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Changing Dysfunctional Relationships Between Family and Hospital

One of the most significant aspects of hospitalization is disruption of family life (1). The negative consequences of this experience, including anxiety, regression, passivity, dependency, and long-term emotional distortions, particularly in children, have been well-documented (2, 3). However, any member of the family will suffer when abruptly removed from the family context and placed in an environment where the "art" of medicine (4) often takes a back seat to concentration on technology and organizational flow.

Several hospitals have experimented with programs for increased family involvement in the hospitalization experience. Psychiatric units pioneered experiments in this area (5, 6) and were closely followed by a series of programs emphasizing parental support for pediatric patients (7, 8, 9). However, there has been a notable lack of interest in translating this concept of family involvement toward adult hospitalized patients with nonpsychiatric diagnoses.

This paper reports one such program (which included both adults and children as the identified patient) in operation during the period of 1971-1978 at Stanford University. Specifically, the paper will discuss ways of modifying a non-psychiatric in-patient's physical and social environment in a direction which encourages continuity with normal life, and which utilizes the family as a powerful and effective change agent in helping the patient adjust to illness. However, before proceeding to a close examination of this intervention, let us first consider what traditionally occurs to patient and family in the hospital.

Analysis of the Family in the Hospital

Some of the critical factors pertinent to family involvement in a hospital setting may be identified as follows:

1. Physical environment:
   Isolation of the patient from his or her family; physical disruption of the family unit.
2. Social environment:
   a. Major responsibility for care given to hospital personnel.
   b. Negative staff assumptions.

From a strictly medical viewpoint, the family in the hospital is often a non-existent entity. Patients, not families, are hospitalized and their families are rarely seen as integral aspects of the patients.

Typically, the emphasis of hospitalization is on restoration of illness-determined losses, rather than on the functional totality of the patient (10). Medical staff tends to regard consideration of family context as optional rather than as integral. For staff, the family is either a nuisance or irrelevant (11). In a few cases, especially with child patients or dying patients, a total shift in emphasis occurs, so that the patient is ignored and the focus is exclusively on the family. Yet no effective integration of the patient-family unit into the hospital has been achieved, and too often, staff assume an adversary position toward the family. If we

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examine hospital programs we see that there is little importance given to keeping alive family relationships. Similarly, examining the professional literature we find that family programs are rarely discussed.

The result of these conditions is that the patient becomes characterized by passivity, dependency and loss of role function. The family role in health care usually becomes minimal and observational rather than major and participatory. Transfer of caring skills to family members is either nonexistent or incomplete.

The consequences for the family are numerous tensions and stresses, as well as pressure to redefine their entire family system. Family therapy teaches us that the family is a homeostatic system which can easily be thrown into a state of disequilibrium. The effect of patient hospitalization on the patient's family is monumental family disruption. The hospital intrudes in a major way into the family life. Role functions set aside or lost by the patient must be assumed by other family members. This in turn will affect their own roles within the family. Also, the longer the separation of the family, the more the separation becomes institutionalized and the more severe its long-term impact on family relationships.

This interaction of hospital and family has been defined as "interinstitutional disarticulation" (10), or a relationship which has changed one of the interacting institutions (in this case, the family), instead of achieving a functional interaction between the two in which relating parts have been able to maintain their own structure and function. Several factors are responsible for this negative relationship. One is simply a skill deficit on the part of involved staff: poor interviewing techniques, lack of empathy, ignorance of family dynamics. However, other critical factors include deeply ingrained values, less susceptible to change, which have to do with convictions about the appropriate role of physician and patient; and with organizational patterns within the hospital which encourage the isolation of the patient from his or her family.

An Alternative Model

These multiple deficits of the present hospital-family model suggest that alternative interaction models between hospital and family must be developed. There is a need to identify appropriate social and structural interventions which address the three areas of skill training, role expectations, and organizational structure. Cross-cultural data suggest that hospitals do not have to necessarily isolate the patient from his or her family. In developing countries, especially in Asia and Africa, families live in the hospital, taking over responsibility for much of patient care (10, 12). In some instances, whole communities become hospitals. It is important to note that in these situations, in contrast to the family's role in our Western system, the family is not the guest of the hospital, but develops a viable role as a legitimate health care provider.

Of course, this alternative model assumes the essentially beneficent impact of family on patient. Certainly that is not always the case. Indeed, for certain medical conditions induced by familial chaos and disorganization, such as anorexia nervosa or psychosocial dwarfism, removal from the home environment may be necessary to facilitate recovery (for an alternative viewpoint, see 13). However, the cross-cultural evidence and our own anecdotal observations tend to suggest that in a moderately well-adjusted family, the presence of family members in patient care exerts a positive influence on patient health. In terms of the patient, he or she receives support, security, and familiarity. In terms of the family, members learn how to monitor the patient's condition, and at times how to intervene therapeutically with the patient. This process in turn reduces the prevalent feelings of helplessness and ignorance which family members so often experience (14). In essence the family members' role changes from a passive one, relying on experts, to an active role, in a sense becoming experts themselves.

Intervention: The Stanford Family Focus Program

The Family Focus program at Stanford University Medical Center (15), was developed as a

concrete illustration of this alternative model. The program was administered by the Physical Therapy Department for the purpose of providing transitional health care for a nonpsychiatric inpatient population. Both adult and child patients with a variety of diagnoses, e.g., cancer, strokes, amputations, and premature birth, spent the last three to five days of their hospital stay in a small apartment-like unit which was completely detached from the main hospital. In addition to the patient, the entire family was also present in this unit, as well as other relatives, friends, even pets, i.e., whoever and whatever constituted the essential support system of the patient. The program was characterized by a multidisciplinary approach to health care involving physical therapist, occupational therapist, doctors, nurses, psychologists, and dietitians.

There were several objectives in this program relevant to the current discussion:

1. To train family members to assume carry-over of health care skills.
2. To help the patient and family cope with psychological, physical and interpersonal ramifications of disability.
3. To integrate the patient into the family (16).

The emphasis of the program was to locate individual patients in their physical, interpersonal, and emotional contexts, the assumption being that both wellness behavior and illness behavior are shaped by specific contingencies in the environment (17).

Analysis of the role of the family in the hospital setting suggested three major areas in need of changes:

1. The patient's location in a traditional hospital environment.
2. The patient's relationship to his or her family.
3. Specific psychosocial training of staff in order to modify their attitudes and behavior toward patient and family.

In a sense, the Family Focus program could be conceptualized as a wide-ranging intervention strategy which had two main emphases: modification of the physical environment and modification of the social environment.

Physical Environment

It is well-known that arrangement of the physical environment has a strong saliency in influencing behavior: physical environment provides many of the cues for eliciting various aspects of our behavior (18). Physical environment provides our primary frame of reference, and it is difficult to understand a phenomenon unless one can grasp its frame of reference (19). For example, a hospital bed may elicit certain behaviors in a patient (e.g., passivity, depression) and the livingroom couch may elicit quite different behaviors in the same patient (e.g., relaxation, casualness).

As was pointed out earlier, the traditional hospital environment is too often characterized by sterility and impersonality, resulting in a concomitant passivity and isolation in the patient. In the Family Focus program this environmental deficit was dealt with in two ways. First, the physical setting of the unit was separate from the hospital, thus making it "neutral territory." Second, the physical structure was designed to be personal and functional, emphasizing qualities of home life rather than institutional life.

The simple change of physical environment elicited surprising new behaviors in health care professionals, patients and families. For example, personnel tended to show more respect for the patient's and family's wants and needs. A small but telling example is the fact that physicians in the traditional hospital wore official garb and rarely knocked before entering a patient's room. At Family Focus, they tended to remove their white coats and always knocked before requesting entrance. In a subtle but important way the environment was arranged so that the family was allowed to regain some control over it: their home became their castle.

Similarly, the family could take more initiative in determining treatment times as well as visits from other health personnel. Patients and families began to verbalize their needs in relation to treatment more frequently. Further,

the change in physical setting allowed patient and family a chance to rehearse old behaviors and assume new ones in relation to commonplace physical structures (getting into a car, sitting down to a meal).

The consequences of these behavioral changes were many. A more equal relationship between doctor and patient was encouraged. Treatment became integrated into family life, as family members gained more input into its content and occurrence. Finally, the sense of functioning physically as a family unit was restored.

A brief case history can illustrate how changing the physical environment can produce important behavioral changes in patient and family member. The patient under consideration was an 88 year old man who suffered a CVA with consequent right-sided hemiparesis, severe expressive and receptive aphasia, and partial bladder and bowel incontinence. In the hospital he had been described as a problem patient, combative, hostile, a wanderer who had to be placed in restraints. It was generally felt that he was too much of a burden to be cared for at home by his frail wife.

In the Family Focus unit, two changes were instituted:

1. The patient was removed to a new physical environment.
2. It was decided to remove the patient's restraints, as in that environment there would be no adverse condequences for his behavior (i.e., he didn't interfere with other patients or disturb the nurses).

Change in behavior was immediately noticeable. Once the patient was not tied down, his incontinence disappeared, as he was now able to walk independently to the bathroom. Further, his "wandering" identified in the hospital now became simply exploration of a new environment. Thus, the two critical problems described in the hospital environment were eliminated once certain environmental factors could be altered. The consequences of these changes were gratifying. On the part of the staff, "wandering," while not physically stopped, was reinterpreted as appropriate behavior. The patient regained a sense of independence and pride in himself, and the wife was reassured of her ability to care for her husband at home.

Social Environment

Like the physical environment, the social environment (all verbal and nonverbal actions of individuals) can have a significant impact on behavior (18). Family Focus modified the social environment of the patient in two ways:

1. Restoration of the family's primacy in patient care.
2. Specific training of staff to modify their attitudes and behavior toward the family.

An effort was made to utilize family members to facilitate medical and therapeutic goals. However, the intent was not to train health care personnel to be mini-psychotherapists (20), nor was it so much to change family dynamics as to learn to understand them in order to promote specific medical objectives. These two approaches need to be considered separately.

Inclusion of Family in Treatment

Consideration of the family as a resource led to many new behaviors on the part of the patient, family, and staff. In the Family Focus program, there was an opportunity for all family members to observe and learn how to be involved in patient care. Most important, family members could practice what they learned through a process of successive approximation (21) in which transfer of patient responsibility to the family was accomplished through a series of increasingly difficult tasks whose successful completion was rewarded appropriately by the staff. Family members also learned to adapt themselves to new roles: for example, the husband of a disabled woman might learn how to cook. The consequences of these behavioral changes were a sense of competency and independence in the family.

Consideration of the family as a resource also led to the restoration of important old behaviors. For example, the family had an opportunity to engage in normal activities together,

such as eating meals, sleeping, watching TV, playing games, behaviors made difficult by the exigencies of the traditional hospital setting. As a consequence, there was an opportunity to re-establish normal relationships among all members of the family.

A further case history might be illustrative of the advantages of recreating some facsimile of the patient's social environment. For some time the Family Focus staff worked with a Samoan family in which the patient was an eight year old child being prepared for major heart surgery. It had been recommended by the hospital personnel that the child be sent to a foster home because his family could not adequately regulate diet or medication schedules. The family was a large one and also largely nonEnglish speaking. However, by "treating" the whole family in the home-like setting of Family Focus, we were able to devise workable if unusual solutions to these problems. For example, rather than simply verbally instructing the mother, whose grasp of English was limited, the staff *modeled* cooking procedures and food preparation. An older sister whose knowledge of English was more extensive was given responsibility for organizing the medication schedule. Further, in a more home-like environment, it was easier for relevant staff to establish rapport with the mother who had been intimidated by the officiality of the Stanford Medical School. Finally, we were able to utilize the powerful influence of the grandmother, who had never once appeared in the traditional hospital setting, but was included as a pivotal figure in the Family Focus experience. Utilizing all these largely ignored resources it was possible to return responsibility for the child's recuperation to the family.

A final consequence was changes in staff awareness. By experiencing the patient in the context of an approximation of his or her home environment, we learned the clear-cut situation —specificity of patient behavior (22), thus effectively challenging any stereotypes we may have formed about the patient based on the personality characteristics he or she had exhibited during hospitalization. It became clear that as the environment varied, so did the patient's behavior, attitude, mood, etc. Patients were not consistently belligerent, cooperative, depressed, friendly; rather, these so-called "character traits" appeared to be elicited by different contingencies and cues in the environment. For example, in the hospital setting, the stroke patient previously described had been labeled as senile and uncooperative; indeed he did display these behaviors. However, in Family Focus the staff was exposed to the patient's wife (his social environment) as well as to the patient. She saw him not as senile but as lovable, not as uncooperative, but as her partner of 30 years. To the extent that staff were able to see the patient as this family member saw him, a more holistic perception of the patient was realized.

Staff also learned to avoid stereotypes about family roles. For example, we discovered that different family members could assume different roles regarding patient care. In violation of our stereotypes about whom we should identify as the primary caretaker in the family, we discovered that often a less obvious choice provided the real power in the family.

Staff Training

It was important for our staff to develop a basic knowledge about how to deal most effectively and most humanistically with families. Simple awareness of "family" was insufficient. Anyone can add as a reflexive addendum, "And let's not forget the family." What was needed was an understanding, at a relatively sophisticated clinical level, of family structure, dynamics, and techniques to intervene in family interactions.

It is important to add as a qualifier that interactions between staff and family members were complex. Even well-intentioned families and well-trained staff did not automatically function as mutual allies in the health care of the patient. Clashes sometimes occurred over divergent definitions of the patient's welfare; over implementation of a treatment strategy; and over control of the patient.

Nevertheless, it remains true that health care workers need the skills not only to change their own relationships with patients, but also to

facilitate and reinforce change within the patients and families themselves. The Family Focus program provided an opportunity for training in and exercise of various behavioral science skills for health care personnel involved in the program. It was felt that health care personnel had primary responsibility for modifications in all areas identified as change targets (patient relationship to physical structure, patient relationship to health care personnel). Training occurred informally through small group supervision, discussion and mini-lectures. Awareness of relevant theory was transmitted by a process of generalization from specific cases to more broadly applicable conclusions. Some of the areas of skill training which proved particularly important in working with families are summarized as follows:

1. *Interviewing Techniques:* Including how to establish rapport; how to paraphrase and engage in reflective listening; how to pay attention to nonverbal skills such as eye contact, personal distance, and body posture.
2. *Observational Skills:* These were used for recording and analyzing interactions and communication patterns; skills consisted of monitoring such variables as eye contact, the presence or absence of family members, spatial positioning, the amount of talking and by whom, double messages, etc. A second aspect of observational skills involved how to interpret what was observed.
3. A third category of skills involved learning *how to change patient and family behavior.* Again the goal was not for health care personnel to become minipsychotherapists, but rather to understand how a particular family related. Behavior modification principles were explored as a way of changing patient and family behavior (18, 23, 24). Family therapy techniques were also presented (25, 26, 27, 28). This category included learning how to use one's own emotional responses therapeutically. This kind of discrimination training enabled the health care professional to decide when to emphasize and when to ignore or confront a patient or family.

Value Modification

In the start of this article, three important factors contributing to the negative relationships between family and hospital were enumerated: organizational patterns, skill deficits, and ingrained values. The first was modified by an alteration in the physical, and to some extent the social environment of the patient. The second was modified through remedial training. The third—ingrained values—was only addressed indirectly. Values of staff were directly affected and modified by their personal experiences in the Family Focus unit. Skeptics were transformed into believers simply because they could not deny the evidence of their own eyes—that formerly depressed patients flourished, that formerly hostile patients suddenly become cooperative. In addition, discussions between various staff members often took place, which informally explored appropriate roles for patients, family, and staff, and how the more traditional functions might benefit from modification.

Evaluation

Because the emphasis of the Family Focus project was student training, evaluation focused primarily on student, rather than patient, response to the unit. Unfortunately, initial efforts to identify an appropriate control patient population foundered. There were not enough patients to randomize admission to Family Focus, and the hospital tended to treat the unit as a dumping ground for problem patients. Practically, controls often received exposure to some of the Family Focus principles and training. Finally, the questionnaire used to assess change in the patient population (the Suinn-Feldman Rehabilitation Self-Description Scale) suffered from a large number of nonrespondents. Responses to this instrument in general identified no significant difference between experimental and control patients and families

in positive or negative outlook. However, empirical impressions of the staff confirmed an overall positive impact of the program on patient attitude and physical functioning. In addition, much anecdotal evidence in the form of letters, phone calls, and return social visits from patients reinforced the conclusion that the program had contributed significantly to patient well-being. Pre and post tests for students showed little change on the Attitude Toward Disabled Persons Survey, indicating that students came into the curriculum with attitudes toward the disabled close to the norm and ended with essentially the same perceptions. However, when responding to a videotaped segment of a Family Focus therapy session, students showed a significant increase in the amount of importance they attributed to psychosocial variables during the course of patient treatment. Anecdotal data from students also indicated that the Family Focus experience provided a valuable learning environment. In general, they felt they had a better understanding of how family interactions affected rehabilitation. They felt more comfortable communicating with family members, helping to resolve interpersonal conflicts, and providing encouragement and support for patients and families.

Recommendations for Establishment of Family Units

The idea of meaningful involvement of the family in the care of the hospitalized patient is not new. As has been pointed out (10) this concept has already been applied in many of the developing nations of South America, Africa and Asia. Modifications of this concept would appear to have considerable relevance to our own culture.

For example, as we learned in the Family Focus program, even a large family is prepared to accommodate to a small space in exchange for the rewards of living together. Thus, one might propose the development of cottage complexes housing entire families, organized around a central hospital facility (which could still care for acutely ill and emergency patients).

Establishment of these quasi-independent units would have several benefits. First, a cottage-like atmosphere would reduce the sense of depersonalized, institutionalized health care too prevalent in a major medical center. Second, in contrast to the cot-by-the-bedside model, a live-in unit would allow for at least a semblance of normal family composition. Clearly, because of exigencies of work or school, not all family members could remain with the hospitalized patient for an extended period of time in such a unit. However, it would provide a cozy, home-like atmosphere where family members in addition to the primary caretaker(s) would feel free to come. Finally, as we observed in the Family Focus unit, a sense of territoriality or nest-making would be more likely to occur, with consequent positive results for family's initiative and self-esteem.

However, modification of the physical environment as described above is insufficient. Merely pulling the family together physically will not produce the desired effects. Thus, a Family Unit would have to address itself to the problem of defining specific functions for participating family members. These might approximate functions held in the original home environment (food preparation, housekeeping, engaging in joint projects, decision-making etc.) and might also involve assumption of new functions (bathing patient, exercising with patient).

Especially important in the concept of a Family Unit would be the principle that the patient is an equal member of the family, not simply a passive recipient "done to" by either family or health care workers. In this regard, reestablishing the patient in a modified, but meaningful role in the reconstructed family context would be critical.

Further, it would also be essential for the Family Unit to acknowledge the reciprocal, mutual nature of most family systems. One implication of this axiom would be an awareness that the emphasis on family involvement exclusively when the child is the patient is misplaced. Our own Family Focus experience reinforced the belief that children can have a therapeutic effect

on their ill parents as well as vice-versa.

Finally, a Family Unit might profitably make use of the concept of extended family. Often, as we saw in Family Focus, extended family members were eager and available to participate in the unit. In addition, rather than creating an aggregate of isolated nuclear families, efforts could be made to involve members from different families all living within the cottage complex in training sessions, support groups, even back-up units for each other. In this way, the concept of a therapeutic community could be promoted.

A successful Family Unit such as the one proposed here would have to include educational efforts directed toward patient and family members, as a means of providing them with the skills for adopting these new health care roles. Similar educational experiences would have to be aimed at staff, to ensure their comprehension and support of this alternative model.

Clearly, such a program is visionary, and inevitably fraught with problems. One area of difficulty would be possible role conflict and competition between family members and health care personnel. Such a program would also have to contend with feelings of confusion and guilt among family members and staff to whom such a model was alien, and implementation of such a plan would require a major disruption of the existing hospitalization system.

However, the advantages would be myriad: an increased sense of dignity and competence on the part of both patient and family; an increase in individual and family self-responsibility for their own health care; a more mutual and humanistic relationship between health care personnel and patients; an emphasis on treatment of the whole person rather than the disease entity; and a respect for the preservation, insofar as possible, of the patient's social and physical environment. Other benefits might well include increased patient compliance with medical regimen and reduced costs because of a reduced need for support personnel. However, the potential efficacy of such a model can only be definitively established through continued clinical and research efforts.

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On the Nouvelle Cuisine

We know now that men can be made to do exactly anything - after a hundred years of democracy and eighteen centuries of the Christian faith. It's all a question of finding the right means. If only we take enough trouble and go sufficiently slowly, we can make him kill his aged parents and eat them in a stew.

Jules Romains, *Verdun*