A COLLABORATIVE FAMILY-SYSTEMIC APPROACH TO TREATING CHRONIC ILLNESS: IRRITABLE BOWEL SYNDROME AS EXEMPLAR

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ABSTRACT: This article describes an evolving collaborative relationship between a family therapist and a physician focused on the treatment of irritable bowel syndrome, a highly prevalent disorder which has several psychological characteristics. We began with a unique approach utilizing (1) simultaneous treatment by both specialists; (2) a focus on the relationship context of illness. This approach draws on family systemic theory and practice as well as a circular model of mind and body interaction. Because the intervention was significantly helpful to patients, the premises which informed it were then incorporated into a five session group treatment model. Results and clinical report support the efficacy of a collaborative systemic approach between a medical specialist and family psychologist in treating adult chronic illness.

KEY WORDS: irritable bowel syndrome; chronic illness; collaborative health care; family based intervention.

Can a medical expert and a family therapist collaborate efficiently and effectively? This article describes an evolving collaborative, psychologist–physician approach to the treatment of a highly prevalent,

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chronic adult illness, irritable bowel syndrome (IBS). IBS is a gastroenterological syndrome which affects approximately 10 to 15% of the population and can severely compromise quality of life (Thompson, Creed, Drossman, Heaton, & Mazzacca, 1994). As one patient put it, "I can barely remember life without embarrassment and without pain."

There is a general increase in interest in psychotherapist–physician collaboration, often in primary care settings. Our collaboration began as a clinical research project, which grounded our thinking in empirical evidence. We began as co-investigators of a research project testing the efficacy of seeing patients together, focusing on the relationship context of IBS. Then, by extrapolating the clinical premises that had proven significantly helpful to patients, we developed a group treatment model. Throughout, our foundation has been the groundbreaking work generated by the collaborative health care movement (McDaniel, Hepworth, & Doherty, 1992), of which there is little awareness within the traditional medical community. However, as Nymberg and Selby (2000) note, "Despite the solid conceptual foundation for the collaborative care model and the recent movement in medicine toward large, integrated healthcare systems, the process for actually operationalizing this approach in mainstream medicine remains largely enigmatic" (p. 108).

Our effort is the first direct collaboration between a psychologist and gastroenterologist and presents three unique features: (1) the simultaneous treatment of patients by a psychologist and medical specialist in the initial phase; (2) the integration of a family systemic perspective in medical treatment; and (3) the development of a systemic treatment model without the necessity of involving family members. Though it is always preferable and advantageous to include significant others, most physicians in medical settings find this inclusion unwieldy and actually prohibitive. In both individual and group models, our treatment included a detailed family health history, as well as beliefs and attitudes of significant others, at home and at the workplace, regarding the patient's illness.

THE MEDICAL BACKGROUND

As Drossman noted (1984), "It is a matter of common experience that gut symptoms can be produced or exaggerated by emotional factors—the lump in the throat, the anorexia, the 'butterflies in the stomach', the nervous diarrhea at moments of stress" (p. 1249).

However, in spite of this fairly universal experience, gastroenterological interest in psyche–soma connections has been minimal. Interest was likely discouraged by early and excessive assertions regarding the etiology of ulcerative colitis, one of the seven illnesses traditionally designated as psychosomatic. Inflammatory bowel disease (Crohn's Disease and Ulcerative Colitis) has not been clearly responsive to psychological intervention, and unreliably associated with psychological profiles and psychiatric diagnosis (Gerson, 2002).

In contrast, IBS, though not originally identified as "psychosomatic", is in fact, considerably psychologically affected in terms of symptom patterning and is responsive to psychotherapeutic intervention (Blanchard, 2001). Drossman (1996) has emphasized the circular nature of the IBS syndrome. Much more is scientifically known today about the interaction between brain and gut, including nerve connections between the central nervous system and the enteric nervous system ("big brain and little brain"), as well as evidence that they share the same hormones and neurotransmitters (Aziz & Thompson, 1998). In Drossman's circular model, colonic sensation and motility can be altered by emotional processes such as early trauma, life stress and psychological status, while a change in emotions can result from a shift in colonic symptoms such as pain, diarrhea, and bloating.

Supporting this notion, we recently reported, in a global survey of IBS, that patients who acknowledge psychological factors as relevant to their IBS have significantly lower symptom intensity than patients who attribute their symptoms mainly to physical factors (Gerson et al., 2004).

Clearly we are in the midst of a surge of heuristic empirical research in the area of psyche–soma interactions. It may be that certain illnesses, or certain organ systems, like the GI tract, are particularly predisposed to interactive influence.

PSYCHOLOGICAL FINDINGS

What are the findings with regard to psyche–soma interaction in IBS? There is a significant incidence of psychological distress in IBS patients, as well as the suggestion in one well-designed study, that anxiety and depression facilitate the development of symptoms (Bennett, Tennant, Piesse, Badcock, & Kellow, 1998). While the relationship of stressful life events to IBS has been empirically validated, the time lag between psychological distress and symptom outbreak remains unclear (Dancey, Taghavi, & Fox, 1998). Several investigators have explored the effect of childhood sexual and physical abuse on IBS; in some studies the incidence of childhood abuse significantly differentiates IBS patients from those with organic gastrointestinal disease, and in others, results are inconclusive (Drossman, Talley, Leserman, Olden, & Barreiro, 1995). IBS affects three times as many women as men, evoking a range of explanations such as gender patterns in health care seeking, as well as hormonal influences.

Once patients suffer from chronic IBS symptoms, they are unlikely to feel relief without psychological intervention (Drossman & Thompson, 1992; Heymann-Monnikes et al., 2000; Blanchard, 2001). Nevertheless, gastroenterologists do not readily refer patients to mental health professionals. Most patients who seek specialist care continue to have symptoms (Waller & Misiewicz, 1969). They inevitably choose to see yet another specialist, who performs the same cluster of expensive tests, draining health care dollars, and more importantly, rendering the patient even more hopeless and symptom preoccupied. The health cost drains are enormous: IBS consumes $1.6 billion in direct and $19.2 billion in indirect costs (30 billion dollars in health dollars) per annum because of repeated investigative procedures and time lost from work (Sandler et al., 2002).

IBS characteristically evokes shame in the patient, and a range of interpersonal responses and deeply held beliefs in significant others (Rolland, 1994). These attitudes and beliefs affect the experience of illness of the patient, another circular loop. It seemed important to explore the perceived attitudes of family members, friends, and co-workers in order to help patients organize and articulate their experience of illness. There is now a body of literature linking marital quality to illness and immunology (Kiecolt-Glaser & Newton, 2001), as well as a recent study which has pointed to the possible undervalued effect of spousal attitudes in patient coping with chronic heart failure (Rohrbaugh et al., 2004). Weihs, Fisher, and Baird (2002) summarize illness research relevant to family context, dividing the field into "pre-intervention research" which examines the risk and protective factors of family characteristics, and family-based interventions studies. Throughout their comprehensive review, they emphasize that the bulk of social systemic research has been focused on children and adolescents, with a paucity of research dedicated to investigating the link between family relationships and adult illness.

OUR INITIAL COLLABORATIVE MODEL

The heart of this approach was a sequence of three 45-minute, bi-weekly sessions, with the family therapist and physician both present. At the beginning of each of these meetings, we constructed a "circle of effects" on a large drawing pad: On one side of the circle we noted how physical symptoms caused psychological distress, and then moving clockwise to the other side, illustrated how psychological experiences may have affected symptomatology.

In the first session, we completed a detailed inquiry about the initial onset of illness as well as the current circumstances under which symptoms were likely to occur. We then inquired in detail about how significant others related to the patient regarding his/her illness. While discussing psychological events, patients would spontaneously turn to the physician for information on medical aspects of IBS, such as diet and medication. Offering patients the opportunity to spontaneously move between mind and body focus was the foundation of our collaboration.

In the second session, we began with a review of the circle of effects, inquiring about the observations patients had made during the prior two weeks regarding the effect of emotions on symptoms and vice versa. New insights were often evoked. Then patients completed a three generational genogram. We asked the patient to describe various aspects of family life, including health care practices of their parents (often problematic), gastrointestinal symptoms in the family (common), and occasionally evoked a history of sexual or physical abuse, relevant to IBS (Drossman et al., 1995).

In the third session, we inquired about best coping strategies, trying to emphasize the patient's coping strengths. We also asked about "unique outcomes" (White & Epston, 1990), i.e. when the patient expected to have symptoms and they did not occur. We tried to open up new links between psyche and soma, and we finally asked patients to imagine life without IBS (Penn, 2001).

In all three sessions, there was a free exchange between patient, psychologist, and physician. Patients seemed to see the sessions as an opportunity to test their beliefs about psychological as well as physical aspects of IBS by posing spontaneous questions to each of us.

Significant results regarding symptom reduction in this initial phase of our work have been reported in a gastroenterological journal (Gerson & Gerson, 2003), so we will briefly summarize these findings here. Of the 30 IBS patients who participated, 16 were assigned to collaborative treatment (16 patients), six to short-term psychological treatment (similar in thinking to the collaborative), and eight to standard medical treatment (8 patients); all completed symptom diaries before the intervention, afterward, and three months later. Improvement in symptomatology for the collaborative intervention was highly significant in terms of the two-week diary ($p < .0002$) as well as patients' self-assessment of global improvement at the end of the study. Patients in the psychological treatment group seemed improved since a similar percentage of patients in this group reported global improvement, but the sample size likely precluded statistical significance. Notably, the medical treatment group did not report improvement.

A CASE EXAMPLE ILLUSTRATING OUR COLLABORATIVE WORK

Jane D. was a 35 year-old woman with gastrointestinal complaints of one year's duration. She had undergone many medical tests, including colonoscopy and a pelvic sonogram, and was finally diagnosed with IBS. In the first session, she identified an experience of "stress" due to her aborted relationship with her sister, who had not spoken to her for a year because of an "insult" which Jane found mysterious and unbridgeable. Jane liked to experiment "holistically" with treatments that have little empirical validation, but we expressed a sense of openness to the mystery of the syndrome, which seemed to validate her own sense of choice and self-determination.

In the second session, while constructing her family's genogram, Jane began to describe her father's physical abuse of her younger brother and older sister which suffused her childhood. Jane pithily said, "Basically, it was eat dinner and then hide." She could not remember seeing her mother beaten by her alcoholic father, but did remember frequently seeing bruises on her body. Her mother denies the abuse altogether. When asked how she was feeling recounting these memories, she said she was experiencing painful cramping, though she had arrived at the session feeling fine. It was suggested that reflecting on these memories might organize them, and that perhaps writing about them in a journal might externalize them, give her a sense of mastery.

We talked about Jane's feelings toward her mother, her intense frustration about her mother's shoddy self-care in spite of her obesity, diabetes, and high blood pressure. In the midst of this discussion, Jane spontaneously asked the gastroenterologist, "Does it ever go away?" We supported Jane's nascent, fragile wish for a healthier, more pleasurable life.

In the third session, two weeks later, Jane reported noticeable symptomatic improvement. Beyond feeling less pain, she had become more experimental and inventive in her coping strategies. She said she actually thought her symptoms were not significantly reduced, but that they seemed less upsetting to her, that she felt more hopeful about the future.

THE DEVELOPMENT OF A GROUP MODEL

We were encouraged by the effectiveness of weaving together our expertise, by treating symptoms as embedded in circular causality, and by the usefulness of mapping IBS in the relationship life of the patient. However, we were interested in developing a collaborative model that would incorporate the clinical thinking and methodology of our research model, but could reach a greater number of patients. A group model seemed appropriate. There have been other group treatment approaches to IBS: cognitive-behavioral (Toner, Segal, Emmott, & Myran, 2000) and psycho-educational/psychodynamic, (Poitras et al., 2002), but none with a family systemic focus.

Articulating the Clinical Premises Underlying Our Methodology

We summarize our clinical thinking as follows:

1. We drew a map of illness-in-relationship with the patient. Our belief, along with others in the family medical systems arena (Minuchin, Rosman, & Baker, 1978; McDaniel et al., 1992; Rolland, 1994) is that symptoms are part of a social fabric, i.e. illness creates a set of relationships, which, in turn, evoke a particular pattern and meaning to symptoms. We talked about IBS as a multi-person phenomenon, with the reactions of significant others, both present and historical, shaping the meaning of symptoms.
2. We tried to co-construct an illness story with the patient, exploring the relationship of illness in his/her family of origin to present coping, the first experience of IBS, and its subsequent pattern. Symptoms were put into language and were shared. Without being able to identify the effect of unconscious processing and the shift in out-of-awareness experience, we nevertheless tried to make space for this shift to occur (Westen & Gabbard, 2002a, b).

3. We stayed within a circular framework, and avoided granting privilege to either mind or body (Ray, 2004). Rather we focused on probing and reconfiguring the artificial boundary between body and mind, self and other, often by locating the principal metaphor of the patient's story, e.g. "the beast in the belly," hoping that metaphor would link physiological and cognitive experience (Penn, 2001). Of course having a psychologist and physician in the room seemed to offer key validation that IBS was not just a psychological or physical illness.
4. Our assumption was that knowledge leads to mastery. We intended to inform patients more adequately about the physiology of IBS, including explaining pain (visceral hypersensitivity) and motility abnormalities of the colon.
5. We highlighted strengths and successful coping whenever possible. Highlighting successful coping seemed to reduce the burdensome anticipatory anxiety which IBS patients experience and to encourage even more active experimentation.
6. We stayed open in our discourse with each other, asking questions when we were uncertain, spontaneously posing hypotheses outside of our own discipline.

The Group Model We Developed

Session One. Both the physician and the psychologist participate in Session One, (though it is largely focused on medical information). Initially, the gastroenterologist presents an overview of the major medical research, as well as why this syndrome is perplexing and difficult for physicians to treat. Next, the patients briefly describe their illness experience, highlighting symptoms and major effects on their lives, with some commentary by the psychologist. The circle of effects—how gastrointestinal symptoms affect self and relationship, and how relationship context effects the expression of symptoms—is presented and discussed. Participants are given a loose-leaf binder with at-home exercises, with an initial assignment to write about their own "circle of effects." Every session thereafter begins with an update on the "circle of effects."

Session Two is conducted by the psychologist who provides a summary of IBS psychological research findings. There is an active discussion of the findings, with an emphasis on personal experience. Group participants are then invited to think about when IBS first occurred in their lives and whether there is a relationship to their present psychological life. The group also reflects on and shares favored coping mechanisms.

Session Three, led by the psychologist, begins with a discussion of various forms of relaxation and stress reduction, i.e. meditation, visualization, muscle relaxation. The group is led in a meditation exercise and given a progressive muscle relaxation tape. Then an accessible version of the family systems perspective on chronic illness is presented, including research data and theoretical considerations.

Participants reflect on their family members' and significant others' reactions to and beliefs about IBS. They discuss issues related to talking to others about their IBS symptoms: With whom can they talk about their illness and how can they best proceed? Two important assignments for the last (fifth) session are described. (1) Participants are asked to prepare a three generational genogram representing coping with illness (sample genograms are handed out and discussed) and (2) They are also asked to create a representation of life without IBS: a written paragraph and a complementary second representation, e.g. photographic, poetic, or graphic and to make a copy for every member in the group.

Session Four is led by our certified nutritionist (Reichler, 1998). She focuses on how certain foods, beverages, and eating patterns can affect and aggravate IBS symptoms.

Session Five. Both the physician and the family therapist are present at Session Five. A review of prior assignments is a major focus of the session, one of which includes an investigation of three generational illness and its management by each participant. Participants describe their current level of symptomatology and coping. The representations of "life without IBS" are shared and distributed. These are often impressively inventive, and evocative. One member wrote a long narrative poem about the food of New York; she traveled throughout the city, as she did as a child with her parents, painlessly and effortlessly tasting anything and everything that tempted her. This group experience creates a collective ritual of hope, evoking a positive shift in identity, a factor noted as a key ritual process in illness by Imber-Black, Proberts and Whiting (2003).

PRELIMINARY FINDINGS WITH REGARD TO GROUP EFFECTIVENESS

In the early phase of our group program, five patients completed a simple measure of IBS activity, the Bowel Symptom Scale (BSS)

(Bensoussan et al., 1998). This was repeated three months after completion of treatment. The mean BSS decreased in all five participants, from a mean of 173 to 97, but failed to reach statistical significance.

In preparing for a later group, we decided to use a more rigorous measure of symptom severity, the IBS Severity Scale (Francis, Morris, & Whorwell, 1997). Group Four had a total of seven patients. There was no significant improvement in symptoms three months after completion of treatment, though written evaluations of the group were quite positive. We noted that a recent publication reported sustained improvement after intervals of one year or greater post-hypnotherapy treatment of IBS (Gonsalkorale, Miller, Afzal, & Whorwell, 2003). We decided to send the patients in Group Four an additional questionnaire after one year had elapsed. When results for all seven patients were compared to data before treatment began, there was now statistically significant improvement with a decrease in mean score from 216 to 113, ($p < .05$). In Francis' article, an improvement in score of 50 points was felt to be significant. Six of our seven patients had improvement in score of more than 50 points. To explain the delayed benefit, we hypothesize that it may take time for mind–body connections to solidify, which then reconfigure responsiveness to urgency and pain.

CLINICAL EXAMPLES FROM THE GROUP EXPERIENCE

The range of reactions to the group experience was broad. One of the great strengths of the group approach is the opportunity for IBS patients to hear other patients' stories. A few participants were reserved about linking psychological and physical experience, wary that this meant their symptomatology would be dismissed or that they would be blamed for its occurrence, but this wariness generally dissolved by the third session. Moments of self-discovery often centered on how interpersonal stress—in some cases around IBS itself—had a deleterious effect on symptomatology. For example, two members of a recent group were helped to see that their partners' hovering concern and anxiety increased their own distress, with physiological sequelae. They were encouraged to ask their partners to experiment with a new form of relatedness—controlling anxiety as a gesture of concern. Throughout the group meetings, participants offered each other psychological, dietary, and life style advice and pointers.

The modal reaction was best stated by one participant: "It is very frustrating and upsetting to be told over and over again nothing is wrong when there definitely is something wrong even if it's not purely physical. Sharing my feelings about IBS and actually being understood was a great help."

CONCLUSIONS

It appears that a collaborative, balanced focus on psyche and soma, self and other, can result in significant experiential and empirically validated symptomatic relief in patients. Whether patients have blocked affect, which is then trapped in somatic experience, are unaware of how symptoms negotiate and maintain relationships, or have grown hopeless about their physical distress, a wide-angle view seems refreshing and expanding. We view IBS as a chronic illness embedded in a life story, which we try to co-construct with the patient, often uncovering previously unattended areas of interpersonal anxiety or conflict.

An important part of the life story is the role of others: What are their IBS beliefs (support, blame)? How do others in the family cope with health issues? How are relationships affected? How we recognize the presence of significant others adds resonance and depth to the treatment intervention. Theoretically and clinically, we believe that the presence of family members would add breadth to our treatment. However, we believe that a strength of our approach is the use of family systems theory with the patient, alone or in a group program. This parsimonious structure facilitates patient participation while still embodying collaborative and systemic principles. We hope to interest medical specialists in developing ongoing, collaborative relationships with psychologists, and to motivate psychologists to forge these relationships.

Above all, we have told the patients we worked with that though we are collecting data and evaluating outcome, "They are their own experts and principal investigators." Our research and clinical experience impresses us more and more with the empowerment of this redefined role for IBS sufferers.

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