Involving Family in Psychosocial Interventions for Chronic Illness

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ABSTRACT—***Interactions with close family members have consequences for the emotional and physical well-being of individuals who are dealing with a chronic physical illness. Therefore, inclusion of a close family member in psychosocial interventions for chronic illnesses is a logical treatment approach that has the potential to boost the effects of intervention on the patient and also benefit the family member. However, randomized, controlled studies indicate that such family-oriented interventions generally have small effects. The efficacy of these treatment approaches might be enhanced by targeting specific interactions that emerging research identifies as promoting or derailing healthy behaviors and by better incorporating strategies from family caregiver interventions. In addition, family-oriented interventions should be more fully evaluated, by assessing the benefits for both patients and family members. Future research in this area can tell us much about how and when to involve family in treatment of specific chronic illnesses and, in turn, may inform conceptual models of the impact of family interactions on health.***

KEYWORDS: *chronic illness, psychosocial interventions, family, social support*

> Family is not an important thing, it's everything.
>
> —Michael J. Fox

Regardless of an individual's celebrity, few circumstances in adulthood are more stressful than a chronic illness, and family plays an important role in psychological adjustment and symptom management. Emotionally and instrumentally supportive actions on the part of family members, as well as family conflict and criticism, have been linked with patients' emotional well-being, health behaviors, immune function, blood pressure, and illness events (Kiecolt-Glaser & Newton, 2001; Schmaling & Sher, 2000). These associations have been observed across illnesses as diverse as cardiovascular disease, chronic pain disorders, arthritis, cancer, renal disease, and Type 2 diabetes, as well as in healthy individuals who are at risk for illness. In turn, illness in a loved one can erode family members' psychological and physical well-being over time and compromise their ability to be supportive, especially when the illness is life threatening or the patient requires assistance with daily activities.

Psychosocial or behavioral interventions for chronic illness, such as patient education, support groups, and cognitive-behavioral therapies, have been shown to have effects on health and emotional well-being that surpass improvements attained with usual medical care alone (i.e., medication or surgery). Because of the links between family relationships and chronic-illness management, some researchers have incorporated a close family member such as the spouse in these interventions. The rationale for involving a family member in treatment can be found in the biopsychosocial model of health and illness and specific marital and family-systems frameworks. These conceptual models and frameworks have been supported by empirical evidence showing that close social relationships, especially the marital relationship, affect biological systems, health behaviors, and psychological well-being. Therefore, improving the quality of interactions with a close family member or involving that individual in disease management should promote adjustment to chronic illness. Specific treatment approaches range from enlisting the family member's help in changing the patient's health behaviors (e.g., training the spouse of a patient with chronic pain to help the patient practice progressive muscle relaxation) to also addressing issues of how spouses can provide effective emotional and instrumental support (e.g., counseling for couples dealing with the wife's breast cancer).

Incorporating a close family member in psychosocial treatment may have a positive impact on patient health behaviors,

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emotional well-being, and symptomatology as the result of increased empathy and supportiveness of the family member. In addition, the family member's caregiving burden may be eased by the validation of his or her caregiving experiences and improved interactions with the patient. In the following sections, we summarize our findings from two recent systematic reviews of the literature that compared family-oriented psychosocial intervention with usual medical care alone and with patient-oriented psychosocial intervention.

ARE FAMILY INTERVENTIONS MORE BENEFICIAL THAN USUAL MEDICAL CARE?

In our first review of the literature, we included studies that compared family-oriented psychosocial interventions (which included usual medical care) to usual medical care that did not include a psychosocial component. We reviewed the findings of 70 randomized, controlled studies that compared these two approaches and that recruited a family member, such as the spouse or an adult son or daughter, for every patient (Martire, Lustig, Schulz, Miller, & Helgeson, 2004). These interventions focused on different illness populations; used psychological, social, or behavioral approaches; and were targeted at either the patient's closest family member (the primary caregiver in some studies) or both patient and family member. Because we included different illnesses in this review, our focus was on outcomes that were generalizable across illnesses, and we examined effects on the patient (i.e., depressive and anxiety symptoms, relationship satisfaction, physical disability, and mortality) as well as on the family member (i.e., depressive and anxiety symptoms, relationship satisfaction, and caregiving burden). Almost half of the studies focused on populations with dementia; the remainder focused on those with cardiovascular disease, cancer, general medical frailty, chronic pain, stroke, rheumatoid arthritis, and traumatic brain injury.

For patients, interventions that included only patients' spouses had small, positive effects on reducing depressive symptoms across various illnesses, but interventions that included mixed groups of family members (e.g., spouses and adult children) did not decrease depressive symptoms. In addition, family-oriented interventions that focused on individuals dealing with hypertension or cardiovascular disease resulted in a small decreased risk for patient mortality, especially if the interventions included mixed groups of family members and used behavioral treatment approaches. For family members, we found that family-oriented interventions slightly reduced the psychological burden of caregiving, as well as depressive and anxiety symptoms. This latter finding has important implications for family members' physical health because caregiver burden and distress have been linked to an increased risk for morbidity and mortality (Schulz & Beach, 1999).

ARE FAMILY INTERVENTIONS MORE BENEFICIAL THAN PATIENT INTERVENTIONS?

From a behavioral-medicine perspective, the more interesting question than whether family interventions are more beneficial than usual medical care is whether targeting both the patient and the family member with psychosocial or behavioral strategies is better than targeting only the patient with these strategies (with both treatment approaches including usual medical care; see Fig. 1). In other words, is there an advantage to patient and family member when the family member is included in a psychosocial intervention? Unfortunately, few studies have been

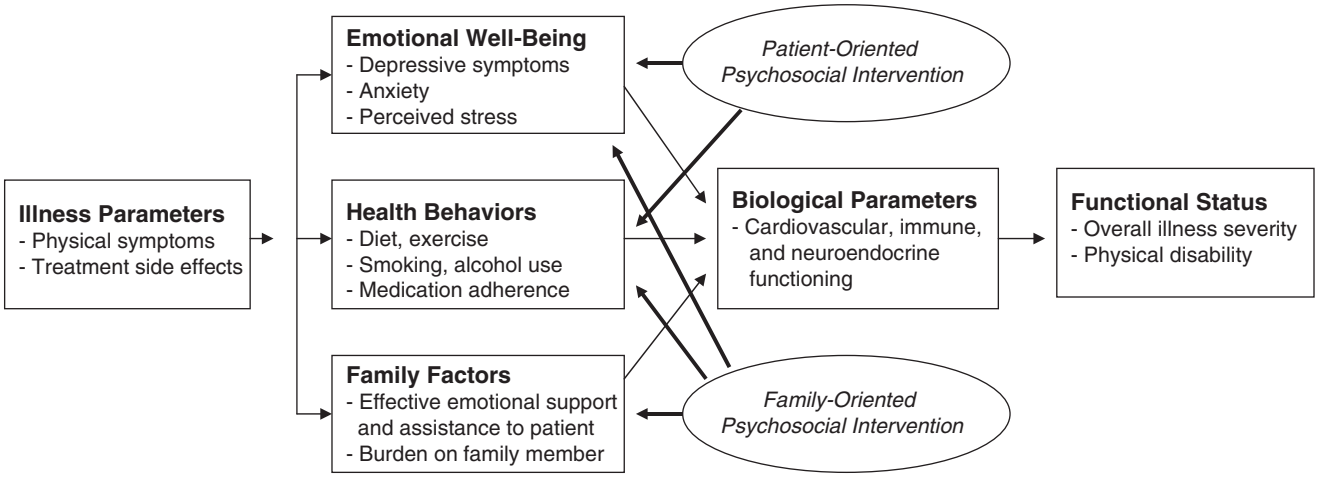

Fig. 1. Heuristic model showing domains of functioning (i.e., emotional well-being, health behaviors, and family factors) that mediate parameters of chronic illness in their effects on a patient's functioning. Intervention that incorporates or involves a close family member may have added benefit as compared to intervention aimed only at the patient, due to the former's effects on the third domain of functioning (i.e., family factors). The type of family-oriented intervention depicted in this model includes standard content (e.g., education regarding illness etiology and cognitive-behavioral skills training for illness management) and incorporates a close family member by treating that individual as a collaborator in the patient's intervention and/or by addressing his or her personal concerns, burden, and supportiveness of the patient. Examples of specific constructs are provided for each domain of functioning.

designed to answer this question, and those show mixed findings for patients and focus little attention on whether family members benefited from being included.

The findings of 12 randomized, controlled studies comparing family-oriented intervention to patient-oriented intervention were recently reviewed (Martire, 2005). Approximately half of these studies showed significant improvements over time for those receiving family intervention or reported that there was also a statistically significant advantage of family intervention over patient intervention. For example, individuals with chronic low back pain who attended exercise sessions in combination with couple-oriented behavioral therapy showed greater lessening of pain and pain behavior (e.g., grimacing, limping, groaning) and greater diminishment of the impact of pain on their lives than did individuals who received only an exercise intervention. Our own research with osteoarthritis patients and their spouses showed that patients felt they managed their arthritis more effectively if they received a couples-oriented education and support intervention than if they received education and support with other patients only (Martire et al., 2003). Consistent with these positive findings, a more recent study showed that problem-solving therapy for cancer patients and their significant others reduced the patients' psychological distress more than did patient-focused problem-solving therapy (Nezu, Nezu, Felgoise, McClure, & Houts, 2003). Significant improvements over time as the result of family-oriented intervention have also been reported regarding blood-pressure control in hypertension; stress and cardiovascular complications in postcardiac surgery; and pain, psychosocial adjustment, and number of medical visits in chronic pain.

In contrast to the positive findings for family-oriented interventions, an educational intervention for individuals with rheumatoid arthritis and their significant others resulted in decreased self-efficacy and increased fatigue, whereas a similar patient-oriented intervention was found to enhance self-efficacy and reduce fatigue (see review by Martire, 2005). Such unexpected negative effects of family-oriented intervention may occur in studies that do not address communication issues between patients and partners, or partners' personal concerns. We return to this issue in the next section.

In the remaining studies, the more efficacious approach for patients depended on factors such as patient gender and specific type of intervention (i.e., educational versus behavioral approach; see review by Martire, 2005). For example, a couple-oriented behavioral program for obese individuals with Type 2 diabetes resulted in more weight loss for female patients than did a patient-oriented program, whereas male patients lost more weight in the patient-oriented program. (Spouses who participated in the couples program lost more weight than spouses of individuals in the patient-oriented program, regardless of their gender.) In addition, studies focused on rheumatoid arthritis or osteoarthritis showed that family-oriented interventions that used cognitive-behavioral rather than educational approaches resulted in greater reductions in joint swelling or pain-related outcomes than did cognitive-behavioral interventions for patients only.

These studies illustrate how research can reveal for whom and under what conditions family intervention may be especially beneficial, by identifying patient, family member, or intervention characteristics that moderate the effects of family intervention. A recent study showed that a couple-oriented intervention for breast cancer patients that was designed to enhance support exchanges (e.g., effective communication, problem solving as a team, respecting differences in coping styles) was most helpful to patients with unsupportive partners (Manne et al., 2005). This study, as well as others (e.g., Helgeson, Cohen, Schulz, & Yasko, 2000), raises an important question about patient-oriented interventions that have targeted individuals with unsupportive relationships and have had small effects on patient outcomes: Would the effects of these interventions have been stronger had the interventions included a family member?

HOW CAN WE ENHANCE THE EFFICACY OF FAMILY INTERVENTIONS?

As described above, the findings of randomized trials indicate that family-oriented interventions do not consistently outperform patient-oriented psychosocial interventions. There are several explanations why the promise of family interventions has not been fulfilled. Methodological flaws, such as failing to ensure the full participation of family members, may explain why this approach has had null or weak effects in some studies. In addition, family-oriented interventions have not consistently targeted family interactions that affect health and issues surrounding the burden of illness on a family. Interventions appear to be more beneficial for patients (Martire et al., 2004) and for family members (Martire, 2005) when they address such issues. Research on family caregiver interventions illustrates the value of particular strategies such as stress management, skills training, and validation of the family member's experiences as a provider of support (Schulz et al., 2002).

But how can we explain the generally small effects of interventions targeting family support or the relationship between patient and family member? One explanation may be found in the empirical literature that is the foundation for many family-oriented interventions for chronic illness. Early correlational research revealed that patients sometimes perceive well-intentioned family actions or communications as unhelpful, and that overprotective or solicitous behaviors may be perceived as helpful by patients but also cause them to be more physically inactive and dependent (Lyons, Sullivan, Ritvo, & Coyne, 1995). Thus, past family-oriented interventions may not have been successful in (a) reducing the frequency of family actions or communications that derail healthy behaviors and distress patients or (b) bolstering interactions that promote healthy behaviors and emotional well-being.

More recent conceptual and empirical work might be useful in developing family interventions that have greater impact and more consistent effects. Here, we provide examples of relevant research in two of several useful areas: autonomy support and social control. We chose to highlight these two areas of research because they focus on health behaviors, and management of today's most common chronic illnesses often requires patients to make substantial changes in diet and exercise and to adhere to a medication regimen despite unpleasant side effects. Autonomy support refers to behaviors that are characterized by warmth, empathy, and understanding for an individual's situation; patient-centered communication; and the provision of choices for making health behavior changes. A program of research on individuals with Type 2 diabetes has shown that patients with health-care providers who are more supportive of their autonomy feel that they are better able to regulate their blood glucose and show improved glucose control over 1 year (Williams, Freedman, & Deci, 1998). Complementing these findings, our work has demonstrated that older adults with disabling arthritis who feel that they have no choice over the amount, timing, and manner of physical assistance from their spouses experience increased depressive symptoms over time (Martire, Stephens, Druley, & Wojno, 2002).

Emerging work in the area of health-related social control also might be useful to incorporate in family interventions. Social control is thought to be distinct from social support and refers to an individual's attempts to regulate or influence the behaviors of another person through actions, affective responses, and corrective feedback. Early theory on social control suggested that it may deter poor health practices but at the same time cause distress by evoking irritation, resentment, or guilt. However, more recent research has identified tactics that may promote healthy behaviors and also be appreciated by patients—tactics such as persuasion (e.g., efforts to convince or motivate), modeling (enacting the behavior), reinforcement, and using logic (e.g., pointing out positive consequences; Lewis & Butterfield, 2005).

As these lines of research move forward and are conceptually and empirically synthesized with previous research, findings can inform the development of psychosocial interventions for specific illness populations. Specifically, future interventions may include content aimed at teaching family members how to support patients' need to make their own choices and carry out daily activities independently. This type of family-oriented intervention may show stronger and more consistent advantages over psychosocial treatments focused only on the patient.

CONCLUSIONS

There is not yet strong evidence for the efficacy of family-oriented interventions. However, including family members in health care is an approach that has much face validity. Moreover, the small effects that have generally been observed across studies, particularly with regard to the emotional well-being of family members, make a compelling argument for further research using well-designed studies that can more fully reveal what type of patient may benefit from this approach.

Future research may better evaluate the added benefit of family-oriented interventions by including specific features that have often been disregarded in past studies, such as random assignment of participants and adequate statistical power to detect between-group differences. In this research, it would be optimal to assess outcomes for both the patient and the family member. Finally, we have much to learn about the causal mechanisms linking positive and negative aspects of close social relationships to physical health (e.g., psychological, behavioral, and biological pathways), and such knowledge is critical for developing family-oriented interventions that truly make a difference for patients and their families.

Recommended Reading

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Acknowledgments—Preparation of this manuscript was supported in part by National Institutes of Health Grants K01 MH065547, R24 HL076852-076858 (Pittsburgh Mind-Body Center), and R01 NR008272.

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