

3

A DYNAMIC MODEL FOR UNDERSTANDING THE PHYSICIAN'S RELATIONSHIP WITH PATIENTS AND THEIR FAMILIES

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Because multiple sclerosis (MS) has no known cure and no guaranteed methods of treatment, much of the traditional doctor-patient relationship is rendered ineffective. The customary consultation/diagnosis/prescription/cure relationship between the individual and his/her physician needs to be replaced by an ongoing partnership between the healthcare team and a family in which the relationship itself becomes the primary treatment agent. This ongoing treatment relationship can be thought of as the central component of an "Evolving Education Model" of care.

AGAINST TRADITION

Doctor-patient relationships have historically been grounded in one of two familiar models. In the "Acute Model," a paternalistic relationship exists between doctor and patient; the patient seeks the advice of a physician, who then prescribes

a particular treatment without significant attention paid to the wishes or opinions of the patient or his/her family. A more equal, less paternalistic relationship exists in the "Contractual Model," in which the physician provides information to the patient with the understanding that he/she may or may not accept a particular recommendation. As with the Acute Model, this model involves strict confidentiality with very little, if any, attention paid to the family's needs or problems.

The "Evolving Educational Model" incorporates aspects of these earlier approaches, but goes beyond to allow for the growing, changing needs of a family struggling to cope with the impact of chronic illness. In the initial stage of the chronic illness, an acute medical problem may require immediate intervention. The family may be overwhelmed and distraught, and therefore temporarily unable to make effective, rational decisions. The physician assesses the situation, develops the appropriate treatment plan, and begins the educational process which will gradually enable the patient and family to assume a more equal, active role in the planning and decision-making process. Once the patient's medical and emotional equilibrium is restored, a more interactive and dynamic relationship can be formed. With careful attention given to issues of confidentiality, privacy, and autonomy, the physician and family decide who in the family will give and receive medical information, and who will have a say in the treatment planning. The rationale for this decision is discussed in detail and reassessed as family roles evolve, or whenever changes occur in the patient's condition or in the family's ability or willingness to participate in the treatment process.

As an example of evolving family roles, consider the case of a 15-year-old diagnosed with MS. At the time of diagnosis, the patient is a minor whose care and treatment are primarily the province of the doctor and the parents. As the patient matures and becomes more independent, the physician's relationship with the family will necessarily change. One particular young woman left her home in Colorado to attend college in Texas. She elected to spend the summer in Nevada rather than return to the cooler climate of Colorado and the support system

of her family. While the physician believed that this patient would indeed feel better in the cooler climate, he felt that it was important to provide her with the pertinent information and advice and then to support her as she made her own decisions. At the same time the parents needed some supportive counseling to help them deal with their concerns and feelings about their daughter's growing independence and her need to make such decisions herself. Parents' concerns for their children's safety and welfare may lead them to try to extend or even re-create an earlier parent-child relationship long after a child has begun to establish an independent lifestyle. In these instances, the physician's task is gradually to shift his/her relationship with the various family members, while enabling them to get the support they need to understand and deal with these role changes.

A different kind of shift may need to occur in the doctor's relationship with the family if a patient experiences significant cognitive impairment. A man in his fifties who has always participated actively in his treatment planning may eventually become unable to engage in an effective decision-making process. While continuing to support and adhere to the patient's wishes whenever possible, the physician must increasingly involve family members in the planning and decision-making process. The patient and family must gradually be educated about the cognitive impairment in order to plan effectively for this transition.

SETTING THE STAGE

The early contacts between patient and physician can set the stage for the entire therapeutic relationship. Using a supportive, educational approach, the physician should engage the family in the treatment process and create an atmosphere that encourages open communication and cooperation over the course of the relationship. This approach begins with the initial evaluation and diagnosis. The physician should communicate the diagnosis as soon as it is reasonably certain, as the coping

process cannot begin until the problem has a name and a definition (Scheinberg et al., 1984). Too often, physicians shy away from an illness they cannot cure and delay sharing vital information with patients and families. The physician's own discomfort is communicated to the patient, who leaves feeling abandoned and burdened with the weight of uncomfortable feelings and unasked/unanswered questions. Hearing the diagnosis from a physician who conveys the information in a supportive and informative manner gives the patient a greater sense of mastery; the message is that the confusion and uncertainty of the past have now been explained and we can work together in the future to deal with the problems. One patient described it this way: "We were not alone when we learned of the diagnosis. Dr. M was there and he helped us." Thus, the stage is set for the future; as problems arise, the patient and family will feel comfortable turning to the physician for guidance and support.

PROVIDING ONGOING SUPPORT

In the Evolving Educational Model, the doctor-patient relationship needs to be one of mutual respect. Presumably the patient selects a physician whom she/he trusts will provide high-quality care. By the same token, the physician needs to recognize the patients' individual needs, priorities, and opinions. The support provided to patients should convey the message that they will not be alone in their efforts to cope with their disease and make meaningful, effective choices for themselves. The following examples will help to illustrate this important point:

A man with MS comes to the neurologist for an office visit. In front of the entire comprehensive care team, the patient begins to yell at the doctor, complaining that he is not getting better, that he hates the doctor and is going to go to see Dr. X (another practitioner who is using an unproven, experimental drug). All of the patient's rage and frustration over his chronic illness is, at that moment, directed at the physician. The physician responds, "The bottom line is that when you and I leave this clinic today, you are still going to have MS. You need to do

what is best for you and live with MS in your own way. My responsibility is to provide you with information about the risk and the benefits of whatever treatment you want to discuss. You are the one who has to decide what is best for you. I need to tell you that Doctor X has not published any reasonable, scientific data, that he has been resistant to having his methods studied and that the treatment could be quite dangerous. You have to decide what you want to do with this information. After you go there, I would like you to come back and see me. If you are better, the second happiest person in this world for you will be me. If the treatment doesn't work, you need to know that I am available to talk to you about other options."

This exchange between physician and patient exemplifies the core of a relationship in which the physician respects the patient enough to recognize his/her right to make personal decisions and, at the same time, is willing and able to function as a significant part of the patient's support system.

The second example involves a patient who is tripping over her big toe because of a foot drop, but refuses to use a brace. The physician can insist that the patient get a foot brace which she will then put away in the same closet with others that were previously prescribed. By insisting that she get a brace which she is not ready to use, the doctor is confirming her fears prematurely confronting her denial, and threatening her feeling of autonomy. The patient will therefore continue to hunt for a doctor who will support her denial and tell her that she is doing just fine as she is. By allowing a patient to do things in her own time, the doctor provides information and guidance without impinging on her sense of control. This woman may need to fail several times before she comes to the decision that the time is right to heed the doctor's advice about a foot brace.

Of particular significance in these examples is the idea that medical treatment per se is only one component of the ongoing doctor-patient relationship. Treatment can be thought of as the content part of the relationship, but healing is the process component. Healing takes place in and around and through the treatment that is offered. It is the process of being with the patient and family, understanding and appreciating the change:

they are experiencing, and creating a safe, respectful, and non-judgmental place for them to cope with these changes. In this healing process, the physician serves as a "container" for the family's fears, uncertainties, and negative feelings related to the MS; he/she helps to make these experiences more manageable by serving as a supportive presence and a role model for family members in their efforts to adapt and cope.

THE IMPORTANCE OF A HEALTH CARE TEAM

Multiple sclerosis affects the entire family system in which the disease occurs. Its effects are social, economic, and emotional as well as medical. The notion of a solitary medical practitioner working to effect a cure is no longer applicable. Rather, the far-reaching impact of the disease requires the intervention of a multidisciplinary team working in a coordinated fashion to help the patient and family cope with the stresses of chronic illness. The remainder of this chapter therefore focuses on the relationship between the patient as part of a family system and the physician as part of a healthcare team.

Identifying Important Resources

Once the diagnosis is known, the healthcare team can begin to help the patient and family with the coping and adjustment process. While educating family members about MS, the team can utilize this interaction time to assess the family's existing strengths and resources. Healthcare practitioners have tended in the past to be reactive—to respond only to losses and negative events. The family's ability to cope with the stresses of chronic disease will depend on the internal and external resources they bring to bear on the problem. It is the job of the healthcare team to help patients and families recognize, appreciate, and utilize all their existing strengths to cope with the challenges that arise. Families also need to learn about

resources available in the community. What is helpful for one family may not be for another, but the goal is to provide a menu of options so that families can choose what is most useful for them. The education process needs to be an ongoing one in order to meet the changing needs within the family. Information that would have been irrelevant to a family in the early stages of the disease may suddenly take on new meaning as significant medical, economic, or social changes occur.

Defining Problems in a Manageable Way

Most families, at one time or another, become overwhelmed by the enormity of the problems created by MS. An ongoing task of the healthcare team is to identify smaller, more manageable problems that have workable solutions. This approach is particularly useful for the family that comes to the doctor demanding either a cure for the patient's MS or that she/he be able to walk again. The family is frightened by the disease and unable to focus on any goal other than a total eradication of the problem. Healthcare providers who fall victim to these demands eventually develop a feeling of failure and withdraw in frustration from both the family and the patient. Rather than "buying into" the family's demands for a cure or a miracle, the team must help the family to recognize and experience its grief, then focus on more specific quality-of-life problems that can be solved in a satisfactory way. In so doing, the team also reinforces its own sense of competence in helping families with their coping efforts; the identification and pursuit of realistic goals lessens the feelings of frustration and failure which can be so much a part of the management of a progressive disease, and which not infrequently leads to professional burnout.

Recognizing the Interplay of Disease and Socioemotional Factors

By its very nature, chronic, debilitating disease highlights pre-existing behavioral patterns within a family system and creates additional emotional turmoil. As the family strug-

gles to adapt to the demands of the MS, the illness can take on more than its share of importance in daily life. Everything is blamed on MS, and MS is seen as the focus of all problems. As a result, stresses and upsets within the family are often expressed to the physician in terms of MS-related symptoms or problems. One possible consequence of this is a variety of inappropriate or unnecessary medications, hospitalizations, and long-term placements. The following case is illustrative:

A woman calls her physician in a crisis. "My left arm is numb and weak, and I am dragging my left leg. I'm having a terrible problem and you must see me immediately. I need to be on steroids. Please put me in the hospital." Knowing something about the dynamics within the family, the doctor asks her how things are going between herself and her husband. The woman responds angrily that her husband thinks she is faking. She then continues to describe all the ways in which her husband has been upsetting her and making her furious, and never mentions her physical symptoms again. The doctor recommends that she make an appointment the next day with the psychotherapist who has been seeing the couple in marital counseling and asks that the woman call the next week to report on how she is doing. The woman thanks the doctor and hangs up feeling greatly relieved. Had the healthcare team been unaware of the marital problems within the family, the doctor might have responded too quickly to the patient's physical complaints and perhaps medicated or hospitalized her unnecessarily.

Similar examples abound of individuals placed prematurely in long-term care facilities. Family members begin to experience total overload as their emotional, social, and financial resources are sapped by the illness, and their needs are ignored by healthcare providers. If they exhaust the physical and emotional energy needed to cope, their response is often to withdraw physically and emotionally from the patient, resulting in an increase of medical, social, and emotional problems. Long-term placement looms as the only solution. By providing ongoing emotional support for the family, the healthcare team can prevent this overload and enable the family to more equitably meet the needs of all its members.

Support For the Family

The family experiences its own reactions to the diagnosis of MS in one of its members. From the outset, family members must be permitted and encouraged to express their own grief and anger. They will be unable to support the patient in any effective way over the course of the illness if they are overwhelmed by their own reactions.

The healthcare team can instruct families how to assimilate MS into their lives without allowing their personal and family needs to be totally submerged by the disease. Family members must be encouraged to pursue personal goals and maintain satisfying outside interests and activities so as not to feel like hostages to the MS. Spouses and elderly parents in particular can experience guilt over their own good health and their feelings toward the patient. The healthcare team can assuage this guilt by supporting people's efforts to maintain an independent life beyond the MS. This in turn will have reciprocal benefits for the team and the patient. Over the course of the illness, family members serve as a valuable extension of the healthcare team. To the extent that they continue to feel good about themselves and satisfied with their own lives, family members can be more effective in their care of the patient. Ultimately, a primary goal of the healthcare team is quality care of individuals with MS, free from unnecessary hospitalizations or treatments, and free of the threat of premature or inappropriate long-term placement.

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