is not directly proportional to the working quality of life of the staff.

Faith Mullen, Esq.

Ms. Mullen is a Senior Policy Analyst with the Public Policy Institute of the American Association of Retired Persons. Ms. Mullen said surveyors and residents each bring important insights to the process of evaluating quality of life issues. Surveyors may be in a better position to evaluate certain technical quality of life issues because of their familiarity with regulations. On the other hand, their expertise cannot be a substitute for resident satisfaction. Ms. Mullen cautioned that collecting information from residents has some limitations: the longer a resident is in a facility, the lower his or her expectations are likely to be; resident satisfaction may be heavily dependent on a resident's recent experiences and own personality; residents are dependent on staff and susceptible to staff influences; and there may be barriers to communicating with some residents.

Michael Tripple

As assistant director of the Minnesota survey agency, and representing the Association of Health Facility Survey Agencies, Mr. Tripple brought a regulatory perspective to the response panel. He noted that when the survey process changed about a year ago putting more emphasis on quality of life (QoL) aspects, there was a fair amount of enthusiasm, and awareness of quality of care as well as quality of life has increased. The changes that became effective in 1995 were good, but progress cannot be static, he said. In addition, he noted that one must recognize limitations of the survey process itself. Surveyors conduct a short review of a facility for three or four days once every 9-15 months. It is difficult to expect that on-going permanent compliance can be guaranteed by this process alone. The complaint process is also not sufficient in itself to assure compliance with QOL concerns. Rather, emphasis must be placed on internal systems-- screening, tools, or other systems that produce credible information. Perhaps the long-term care ombudsman or family councils need to be used more extensively.

Mr. Tripple also endorsed the suggestion for developing some measure of consumer satisfaction. However, he cautioned that

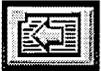
this data must be reliable. QOL is more subjective than quality of care. Surveyors need training to be familiar with QOL, he said. Since the nursing home population can change -- even on a day-to-day basis, this becomes a challenge for surveyors. The more we can get from the academic perspective saying this is a reliable tool, the better, he said. He recommended that regulations establish the minimum levels for compliance. Where regulations restrict individual freedom, there must be flexibility as long as the rights of individuals don't infringe on each other.

The role of nursing assistants is another critical issue, he said. Training requirements need reviewing and may require restoring sanctions under nurse aide registry provisions. Finally, Mr. Tripple said surveyors need to be part of the development of training components to develop interview techniques and other measures to assess and document QOL compliance.

Cat Selman, BS, ACC.

Ms. Selman is an activities consultant who serves as Vice President of the National Association of Activities Professionals (NAAP). She noted that the perspective she offers is that of the hands-on practitioner who interacts with the resident on a day-to-day basis. In response to Dr. Kane and Dr. Uman's papers, Ms. Selman noted that despite the power of some consumers to choose between facilities, this option is often not available to Medicaid recipients who cannot go elsewhere if not satisfied. Moreover, many residents and families are unaware of what to expect when they enter a nursing facility. Disagreeing with Dr. Uman, Ms. Selman commented that NAAP has found that new residents normally have the least amount of expectations for QOL. Their concerns normally focus on nursing, food, and cleanliness. These are quality-of-care issues, she noted. Furthermore, Ms. Selman felt that Dr. Uman's time frame of two weeks was insufficient time for residents to become adjusted to a long-term care environment and that resident satisfaction surveys would be skewed. As an alternative, most studies use a 90-day period to indicate adjustment to long-term care environment, she noted. NAAP members report that more than 50 percent of residents have marked degrees of cognitive impairment. Accordingly, the cognitively impaired often live from moment to moment. Thus, implementing indicators based solely on intact residents will not work on the nursing home population as a whole, she said.

In response to Dr. Kane's comments, Ms. Selman strongly endorsed that the current LTC structure, when implemented as written can provide more than "acceptable" levels of quality of life. Furthermore, she said the NAAP believes that improved quality of life is a reason for nursing home placement for the resident, which is not necessarily exchanged for nursing care. Specifically quality of life is the responsibility of the entire interdisciplinary team and the activity professional who is responsible for providing a calendar of events which reflects past and present interests and sees that these provide a successful experience. It is this approach that leads to quality of life. Ms. Selman concluded by stating that quality of life goes beyond quality of care and it is the job of the home to support residents as individuals, validate their presence, and encourage them to continue to pursue the interests which gave their life meaning prior to admission. Failure to thrive has been documented in infants, she said; now it is time to do the same for the long-term care resident.



[Return to Sharing Innovations in Quality Page](#)

Last Updated September 25, 1997

	Medicare	Medicaid	Help	Feedback	Search	FAQs
---	--------------------------	--------------------------	----------------------	--------------------------	------------------------	----------------------

the amount that can reasonably be estimated would have been paid for those services under Medicare payment principles (42 CFR 447.272), and

- In establishing payment rates, states must still take into account the situation of hospitals which serve a disproportionate number of low-income patients with special needs, as this requirement was incorporated in the new law (1902(a)(13)(A)(iv)).

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) comprehensively revised the statutory authority that applies to nursing homes participating in Medicaid. This revision, often referred to as nursing home reform, responded to general concern about the quality of nursing home care paid for by the Medicaid and Medicare programs, as well as findings and recommendations of a 1986 Institute of Medicine report. The repeal of the Boren amendment eliminated the requirement that states provide an assurance that, effective October 1, 1990, their rates:

"take into account the costs of complying with subsections (b) (other than paragraph (3)(F) thereof), (c) and (d) of section 1919 and provide, in the case of a nursing facility with a waiver under section 1919(b)(4)(C)(ii) for an appropriate reduction to take into account the lower costs (if any) of the facility for nursing care."

However, states are still required to comply with all of the subsections of Section 1919 of the Act. The repeal of the Boren amendment has not relieved states of the responsibility of promoting quality of care for their beneficiaries served in nursing homes.

Enclosure 2

Public Process Options

States that do not use their existing administrative procedures to satisfy the public process requirements may use, at their option, one of the public processes established in the Federal Register for Section 1115 waiver demonstrations (see 59 FR 49250, September 27, 1994). This allows states the flexibility to design their public process based on examples of what we find acceptable. Options which HCFA considers acceptable and which states may elect to follow include:

- Hold one or more public hearings, at which the proposed rates, methodologies, and justifications are described and made available to the public, and time is provided during which comments can be received. Hold one or more additional public hearings, at which the final rates, methodologies, and justifications are described and made available to the public.
- Use a commission or similar process, where meetings are open to members of the public, in the development of proposed and final rates, methodologies, and justifications.
- Include notice of the intent to submit a state plan amendment in newspapers of general circulation, and provide a mechanism for members of the public to receive a copy of the proposed and final rates, methodologies, and justifications underlying the amendment, and an opportunity, which shall not be less than 30 days prior to the proposed effective date, to comment on the proposed rates, methodologies, and justifications.
- Include any other similar process for public input that would afford an interested party a reasonable opportunity to learn about the proposed and final rates, methodologies, and justifications, and to comment on the proposed rates, methodologies, and justifications.

Clarification of Public Process Requirements In Relation to Existing Public Notice Regulation Although we believe that Sections 1902(a)(4)(A) and 1902(a)(30) of the Act may authorize a separate Federal requirement for public notice, it would be unduly burdensome to continue to hold states to a separate Federal requirement for institutional services when all states are required to establish their own public process for determination of rates under BBA. HCFA believes that whatever public process states elect to implement which meets the requirements of the new 1902(a)(13)(A) will satisfy HCFA's general



Volume II, Number 4; December 1996/January 1997

- ❑ Advocate for Nursing Home Residents Receives HCFA's Highest Award
- ❑ HCFA Prepares for Y2k
- ❑ From the Administrator
- ❑ HCFA On-Line: Market Research
- ❑ Upcoming Events
- ❑ HCFA Approves Maryland Medicaid Health Reform Waiver
- ❑ Medicaid Conference Focuses on Minority Health Care
- ❑ ResDAC to Improve Access to HCFA Data
- ❑ Key Regulations/Notices
- ❑ 1997 Medicare Facts
- ❑ Credits

Advocate for Nursing Home Resident Receives HCFA's Highest Award

Mrs. Elma Holder, a founder of the National Citizens' Coalition for Nursing Home Reform (NCCNHR), was recently presented the Administrator's Achievement Award, HCFA's highest award, in recognition of her success in promoting the rights and interests of the nation's nursing home residents. In presenting the award, HCFA Administrator Bruce Vladeck praised Mrs. Holder's leadership in spurring nursing home reforms that have significantly improved conditions for the nation's approximately 1.5 million nursing home residents.

"Without Elma Holder, there would not have been an OBRA 87," Vladeck stated, citing the Omnibus Budget Reconciliation Act of 1987 that tightened state and federal regulation of the nation's 16,700 nursing homes. He added, "Conditions in nursing homes would look very different from the way they are today."

In commenting on the OBRA 87 nursing home reforms, Vladeck told a gathering of approximately 200 long term care and citizen advocates at the award presentation that the last of the reforms, which went into effect July 1, 1995, gave the States a variety of ways to penalize nursing homes -- including fines and/or termination of Medicare or Medicaid reimbursement.

Over the past 15 months, Vladeck noted, the States, under contract with HCFA, have surveyed 40,000 nursing homes, of which 30,000 were found to have problems and were threatened with some form of penalty. In about 90 percent of the cases, the problems were corrected without the penalty being imposed.

"We have good evidence that the reforms in place since 1990 have led to concrete improvements in care throughout the industry," Vladeck said. Some examples he cited include: a 50 percent reduction in physical restraint use and in dehydration incidents, a 25 percent decrease in antipsychotic drug use, and a 30 percent drop in the use of indwelling catheters.

In working to protect the rights and interests of nursing home residents, Mrs. Holder served as director of NCCNHR from 1978 through 1995. She now works with NCCNHR on policy and fund raising. She

Secondly, suits are being won against nursing homes for physical restraint use leading to adverse consequences of long-term restraint use. Several criminal cases have been successfully prosecuted by offices of State Attorneys General and the Department of Justice.⁶ For example, in the case of the Commonwealth of Pennsylvania v. GMS Management, the Attorney General successfully prosecuted a nursing home for involuntary manslaughter of two residents. Both residents died of sepsis secondary to numerous, severe pressure ulcers which resulted from long-term physical restraint use, prolonged immobility, and inadequate nutrition.⁷

Thirdly, suits are being won against nursing homes and hospitals for restraint-related deaths and are strongly supported by the work of Dr. Steven Miles. For example, a Texas jury gave a unanimous verdict of gross negligence in a case of a 66 year old woman who died after being found hanging from her rehabilitation hospital bed with a vest restraint wrapped around her neck. They awarded her daughter over five million dollars.⁸

The new trends in litigation related to physical restraints represent a significant shift away from the belief in liability in cases of non-restraint. Ironically, further reduction in the use of physical restraints may, at least in part, occur as suits are won against nursing homes for overusing or misusing these devices. As more research provides evidence to support this shift in legal liability, clinical practice will also change. Clearly, fear of liability is an inadequate reason to use restraints.

[Editor's note- footnotes for this article can be found on page 9 of the Newsletter]

Acute Care Hospitals Report

by Jerry Arzt

Hospitals are even more prone to be sued, for a variety of reasons, than nursing homes. Therefore, it is not surprising that they have sometimes viewed restraints as a necessary strategy to head off suits that might result from a patient falling, or from patients interfering with treatments. The scientific evidence that restraints do not decrease the risk of injuries from falls is overwhelming. Other studies have even questioned whether restraints can effectively prevent treatment interference. Finally, the severe negative physical and emotional consequences of restraint use are well documented.

The question we are seeking to answer today is how these scientific facts impact on the practical and legal position of health care facilities. The conditions and issues in hospitals are not exactly the same as those in nursing homes, presented above. Nevertheless, the situation of hospitals can be instructive for any facility with a restraint reduction program.

Professor Marshall Kapp, of Wright State University, recently presented a seminar in Washington, DC, entitled "Injury Risks and Legal Consequences of Hospital Restraints." What follows is excerpted from material included in that presentation.



We have reported in the past that we knew of no instances in which nursing homes had been successfully sued solely for "failure to restrain." Professor Kapp finds that this has not been the case for hospitals. One search of legal data bases covering court cases from 1980 to 1995 revealed, according to Professor Kapp, 43 verdicts regarding "failure to restrain" of which hospitals were found "liable in 18 instances....," and "not liable 19 times....," Six cases were settled. Another search found 23 cases where a hospital was liable for "failure to restrain." (However, it is not clear from this kind of summary whether or not the specific circumstances of each case went beyond simple "failure to restrain" to include other inculpatory facts.) On the surface, these are alarming statistics. However, Professor Kapp sees the situation as radically altered over the last decade, because "standards of care in this arena" have undergone "a process of rapid evolution."

Professor Kapp recounts the changes wrought by OBRA 87, the various FDA alerts, standards, and reporting requirements, as well as the new Joint Commission of Healthcare Organizations (JCAHO) standards which reflect to a great degree the new understanding of restraints found in OBRA 87. Professor Kapp also summarizes new standards of care put forward by numerous professional and advocacy organizations, both in the USA and Canada, which reflect advances in scientific knowledge



Volume II, Number 2; October 1996

1. Meetings Held on Nursing Home Enforcement Regulations
2. Medicare Service Center to Open
3. From the Administrator
4. Fraud Investigation Database Nears Completion
5. HCFA Promotes Removal of Restraints in Nursing Homes
6. Study Finds Differences in Health Care Utilization Patterns
7. Upcoming Events
8. New Appointments
9. October is Breast Cancer Awareness Month
10. HCFA Announces Hospital Payment Rates for FY 97
11. Medicare/Medicaid History Video Available
12. Ann Landers to Offer Advice at Flu Prevention Press Conference
13. Key Regulations/Notices
14. To Our Readers
15. Credits

Meetings Held on Nursing Home Enforcement Regulations

In a series of listening sessions in Seattle, Chicago, and Atlanta over the last two months, nursing home residents, staff, and surveyors discussed with HCFA staff their views on nursing home quality and improvements.

At the session in Seattle, HCFA Administrator Bruce Vladeck and HCFA's Health Standards and Quality Bureau (HSQB) Director, Dr. Richard Besdine, discussed with participants the need for more communication between residents and staff and the problems that result from high staff turnover.

Facility administrators proposed that on-site surveys focus more on patient care rather than on citations for potentially harmful situations. Nursing personnel recommended that HCFA consider having surveys completed by peers (therapists reviewing therapists, etc.), and called for HCFA to issue clearer definitions of terms such as "potential for harm" and "substandard care." The state surveyors noted that the improved enforcement standards have resulted in fewer citations and that they prefer including nursing home administrators in the surveyor team deliberation process.

After gathering information and suggestions regarding HCFA's nursing home policies, HSQB's Center for Long Term Care plans to reexamine the agency's policies and determine any changes that need to be made. For more information on the listening sessions, please contact Kathy Lochary at 410/786-6770 (e-mail: KLochary@hcfa.gov).

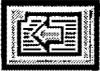
Fraud Investigation Database Nears Completion

Medicare contractors have entered over 1000 fraud cases into HCFA's Fraud Investigation Database (FID), a nationwide computerized system devoted to Medicare fraud and abuse data accumulation.

The FID contains information on the status of all Medicare fraud cases being handled by HCFA, its contractors, and law enforcement agencies. Organizations with access to the FID will be able to monitor volume and types of cases, identify trends, and track case development across the country through simple data review.

Among the organizations with access to the FID are: HCFA central and regional offices, the Office of the Inspector General, the Federal Bureau of Investigation, the Department of Justice, the Civilian Health and Medical Program for the United States, the Postal Inspectors Offices, Medicaid Fraud Control Units, and Medicare contractors.

Many of HCFA's law enforcement partners are using the FID to track fraud cases around the country. Organizations are looking forward to December 31, 1996, when all cases from 1993 to present will have been entered into the database. For additional information on the Fraud Investigation Database, please call Shantelle Goodall at 410/786-0189 (e-mail: sgoodall@hcfa.gov) or Glenn Locklear at 410/786-0189 (e-mail: glocklear@hcfa.gov).



HCFA Promotes Removal of Restraints in Nursing Homes

In an effort to reduce the use of chemical and physical restraints in nursing homes, HCFA's regional offices are working with providers of nursing home services and state and federal surveyors to increase awareness and training.

This activity, named the Restraint Reduction Initiative, began in HCFA's Philadelphia Regional Office. Studies indicate that, for this region, the use of restraints in nursing homes is approximately 25 percent, five percent higher than the national average. HCFA's goal is to reduce the national restraint rate to 10 percent or less.

The impetus for this initiative came from the realization that, despite federal regulations limiting restraint use, a number of nursing homes still use physical or chemical restraints for their residents. A physical restraint is any device that limits a person's ability to move about freely in the environment or limits access to one's body. A chemical restraint is any psychoactive medication used for purposes of discipline or convenience and not needed to treat medical symptoms.

In working with nursing homes and medical societies, HCFA has helped train hundreds of individuals on the dangers of restraints, the need for individualized assessment, and alternatives to restraint usage. A two-day conference, in which national consumer and advocacy groups will discuss ways to educate the public about restraint use, is planned in Philadelphia in early December. For more information on this conference or initiative, please contact Jerry Arzt at 215/596-6952 (e-mail jarzt@hcfa.gov).



Study Finds Differences in Health Care Utilization Patterns

Race and income continue to be major factors influencing the type of services the elderly receive, according to a recently released HCFA study.

	Medicare	Medicaid	Help	Feedback	Search	FAQs
---	----------	----------	------	----------	--------	------

Specification of HCFA's MDS/RAI and Effective Dates

OBRA 87 required that HCFA designate a resident assessment instrument (RAI) that includes a minimum data set (MDS). HCFA's RAI consists of the MDS, triggers, and 18 Resident Assessment Protocols (RAPs). States were then required to specify an RAI for use by all certified long term care facilities to assess and plan care for residents. Each State's RAI must consist of at least HCFA's MDS. Any State-specific items are included in an optional Section S.

The original MDS/RAI was introduced by HCFA in 1990 and implemented in all States by mid-1991. HCFA published version 2.0 of the RAI in State Operations Manual #272 in May 1995. SOM #272 required States to adopt version 2.0 of the RAI by January 1, 1996. An extension was granted to those States that had developed automated systems to collect MDS data from facilities.

The SOM process is HCFA's mechanism for formally designating the RAI. The version of the MDS/RAI contained in SOM#272 is dated 10/18/94N. The 10/18/94N form continues to be the version of the MDS/RAI to which Federal requirements pertain. However, HCFA corrected a number of minor errors on the MDS in releasing a revised version of the form at the September 1996 RAI Coordinators' conference. The corrected version of the form is dated 10/18/94H. States, facilities and software vendors were instructed by HCFA that they could use the revised 10/18/94H version, although a formal SOM containing this version has not yet been released by HCFA.

With the pending introduction of a prospective payment system (PPS) for SNFs on July 1, 1998, SNFs will be required to complete the MDS more frequently for patients whose stay is covered by Medicare. Several codes have been added to Sections AA8b and A8b, "Reasons for Assessment" to accommodate the Medicare schedule. HCFA has released a revised MDS dated 1/30/98 that includes changes needed for the SNF PPS system. At this point, software vendors may begin to transition their products to be compatible with the 1/30/98 form. HCFA will publish a new SOM in the interim, which will designate the 1/30/98 version of the RAI as the version to be used by all States and facilities when HCFA's MDS automation requirements become effective. States will continue to have the ability to add additional items to Section S if they so desire. Section T of the MDS will also be required for Medicare-covered patients each time an MDS is required after July 1 for payment purposes. Section U may also be required for Medicare-covered patients at some point in the future.

HCFA published final regulations requiring facilities to encode and transmit MDS data to the State on December 23, 1997. Those regulations go into effect on June 22, 1998. The standard data collection system developed by HCFA for receipt and validation of MDS records at the State level will be programmed to receive the 1/30/98 version of the MDS. HCFA's automation requirements also dictate that States previously granted an extension from implementing version 2.0 of the MDS will have converted to version 2.0 of the MDS by the effective date of the automation requirements.

SN/1-30-98

Return to :



[MDS 2.0 Technical Information Home Listing](#)

or



[HSQB Home Listing](#)

Last updated February 27, 1998

	Medicare	Medicaid	Help	Feedback	Search	FAQs
---	----------	----------	------	----------	--------	------



Quality of Life - Quality of Death in Long Term Care

PANEL 4

Presenter:

Robert Rubinstein, Ph.D., Director of Research Philadelphia Geriatric Center

Dr. Rubinstein is a cultural anthropologist who has focused his interests on the social and community life of nursing homes. He has received funding from the National Institute on Aging to study death and dying in four ethnically and religiously diverse nursing homes in Philadelphia.

Response Panel:

Anita Rosen, Ph.D.
Senior Staff Associate for Aging
National Association of Social Workers

Naomi Nairman, MPA
President/CEO
American Hospice Foundation

Toby Edelman, Esq.
Attorney
National Senior Citizens Law Center

Sarah Greene-Burger, RN-C, MPH
National Citizens Coalition for Nursing Home Reform

Quality of Life - Quality of Death in Long Term Care Robert Rubinstein, Ph.D. and Miriam Moss

Dr. Rubinstein's presentation focused on a dimension of quality of life that is often ignored, the quality of dying in long term care facilities. He stressed that although it is right and natural to view nursing homes as places of living and life, there is a need to bring recognition to the fact that nursing homes are also places of dying and death. Although great effort has been directed toward understanding and gaining knowledge about the quality of life in nursing homes, very little of this attention has been directed toward understanding the effects of death on staff, family members and surviving residents, and on overall institutional quality. He expressed his astonishment that although nursing homes are accepted as places of life and death there is virtually no systematic knowledge on the processes of death and dying in these settings. Dr. Rubinstein believes such knowledge may be significant in evaluating the quality of life in long-term care settings.

Dr. Rubinstein provided some conceptual background for quality of dying through a broad overview of the literature on death and dying. This overview included discussions on:

1. The cultural beliefs regarding the meanings of a "good death" and a "bad death";
2. The relationship of quality of life to quality of death;
3. Hospice in long term care;
4. Death of the "old";

5. Concerns of the aged about dying;
6. Staff issues (limited skills to address the emotional needs of residents who are dying);
7. Reactions of family members; and
8. The issues surrounding the measurement of quality of dying.

Throughout this discussion Dr. Rubinstein noted the limited amount of research for each of these areas and the need for further investigation.

Next, he provided a brief discussion on the multidimensional nature of quality of dying before describing in-depth specific dimensions of this construct. The following dimensions which are potentially measurable components of quality of death discussed:

1. Physical status and the experience of pain;
2. Preparation for death;
3. Resident functioning (level of consciousness and ability to participate in meaningful activities);
4. Psychosocial aspects of dying;
5. Institutional procedures and staff education;
6. Coordination of information;
7. The dying person; and
8. Hospice care.

Tables of key issues for each of these dimensions were also provided. For example the key issues listed for the Preparation for the Death dimension were:

1. Is there a system in place to insure adequate and prompt flow of information concerning death and dying? To staff at all levels? To family? To the dying resident? To surviving residents?
2. Is the system reviewed periodically to insure its optimal functioning?
3. What formal or informal criteria are used to identify a dying person? How are these criteria communicated and discussed?

In conclusion, Dr. Rubinstein offered his ideas for future quality of dying research. His research agenda included the following topics:

1. What is the optimum content of hospice services for end-stage dementia either as a primary diagnosis or when combined with other disorders?
2. How is terminality determined or derived "on the ground" in different settings?
3. What positives do families find in nursing home terminal care?
4. What policies do nursing home have, either expressed or de facto, concerning terminal care?
5. How does terminal care of the dementia patient in fact differ from terminal care of the cognitively intact resident?
6. To what extent are guidelines from the National Hospice Organization and the philosophy of

6. To what extent are guidelines from the National Hospice Organization and the philosophy of hospice care different from actual practices in nursing homes?

Response Summaries

Anita Rosen, Ph.D.

Representing the National Association of Social Workers, Anita Rosen initially outlined some major changes in the industry that she thought had a bearing on the discussions. First, Dr. Rosen said there is an integration taking place between long-term care and acute care. As a result of this integration, the psychosocial model is perhaps becoming more suitable than the medical model, even though most nursing homes are based on the medical structure. She suggested that a third integration take place which would require that palliative care be given more universally. Professional social work practice focuses on the psychosocial model but is the only profession for which HCFA does not require educational credentials or certifications. She said that too often, social services designees do not have a recognized M.S.W. degree or B.S.W. with supervision.

Dr. Rosen expressed special concern over the residents without family or friends, whom she considers "the most vulnerable." One of the most difficult issues social workers face is assisting someone who is dying when they have no contacts on the outside, she noted. In such instances, it is difficult to know who this person is or was and what the social worker should be recommending. Another disturbing situation, in her view, is that there are so few ethics committees in nursing facilities. Until we look at nursing homes like other health care institutions, she said, there will not be accountability.

Dr. Rosen also noted that death and dying is a societal problem, yet most people lack training in death and dying. The subject is not well addressed in professional curriculums, and it is most ignored at the lowest levels of education. Pay and reimbursement is also an issue, she said. While palliative care is commonly conceived to be beneficial, hospice care is not for everyone. It has been oriented toward home based services. Moreover, hospice has not been available in all states for Medicaid residents.

Dr. Rosen was pleased to note the recognition given to social services by Dr. Kane. These include such important tasks as: adjusting to the nursing home, providing counseling services, helping with depression and advance directives, serving as a patient advocate, aiding families in mourning and grief work and participating in ethics committees. Too much time is currently spent in financial paperwork and not enough attending to duties mentioned previously. In closing, Dr. Rosen expressed concern that surveyors may not be attuned to psychosocial issues, and professional social workers should be included on or consultant to survey teams.

Naomi Naierman, MPA

In responding to Robert Rubinstein's paper on the issue of dying in nursing homes, Naomi Naierman, President/CEO of the American Hospice Foundation, focused her remarks on hospice services that she said have been put in a box from which in practice, it has long been released." She indicated that a dying person's chief concerns are related to pain, loss of control and abandonment and, she noted, hospice meets these needs with a team of caregivers to help the patient and family. As a patient-centered system of care, Ms. Naierman said, hospice helps the dying person, not only to manage pain, but also to put life in order, emotionally, socially, legally and spiritually. Families and other residents are able to grieve and come away feeling all the loose ends have been tied up. The positive emotions emanating from this process often have a ripple effect on the nursing home. Ms. Naierman, however, disagreed with Dr. Rubinstein's comment that hospice has been created primarily for cancer patients. On the contrary, she noted, hospice has been successfully applied to persons with AIDS, Alzheimer's disease, and end-stage renal and cardiovascular conditions.

In closing, Ms. Naierman recommended that additional research be conducted to determine whether hospice results in lower hospitalizations and emergency visits of nursing home residents; the impact that hospice has on the quality of life of surviving residents; a comparison of residents treated by hospice compared to individuals who are not in a nursing home and what can be learned from hospices for conditions other than cancer.

Toby Edelman, Esq.

Commenting on Dr. Rubinstein's paper, Ms. Edelman began by expressing her initial view that end of life should not be the focus of a session on quality of life in nursing homes. People do not go to nursing homes to die; they go, generally, because they cannot manage to live on their own any longer. However, because so many people do in fact die in nursing homes, she said she finds it reasonable and appropriate to look at death in nursing homes.

Ms. Edelman then raised two concerns about Dr. Rubinstein's paper. First, she expressed the view that the paper did not give sufficient attention to cultural differences. The "good death," while perhaps reflecting the dominant culture, is not universally accepted, she noted. Not all people place such high value on consciousness, intentionality, and choice. Particularly at the end of life, she said, people may revert to religious or racial or ethnic or cultural or regional differences. Second, Ms. Edelman expressed concern about incorporating hospice principles into nursing home care at the end of life. While hospice principles of pain management and individualized care are relevant and appropriate for all nursing homes, other principles may not be. People choosing hospice have made a particular decision about end of life issues. People choosing a nursing home may have made different choices; they may have intentionally chosen a nursing home because they do not want to forego possible treatment. A right to hospice care should not be made into a duty to choose hospice care.

Finally, Ms. Edelman questioned the demands of the reimbursement system, which are often interpreted to require a resident to move to a so-called hospice bed to receive hospice care. She said moving residents within a facility at the end of life in order to accommodate requirements or facilities' interest in maximizing reimbursement rates creates tremendous problems for residents, who are removed from a familiar environment and customary caregivers.

Sarah Greene Burger RN-C, MPH

As an advocate for change in nursing homes and representative of the National Citizens Coalition for Nursing Home Reform, Sarah Greene Burger noted that pain is a frequent complaint among 40-70 percent of nursing home residents, who often wait many minutes for responses to requests for medication. Even those cognitively impaired residents in the last stages of dementia can reliably express signs of pain. She suggested that the hospice principles of palliative care should be incorporated into nursing facilities, many of which do not currently provide appropriate or adequate responses to resident indications of pain.

Ms. Burger highlighted a recent publication mentioned by Dr. Rubenstein entitled *Briefing Book for a Good Dying: Shaping Health Care in the Last Months of Life* by Brock and Foley. This book identified three elements during the dying process which enable a person's needs to be met. The first element is sustaining relationships. Long lasting associations can best be achieved by having a stable staff that is permanently assigned to the resident. Over time, staff and residents establish a relationship which includes a natural give and take. The second component -- sustaining the integrity of self, is based in great part on the fact that staff know each resident, their life story and their responses to events, large and small. The final element is achieving closure to one's life through reconciliation with one's past and one's self identity and with others, which is also made possible through lasting relationships with staff. She cautioned that quality-of-life indicators can only address those inputs which are measurable. With this in mind, quality-of-life indicators are not an end in themselves, but alert us to changes that need to occur. In sum, this data must be combined with "best practices," she said. In each case, the practice must always start with the individual.



[Return to Sharing Innovations in Quality Page](#)

Last Updated September 25, 1997



[Return to the Brookings Home Page](#)

Brookings Study

Persons with Disabilities: Issues in Health Care Financing and Service Delivery

Edited by Joshua M. Wiener, Steven B. Clouser and David L. Kennell

Date of Publication: December 13, 1995

324 pages

Paper: \$16.95 (ISBN 0-8157-9379-0)

Brookings Bookstore: 202/797-6258 or 1/800-275-1447

Are We Adequately Serving Persons with Disabilities?

As the American population continues to age -- and the number of the very oldest Americans grows even faster -- the policy debate over how to best care for persons with chronic disabilities becomes increasingly relevant. At the same time, new attitudes over how the needs of both younger and older disabled Americans should be addressed make these issues ever more complex.

A new collection of studies published by Brookings explores in detail the policy issues posed by providing services to this population. In *Persons with Disabilities: Issues in Health Care Financing and Service Delivery*, researchers present policy-relevant analyses on the acute and long-term care needs of disabled Americans. The volume is edited by Brookings senior fellow Joshua Wiener, Health Care Financing Administration official Steven Clouser, and David Kennell of the consulting firm of Kennell and Associates.

Persons with Disabilities represents a selection of five years of research conducted by a consortium of research organizations led by Lewin-VHI, Inc., and including Brookings, Duke University, Mathematica Policy Research, Inc., the Johns Hopkins University, the Urban Institute, DataChron, and the MEDSTAT Group. The Health Care Financing Administration funded the research.

"Chronically disabled persons often require a broad array of both acute and long-term care services," the editors note in their introduction. "It is commonly recognized that the disabled population needs nursing home, home care, and other long-term care services, but it is less widely appreciated that they also use physician and hospital care extensively. Though most long-term care services are provided by family members and friends, government is a major source of financing for paid long-term care services in the United States."

In Part I, Health Care Financing Administration administrator Bruce Vladeck reviews the progress of the past ten years and presents an agenda for future action.

Part II deals with public and private roles in financing long-term care. Lisa Alexih and Steven Lutzky analyze the rapidly growing market for private long-term care insurance, focusing on whether government should play a greater role in regulating such insurance and educating the public about it. Brian Burwell and William Crown focus on Medicaid estate planning -- the practice whereby elderly people divest their assets in order to appear poor enough to qualify for Medicaid nursing home benefits.

Part III of the volume provides quantitative estimates of the use of and expenditures for acute and long-term care services. Lisa Alexih, John Corea, and David Kennell examine health care expenditures for those with and without disabilities. In a related chapter, Kenneth Manton and Eric Stallard track

trends in Medicare utilization and expenditures for persons with disabilities. Judith Kasper analyzes the effect of cognitive impairment, such as Alzheimer's Disease, on the use of physician and hospital services. In addition, Joshua Wiener, Catherine Sullivan, and Lisa Alecxih estimate out-of-pocket expenditures for nursing home care now and in the future.

The book's final section deals with the public policy efforts over the last decade to expand noninstitutional long-term care services. Korbin Liu, Jean Hanson and Teresa Coughlin analyze why some persons who met the disability eligibility criteria for Connecticut's home care program did not receive services. Sharon Long explores whether the provision of paid home and community-based services supplements or displaces informal care provided by family and friends. Jennifer Schore reports on the huge geographic variation in the use of the Medicare home health benefit. And, finally, Joshua Wiener and Catherine Sullivan synthesize the available policy research on the younger population with disabilities.

Financial support for *Persons with Disabilities: Issues in Health Care Financing and Service Delivery* was provided by the Health Care Financing Administration's Office of Research and Demonstrations. Earlier versions of the research published here were presented at a conference at the Brookings Institution in November 1994.



[Top of the page](#)



[The Brookings Home Page](#)

<META NAME="keywords" CONTENT="Medicare, Medicaid, health care, HCFA Review, initiatives, quality assurance">

Health Care Financing Review

Summer 1995
Volume 16, Issue 4

New Initiatives and Approaches in Assuring Health Care Quality

Copies of the current issue of the Health Care Financing Review are available from the U.S. Government Printing Office at (202) 512-1806. The Price of a single issue is \$15.00. The price of a one-year subscription is \$29.00 per year and includes four quarterly issues as well as an annual statistical supplement. Questions regarding the submission of articles to the Review should be directed to Linda Wolf, Editor-in-Chief, at (410) 786-6572. Articles in this issue include the following:

Issues in Measuring and Improving Health Care Quality **Maria A. Friedman, D.B.A.**

This issue of the Health Care Financing Review focuses on issues and advances in measuring and improving the quality of care, particularly for Medicare and Medicaid beneficiaries. Discussions of quality-related topics are especially timely, given the growing and widespread interest in improving quality in the organization, financing, and delivery of health care services. This article has several purposes. The first is provide a brief description of some of the causes underlying the growth of the care quality movement; the second is to provide a contextual framework for discussion of some of the overarching themes that emerge in this issue. These themes include examining conceptual issues, developing quality measures for specific sites and populations, and creating or adapting data sets for quality-measurement purposes.

Health Care Quality Improvement Program: A New Approach **Barbara J. Gagel, M.B.A.**

The Health Care Financing Administration (HCFA) has embarked on a new program to ensure the quality of care provided to Medicare and Medicaid beneficiaries. The approach, entitled the Health Care Quality Improvement Program (HCQIP), focuses on improving the outcomes of care, measuring improvement, and surveying for patient satisfaction. HCQIP, still in its infancy, is undertaken in collaboration with the providers of care. This article describes HCQIP.

Toward a 21st Century Quality-Measurement System for Managed-Care Organizations **Rodney C. Armstead, M.D., Paul Elstein, Ph.D., and John Gorman**

As the Nation's largest managed-care purchaser, the Health Care Financing Administration (HCFA) is working to develop a uniform data and performance-measurement system for all enrollees in managed-care plans. This effort will ultimately hold managed-care plans accountable for continuous improvement in the quality of care they provide and will provide information to consumers and purchasers to make responsible managed-care

choices. This effort entails overhauling peer review organization (PRO) conduct of health maintenance organization (HMO) quality review, pilot testing a new HMO performance-measurement system, establishing criteria for Medicaid HMO quality-assurance (QA) programs, adapting employers' HMO performance reporting systems to the needs of Medicare and Medicaid, and participation in a new alliance between public and private sector managed-care purchasers to promote quality improvement and accountability for health plans.

Measuring Quality of Care Under Medicare and Medicaid
Stephen F. Jencks, M.D.

The Health Care Financing Administration's approach to measuring quality of care uses an accepted definition of quality, explicit domains of measurement, and a formal validation procedure that includes face validity, construct validity, reliability, clinical validation, and tests for usefulness. The indicators of quality for Medicare and Medicaid patients span the range of service types, medical conditions, and payment systems and rest on a variety of data systems. Some have already been incorporated into operational systems while others are scheduled for incorporation over the next 3 years.

Quality of Care in Teaching Nursing Homes: Findings and Implications

Peter W. Shaughnessy, Ph.D., Andrew M. Kramer, M.D., David F. Hittle, Ph.D., and John F. Steiner, M.D.

This article explores policy implications and selected methodological topics relating to long-term care (LTC) quality. We first discuss the Teaching Nursing Home Program (TNHP), in which quality of care in teaching nursing homes (TNHs) was found to be superior to the quality of care in comparison nursing homes (CNHs). A combination of outcome and process/structural measures was used to evaluate the effects of care and underlying reasons for superior TNH outcomes. Second, we explore policy and analytic ramifications. Conceptual, methodological, and applied issues in measuring and improving the quality of LTC are discussed in the context of TNH research and related research in home care.

Reconciling Practice and Theory: Challenges in Monitoring Medicaid Managed-Care Quality

Marsha Gold, Sc.D., and Suzanne Felt, M.P.A.

The massive shift to managed care in many State Medicaid programs heightens the importance of identifying effective approaches to promote and oversee quality in plans serving Medicaid enrollees. This article reviews operational issues and lessons from the ongoing evaluation of a three-State demonstration of the Health Care Financing Administration's Quality Assurance Reform Initiative (QARI) for Medicaid managed care. The QARI experience to date shows the potential utility of the system while drawing attention to the challenges involved in translating theory to practice. These challenges include data limitations and staffing constraints, diverse levels of sophistication among States and health plans, and the practical limitations of using quality indicators for a population that is often enrolled only on a discontinuous

basis. To overcome these challenges, we suggest using realistically long time frames for system implementation, with intermediate short-term strategies that could treat States and managed-care plans differently depending on their stage of development.

Development and Testing of Nursing Home Quality Indicators

**David R. Zimmerman, Ph.D., Sarita L. Karon, Ph.D., Greg Arling, Ph.D.,
Brenda Ryther Clark, R.N., M.S., Ted Collins, R.Ph., Richard Ross,
and Francois Sainfort, Ph.D.**

In this article, the authors report on the development and testing of a set of indicators of quality of care in nursing homes, using resident-level assessment data. These quality indicators (QIs) have been developed to provide a foundation for both external and internal quality-assurance (QA) and quality-improvement activities. The authors describe the development of the QIs, discuss their nature and characteristics, address the development of a QI-based quality-monitoring system (QMS), report on test of the QIs and the system, comment on methodological and current QI validation efforts, and conclude by raising further research and development issues.

A Data-Driven Approach to Improving Care of In-Center Hemodialysis Patients

William M. McClellan, M.D., M.P.H., Pamela R. Frederick, M.S.B., Steven D. Helgerson, M.D., M.P.H., Risa P. Hayes, Ph.D., David J. Ballard, M.D., Ph.D., and Michael McMullan, M.B.A.

Health care providers, patients, the end stage renal disease (ESRD) networks, and HCFA have developed the ESRD Health Care Quality Improvement Program (HCQIP) in an effort to assess and improve care provided to ESRD patients. Currently, the ESRD HCQIP focuses on quality indicators (QIs) for treatment of anemia, delivery of adequate dialysis, nutritional status, and blood-pressure control for adult in-center hemodialysis patients. QIs were measured in a national probability sample of ESRD patients, interventions and evaluations of the interventions are beginning. The ESRD HCQIP illustrates a way to mobilize the strengths of the public and private sectors to achieve improved care for special populations.

Florida's Medicaid AIDS Waiver: An Assessment of Dimensions of Quality

Marie E. Cowart, Dr.P.H., and Jean M. Mitchell, Ph.D.

Some State Medicaid agencies have implemented home and community-based waiver programs targeting acquired immunodeficiency syndrome (AIDS) patients. Under these initiatives, state Medicaid agencies can provide home and community-based services to persons with AIDS (PWA) as an alternative to more costly Medicaid-covered institutional care. This article evaluates quality of care under the Florida Medicaid waiver for PWA along two dimensions: program effectiveness and client satisfaction. Clients are really satisfied with their case managers and the range and availability of services. Case managers appear to be well

Nursing Homes: Too Early to Assess New Efforts to Control Fraud and Abuse (Testimony, 04/16/97, GAO/T-HEHS-97-114).

Although Medicaid is the largest single payer for nursing home care, Medicare pays a substantial portion of the health care costs of nursing home residents. For the opportunistic provider, a nursing home represents a vulnerable elderly population in a single location and the opportunity for multiple billings. Many nursing home patients are mentally impaired, and their care is controlled by the nursing home. Because these patients would not realize what items or services were billed on their behalf, some providers may take advantage of the situation by submitting fraudulent claims. GAO testified that fraudulent billing has occurred because (1) the complexities of the reimbursement process invite exploitation and (2) poor control over Medicare claims has reduced the likelihood that inappropriate claims will be denied. GAO is encouraged by recent efforts to combat fraud and abuse--the pending implementation of provisions in the Health Insurance Portability and Accountability Act and a proposal made by the administration.

----- Indexing Terms -----

REPORTNUM: T-HEHS-97-114
TITLE: Nursing Homes: Too Early to Assess New Efforts to Control
Fraud and Abuse
DATE: 04/16/97
SUBJECT: Health care programs
Nursing homes
Fraud
Medical expense claims
Claims processing
Therapy
Elderly persons
Health care cost control
Program abuses
Overpayments
IDENTIFIER: Medicare Program
HHS Operation Restore Trust
Medicaid Program

Fraud and Abuse: Medicare Continues to Be Vulnerable to Exploitation by Unscrupulous Providers (Testimony, 11/02/95, GAO/T-HEHS-96-7).

GAO discussed challenges Medicare faces in battling fraud and abuse in the health care system, focusing on reasons that: (1) Medicare is an appealing target for unscrupulous providers; and (2) abusive practices persist despite efforts by program managers and law enforcement agencies. GAO noted that: (1) although most Medicare providers abide by program rules, Medicare has difficulty preventing fraudulent and abusive practices; (2) some unscrupulous providers such as home health agencies, pharmacists, and medical suppliers are attracted by high reimbursement rates for some supplies and services and the few barriers to entry into the Medicare marketplace; (3) exploitative providers often escape detection because of inadequate claims oversight, insufficient resources, and fragmented authority responsibilities; and (4) those providers convicted of fraud face minimal sanctions.

----- Indexing Terms -----

REPORTNUM: T-HEHS-96-7
 TITLE: Fraud and Abuse: Medicare Continues to Be Vulnerable to Exploitation by Unscrupulous Providers
 DATE: 11/02/95
 SUBJECT: Medicare programs
 Program abuses
 Fraud
 Medical expense claims
 Overpayments
 Medical services rates
 Health care cost control
 Billing procedures
 Claims processing
 Nursing homes
 IDENTIFIER: Medicaid Program
 CHAMPUS
 Civilian Health and Medical Program of the Uniformed Services
 HCFA Medicare Transaction System
 HHS Operation Restore Trust
 California
 Florida
 New York
 Illinois
 Texas

We regret that electronic text of GAO Testimony is not available at this time.

See the GAO FAQ - Section 2.0 for printed copy ordering information. The FAQ is automatically retrieved with all WAIS search results or can be obtained by sending e-mail to: info@www.gao.gov

Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform
(Testimony, 04/12/94, GAO/T-HEHS-94-140).

The long-term care system has evolved in a patchwork fashion and is today comprised of multiple programs that individuals find hard to access. Despite millions of dollars in outlays, the system often fails to meet the diverse needs of the disabled, and many believe that access to services could be improved with the same level of funding. This testimony focuses on three trends underlying the quest for reform. First, demographic changes make rising demand for long-term care inevitable across all ages, not just for the elderly. Second, spending will escalate sharply across all ages, not just for the elderly. Third, despite high costs, disabled persons are increasingly unhappy with available services and their ability to obtain them.

----- Indexing Terms -----

REPORTNUM: T-HEHS-94-140
TITLE: Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform
DATE: 04/12/94
SUBJECT: Long-term care
Community health services
Health care cost control
Elderly persons
Disadvantaged persons
Aid for the elderly
Medicaid programs
Home health care services
Nursing homes
State-administered programs
IDENTIFIER: Social Services Block Grant

We regret that electronic text of GAO Testimony is not available at this time.

See the GAO FAQ - Section 2.0 for printed copy ordering information. The FAQ is automatically retrieved with all WAIS search results or can be obtained by sending e-mail to: info@www.gao.gov