

The Development of a Comprehensive Health Care Program for Patients with Active Tuberculosis

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Introduction

In recent years workers in many fields of medicine have recognized that new systems must be developed for the delivery of health services to all the people of the United States. Community-oriented modifications of anti-tuberculosis health services have become mandatory so that effective long term therapy (minimum of 24 months to several years, or even life) can be achieved. Deuschle in 1959 found that tuberculosis control in Navajo Indians living in Arizona could not be maintained until an amalgamation was created between modern scientific techniques and an understanding of special Navajo cultural mores. Ambulatory tuberculosis treatment was not effective in the Chinese community of San Francisco until clinic hours were made compatible with Chinese cultural living patterns (Curry, 1964). It was discovered that more successful treatment of problem patients, uneducated Negroes and/or skid row alcoholics, could be achieved by locating ambulatory treatment centers within their communities (Cohen and Blacker, 1962; Curry, 1964; Cohen et al, 1966; Curry, 1968). Curry in 1968 developed district treatment teams (each containing a physician, two public-health nurses and a clerk) for each special community. Each team viewed the patient as a complete entity so that medical, social, emotional and environmental problems were reviewed in relation to the patient's illness. In addition, Curry in 1968 and other workers (Vandiviere, Kane and Kavasch, 1970) have recognized that the patient must be enlisted as an active member of the therapeutic team. Flexibility in the organization and delivery of tuberculosis health care must be maintained as too often the convenience

of the patient is sacrificed to the convenience of the treatment staff (Moulding, 1966; Fox, 1968). Kane and Deuschle in 1967 pointed out difficulties in doctor-patient communications with the "hill people" of Eastern Kentucky, as physicians from across the nation have been educated in the handling of "clinical material" rather than people.

Another dimension of particular importance in the field of tuberculosis treatment is the rising cost of hospital care. With the advent of chemotherapy the months of hospitalization required for effective anti-tuberculosis therapy have been dramatically decreasing over the past several years. However, traditionally in the United States a patient with positive sputum must remain in the hospital until his sputum has converted to negative—usually a minimum of three months. Any complicating circumstances, even the failure to collect a sputum culture, may increase the hospital stay to six months and up to 24 months for the "problem" patient. On the other hand, developing countries do not have sufficient hospital beds to accommodate the population with active disease. The now classical studies from Madras, India (Tuberculosis Chemotherapy Centre, Madras, 1959; Velu et al, 1960; Devadatta et al, 1961; Dawson et al, 1966) have shown conclusively that patients with active far advanced tuberculosis can receive as effective treatment at home (despite crowded housing, poor nutrition and hygiene) as patients who spend their first year of treatment in the hospital. Furthermore, no increase of infection in contacts of these patients treated at home was found (Andrews et al, 1960; Ramakrishnan, 1961). In Hong Kong (Moodie, 1967)

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approximately 12,000 patients with active tuberculosis were not hospitalized but received supervised chemotherapy in clinic centers.

The Van Etten Home Care study, initiated in February 1967 under the Department of Medicine of the Albert Einstein College of Medicine Bronx Municipal Hospital Center, was designed as a control study of home versus hospital treatment for patients with active tuberculosis. The purpose of the study was to determine if domiciliary tuberculosis care for a population of socially deprived patients located in Metropolitan New York could be as successful as has been demonstrated for the very different population in Madras. Results (Eddison and Farmer, in preparation) have shown that such sputum positive patients can be treated successfully in the home rather than by conventional hospitalization without an increase in tuberculosis infection in the contacts of these patients. Furthermore, the cost of home treatment is a fraction of that found in conventional hospitalization. However, among the ghetto dwellers who contract tuberculosis there is a significant percentage of individuals who are chronic alcoholics, street livers, sociopaths, etc.—generally, hopeless individuals whom traditional hospital services have thought could not be rehabilitated. In order to achieve effective medical therapy in this hard core problem group, “pill pushing” alone was not sufficient. In addition, both psychosocial problems and educational deficiencies had to be treated.

During the development of the Van Etten Home Care program, it was discovered that the most important aspect of a comprehensive health care service was a basic philosophy concerning human relationships which must be believed and practiced by all staff members. This philosophy, then, became the major force in the creation of a functioning multidisciplinary team that delivered the actual services to the individual patient. Basic concepts essential to both this philosophy and the development of a functioning treatment team could be utilized in many medical fields other than those restricted to tuberculosis treatment. Though many of the special services rendered Van Etten Home Care patients were designed to reach the hard core problem patient, they also illustrate the effectiveness of certain basic concepts in the delivery of a comprehensive health service.

Basic Philosophy

In the Van Etten Home Care program a system of comprehensive health care was developed in which pure medical therapy played a small role and in which medical, social, psychological and educational services were delivered by a multidisciplinary team. The four guiding principles of the service were: 1) the belief that the psychosocial situation must be treated in order to achieve effective medical therapy;

2) the belief that the patient's entire family must be treated as a unit rather than the patient alone; 3) the belief that the family unit should not be treated by individual members of the staff but rather by staff working cohesively as a team; and 4) the belief that the total treatment program must be given in an atmosphere of true caring for the patient and his family on all levels.

The key to the success of the program can be found in the interpersonal relationships between staff members (clerical included), between patients, and between staff and patients. Because of the constant interaction between these individuals, it is difficult to describe specific treatment concepts and/or methods which relate directly to specific treatment results in the individual patient. However, it is possible to describe the basic philosophy in broad terms.

The tenor of all interpersonal relationships within such a program must be set by the establishment of one major premise—the conviction that all men are equal. It is important to define, insofar as is possible, what this really means for both staff and patients: 1) Patients are humans of equal importance to staff and to each other regardless of past behavior, education, environment, race or creed. 2) Staff members are of equal importance to patients and to each other regardless of their individual function, title, education and skill.

Simply to state that all men are equal is not sufficient. Each staff member must believe the concept to such an extent that his belief is reflected in his delivery of services. In order to achieve this, a staff member must be secure within himself and have confidence in his own intrinsic worth so that he can effectively treat the patient with openness of feeling, truthfulness, thoughtful understanding and respect. In turn, the patient begins to respond with a gradual strengthening of his own ego, with the development of better interpersonal relationships with other patients as well as staff, with the ability and desire to learn through new experiences without fear of ridicule, and with the development of greater insight into his own behavior. For example, as the patient begins to gain confidence he begins to realize that: he does not have to remain a result of his past environment but rather that he has the strength to begin a change; staff may disapprove of his behavior but not of his person; staff recognizes that he does try even after repeated failures; he does have something to offer not only to himself but to others and to the program and; once he has reached a new level of functioning a little bit more is expected of him until he is able to take over full responsibility for himself. The patient becomes a responsible member of the community of the Program and as such shares in its joys and its problems. As the patient gains more strength and ability he begins to help the less able

patient with problems related to the regularity of medication, to the consumption of alcohol, to the use of drugs, to education, etc. Therefore, a treatment program is developed in which patients not only receive treatment from staff members but also from other patients, so that a casual visitor to the service should be unable to distinguish between patients and staff. In the end the patient receives effective medical treatment for his disease, in this case primarily tuberculosis; but in addition, his original sense of hopelessness and futility is replaced gradually by a sense of well-being, faith in the future, and most important belief in his own intrinsic worth as a human being. However, in order to achieve success, it must be emphasized that a treatment team cannot resort to punitive measures or rapid disciplinary discharge from the program. The first step forward in social rehabilitation may not be realized for a year or longer.

Multidisciplinary Teams

Since funds were limited for the Van Etten Home Care program, all staff members automatically became members of one multidisciplinary team. The team was composed of:

1) Supervisory personnel in medical, paramedical and clerical fields—the Director of the Program, the Director of Family Therapy, the Executive Physician Aide and the Assistant Administrator. (Funds were never provided for an Administrator.)

2) A treatment unit consisting of:

- a) medical personnel—three part-time physicians ($\frac{1}{2}$, $\frac{1}{4}$ and $\frac{1}{4}$ time) who provided the equivalent of one full-time internist
- b) paramedical personnel—one trained social worker and one licensed teacher in the Family Therapy Department as well as two physician aides, a homemaker and a nurse's aide in the Physician Aide Department
- c) paraprofessional personnel—one untrained worker in Family Therapy
- d) clerical personnel—one medical typist
- e) job trainees and volunteers—patients, varying in number from zero to three or four at once
- f) students—medical and educational, varying in number from zero to four in each discipline.

3) Part-time specialty consultants in pediatrics, psychiatry and psychology (approximately $\frac{1}{8}$ time for each).

This team could be multiplied for larger programs which, in addition, would require "core personnel" composed of supervisory personnel for the total program and appropriate consultants for the delivery of specialty services to all teams. There should be

ample opportunity for the participation of students from a variety of fields; for example, social work, nursing and psychology.

It must be emphasized that the assignment of personnel to multidisciplinary teams does not guarantee that the teams will function effectively in the delivery of comprehensive medical care. Success can be achieved only if the basic philosophy—all men are equal—is accepted, believed and manifested by each staff member. Thus a freedom of relationships between the staff member and his patients as well as between himself and his fellow team members is created. Without this freedom, both he and the whole team will fall short of total success.

The most effective method by which the Van Etten Home Care Service was able to develop a functioning multidisciplinary team was through the establishment of a staff group session. The entire staff (including clerical workers) met one hour a week under the leadership of the psychiatrist. Through a general discussion of the goals of the program, the psychiatrist was able to bring out unexpressed hostilities between various staff members, between professional and non-professional staff, and between staff and certain patients. Gradually each staff member gained insight not only into his own function within the total program but also into the function of every other staff member. Each individual became aware of the interaction between staff members, between staff and patients (both therapeutic and atherapeutic), between staff and community agencies, and between staff and the community at large. With an understanding of these interrelationships came the acceptance of the philosophy that all individuals were equal human beings whether they were professional staff, non-professional staff, or patients. Those staff members in authority were no longer able to take refuge behind their professionalism but had to recognize that non-professional staff were of equal importance to the patient and that no one staff member was a superior human to any other staff member or patient. On the other hand, staff learned that this equality in human relationships did not negate the need for authority in the organizational structure of the program. Gradually staff recognized that chaos would exist without trained individuals to supervise and to undertake the burden of ultimate authority for major decisions. As each staff member became secure in his knowledge of all these interrelationships, he became able to work cohesively and flexibly within the multidisciplinary team. The team, then, was able to deliver effective comprehensive health care to the patients.

Services Rendered

A comprehensive health care service should deliver both comprehensive medical and psychosocial care and, in addition, other services appropriate for

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the consumer population. In the Van Etten Home Care program, the medical services represented only a small percentage of the total effort. They were comprehensive in that all members of the family unit were treated for tuberculosis (or tuberculous exposure) and other concomitant diseases by Home Care internists and a pediatrician as well as by specialty services throughout the Albert Einstein College of Medicine Bronx Municipal Hospital Center. A family evaluation conference was held once a week, attended by all staff, in which the family's medical and psychosocial course was reviewed and the treatment plan was reviewed, amended, terminated or renewed as appropriate. Minutes of the conference were recorded in individual patient charts. All new admissions were reviewed in 1-4 weeks, stable families in 4-8 weeks and families no longer requiring intensive care in 8-12 weeks. Chart reviews were conducted once a month and laboratory reports were scanned daily by a physician so that any abnormalities might be noted for immediate action. A part-time psychiatrist was a vital member of the team. Families were presented in weekly psychiatric conferences. Appropriate therapy was instituted which might have included chemotherapy, individual psychotherapy, group psychotherapy and/or family therapy (administered by the Family Therapy staff but when necessary under direction of the psychiatrist), or referral to the appropriate psychiatric service in the community. In this way psychiatric illnesses (including impending acute psychoses) were treated without hospitalization, catastrophic situations within the family unit were prevented, and crisis intervention was provided through either long or short term therapy which also prevented acute psychiatric hospitalization.

Physician aide staff were trained by a physician in the performance of a variety of skills and services related to the medical care of the families. While the tuberculosis source patient was still hospitalized, members of the physician aide staff began intensive education of the patient and his family in the principles of contagion, in the establishment of appropriate patterns of behavior so that medication would be taken faithfully and regularly for as long as needed (sometimes for life), and in self and/or family administration of injectable medication where appropriate. This educational process was continuous throughout the family's stay in the Van Etten Home Care Service, through home visits and/or frequent clinic visits. Patients thought to be poorly motivated received their medication daily in Home Care. Special "Patient Care Control" wall charts were established so that regular physician visits, appropriate specialty clinic visits (including those required to check early signs of drug toxicity), blood work, x-rays, injections, family therapy sessions, group therapy appointments, teaching sessions, special activities and transportation of fam-

ilies could be scheduled in the most efficient manner. These charts were constructed so that not only was the schedule for each family member available at a glance, but also, any failure to complete a scheduled appointment stood out and could be corrected rapidly. In addition, physician aides reinforced and participated in the psychosocial treatment for each family unit; when appropriate certain physician aides worked with the family therapists in special programs.

Effective medical therapy could not have been achieved for this particular population group without the psychosocial and educational services delivered by members of the family therapy staff. They have been the moving force behind new methods of treatment and programming; for example, the work program, overnight camp trips, vocational training for patient employees and volunteers, and special activities organized by patients.

The long and short term family therapy treatment goals for each family member as well as his family unit fell into two categories: 1) concrete services, ie, coordination of programming, environmental manipulation—rehousing with moves to better neighborhoods, help in securing of adequate financial support, assistance with union employment problems, rapid processing of prosthetic aides, etc.; and 2) counseling services, when appropriate with psychiatric consultation, to help develop and make use of the patient's own strengths in order to maintain or develop a useful, gratifying place for himself within his family unit and the community.

Whenever possible, existing community resources were used and personal contact was established by the family therapist with staff in other agencies, thereby utilizing a maximum of service with a minimum of duplication of effort. Members of the family therapy staff have worked intensively with the Department of Social Services (formerly Department of Public Welfare), the Board of Education, the Board of Higher Education (including the adult Head Start Program), New York Tuberculosis and Health Association, Personal Aides to the Homebound, Just One Break, the Office of Vocational Rehabilitation (and other vocational agencies), Bureau of Child Welfare, Family and Criminal Courts, etc.

Psychological testing and evaluation of individual patients in conjunction with their family units produced a major impact on the services rendered family units. Case discussions, staff concerns and treatment problems were discussed prior to the testing sessions so that results could be meaningful. Initial batteries of psychological tests revealed that most of the patients had IQs in the defective or borderline range. It was recognized at the time of testing that some individuals could function at higher levels and could be trained for limited vocations. However, the changes seen in these patients after six months on the service

were not predicted. Many had been functioning at a deficient level as the result of their illiteracy, cultural and social deprivation. They were not retarded.

In 1967 a small exploratory adult patient education program was initiated through the services of a volunteer teacher. Patients responded with an excitement and eagerness to learn. Staff members became aware of the multiple problems of the adult illiterate whose excellent memory with appropriate responses to queries serves him well. However, he may have had to leave his job because work orders which he could not read came with his advancement. Following this he may have turned to alcohol and street living. He may not follow written medical instructions or he may refuse to read eye charts, etc. He is well defended and will not freely admit to his deficiency. Therefore, he will not seek the aid of an educational agency in the city and in fact, adult educational programs begin with the premise that an individual can read and write. There have been on the Van Etten Home Care Service a significant number of young adults between the ages of 19 and 35 who cannot read one word, who may not know the alphabet, and who may or may not be able to sign their names. Therefore, it became mandatory to expand the educational program in order to achieve both effective social and vocational rehabilitation as well as adequate tuberculosis treatment.

Several family therapists trained as teachers embarked on a teaching program designed not only to teach reading, writing and arithmetic (since many were unable to add and subtract simple numbers, welfare budgets were grossly mismanaged and misused), but also to broaden cultural and social horizons. In addition, family therapists taught Spanish speaking patients and children English, kept teenage patients up-to-date in their school work, gave preschool children an initial school experience, and evaluated behavioral problems and possible retardation in problem children. A fascinating and productive extension of the adult teaching program was the use of an illiterate adult patient for the teaching of preschool children. The fear that a child might catch the adult not knowing something in the lesson increased the speed of the adult's learning considerably. The educational program could not have succeeded without the help of student teachers from Pace College whose requirements for an Educational Psychology course were met by teaching patients and family members on all levels. Experience with this patient population suggests that a great majority of ghetto dwellers with tuberculosis have never functioned at a level compatible with their potential abilities. Therefore, it is felt that educational opportunities should be provided at all levels, including

high school equivalency, in order to equilibrate function with ability.

An important aspect in the development of the Van Etten Home Care program was the ability to explore new and on occasion radical treatment methods. The most effective of these methods was the institution of overnight (1-4 nights) camping trips which, by patient demand, were scheduled throughout eight months of the year. One camp site, located in the Catskill Mountains (New York State Reserve) had to be reached by a half mile hike uphill, with all supplies except water and wood back-packed into the site. Because reservation of the lean-to was not possible, these trips were taken off season in extremes of weather. The camping activities of wood cutting (usually obtained by felling trees), collecting water, cooking, and cleaning filled most of the daylight hours at the mountain site. However, the majority of trips were to a lakeside camp site in upstate New York to which patients with physical limitations could be driven. Here everyone participated in general camp activities including tent raising (occasionally collapsing) and special group activities such as fishing, swimming, hiking, boating, and canoeing. Many ghetto dwellers had never had normal childhood experiences and thoroughly enjoyed learning children's songs and games; for example, Red Rover, Tisket a Tasket or Hide and Seek. Because staff and patients shared a variety of camping experiences, patients became convinced that all men were equal in Van Etten Home Care. With this conviction, a freedom in interpersonal relationships between patients and between patients and staff began to emerge. As patients gained self confidence they began the long climb towards social rehabilitation.

This freedom of interpersonal relationships carried over into the daily activities within the program. The patient-staff coffee pot, located in the waiting room, provided opportunity for socialization between patients and between staff members and patients. Patients took great pride in the preparation of daily lunches, frequently an ethnic specialty, which were shared by patients and staff alike. Much social and psychological rehabilitation was effected here by staff members who superficially appeared to be relaxing. Of practical importance was the fact that these lunches often provided the only solid meal per day for patients whose Welfare food budget of 66 cents per day per person was not sufficient.

Many patients, including alcoholics, spent all day in Van Etten Home Care activities. Some were taught a variety of crafts which included leather carving, copper and silver smithing, silver jewelry work, enameling, painting, plastics, decorator candles, paper mache objects and jewelry, pottery, tapestries, unusual small pieces of decorative furniture, wood working, refinishing and repair of old furniture, etc. Pa-

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tients skilled in sewing, knitting, crocheting and needle work taught their skills to other patients. Children participated in supervised simple projects and were taken on special trips; for example, the zoo, or most successful, an overnight camping trip to upstate New York. Adult patients still under supervision who had progressed in their own rehabilitation, became "staff" members and joined in the supervision and care of children on these trips. Other patients became full-time volunteers registered in the Bronx Municipal Hospital Center Volunteer Corps. They worked in program areas best suited for their own rehabilitation: some in supervision of work projects; some in teaching of either reading and writing or a skilled trade; some as messengers; some supervising children while their parents were participating in Home Care activities, shopping, etc. (staff members also used this service, thereby decreasing absenteeism); and some in training programs for specific staff openings. The goal of the latter training program was that the patient would become sufficiently proficient to either remain with the Service if he wished or be located in another position complete with training, work experience and reference. Former patients were trained and employed full-time as physician aides, family therapists and medical secretaries.

Patients organized special activities and entertainment with appropriate help and supervision from staff members when needed. The biggest patient party of each year was the December Holiday Party attended by Santa Claus (a patient) who called each child by name to give him his own present (the only holiday gift for many children). Entertainment was provided by a volunteer teen-age band that also played for Halloween parties for which patients made crepe paper costumes and joined the children in ducking for apples and other games. Staff costumes at the 1968 Halloween Party reflected the freedom of attitude toward that "dread disease—tuberculosis" by ingenious costumes for the TB germ, a box of Kleenex, an x-ray, urine collection tubes, a needle, and a vampire.

Services rendered Van Etten Home Care patients included quality medical and social services as well as special services and programming developed in order to reach all levels of the patient population including hard core problem patients. The atmosphere created by these special services coupled with the basic philosophy of the program provided a therapeutic treatment milieu for all patients so that any given patient could take from the total program the support he needed for his own independent function.

Summary

Concepts basic to effective medical care evolved from the development of a comprehensive health service program for patients with tuberculosis. The

key to success was found in a basic philosophy underlying all interpersonal relationships—the conviction that all men are equal. This philosophy then became the motivating force behind the creation of a functioning multidisciplinary team in which there was developed a freedom of relationships between each team member (clerical included), and between team members and patients. The effectiveness of this approach in comprehensive medical care was illustrated by examples of special services and programming which were designed to reach all levels of the patient population, including hard core problem patients.

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