“Her Illness Is a Project We Can Work on Together”

Developing a Collaborative Family-Centered Intervention Model for Newly Diagnosed Multiple Sclerosis

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This article presents a model for intervening with families that are addressing a new diagnosis of multiple sclerosis (MS) in one member. The model is collaborative, integrative, and family-centered. It involves both working with the family collaboratively and providing strategies to promote greater collaboration within the family. The model integrates elements of crisis intervention theory, psycho-education, and family-centered approaches. The model was developed with families addressing MS, and was piloted with three families. The intervention was found to improve family members' ability to collaborate with each other. Such increased collaboration may enhance the family's ability to manage long-term illness more effectively, help the family address the impact of the illness on all family members, and generally improve the family's quality of life. Int J MS Care. 2013;15:130–136.

The value of collaboration in psychotherapy,^{1,2} in developing community-based programs for families,^{3–5} in families with a member who has a chronic illness,^{6,7} in the relationship between health and mental health providers,^{8,9} and in research¹⁰ has been well established. This article presents a model for intervening with families facing a new diagnosis of multiple sclerosis (MS) in one member. The model focuses on collaboration and integrates elements of crisis intervention, psycho-education, and family-centered approaches.

Intervening at the Time of Diagnosis

The diagnosis of MS is often experienced as a traumatic event by the patient and the family. It is usually delivered during a brief meeting with a physician, and patients generally emerge with little understanding of the illness and what life changes it may entail.^{11,12} The period following the diagnosis is often experienced as

a critical life transition and family crisis.^{6,13,14} Patients and family members long remember this period and express regret that they did not have appropriate support and guidance. When faced with the prospect of having to cope with a long-term illness, the family may find its usual way of operating to be challenged. Often the family must reorganize itself to meet this challenge. For example, if one of the spouses has been the primary emotional caretaker in the relationship, the other spouse may shift roles and provide more emotional care, and children may take on more responsibility for household chores.

This time of challenge also creates opportunity. Because the family must change its identity, worldview, and style of functioning to respond effectively to this crisis, it may become more receptive to outside help. Intervention close to the time of diagnosis can have a more significant influence in promoting adaptive change than intervention at other times.

Intervening with Families

Although most psychosocial intervention with people with MS is individually oriented, chronic illness also has important familial aspects. As described by Kleinman,¹⁵ there is a distinction between disease and illness.

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DOI: 10.7224/1537-2073.2012-022

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Disease refers to purely biological aspects, to changes in the biological structure and functioning of the afflicted person. The concept of illness, however, refers not only to the patient but also to members of the family and the wider social network as they experience and try to live with, find meaning in, and respond to the disease. Patients and their families often exhibit reactions in multiple areas of psychosocial functioning,⁷ as psychosocial consequences can be as disabling as physical symptoms of illness. Any intervention, to be effective, must address the impact of the illness on both the individual and the family. In fact, improvements in family functioning have been shown to be related to improvements in health-related outcomes.¹⁶

Psycho-education

One of the most crucial initial challenges for a family is to understand the illness and make informed choices regarding treatment. Although information about MS is readily available, accurate and reliable sources may not be easily located by the family. Advances in treatment choices have increased the need for comprehensive education of patients and families. The provision of patient and family education has been described as an ethical issue when medication choices are involved.¹⁷ People with MS and their families have expressed the need for more accurate and up-to-date information about the illness in language that is understandable by the layperson.¹⁷

Psycho-education has long been used successfully in both general health care and mental health care.¹⁸ In a recent meta-analysis, improvements in physical health were found to result from psycho-educational interventions with families living with cardiac disease and cancer.¹⁹ In MS, the importance of patient and family education has been highlighted as the need for shared decision making about treatment has become recognized.¹¹

The Collaborative Approach

Generally, we interact with families using the collaborative guidelines spelled out by Anderson.^{1,2} According to Anderson, collaborative therapy is not a "model of therapy," but rather "a way of being in relationship." The "heart and spirit" of this approach involves a stance that conveys to patients "that they are valued as a unique human and not as a category of people; that they have something worthy of saying and hearing; that you meet them without prior judgment."^{2(p44)} Anderson further specifies this "way of being" in collaborative relation-

ships with the following pragmatic advice: truly listen to and hear patients by asking questions to clarify and learn more about what the patient is saying and by showing curiosity about what the patient presents; "maintain coherence" with patients—that is, work within patients' experiences and allow them to develop and tell their story in their own words, from their own point of view; believe and do not doubt patients, since it is their subjective experience we are trying to understand; "stay in sync," making sure the patient has understood what you have said and ascertaining whether they agree or disagree. Many elements of Anderson's approach to collaboration parallel Buber's²⁰ discussion of "genuine dialog," especially not imposing one's view on the other and allowing the patient's and family's views to develop freely.

Essential to this stance is an attitude of "not-knowing," wherein all knowledge is considered "tentative and provisional."² Therefore, the clinician's knowledge and understanding are not privileged above the patient's knowledge and understanding: "The patient is considered the expert in his or her own life and is the clinician's teacher."^{2(p46)} This approach allows conversations in which opportunities for new meanings and behavior are opened for patients.

Despite Anderson's emphasis on trusting, believing, and working within the patient's reality, we believe that skepticism and disagreement regarding the patient's perspective have a place in a collaborative relationship. Even with open disagreement, a relationship can remain collaborative as long as one continues to "affirm" and value one's partner in dialogue,²⁰ does not try to impose one's view on the other, and does not regard one's own position as the "truth," maintaining a willingness to be found wrong.²¹ We assume, with Anderson, that when we collaborate with families in the manner she proposes, patients will identify with and emulate the clinician's collaborative efforts. In this way, the clinician's stance not only serves to open new possibilities for patients but also promotes greater collaboration with each other. However, we believe that more can be done to actively promote collaborative behavior in the family.

Structure of the Intervention

The intervention consists of three components, each lasting 1½ hours and spaced 3 to 4 weeks apart. Approval was obtained from the Institutional Review Board of the Harvard School of Public Health. Patients and their

families were recruited through area neurologists. Three patients with a confirmed diagnosis within the last 12 months, and their families, agreed to participate. All meetings were videotaped, with participants' permission.

First, the "illness story" is elicited from each family member and shared with the other family members, and the family is asked about its history of adaptation to challenging situations. This is followed by a psycho-educational component, during which we pass along to the family information about the medical aspects of the illness as well as health-promoting practices gleaned from the literature and from our experience with other families. Finally, a family collaboration component is designed to enhance and promote collaboration between family members to meet the challenges of chronic illness. Collaborative intervention respects the uniqueness of the patient; it requires the clinician to present information relevant to particular individuals and ask whatever questions may be needed. The three components of our intervention, therefore, are both structured and open-ended. We used pre-formulated questions in each of the sessions, and we presented prepared information in the psycho-educational session. In the spirit of collaboration, we continuously revised the intervention in response to feedback from participant families.

Creating a Shared Illness Narrative

The most basic generous question is what has happened to you? Not your disease, but what has happened to your life?²²

The meaning families ascribe to their experiences with illness "is a critical mediating factor in determining family adjustment and adaptation."^{6(p6)} Therefore, interveners "can facilitate better patient and family adaptation to chronic illness . . . [by] paying more attention to the meaning-making process and supporting . . . families in making these processes more explicit."^{23(p300)}

A patient's story of the illness, his or her "illness narrative,"²⁴ involves making meaning of the illness experience, which can facilitate adaptation and collaboration when this meaning is made more explicit and subject to dialogue within the family. The illness narrative helps the patient and family integrate their experiences of the illness into the new reality of their lives and give them coherence.¹⁵ Often, family members do not have a shared story about the illness.²⁵ The process of hearing each individual's experience of how the illness affects them enables the family to construct a shared and multifaceted story. One result of this process is that the person

who carries the diagnosis of MS begins to see that the illness is not just an individual problem but a problem for the entire family, to be addressed by the family as a whole.

Clinical Illustration

In their first meeting, the "A" family, in which a young adult son, Robert, had been diagnosed with MS, shared their emotional reactions with each other for the first time. The mother, Carol, said, "I felt so guilty. He got it from me. . . . and I was very angry. That was my first reaction, and it still is." She added that she worried greatly but tried not to call her son because "I want him to have some space and not know how upset I am. When it's your child, you want to fix everything, and you can't." Robert responded in kind: "I didn't realize that she was keeping her distance just as I had been keeping mine, for essentially the same reasons." He wanted his family to know that he is independent and capable of "taking care of things." At a later point, Robert stated that he had come to understand that he is "not the only one who is affected."

We responded to this interchange by suggesting that mother and son could help each other by communicating their concerns more directly. Our input and the family discussion allowed them to share their concerns more openly and thereby to relate to each other in a way that was helpful to both.

Psycho-education

We approached psycho-education from a collaborative perspective. That is, we viewed the psycho-educational component as passing along to newly diagnosed families what we had learned from other families' experiences of adapting to MS. We also maintained a willingness to revise our preconceived notions of what is helpful. We thus moved fluidly between the roles of learner and teacher, an important aspect of a collaborative relationship.

Patients have reported to us that they emerge from appointments with physicians without fully understanding the facts about their medical situation. We provided up-to-date information about MS, covering theories about the cause and course of MS, current treatment options, and psychosocial strategies that had been identified as useful to previous patients and their families.^{13,26} We also alerted patients and family members to changes in mood that commonly occur after a diagnosis of MS, including sadness, grief, anxiety, and uncertainty about

the course of the illness. Given the high prevalence of depression in MS patients,²⁷ we informed families of the symptoms of depression. We emphasized the importance of social support networks, since they have been linked to better medical outcomes in cancer, coronary heart disease, and stroke^{25,28}; psychological adjustment²⁹; and reduced rates of depression in MS.³⁰

Clinical Illustration

At one psycho-educational meeting, the mother of the patient asked about possible environmental factors in the cause of her son's illness. She noted a cluster of cases that she knew of in her geographic area. We did not know the answer to her question but told her that we would research it and report back to her. We found no evidence for environmental factors in the cause of MS and provided that information during subsequent meetings.

Promoting Collaboration Using Reflexive Questions

Collaborative dialogue among family members about the illness experience is essential to developing an adaptive response.⁶ However, direct promotion of collaboration has been relatively ignored. We promoted collaborative dialogue among family members in two ways. First, we relied on the observation of Anderson² that patients will emulate the clinician's collaborative efforts. Second, we identified issues and tasks that confront families facing MS and posed reflexive questions about them for discussion.

Reflexive questions are a type of question intended to help individuals and families develop new understandings and new patterns of behavior. Reflexive questions are formulated in such a way as to encourage family members to reflect on their current perceptions, interpretations, and patterns of interaction and to consider new possibilities.³¹ In asking these questions, the interviewer encourages family members "to mobilize their own problem-solving resources."^{32(p172)} Collaboration involves creating "the kinds of conversation and relationships . . . that allow all the participants to access their knowledge"^{10(p371)} and eliciting "the patient's and family's own natural resources—their strengths, competencies, and accomplishments."^{9(p287)} For these reasons, we believe that reflexive questions are particularly well suited for a collaborative approach.

The following types of reflexive questions are relevant to families in which a member has been recently diagnosed with a serious illness.

1) *Observer-perspective questions*: These questions are intended to promote collaboration by asking family members to view certain behavior, events, or experiences in interactional terms.³² Examples include the following: What do other family members think and feel about the situation? What do you think they think you are feeling or thinking?⁶

2) *Normative comparison questions*: These questions are oriented toward normalization, and counteract the tendency to pathologize the reaction to the diagnosis. For example: How do you think other normal, average families would deal with a situation similar to yours?³²

3) *Future-oriented questions*: These questions encourage the family to reflect on how they might work together in the future, and can trigger hope and optimism.³² Moreover, they are important because a key task is to develop flexibility in preparing for a long-term disorder.⁶ Some examples: Are there any future goals that you all agree on and see yourselves as working toward together right now? How do you plan to reach those goals? Can you imagine how the family can draw on past experiences to manage future challenges?³²

Clinical Illustration

In the following excerpt, reflexive questions helped a couple, the "C"s, in which the wife had recently been diagnosed with MS, to better collaborate with and support one another. Joe is a Vietnam veteran who suffers from posttraumatic stress disorder and other medical problems. He often relates events to his experiences in Vietnam, and in doing so fails to provide understanding and empathic responses to other family members. He is an affable "bear" of a man but at times appears threatening. In his personal relations, he can act like a "bull in a china shop." His wife, Eve, excluded him from her medical appointments and did not share many of her thoughts and feelings with him about having MS because he tended to dominate the interactions with his own thoughts and feelings.

We posed an initial reflexive question: Can you imagine how experiences overcoming problems together in the past can help you now? Joe began by recalling that they both lost their fathers very early in their relationship.

Joe: Her father drove trailer trucks, and he had a stroke or the accident caused brain damage. Somehow I was called upon. I drove her and her mother down to see her father. So that sort of tightened us up. We had something very difficult and unique to deal with in life. . . . It was a hammer. It hammered both of us. We had a lot of commonality.

Authors: So you see that in your situation now, the potential to be closer?

Joe: Yeah—and a strength. I would like to hear what she has to say about what I just said.

Eve: We had a bond. We went through a lot, a lot of death. We've gotten strength, but it doesn't mean we don't have our issues. . . . But when it comes down to the nitty gritty, we work well together.

Joe: If you're ever in a jam, here I am. Do you have a strong feeling of that?

Further along, we posed another reflexive question: What do you think each other is thinking and feeling about the MS? We asked them to write down their responses and then discuss them with each other. Joe began by saying that he thought Eve was looking at MS from a narrow point of view, and that made it scarier. We asked Joe to ask Eve how she is doing with the MS. Joe responded, "Yes, I really want to know. I'm interested." Eve then said: "I don't let my guard down that much. . . . But I did when I got sick last time, because I felt so miserable. And then I asked myself: 'Why me?' . . . Essentially, it's the first time I cried about it; but I was by myself, I had my own private cry . . . I do get scared about it [the MS], and I wonder how it's going to develop." Joe then revealed that he has known people with severe MS and has not told Eve in order to protect her. After they shared their thoughts and feelings about her illness, Eve said, "We can see this as a project. We can work on it . . . it could be . . . a project we could work on together."

Initially, Eve had excluded Joe from her thoughts and feelings about MS. As the interviews progressed, however, we saw greater involvement with each other as they checked to see what the other was thinking or feeling, not just in response to our questions, but also spontaneously. One reflexive question helped them to reflect on past situations in which they had worked well together and to bring those experiences to bear on their current situation. Another reflexive question encouraged them to share their ideas about what they thought the other

was thinking and feeling. This led to checking more with each other about the other's experience, which is a foundation for greater collaboration. As a result, Eve proposed that the illness "could be a project we could work on together," and Joe later added, "Her illness is a project we can work on together."

Additional Aspects of Working Collaboratively

Learning from the Patient

One consequence of collaboration is that all parties may be changed in the process. New meanings and understandings may emerge for both patient and clinician.¹⁰ For example, clinicians may have preconceived ideas or assumptions changed as they remain open to learning from patients. This was the case in our work with the "A" family. Robert was recently diagnosed with MS; he was living with his fiancée. His parents lived nearby. All four attended the sessions. Robert's mother, Carol, was emotionally expressive, nurturing, and involved with Robert, while the father, Peter, was detached. Peter is a recovering alcoholic and believed his commitment to sobriety required some detachment from the family. He also felt that his involvement with the family in the past, when he was not sober, had contributed to ongoing family problems. Peter's current stance, therefore, was that "my role is staying out of the way."

Our notion of collaboration prompted us to question Peter about his detachment, with the intent of fostering greater involvement with the family. However, when we began to ask questions, our initial assumptions about collaboration were challenged. Peter was asked the question, "How do you think others in the family perceive you?" He responded, "Others may wonder about my being detached—but they may want to be more detached themselves." Robert responded approvingly to his father's statement. He said that his father is "cooler" than his mother, more willing to hear and let things be, which Robert "really appreciates." Robert added that, of course, he also needs and values his mother's nurturance. Upon hearing this, we recognized that there is a need for a balance between involvement and detachment in facing the challenges of a long-term illness. Collaboration does not necessarily mean "involvement" only, but the active negotiation of each member's needs, including, at times, the need to be left alone or to let things be.

Collaborative Disagreement

We utilized collaborative disagreement³³ with a couple, the “B”s, to address Fred B’s insistence that his wife, Barbara, who had been recently diagnosed with MS, do certain things that he was convinced would help her. In Buber’s terms,²⁰ he was trying to impose his view on his wife rather than assist in unfolding hers. By collaborating with Fred while voicing our disagreement with him, we helped him collaborate better with Barbara; this allowed her to take things at her own pace and in her own way. Following is an excerpt from that discussion. Just prior to this excerpt, Fred was relentless in insisting that Barbara reach out to others in order to cope better with her newly diagnosed MS, something Barbara had difficulty doing.

Authors (to Fred): We see this as forceful caring.

Fred: I always have to watch out, because I do this all the time. It’s like bullying almost, because I’m impatient. (To Barbara) But it’s not bullying. It’s too great. It’s sort of evangelical. It works, it really works.

Authors: It’s good to put it out there, Fred, but she has a mind of her own and you have a mind of your own. She’s going to find her own way. . . . Do you see it as forceful caring?

Fred: I would just hope that it’s clear that it’s available.

Barbara: I think probably that it helps me because with a deep conviction that I have that eventually it will be something that I can manage.

Fred: I don’t have the slightest doubt.

Barbara: It’s just that in the here and now, it’s sometimes hard to get to that point.

The clinician is careful to acknowledge the caring intent in Fred’s attempts to impose his views on Barbara. Acknowledging his caring intent is crucial to collaborating with Fred by showing that we understand and accept it. After the clinician suggests that Fred may be overly forceful in his caring, Fred partially agrees but also defends what he is saying, because for him the message is so important. The clinician persists in his skepticism, in fact disagreeing with Fred’s approach and stating that Barbara has to find her own way. However, the clinician must find a way to collaborate with Fred and not impose his own view, so he asks Fred whether he too might see what he is doing as “forceful caring” (implying that it may be too forceful and not effective). Fred does not entirely agree, insisting that it needs to be clear that what

he is proposing is “available.” Barbara partly supports Fred while saying it is hard for her to get to the point he wants for her. A short time later, Fred turns to us and says: “Sometimes I’m too positive with Barbara and not sensitive enough to her. I’m trying to be a bit more sensitive.”

Family Feedback and Developing a Workbook

An aspect of our collaboration with patients’ families was inviting ongoing feedback about the intervention. We told the families that we continually strive to improve what we do and therefore want to collaborate with them to develop the most effective intervention we can. We utilized verbal and written feedback to make changes in the intervention and in the materials we used. Developing a workbook based on patient feedback that would be used by families with a member newly diagnosed with MS is perhaps the most tangible expression of that collaboration.

One family member stated, “If I could obtain a summary of your comments at the last meeting about what is known about the disease—it would be a great reference source for me.” In response to this feedback, we created a “take-home workbook,”³³ which we handed out during our first meeting with subsequent families. The workbook covered much of what we hoped to accomplish in the meetings to follow. Family members were instructed as follows: “Use the workbook in the weeks between meetings. We hope it will stimulate conversation, raise questions, and help you prepare for the next meeting. We’ve included some summaries that you can read, so we can cut down on ‘lectures’ during the meetings and have more collaborative discussion.”³³ The workbook contains information about MS and psychosocial strategies that other patients and their families had reported to be helpful to them. Resources with the potential to be useful to the family were listed.

PracticePoints

- A new diagnosis of MS is a crisis for the individual as well as the family and requires reexamination of priorities and family reorganization.
- Intervention close to the time of diagnosis may have a more significant influence in promoting adaptive change than intervention at other times.
- Psycho-educational interventions have demonstrated positive outcomes in other medical conditions and should be promoted in MS.

Questions to be discussed by family members between meetings were also included. We found that the workbook enabled family members to come to each session as informed partners in the process rather than passive recipients or listeners. We revised the contents of the workbook in response to feedback from the families. The workbook is available from the first author (DR).

Conclusion and Future Directions

We set out to intervene at a moment of crisis, and to help families collaborate in order to further their adaptation to life with a chronic illness. We found that family members were able to collaborate better with each other as a result of our intervention. We believe that increasing collaboration will enhance the family's ability to manage long-term illness more effectively, help the family address the impact of the illness on all family members, and generally improve the family's quality of life.⁶ Currently we are seeking additional ways to utilize this model. We hope to offer the intervention to other clinicians, together with our consultation and training. The workbook developed for this study has been put to use in multifamily educational support groups being conducted at the first author's MS center, and has been distributed to individual families who seek further information about MS, under the title *An Introduction to MS*. We plan to further test this model using a randomized, placebo-controlled or alternate-intervention study. Measures of health-related quality of life, social support, anxiety, depression, and family functioning could be used as outcome measures in such a trial. □

Acknowledgments: We would like to express appreciation for the families who participated in the intervention.

Financial Disclosures: Dr. Rintell has served as a consultant to Novartis Pharmaceuticals, Biogen Idec, and Acorda Therapeutics, and has received honoraria from Teva Neuroscience. Dr. Melito has no conflicts of interest to disclose.

Funding/Support: This research was conducted with financial support from Biogen Idec, Inc.

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