Home care

A shifting of ethical responsibilities[1]

George A. Kanoti, S.T.D.

The rise in home care of traditionally hospitalized patients raises ethical questions with regard to transferring the ill from professional medical care to other members of the family. The author believes that responsibility can be shifted ethically if certain conditions are met: these include well-defined criteria for patient selection, education programs for home care providers, criteria for both care givers and environment, continued research into the adequacy of therapy, and participation of health care professionals in the social process of assessing and reassessing the institutional structures of medical treatment.

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The extent of home care in the United States today is impressive. Studies have shown that approximately 848,000 non-institutionalized adults stay in bed all or most of the day because of a chronic health problem, while roughly 1 million adults receive injections, physical therapy, bandage changes, or other types of nursing or medical treatment at home; moreover, a market survey predicts that expenditures on home care in the United States will triple to $18 billion by 1990.[1] Further analysis of the data reveals that patients traditionally cared for in a hospital setting are more and more frequently being treated at home regardless of the nature of their illness (chronic, terminal, or acute). Minor surgical procedures for which patients were once admitted are now performed and the patient discharged the same day. Mastectomy patients are now commonly discharged within two days rather than

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seven, while patients with illnesses such as pneumonia and chronic obstructive pulmonary disease which previously required hospitalization are no longer being admitted to the hospital. Nationwide surveys have shown a significant decrease in the use of hospital beds over the past decade.

Ordinary nursing care usually involves weighing the patient, shifting his or her position in the bed, changing bandages, and providing personal hygiene. In addition, home nutritional care may involve a special diet or even total parenteral nutrition. Some patients receive chemotherapy and/or ventilator care at home. Family members who are not skilled in patient assessment may now evaluate the physical, psychological, and spiritual conditions at home and adjust treatment accordingly. In a study conducted at the University of Minnesota, Bivalec and Berkman[3] put together a questionnaire to determine the needs of families of home care patients. They enumerated five major areas of learning necessary to prepare individuals who would provide home care, and these were further divided into a detailed set of skills and knowledge. Subsequently, a course in home care skills was developed. Most of these skills were practical: how to give the patient a bath, how to handle a bedpan and urinal, how to change an occupied bed, information on nutrition and feeding, dealing with constipation, how to use oxygen at home, information regarding resources in the home, and data on the cost of home care. However, some skills involved administration of specific drugs and the use of complex medical technology. All of this raises the serious question of whether shifting responsibility for care from the professional environment to the home is ethically defensible, a question which I hope to resolve in the discussion that follows.

History

The concept of home care is not new; in fact, most people practice home care to some degree during their adult life, though usually to a very basic and unsophisticated degree. Parents must often assess their child's health. For example, if a child complains of stomach pains at breakfast, they need to weigh the seriousness of the complaint and symptoms against such other factors as the child's attitudes toward school (stress over curricular activities, scheduled tests, or disagreement with the teacher). Knowledge of marked physical exertion in gym class the day before, coupled with a normal temperature, would suggest nothing more severe than sore abdominal muscles, for example.

In the Western world, at least, there is a sense of obligation to provide the ill with competent, knowledgeable, skillful, and dedicated care. The question faced by the family is how to provide the best care for their loved ones. The advent of scientific medicine and its extraordinary achievements in the last four decades produced a subtle but definite change in society's answers to this question.[4] While most persons in the 1930s and early 1940s believed that a hospital was a place to enter "at your own risk," this attitude slowly shifted; the common conviction developed that the best medical knowledge, skill, and dedication required a professional, someone who was dedicated and trained to care for the ill, and that meant going to the hospital. Confidence in the ability of the health care provider led to voluntary surrender of freedom to physicians and other professional care givers, who were looked upon as having an interest in the welfare of the patient, dedicated to do no harm, and possessing the knowledge and skill necessary for cure. At the same time, people came to believe that an almost endless store of funds was readily available, as exemplified by the allocation of money for end-stage renal disease in the 1960s, providing dialysis and surgery without regard for cost.

Today, economic and psychological pressures challenge the conviction that the ethical responsibility to *care* for the patient—that is, to do good rather than harm, to respect his or her freedom, and to distribute medical resources fairly—is best met in the professional health care facility. Diagnostic-related groups (DRGs) and prospective payment programs are examples of the economic forces that have stimulated re-thinking of ways to meet this responsibility. Economic conditions have changed: resources are becoming scarce, and the abundance, yet impersonal nature of high technology medicine make many question whether the ill person will receive individualized humanistic care. Slowly, almost without direction, the responsibility for the ill is shifting. Still, questions remain: Is it responsible to shift care of patients from the hospital to the home? Is it responsible to shift the ethical obligation for care from professionals to family members or other individuals? It is my belief that home care *is* responsible, *provided* that certain criteria are met.

Criteria

In order for patient care to be shifted responsibly from the professionally staffed hospital to the home, well-defined standards for discharge and/or admission to home care programs must be established. Those who will care for the patient at home must receive adequate training; standards for the adequacy of home environment must be established, along with the capability of family members or others to provide care and the effectiveness of the treatment employed. There must be adequate support systems for both patient and care givers. Finally, health care professionals must participate in the process of assessing and reassessing the institutional structures of health care. There are already good examples of institutions attempting to establish practical ways of meeting such criteria. Standards for patient selection have been developed by the Department of Surgery of Jefferson Medical College (*Table*); only if these standards are met can patients be considered candidates for home care.[5] At St. Mary's Hospital in Milwaukee, a list of standards has been developed to evaluate care givers with regard to not only specific home care skills but also psychological resources; this involves visiting the home in order to determine whether the environment is suitable for the planned therapy and whether modifications of said therapy are practical in the home.[2]

The question of support systems for home care providers is already being addressed by some groups. One effective program known as HOME (Home Oncology Medical Extension) was developed at the North Shore University Hospital in Manhasset, New York, specifically for patients with advanced cancer whose only alternative would be hospitalization. In this progam, the patient is managed at home by an interdisciplinary team centered around the oncology nurses, assisted by medical oncologists, social workers, dietitians, and other medical technologists. A van is used to transport the home care team to the patient's residence. In Dr. Vinciquerra's words:

> From October 1978—December 1981, 2647 home visits were made to 399 patients .... The average survival for our patients has been 60 days. The average age is 63+, range from 15–89. This overall patient and family acceptance of this program to date has been excellent .... The median survival for patients treated at home is 60 days compared with 23 days for hospital-based care patients .... Our initial data comparing home and hospital care suggests the potential for increased caloric intake and improved survival for patients treated at home.[6]

Table. Home TPN in cancer patients: requirements for patient selection

—Intravenous admistration required to maintain fluid and nutritional equilibrium
—Capable of self care: able to spend greater than 50% of time out of bed
—Mentally, physically, and emotionally able to start, stop, and control infusion
—Expected survival three or more months
—Aware of diagnosis and desire for home treatment
—Gastrointestinal condition precluding oral or enteric feeding and no alternative to parenteral feeding

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The demand for educational programs for the home care provider is a difficult one to meet: technical information must be made understandable, and great patience will be required to help the uninformed develop the skills necessary to care for people at home. In addition to home care providers, education programs must also be made available to traditional health care professionals in the home care arena. Physicians, nurses, technologists, and other health care providers need to know the physical, social, psychological, and medical requirements of home care. There is a real danger that health care professionals will see home care as a pragmatic way to meet the demands of DRGs and prospective payment plans. Conferences and workshops on the details of home care and the necessity for education should be developed so that these individuals can better understand the circumstances and demands of home care. There is also a need for research so that judgments can be made about the effectiveness of available technology and the development of effective home care.

Finally, there is a need to educate the general public. The ethical and legal responsibilities of home care must be argued in the public arena.

The process of social reassessment of the structures of care of the ill has already begun. Laws, payment structures, and institutional practices that will support and protect health care providers, both in the home and within the hospital, must be studied and new protocols initiated where needed. Home health care recipients, care givers, and traditional institutional health care providers must all engage in this dialogue.

Conclusion

If the standards proposed here are met, the ethical principles essential to any decision regarding the responsibility of a given medical practice will be served. These principles are fourfold:

1. Beneficence—do good to your patients,
2. Non-maleficence—do not harm your patients,
3. Freedom—invite your patients to participate in therapy, and
4. Justice—distribute limited resources fairly.

When these ethical principles are served, balanced, and monitored, home care will truly be a responsible means of meeting one's obligations to those in need of medical care.

Chairman
Department of Bioethics
The Cleveland Clinic Foundation
9500 Euclid Ave.
Cleveland, OH 44106

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