NURSING HOME WITHOUT WALLS

by Tarky Lombardi, Jr.

One night, many years ago, I received a call from a woman who said: "My mother is ill and we are trying to keep her at home but cannot afford the level of services needed to care for her. Medicaid will pay for her care in a nursing home but will not pay for the services she needs at home. We are being forced to institutionalize her. What can you do?" That was the dilemma.

History of the Program

In the mid 1970s, the actual and projected increases in the elderly population—those most at risk of chronic impairment—the bias toward overdependence on the institutional care system, skyrocketing health care cost, and preference of patients to remain at home combined to show that a shift in the focus of the provision and financing of long-term care was a necessity.

Everyone was frustrated—federal, state, and local policymakers, the health care community, and particularly patients and their families who wanted appropriate, less costly care in the most preferable setting, their own homes.

As a result of these problems and trends, particularly the gaps and inequities of the public payment system that forced persons into institutions, the need became apparent for an alternative. We envisioned a "nursing home without walls"—a humane, less costly, and more flexible alternative for providing care, which would not only address the immediate crisis but would also pioneer a new direction in the delivery of long-term care. Thus, we created a program to provide long-term care custom-tailored to the needs of the patient at home, without unnecessary services and without requiring the patient to fit into a fixed routine of an institution. This program would assess the need for, coordinate, and provide a broad range of health, social, and environmental services managed on a 24-hour, seven-day-a-week basis. The program would make available in patients' homes the same comprehensive long-term care that was otherwise available only in a nursing home.

The Nursing Home Without Walls (NHWW) legislation was first introduced in 1976. Throughout the 1976 and 1977 sessions of the New York state legislature, the proposal was further refined, and on August 11, 1977, Chapter 895 made New York's Nursing Home Without Walls program a reality.

Prior to implementation, we discussed with officials of the Federal Health Care Financing Administration (HCFA) the possibility of securing a waiver to allow Medicaid reimbursement for services not
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ordinarily covered and in addition to the broad range of services authorized for the program. This additional array of services was important so that NHWW could truly respond to the total range of patient needs—health, social and environmental—and more appropriately and cost-effectively maintain patients at home. The waiver request was approved by the Health Care Financing Administration in October 1978, and state legislation was enacted in 1979 to implement the waiver.

How It Works

The NHWW legislation established the essential design of the program and incorporated specific features that are instrumental in its continuing success as an alternative to long-term institutionalization. These key features, for the most part unique to this program, distinguish it from the more traditional forms of community care.

Selection of providers. Participating providers must be hospitals, residential health care facilities, or certified home health agencies approved as competent and appropriate according to specific criteria.

Partnership between provider and local district. The program requires the joint involvement of NHWW providers and local social service departments to provide a more comprehensive management process, with mutual support and patient advocacy by both agencies and a system of checks and balances with respect to care planning and care costs. In private-pay cases, there is no social service district involvement; all arrangements are made by the provider in conjunction with the patient's physician.

Patient eligibility. Patients must be medically eligible for care in a residential health care facility, since the program is intended as an alternative to institutionalization. Neither age nor payor source is considered.

Requirement for notification and referral. Patients considered for placement in a long-term care facility must be informed of the availability of NHWW and, when deemed appropriate by a physician, be referred for an assessment.

Comprehensive assessments. Each patient receives a comprehensive health, social, and environmental assessment prior to admission and at least every 120 days thereafter. Taken into consideration are all factors and circumstances related to the patient's care and condition, including the patient's strengths and impairments and the potential support of family, neighbors, and friends.

Range of services. The program's range of services, reimbursable by Medicaid, is perhaps the broadest available through any community care program. It includes nursing, physical therapy, occupational therapy, speech pathology, medical social services, respiratory therapy, nutritional counseling, audiology, medical supplies and equipment, personal care, homemaker-home health aide, housekeeper, social day care, respite care, home-delivered meals, congregate meals, transportation, housing improvement, home maintenance, personal emergency response systems, and moving assistance.

Case management and service coordination. The program has total responsibility for managing and coordinating the delivery of all services to the patient and must be available on a 24-hour basis. This intensive approach virtually eliminates fragmentation and duplication of services, ensures on an ongoing basis that the necessary services are provided to meet the patient's needs, ensures that all aspects related to the care of the patient are closely monitored, promotes the development of a positive relationship between the patient and the program, and facilitates provision of the most cost-effective care possible.

Cost cap. Expenditures for patient care are capped at 75% of the average annual rates of payment for skilled nursing or health-related facility care within the social services district in which the patient resides. Generally, all care provided to the patient must be provided within the expenditure limitation, regardless of payor source and whether a service is provided directly through the program or in conjunction with another provider, such as a laboratory, clinic, pharmacy.

Through the interplay of these key elements, NHWW provides each patient with a comprehensive program of long-term care. The NHWW coordinated design forms the basic framework for all patient care and management for initial referral to discharge.

Generally, the program operates in the following manner: A referral is made to the local department of social services for Nursing Home Without Walls care. Nursing Home Without Walls providers and social services representatives jointly assess the patient's health, social, and environmental needs. Based on the results of the assessment and the physician orders, a summary of service requirements, monthly budget, and plan of care are developed. If the patient meets the medical eligibility criteria, can be appropriately cared for in a home setting, and the total cost for care is within 75% of the local average cost for comparable level of residential health care for that patient, the case may be authorized by the local social services official. All care is tailored to the patient's specific needs and circumstances and is coordinated, arranged for, and/or provided by the Nursing Home Without Walls provider, who is available to the patient on a 24-hour basis. Social service districts monitor various aspects of the case, particularly the cost of care, and, when necessary, assist in obtaining authorization and/or arranging for certain services and public benefits. Complete reassessments are conducted every 120 days, or more frequently if the patient's needs dictate. Physician orders are renewed every 60 days.

In private-pay cases there is no social service district involvement; all arrangements are made by the provider in conjunction with the patient's physician.

Growth of the Program

The Nursing Home Without Walls program became effective on April 1, 1978. The first nine providers were approved that same year, and in November the first patients were admitted.

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Statistics are useful in providing information on the overall characteristics and experiences of patients served by the Nursing Home Without Walls program and in providing information on the impact the program may have on patients. The portrayal of patients, their care, and the impact the program has made on them and on their families is the most meaningful method of showing the program's value.

This case shows that the Nursing Home Without Walls program, through its comprehensive, coordinated, and customized program of care, has enabled an extremely impaired but motivated woman to be cared for and rehabilitated at home, and eventually discharged to self-care.

Ms. G., a 30-year-old mother of three young children, awakened one morning unable to move her arms or legs. She was diagnosed a quadriplegic: the etiology of her condition remains unknown. Although she was significantly impaired and medically eligible for placement in a skilled nursing facility, she instead chose the Nursing Home Without Walls program. Following a comprehensive assessment, Nursing Home Without Walls provided her with nursing, physical therapy, nutritional counseling, medical social services, respiratory therapy, and personal care. Environmental adaptations were provided as needed to facilitate her safety and functioning at home.

The patient was extremely motivated to participate in a rehabilitation program provided through Nursing Home Without Walls. Her upper extremity functioning increased and she was eventually taught to conduct her own physical therapy program. Her family was supportive and participated actively in the program. The social workers counseled her regarding her anxiety and interpersonal relationships.

As a result of her care and treatment as well as her motivation, her overall condition improved to the point that, in conjunction with a vocational rehabilitation program, she was eventually employed as the director of an advocacy program for the handicapped. She was discharged from the Nursing Home Without Walls program and has regained a great deal of her independence—which may have been forever lost if she had been institutionalized. She drives a specially modified van fitted with hand controls and is a role model for other handicapped persons. She has developed a support group through which she counsels other Nursing Home Without Walls patients and is a member of her “former” provider's Professional Advisory Committee. This is truly a case which otherwise might have been considered “hopeless,” but because of the patient's motivation and the program's capability to deliver comprehensive, patient-centered care at home, a life was saved and a growing family kept together.

This case shows how the broad range of Nursing Home Without Walls services enables the program to tailor the appropriate services to fit the patient's needs and preferences.

Ms. C. had asthma, recurrent urinary tract infections, personality disorder, and was confined to her bed and wheelchair as a result of a hip fracture sustained several years earlier. The Nursing Home Without Walls provider needed to provide only a limited amount of personal care because the patient lived with a friend who was able to be of support. When her friend died, the greatest concern was for environmental safety. Since Ms. C. would not tolerate having another person stay with her, and since she continued to refuse to see a physical therapist, the program provided her with a personal emergency response system instead of a live-in personal care aide. This enabled her to be monitored while she was alone and to remain safely in her own home without compromising the privacy she desired.

Misconceptions regarding the ability of extremely impaired individuals to be cared for at home often lead to premature or unnecessary institutionalization. The next two cases show how, through Nursing Home Without Walls, even those with very intensive needs and poor prognosis can be successfully managed at home.

A woman in her 40s suffered a massive stroke and was hospitalized in a coma condition. Despite the severity of the illness, her family wanted to care for her at home; but they would be unable to do this without extensive support. In addition, given her degree of impairment and the scarcity of institutional beds, it would have been very difficult to transfer her to a nursing home. Thus, the patient and family faced with the prospect of long-term hospitalization which would have proved very costly in the human sense and which would have been astronomical financially. The Nursing Home Without Walls program, working closely with the family, enabled her to return home. Although she remained in a coma, the family arranged their time so that a member was constantly present. The program provided assistance with her nursing and personal care needs and trained the family to assist with the tube feedings and other daily care. Through close monitoring and care by the Nursing Home Without Walls program and the family, serious bed sores that had developed in the hospital improved and did not recur, which was remarkable considering the woman's comatose condition.

A 67-year-old woman was hospitalized with terminal breast cancer which had metastasized to the bones and heart; her DMS-1 score was 367. She was withdrawn and in a fetal position in her hospital bed;
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Nursing Home Without Walls cares for children as well as for adults and also considers the needs of family members which are often crucial to enabling patients to be cared for at home.

A three-year-old boy with a very poor prognosis suffered from cerebral palsy and seizures and was developmentally delayed. He was initially referred to a rehabilitation hospital but was rejected because he had "no rehab potential." His mother, a young, single parent, had been providing for all of his care with no outside support or respite. She had other children to care for as well. The mother, not knowing where else to turn, called a facility, which was also a Nursing Home Without Walls provider, to request assistance in having her child placed in the institution. She felt she had explored all alternatives and could no longer continue caring for her son at home. However, after hearing a description of the Nursing Home Without Walls program, the mother agreed to an assessment. The child was eventually admitted to Nursing Home Without Walls and remained at home receiving various therapies and assistance with nursing and respite to help her cope and to support her involvement in his care.

Nursing Home Without Walls, through its array of services and features, provides care that recognizes and supports the patient's independent functioning and is less costly than the provision of only traditional services. The following is a perfect example of how careful attention to the patient's specific needs as well as strengths, along with the program's creative coordinated care planning process, can support a person's independence, help maintain their privacy, and reduce the need for and cost associated with extensive hours of daily aide service.

A 34-year-old woman was paraplegic and lived in a trailer in a isolated rural area. She was very motivated to care for herself but barriers within her trailer home severely restricted her ability to perform basic day-to-day activities. Through the Federal waiver, her Nursing Home Without Walls provider had two ramps installed to enable her to enter and leave the trailer on her own using her wheelchair. The handles on doors and cupboards were also adjusted so that the patient could obtain food and other necessities without need for the continuous presence of a personal care aide. A personal emergency response system was provided to further assure her safety and security at night and while alone; home-delivered meals were provided in lieu of having a worker come in to prepare meals.

Nursing Home Without Walls allows motivated patients, who would otherwise be institutionalized to remain in their own homes.

An 87-year-old woman with arteriosclerotic heart disease, arthritis, and chronic ulcers of the leg, who lives alone in a rural area, was admitted to the Nursing Home Without Walls program. An elderly daughter, who also has chronic health problems, is her only source of informal support. Despite her weakening condition and several hospitalizations, she insisted on remaining in her own home—even though nursing home placement was advised by the hospital staff. Nursing Home Without Walls provides her with the necessary services, monitoring, and support to remain in her own home and live as independently as possible.

These cases represent only a few instances where the Nursing Home Without Walls Program has effectively and efficiently provided long-term care to chronically ill and disabled New Yorkers in their own homes. People are cared for and maintained in a manner responsive to their specific needs and preferences, aspects of life that even the best facility environments and dedicated staffs could simply never provide. Nursing Home Without Walls has not just cared for patients' health but has preserved their "lives" as well.

Mr. R. is a 75-year-old male with mental impairment. Due in part to his mental status he was unable to provide for his own personal and health care needs. He lived in a boarding home but the owner did not want to be involved as an informal caregiver. He eventually required hospitalization, after which he was discharged to a nursing home. At that time, Nursing Home Without Walls was not yet available in his community. When the Nursing Home Without Walls provider began operating, the patient was referred, assessed, and returned home under the program. Mr. R. was happily discharged from the institution and at last report had been home under the care and management of the Nursing Home Without Walls program almost a year, without a readmission to the hospital.

An 84-year-old male, following a four-month stay in a long-term care facility was returned to the community through the program. His diagnosis was post acute myocardial infarction, diabetes mellitus, and congestive heart failure. He receives nursing, home health aide, and speech therapy services. Speech communications have improved and family support is excellent. He is very content in his own apartment in a senior housing project which also provides for his noon and evening meals.

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Although NHWW progressed slowly at first, it nevertheless demonstrated early on its ability to provide appropriate yet substantially less-costly care at home for chronically ill and infirm persons otherwise eligible for placement in residential health care facilities.

In 1980, legislative amendments provided a significant stimulus to the program's growth and operation. These amendments clarified patient eligibility criteria, authorized the state Commissioner of Health to increase the total number of patients that a provider could be authorized to serve, and added flexibility to procedures for patient admission and calculation of patient budgets in accordance with the 75% cost cap.

Eventually state officials became convinced that NHWW was workable and effective and that its expansion would have a positive impact on patients, on the long-term care system, and on the state's efforts to contain health-care costs. The program's demonstrated success was instrumental in leading many hesitant, "wait-and-see" agencies to seek approval to provide NHWW care.

Both the individual agencies and the entire program have continued to grow and develop, with providers, communities, and, most important, the patients continuing to tap its far-reaching benefits.

Today there are 95 approved NHWW providers in 51 of New York's 62 countries, rural as well as urban, with a total capacity to care for more than 8,300 patients. Seventy-five programs presently serve about 5,500 patients, and the remaining programs are completing final contracts and operating procedures in preparation to begin service.

Of the 95 approved programs, 46% are sponsored by certified home health agencies, 35% by residential health care facilities, and 19% by hospitals. Voluntary nonprofit agencies sponsor 59% of the programs, public agencies sponsor 36%, and proprietary nursing homes sponsor 5%.

Patients' ages range from newborn to over 100 years; 77% of the patients are 65 or older, nearly 56% are 75 or older, and approximately 3% are children. Most patients (76%) are female, and nearly 61% have care needs at the skilled nursing facility level. While the majority of the patients live with friends or relatives, a surprising 47% live alone. This statistic is evidence of the desire and ability of even the very sick to remain at home with proper manage-

ment and support. Hospitals are the primary source of referral (39%) and 4% of cases are referred directly from residential health care facilities. Most discharges (32%) are to hospitals, 22% of the patients have died in their own homes, and nearly 14% are discharged to self-care because of marked improvement. Although length of stay varies considerably and is a difficult statistic to compile, patients seem to typically stay in the program for about 10 to 12 months. The first New York City patient, admitted to the program in May 1979, remains in the program for nearly 7 years, until her death early in 1986.

While statistics are helpful in profiling the status of the program and the characteristics of the patients, the best way to portray Nursing Home Without Walls' operation and impact is in the patient's own terms. The accompanying case histories vividly convey the dramatic effect this program has had on the lives of many patients and their families. Although few patients in long-term care facilities ever return to the community, NHWW has been successful in bringing many patients back to their homes and families.

Impact of the Program

Benefits to Patients and Families

The Nursing Home Without Walls program continues to have a positive effect on patients and their families. The program provides a viable alternative to long-term institutionalization for patients who prefer to remain in their own homes. It also offers the necessary support for families who may already provide much of the care for an ill or infirm member but who need professional assistance, coordination of care, and occasional relief in order to continue.

Through the NHWW program, patients who would otherwise be institutionalized are served by an entire program of long-term care that is managed and carefully tailored to their needs and preferences. Patients are provided with constant coverage and a single source of communication for all matters related to their care. They do not receive extra or unnecessary services, nor are they required to fit into the routine of an institution. The program has a gambit of services available to best meet the patient's needs, support his or her strengths and independence, and, wherever possible, address the needs of family and other informal caregivers.

Terminally ill patients may die at home with dignity, and their families are provided with the necessary support to help them through the most difficult time. Providers have reported overwhelming patient and family satisfaction with the Nursing Home Without Walls program.

Benefits to the Health Care System

NHWW bridges a major gap in the health care delivery system by extending into patients' homes in a cost-effective manner the comprehensive long-term care otherwise available only in the institutions, and the program provides an essential link in the overall continuum of care. Physicians, local districts, patients, and families have greater flexibility and a broader range of alternatives in planning and arranging for care. Ultimately, the program allows for more appropriate and well-planned use of home health and institutional care systems of a community.

Official and practical recognition that the program had become an integral part of the state's health care delivery system came when the NHWW program was incorporated into a new bed-need methodology for residential health care facilities adopted in New York State in 1983. This methodology requires that a percentage of bed-need be met by expansion of noninstitutional alternatives, chiefly NHWW programs, in lieu of long-term care facility expansion or construction.

A Model for Related State and Federal Initiatives

NHWW continues to contribute to home health and long-term care policies and initiatives on both the federal and state level. For example, NHWW served as a model for the Home and Community-Based Waivered Services provisions of the Omnibus Budget Reconciliation Act of 1981, in which most states now participate. Other federal legislation has also been based on this program.

A Nursing Home Without Walls program directly patterned after the New York model was developed in the state of Hawaii, and legislation has just been introduced to establish a Nursing Home Without Walls program in the state of Rhode Island. Other states have also adopted similar programs and elements of the NHWW design.

Cost Containment and Savings

Costs for care by the NHWW program have been far less than what would otherwise have been expended for institutional levels
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"I can hardly believe that at my age I am having such a full life. I feel like flying. How could I know that my whole life would be changed by all my friends in this new program?" — from a NHWW client.

of care. The significant fiscal benefits of this cost-effective program, which continues to save millions of taxpayer dollars, are described below.

The average cost for patient care in the NHWW program has consistently been about half the cost of skilled nursing or health-related facility care. By returning patients home from long-term care facilities and by helping patients avoid institutional placement, NHWW costs are significantly less. In cases where patients would otherwise be in a hospital or other specialty facility, the savings have been even more substantial.

By caring for patients at home, NHWW leads to further savings by making residential health care facility beds available for those patients who truly cannot be appropriately cared for at home. Costs are contained by facilitating appropriate placement for these patients who, in the absence of an available long-term care bed, would otherwise be hospitalized at higher costs or receive intensive round-the-clock care at home while awaiting institutional placement.

NHWW provides an alternative to nursing home construction and expansion. The average cost of constructing a nursing home bed in New York State ranges from $35,000 to $60,000 (N.Y.S. Department of Health, 1985). Significant capital investment is therefore avoided each time a community meets a portion of its long-term care needs by substituting development or expansion of a Nursing Home Without Walls program for the construction of additional beds.

Although the aggregate savings derived through the program have yet to be compiled, estimates of savings across time show the significant and consistent cost-containment potential of the program. For example:

1. The State Departments of Health and Social Services (1980) analysis of patient expenditure data for the initial experiences of the program showed that, through November 1979, the average monthly cost for a Nursing Home Without Walls patient was about $792 per month, as compared with the average monthly rate for a residential health care facility patient during that same period of about $1,490 per month.

2. A Senate Health Committee (1981) study of patient expenditures found that, for the 466 patients in the program in November 1980, NHWW patients at the skilled-nursing-facility level were cared for at about 50% of the cost of care in a facility, and NHWW patients at the health-related-facility level were cared for at about 51% of the cost of institutional care.

3. The State Department of Social Services (1984) estimated 1983 average monthly expenditures for Nursing Home Without Walls patients at 50% of the costs for comparable levels of care in a residential health care facility, for an estimated savings to Medicaid of approximately $20.4 million for that year.

4. In 1985 data compiled by New York City show the average cost of caring for a Nursing Home Without Walls patient to be 48.4% of the average rate for skilled nursing and health related facility care in the city. The potential savings during 1985 for New York City patients alone was estimated at nearly $33.6 million.

Nursing Home Without Walls is a proven cost-saver and is a major component of the state’s health care cost-containment efforts. When patients are maintained in their homes through the Nursing Home Without Walls Program rather than in an institution, care costs for these patients are substantially reduced and overall system costs are contained.

Conclusion

The Nursing Home Without Walls program is the most innovative, viable, and cost-effective alternative to long-term institutionalization. It is responsive to human needs and addresses the broader economic and public policy issues in health care today. The program continues to benefit patients, families, and communities as a whole and continues to significantly contribute to state and national policies and initiatives in home health and long-term care.

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