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Sharing the Care: The Role of Family in Chronic Illness

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by

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I. Executive Summary

This report is intended to provide background information, experienced-based insights, case examples, and further resources for those interested in enhancing family involvement in chronic care management.

AS THE NUMBER OF ADULTS WITH CHRONIC ILLNESS increases, family members could provide needed support for their care. Although many providers, health care systems, and policymakers are interested in developing programs to mobilize family members, there are few resources to guide them.

This report is intended to provide background information, experienced-based insights, case examples, and further resources for those interested in enhancing family involvement in chronic care management. It draws on the author's review of published medical literature, general Web searches, and conversations with program developers and researchers in the fields of social support and family involvement in chronic illness care.

A variety of family intervention programs have been developed, and three of these are described in the report.

- A couple-oriented education and support program focused on goal-setting around osteoarthritis self-help and care;
- A program stressing communication techniques that support autonomy for patients with heart failure; and
- A technology-enabled program that assists out-of-home family members in the monitoring of heart failure patients' symptoms and test results.

These and many other programs offer insights about the benefits and cautions that should be taken into account if family involvement is to succeed. Not all families are equally able to benefit, and not all family interaction is conducive to healthier outcomes. Experience from the existing programs suggests that patients/families who want to engage in care support are most likely to benefit from it, and that the quality of the pre-existing relationships is an important factor in success. Experience also illuminates some of the realities of family involvement in chronic illness care:

- Some patients with chronic illness have complex self-management regimens that require ongoing high levels of support;

- Some situations and phases of illness require more support than others—for example patients may have high support needs at the time of diagnosis, during flare-ups, or after major events like surgeries or hospitalizations;
- A family’s cultural background can affect its approach to chronic illness care and interactions with health care providers.

Designing a family involvement program begins with several considerations, including: what patients and families to include; whether it will be integrated into other programs; who will deliver the program and in what format; and what will be taught. Thought must also be given to how the program will be evaluated so that it can be refined.

Interest in increasing family support for chronically ill patients is growing, and programs are being rapidly developed. This trend is likely to continue for a number of reasons, including: increasing numbers of patients with chronic disease; the growing complexity of care; the pressure on resources for care; and the growing recognition of the positive effects of family support. Future directions for family inclusion in care may involve: support for patients with multiple chronic illnesses; issues of patients with low health literacy; and cultural and gender-based refinements in care management.

An appendix to this report includes some resources for caregivers, patients and families, and clinicians looking to enhance family involvement in chronic care management.

II. Introduction

THE NUMBER OF ADULTS WITH CHRONIC illnesses like diabetes, heart disease, asthma, and arthritis is increasing, and innovations in care for these patients are being developed at a rapid pace. As health care providers work toward providing medical homes and team-based care for chronically ill patients, it is becoming apparent that family provides the most important “home” for many patients’ daily self-management and that family members can play critical roles in the health care team. Many health care providers, health care systems, and policymakers are interested in developing programs to mobilize family members in the care of chronically ill patients, but few resources exist to guide them.

This report aims to:

- Summarize the reasons why involving family in adult chronic illness care has the potential to improve care processes, patient self-management, and patient outcomes;
- Highlight the differences between family involvement in the care of adults with few or mild disabilities (the majority of adults with chronic illness) and caregiving for adults with significant disabilities;
- Outline the specific ways that family can increase involvement in self-management and medical management of chronic illness;
- Describe examples of programs that involve family in chronic illness care;
- Summarize evidence on the types of patients and families who may benefit more from family involvement;

- Provide guidance for the initial design of a family involvement program;
- Guide readers to tools and references that could be used in a family involvement program; and
- Outline future directions for family involvement program research and design.

This report draws on the author’s review of published medical literature, general Web searches, and conversations with program developers and researchers in the fields of social support and family involvement in chronic illness care.

What Is Meant by the Words “Family” or “Family Member”?

The Institute for Family Centered Care defines the word “family” as two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families, which can include neighbors and friends.

III. Why Involve Family in Chronic Care?

MANAGING CHRONIC ILLNESS IS DIFFICULT for patients and health care providers alike. To avoid disease complications and flare-ups, patients are advised to take medicines on complex schedules, eat certain types and quantities of food on a daily basis, be physically active several times a week, perform regular self-testing (such as checking blood glucose level, blood pressure, or peak flow), and respond to changes in their symptoms and test results. In addition, patients and health care providers manage frequent medical tests and referrals, and continuously update the patient's personal illness management plan. Patients and providers often find it difficult to manage these complex routines and frequent decisions while meeting on average only every three or four months.

Health care plans and providers have responded by developing patient support services such as disease management services, nurse and disease educator visits, community health worker or health navigator programs, group visits, and peer support programs. These services work well to support some patients, yet health care systems have limited resources with which to fund these programs and many patients can't afford the copayments or fees required to access them. Even when available and accessible, professional support services still aren't enough to improve outcomes in many patients.^{1,2} Some patients find it difficult to share their care with a supporter they are in a new relationship with, and others need more frequent or intensive support for self-management than professional and peer support programs can logistically provide. In a recent survey of adults with chronic conditions, 39 percent of those 44 and older said they occasionally, rarely, or never

get the help and support they need to manage their conditions.³

Can family and friends provide the extra support for care that these patients need? Many patients and health care providers feel family members have been overlooked as a source of support for chronic illness care. Over 70 percent of adults with chronic illness say they want to increase the support for their care that they receive from family and friends, and family members are often eager to find ways of effectively helping their loved ones manage their health.⁴ In fact, family and friends have remarkable potential to support patient self-management and medical care, for the following reasons.

Family Members Provide the Daily Setting for Patient Self-Management

Family and friends already affect patient self-management, since daily eating, physical activity, and even stress management happen in the setting of social activities and relationships. Family members often decide which food to buy or keep around the house, what food to make for meals, what activities fit into the family schedule, and how health is placed among other family priorities. Family members often provide the emotional support that helps patients handle the stresses of illness. Friends may play these same roles, and also influence eating in social groups, join the patient in physical activities, help patients maintain their social roles, and help patients avoid stigma related to their illness.

In interviews and focus groups, patients often report that family members help lower stress about self-management and are crucial to patients' success. Yet patients also frequently report that families pose

barriers to achieving self-management goals. For example, they may be tempted by salty foods kept around the house, have difficulty finding time to exercise while fulfilling other family obligations, or have more symptoms when family members smoke in the house.^{5–8} In addition, patients report that chronic illness often strains family relationships in ways they would like to avoid.^{9,10}

Essentially, family and friends create the practical, social, and emotional context for self-care, making it easier or harder for patients to achieve their health goals. If providers can become familiar with and influence this self-management environment they may be far more able to facilitate patient self-management success. Additionally, actively involving families in chronic illness management could help patients with strained relationships re-engage with family members in a more positive and productive way.

Family Members Already Take Active Roles in Self-Management and Medical Care

In addition to providing the context for self-management, many family members and friends take on specific roles in managing their loved one's chronic illness. Over 50 percent of people with diabetes or heart failure report that their family is involved with planning which foods are best for their health, and about 30 percent of families get involved with patient medication-taking and self-testing. Family members are often the first to notice symptoms such as hypoglycemia, shortness of breath, and fatigue, and they often help patients decide how to handle changing symptoms or self-testing results.^{11–13} In general, most symptoms and illnesses are handled by patients and family members without consulting a health care professional. When chronically ill patients do visit a health care provider,

between 30 and 50 percent are accompanied by family.^{14,15} Even among general practice patients, 55 percent would prefer to have a family member come into the exam room with them.¹⁶ Involved family members often wish they had access to information and tools that could help them be more effective in these illness management roles.¹⁷

Family Support Is Linked to Better Patient Self-Management and Outcomes

When family members provide support to patients, patient outcomes improve. Increased support from family, sometimes called social support, is associated with better glycemic control for people with diabetes, better blood pressure control for people with hypertension, fewer cardiac events for people with heart disease, and better joint function and less inflammation for people with arthritis.^{18–21} Family support likely affects these outcomes through multiple mechanisms. Patients with higher levels of family support report better self-management behavior.²² Higher levels of family support are specifically linked to increased patient self-efficacy (confidence that they can complete self-management tasks) and decreased patient depressive symptoms—both factors linked in turn to better chronic illness management and outcomes.^{23–25} Support from family may even affect patient health directly through lower stress hormone levels and fewer swings in blood pressure.²⁶

Family Members Are Uniquely Qualified to Be Effective Supporters

Family members often have the very characteristics associated with successful professional support of chronic illness self-management and medical care:

- Family members usually have frequent and ongoing contact with the patient;
- Family members often share cultural background and value systems with the patient;
- Family members often have a detailed and intimate knowledge of how patients are managing their disease and the context in which they are managing it;
- Patient-family relationships and communication patterns are developed before chronic illness is diagnosed; and
- Family members often have pre-existing relationships with the patient's health care provider, either because they have been in contact with the provider or because they are a patient of that provider themselves.²⁷

Family involvement programs work with patients, families, and providers to mobilize and enhance family support by:

- Tapping into family strengths and addressing family barriers to self-management;
- Developing specific and tailored care roles for family members;
- Giving family members skills and tools to carry out those roles effectively; and
- Developing infrastructure for purposeful family participation in medical encounters.

The ultimate goal of most family involvement programs is to improve patient health by helping family members become powerful patient allies and integrated members of the patient's health care team.

IV. How Is Family Involvement Different from Caregiving?

THERE ARE IMPORTANT DIFFERENCES between the roles played by family helping patients manage chronic illnesses such as diabetes, heart disease, asthma, and arthritis, and the roles played by caregivers for people with advanced disability. Chronic illnesses are reaching younger and younger adult populations, with the largest growth in adult chronic illness diagnosis occurring among people age 44 to 64.²⁸

The majority of people with chronic illness can physically and intellectually carry out self-management tasks and continue to be active in their workplaces, schools, and communities. For these patients, the role of family and friends is to support self-management by facilitating, reminding, and motivating patients to perform self-management tasks, partner in problem-solving and decisionmaking, and help patients handle the emotional stress of the illness.^{29,30} (See Table 1.) Because family members of functionally independent

patients do not often directly execute illness management tasks, family involvement programs for them focus on a different set of skills than do caregiver support programs.

Family members of functionally independent patients also face unique pitfalls when getting involved. Because most patients are able to and desire to be independent in some self-management tasks, involved family may easily overstep boundaries or offer unwanted help.³¹ Family members may be perceived as nagging or criticizing when trying to help, or may even cause patients to be less confident in their ability to care for their own disease.^{32,33} In fact, patients between 44 and 64 say that chronic illness strains their family relationships twice as often as older patients do.³⁴ Thus family programs need to remain responsive to patient preferences, and involve family members in ways that support healthy family relationships, patient autonomy, and patient confidence.

Table 1. Family Roles for Two Types of Chronic Illness Patients*

PEOPLE WITH ADVANCED DISABILITY	PEOPLE WITHOUT ADVANCED DISABILITY
<ul style="list-style-type: none"> • Do self-management tasks for patient 	<ul style="list-style-type: none"> • Facilitate, accommodate, remind, and motivate patient in doing self-management tasks
<ul style="list-style-type: none"> • Be the proxy decisionmaker and problem-solver if patient is unable to participate 	<ul style="list-style-type: none"> • Partner in decisionmaking and problem-solving
<ul style="list-style-type: none"> • Connect patient with outside resources 	<ul style="list-style-type: none"> • Help patient find and connect to outside resources
<ul style="list-style-type: none"> • Emotionally support patient, with higher likelihood of needing outside help in dealing with emotional stress of caring for patient 	<ul style="list-style-type: none"> • Support patient in handling emotional stress of illness and its care
<ul style="list-style-type: none"> • Help patient adapt to new life roles 	<ul style="list-style-type: none"> • Help integrate illness care into existing life roles and support continued involvement in shared social networks
<ul style="list-style-type: none"> • Act as medical “proxy” 	<ul style="list-style-type: none"> • Assist with patient-provider communication

*Family roles usually fall on a continuum between these two approaches, sometimes combining elements of each. For example, one person may want little help managing medical appointments but may ask a family member to directly administer their insulin injections.

V. How Can We Increase Family Involvement?

THE IDEA OF INVOLVING FAMILY IN CHRONIC illness care is not new. Physicians, nurses, dieticians, and self-management class facilitators have long included interested family members in their sessions with patients. In these settings, family members most commonly receive information on the general etiology and symptoms of the illness, and on the patient's role in illness management, but family member roles are often not addressed directly.

Family involvement programs, on the other hand, directly address the part played by family members. Most current programs to increase family involvement in chronic illness care have one or more of these goals:

- Assess the current roles and influences of family members in the patient's management of chronic illness, and use this information to tailor self-management advice;
- Help patients and family members identify new roles for family in home-based illness management;
- Help family members learn skills and communication techniques that will make them more effective at helping patients; and
- Provide structure and tools for family involvement in professional clinical care.

Efforts to increase family involvement could take place in any setting where patients receive illness care or self-management support. For instance, family members could learn supportive techniques in a physician's office, over the phone with a disease manager, in the family home with a community

health worker, or in an illness-based support group. This section begins by describing techniques that could be used in any one of these settings. Then, it discusses programs that involve family in clinical care specifically.

Assessing Current Family Roles and Influences

Asking the patient about the people in their social network, and the current roles family members play in the care of their illness, is an important first step in addressing family involvement in care. Gaining this understanding alone could lead to better informed and more appropriate patient counseling from any care provider. This involves taking a more complete "social history" — one that describes the social context within which the patient is dealing with their illness. Taking this social history may also help patients become aware of the ways that family relationships and behaviors are influencing their disease care. In most cases the patient makes the best informant, as research shows that the patient's perceptions of family behavior and support is more important to patient outcomes than an observer's or family member's point of view.³⁵ However, family members who are involved in patient care can be valuable sources of additional information.

Assessing social context for patients with chronic illness could include questions about the patients' social environment (who is important to them and the quality of those relationships), who influences the patients' habits and decisions the most, negative ways that family may be influencing patient care, and whether the patients would like more support from family. (See sidebar on page 10 for sample questions.)

Sample Questions for Assessing Social Context of Care

- With whom do you live?
- Which other people are personally important to you? These can be relatives, friends, co-workers or schoolmates, church and/or organization members, neighbors, or others.
- What are your relationships like with [those identified as most important]?
- What are your family members' health habits like? For example: eating habits, activity habits, how stress is handled, smoking, and substance use.
- How do other people help you or get in the way when you try to eat healthy food?
- How do other people help you or get in the way when you try to be physically active?
- From whom do you get information about your illness?
- Whose opinions are important to you when making decisions about your care?
- What do your family members think caused your illness? What do they think makes it worse? How do they think it should be treated? How have other people in your family with this illness treated it in the past?
- Which person is most involved with your illness care? Do you feel that person is knowledgeable about the care of your illness? Do you feel that person is helpful?
- When it is time to make a change in your illness care, how does your family handle it? What does your partner do when you have symptoms or health problems?
- Do you get as much help with your care as you would like? In what specific ways could family or friends be more helpful to you?
- Are family members involved in your care in ways that don't seem helpful to you? Is there anything you would prefer they not do?

At present there are no validated tools for collecting information about family influences on adult chronic illness patients, although family assessments used by case managers or home-care providers in other clinical situations could be adapted for chronic illness patients. In addition, there are questionnaires designed for research on the quality of family relationships (such as the Family APGAR) and family values (such as the Family Environment Scale) that could be adapted for use in clinical care.^{36–38}

Questions about family influences can be asked when the topic naturally comes up in patient care, or through a more formal assessment before an appointment or program. They can be asked via a paper questionnaire, by a medical assistant in a provider's office, a disease educator or nutritionist, during a self-management program or support group session devoted to discussing family, or over the phone as part of a disease management program.

Educating Family About Illness and Its Management

Many family members would like to learn more about the patient's illness: its cause, its course, and its recommended management. Educating family members helps insure that their influence over the patient's decisions is well informed. However, existing programs that include family members in disease education sessions show little or no impact on patient outcomes.³⁹ It is likely that additional program components directly addressing the family's role in illness management are needed to help family better use the knowledge gained in these sessions. Educational components can also be incorporated on an "as-needed" basis into family involvement programs, or taught to the family by the patients themselves.

Family Members Set Specific Support Goals

When family members set goals for getting involved in care, their desire to increase their support is transformed into concrete action. As with patients' personal goals, family goals that are short-term and specific are most likely to be carried out. Examples of specific goals are: "I will buy low-salt crackers instead of saltines the next time I do the family grocery shopping"; or "I will ask my sister if she wants to go for a walk with me in the evening two times each week." (See sidebar for more examples of family goals.)

Family members can be guided through the goal-setting process using the same techniques health professionals use with patients, including encouraging realistic goals, assessing family members' readiness to change, and discussing barriers to reaching the goal. In some programs, family members are given a specific goal by the program leader that complements the patient's current goals or the topic of the program session. In other programs, the patient and family member decide together what the family member's goal should be; or the patient sets a self-management goal, and the family member subsequently chooses a goal that will support that patient goal. Yet another model would be for family members to set goals to improve their own health (such as through healthier eating and more physical activity), with the intention of creating a healthier home atmosphere which would in turn indirectly support and influence the patient.

It is particularly important for patients and families to discuss how they will handle situations that require another person's help. For example, family often play a key and necessary role in helping patients who are confused from low blood sugar or dizzy from a heart arrhythmia. Because these situations can be stressful, embarrassing, and even

Examples of Goals for Family Member Involvement

- I will celebrate with my wife each day that she completes her arthritis exercises. *(encouragement)*
- I will ask my husband if he has his pills with him when we are going out to dinner. *(reminding)*
- I will keep my cookies in my desk at work, instead of around the house where my mom will be tempted to eat them. *(creation of a healthier environment)*
- My dad wants to change his cooking style, so I will buy him a low-salt cookbook to give him the information he needs. *(facilitation)*
- I will go with my sister to the first meeting of her self-management class, since I know she is nervous about it, and I'll offer to take notes for her. *(doing illness management together, being a second "set of ears")*
- The next time my brother seems stressed and discouraged about keeping his COPD under control, I'll encourage him to talk about it, and listen without judgment. *(emotional support)*
- The next time my partner seems confused about how to take his medicine, I'll suggest that he write down his question and bring it to his doctor's appointment. *(support for patient-provider relationship)*
- The next time my aunt tells me her sugars are getting higher, I'll offer to look over the numbers with her to see if we notice any patterns she can discuss with the nutritionist. *(help with problem-solving, support for patient-provider relationship)*
- I will bring low-fat chips when I watch the game with my uncle and his friends, and help him think of something witty to say if they tease him about eating healthier. *(help with social pressure, planning ahead for difficult situations)*
- I will watch the kids for the afternoon so my friend can finally get that test her doctor recommended. *(help with competing obligations)*
- I'll ask our group if they'd mind going to a hotel instead of a cabin for our vacation, so our friend with arthritis can still feel like a part of the gang. *(support for continuing social roles)*

debilitating for patients, family members and patients should plan ahead for them when the patient is feeling well.

Program leaders can assess a family member's experiences in trying to reach their goal in follow-up sessions. It is important to encourage family and patients to communicate with each other about the family member's attempts to be involved. How helpful does the patient feel the family member is being? Would the patient prefer that they take on a different role or offer the help in a different way? The most important question a family member can ask a patient is: "How would you like me to help?"

Family Members Develop Effective and Supportive Communication Techniques

Some programs focus on teaching family members the communication techniques that are most likely to be perceived as supportive by the patient, and the most likely to lead to improved patient self-management. For example, there is growing evidence that open family communication about illness management, healthy family responses to stressful illness situations, and family support for patient autonomy are linked to better patient self-management behavior. On the other hand, unresolved family conflicts about care as well as controlling family behaviors are linked to worse patient outcomes.⁴⁰⁻⁴⁴

Autonomy support has been the focus of several family programs for adult patients. Autonomy support emphasizes the patient's needs, feelings, and goals as the primary determinant of self-management success. While family can offer support, it is the patient who must ultimately ensure that illness management tasks are carried out. Therefore understanding the patient's viewpoint and supporting self-motivation are most important for illness management success. Autonomy-supportive

behaviors include empathic statements that acknowledge the patient's feelings and perspectives, offering choices and providing alternatives, providing a rationale for advice, and working together to problem-solve. (See Table 2 on page 13 for examples.)

Behaviors that are not autonomy-supportive include using pressure, criticism, or guilt to induce changes in patient behavior. While urging or demanding that a loved one change a behavior dangerous to their health may seem to family members like the right thing to do, there is evidence that these techniques can backfire, leading to lower self-confidence, avoidance of self-management, or even rebellion by the patient.⁴⁵ One diabetes patient said, "I never used to skip my shot, until it got to the point where every day he'd say, 'Did you—did you?' I got so I wouldn't do it. It wasn't good for me, I knew it, but I didn't care."⁴⁶ Family members often use controlling or overprotective behavior when they are anxious about handling illness symptoms, or afraid of what the illness will bring in the future.^{47,48} When family members are found to be controlling, it can be worthwhile to help them assess their underlying motivation for that behavior.

Focusing on autonomy support can also help family members avoid the stress of taking too much responsibility for illness management. Family members can stop trying to be "health police," and often feel liberated from this burden.^{49,50} Of course, it can be difficult for family members to know when they have crossed the line from "helpful reminding [to] unhelpful nagging."⁵¹ This is another reason that open communication between patients and family members about support can be so important. Support techniques may need to be practiced and refined over time, with feedback from the patient and professionals.

Table 2. Communication Techniques Linked to Better Patient Outcomes

BEHAVIOR/TECHNIQUE	EXAMPLE
Family support techniques linked to improved chronic illness patient outcomes	
Showing empathy for patient's point of view	"I know it's hard during the holidays to be around all that food that isn't recommended on your diet."
Showing concern	"You seem really short of breath today. I am concerned about you."
Offering choices and alternatives to patient	"Should we walk this morning or this afternoon?" "Do you want to help plan our menu for the week?"
Providing rationale for advice given	"I remember the doctor explaining that more weight gain in a short time means you are getting more fluid than your heart can handle. I think we should call the doctor's office since they may tell you to take an extra water pill."
Openly discussing illness and directly addressing conflicts about illness care	"This is the second time that you have run out of your important medication. We need to figure out a plan so this doesn't happen again. I have some suggestions but first I'd like to hear any ideas you have about how we can better plan ahead."
Asking about the patient's experience of the illness and developing accurate perceptions of the patient's feelings and abilities	"What does taking your insulin shot feel like? Now that you've been taking it for a month, does it still make you anxious?"
Focusing positively on successes	"Two months ago you could only walk down the street and back. Now you can go around the block."
Continuing to plan pleasant activities together as a family	"It's tough for us to go walking in the woods like we used to. Why don't we go for a scenic drive this weekend instead?"
Family support techniques linked to worse chronic illness patient outcomes	
Controlling / directive statements	"You should go for a walk." "You know you can't have that sandwich."
Criticizing	"I don't know why you stopped exercising last week. I don't understand you."
Using guilt	"You should be grateful—I worked hard to make this food fit within your diet. Don't you want to live for a long time?"
Being overprotective of patient	"I don't think you should go on that church trip—what if your sugar drops when you're on the bus?"
Taking responsibility for patient behaviors or outcomes	"I can't believe I let your cholesterol get that high; I should have watched your diet more carefully."
Ignoring or downplaying patient symptoms	"Let's not talk about your pain again today, I'm sure it's not really that bad"

Note: Examples adapted with permission from Patricia Clark and Sandra Dunbar, "Family Partnership Intervention: A Guide for a Family Approach to Care of Patients With Heart Failure".⁴⁹

Programs that teach family members communication techniques typically give examples of recommended ways to handle discussions about illness management, followed by discussion or role playing. Program leaders often emphasize that this counseling is not meant to replace psychological care or to address fundamental problems in family relationships. Instead, these programs aim to encourage improved illness-related discussions and behavior between patients and their family supporters.

To date, no one has tested whether counseling from a mental health professional for families with general dysfunction can improve patient chronic illness outcomes. However, since families determine a large part of the emotional and social context in which self-care occurs, it is possible that referring troubled families to psychological care could have the added benefit of facilitating better patient management of chronic illness.

Involving Family Directly in Clinical Care Processes

In addition to supporting home management, family members can also support a patient's interactions with their health care provider team. There are many reasons to involve family in clinical care. Chronic illness care is complex, and a large amount of information often needs to be communicated in short appointments. For this reason, having additional family present at the appointment can bolster the patient's ability to absorb and understand the information. Family members can help the patient keep track of test results and appointments. They can also offer a second perspective to the provider, including their observations of the patient's symptoms and home management, if the patient would like them to do so. Family members can help the patient communicate their concerns

more efficiently and clearly to their providers, and support the patient when bringing up difficult or embarrassing topics. Direct communication between health care providers and family members can address family members' concerns about the patient, and help family members set appropriate goals for supporting patient care. In some cases, a patient may want a family member to be directly involved in decisions about care, due to that person's interest or expertise in medical topics, or because that person has a strong influence on all health care decisions in the family.

Family can participate in clinical care by coming to medical appointments with the patient, or by communicating with health care providers by phone, writing, or email. Providers might consider convening a family meeting at important times in illness management — at the time of diagnosis, after recurrent flare-ups or hospital admissions, or at the time of a significant change in management.

Patients with complex clinical care regimens may find it helpful for family members to take on some care tasks directly. For example, family members can help with maintaining self-testing or symptom logs, recording food intake for nutritional assessments, updating medication instructions and getting refills of medications, arranging or managing appointments, bringing consultant and admission reports to provider visits, or handling insurance issues. Family members should ask patients and providers what tasks would be most helpful in their loved one's situation.

One innovative way to include family in clinical information flow is to allow them to view or even interact with the patient's electronic medical record. Currently, personal health records (PHR) are the only type of electronic medical record available for home access by lay persons in the U.S. Patients can buy software packages for starting a PHR, or use a

free Web site-hosted PHR. Most PHRs allow the patient to share access to the record with friends and family. Personal health records can include diagnoses, prescriptions and refill history, lab test results, home testing results, procedures, and hospital admissions. At this time, most of the information in PHRs is entered by the patient, although several prominent services (such as Google Health, Microsoft's Health Vault, and the VA's MyHealthVet) have limited arrangements to link directly to medical record and pharmacy information, and more such arrangements are being developed.

When family members are involved in visits with health care providers, the three-way communication must be managed carefully. Family members might dominate discussions with providers, discouraging the patient from speaking, or they might discuss their own medical problems beyond those relevant to the patient's care, adding competing demands on the provider's time. Studies reveal that patients often think family members miscommunicate with the health care provider and take on roles during the clinic visit that are different than what the patient expected.^{52,53} The text, *Family Oriented Primary Care*, offers detailed examples of techniques providers can use to manage family and patient conversations.⁵⁴

Ideally, providers can turn difficult interactions with family members into an opportunity for addressing relationship dynamics that may be negatively affecting patient self-management success. Because most providers who care for adults have not received family communication training, programs that increase family involvement in clinical encounters might be more successful if they include a provider training component.

When There Is No Family Member Available

When family members can't attend medical appointments or program sessions, the techniques in this section can be adapted for use with the patient alone. Clinicians or group leaders can educate patients about the importance of family support, teach patients helpful family communication techniques, and help patients set specific goals for increasing family support and addressing family barriers. This could be particularly important to do on an ad hoc basis during a medical appointment or disease education class, when the topics of family support and family barriers naturally arise in the course of discussion.

VI. Selected Family Involvement Programs

THIS SECTION INCLUDES CASE REPORTS FROM three existing family intervention programs: one focused on family goal-setting, one on communication techniques, and one on families helping clinicians monitor patient symptoms and test results.

Goal Setting: The Couple-Oriented Education and Support Intervention

The Couple-Oriented Education and Support (CES) intervention, developed by Lynn Martire, Francis Keefe, and colleagues at the University of Pittsburgh, focuses on increasing spouse support for adults with osteoarthritis.^{55,56} The program was based on the widely used Arthritis Self-Help Course (ASHC) developed by Kate Lorig, which has been shown to increase patient self-confidence, decrease pain and depressive symptoms, and decrease visits with the physician.⁵⁷ In the CES program, patients with painful osteoarthritis in the knee or hip met

in groups with their spouses. The group was lead through six two-hour Arthritis Self-Help Course sessions by a facilitator trained using ASHC manuals and materials specific to the CES program. (See Table 3.) At the end of each session the patient set a health goal, usually related to the session topic. Then spouses set goals aimed at facilitating the patients' goals. Over the next six months couples received monthly booster phone calls to assess progress in meeting their goals.

In a randomized controlled trial, couples in the CES reported fewer angry and critical responses to patient symptoms, and patients reported more spouse support than patients who attended the Arthritis Self-Help Course alone. In another program for lupus patients and their partners with a goal-setting structure similar to the CES, participating patients had increased physical function and decreased fatigue compared to control patients.⁶⁰

Table 3. Couple-Oriented Education and Support (CES) Intervention Topics

ARTHRITIS SELF-HELP COURSE TOPICS	ADDITIONAL CONTENT IN COUPLE-ORIENTED PROGRAM
Etiology and treatment of arthritis	Arthritis as a couple's issue (i.e., how patient symptoms can be affected by patient and spouse feelings and behaviors)
Communicating effectively with health professionals and supporters	Supportive and unsupportive communication techniques for spouses
Managing fatigue	Effective strategies for requesting and providing spouse assistance (i.e., being clear about needs, being sensitive to amount of help needed)
Managing anger, stress, and frustration	Techniques to limit spillover of negative emotions from one partner to the other
Managing pain	Spouse techniques to encourage pain management strategies (distraction, muscle relaxation) and how to practice these strategies with the patient
Appropriate use of medications	Couples' strategies for managing medications
Exercise, eating, and healthy sleep patterns	Spouse strategies for supporting patient health goals

These examples adapted with permission from CES-related publications and personal communication with Lynn Martire, Ph.D.^{58,59}

Learning Autonomy-Supportive Communication: The Family Partnership Intervention

The Family Partnership Intervention developed by Sandra Dunbar, Patricia Clark, and colleagues focuses on increasing family member use of autonomy-supportive communication techniques with heart failure patients.^{61,62} Participants first receive a 60- to 90-minute education session about heart failure care and techniques to decrease dietary sodium. Patients and family members then meet in separate small groups for two two-hour sessions.

The family member sessions, led by a nurse expert and a dietician, include didactic teaching about autonomy support, discussion of family member experiences receiving and giving support, case scenarios, and role play. Case scenarios represent difficult situations related to adherence with various possible family member responses. Family members discuss and then identify the most autonomy-supportive response (examples are available in Clark et al, AACN 2003) to each scenario.

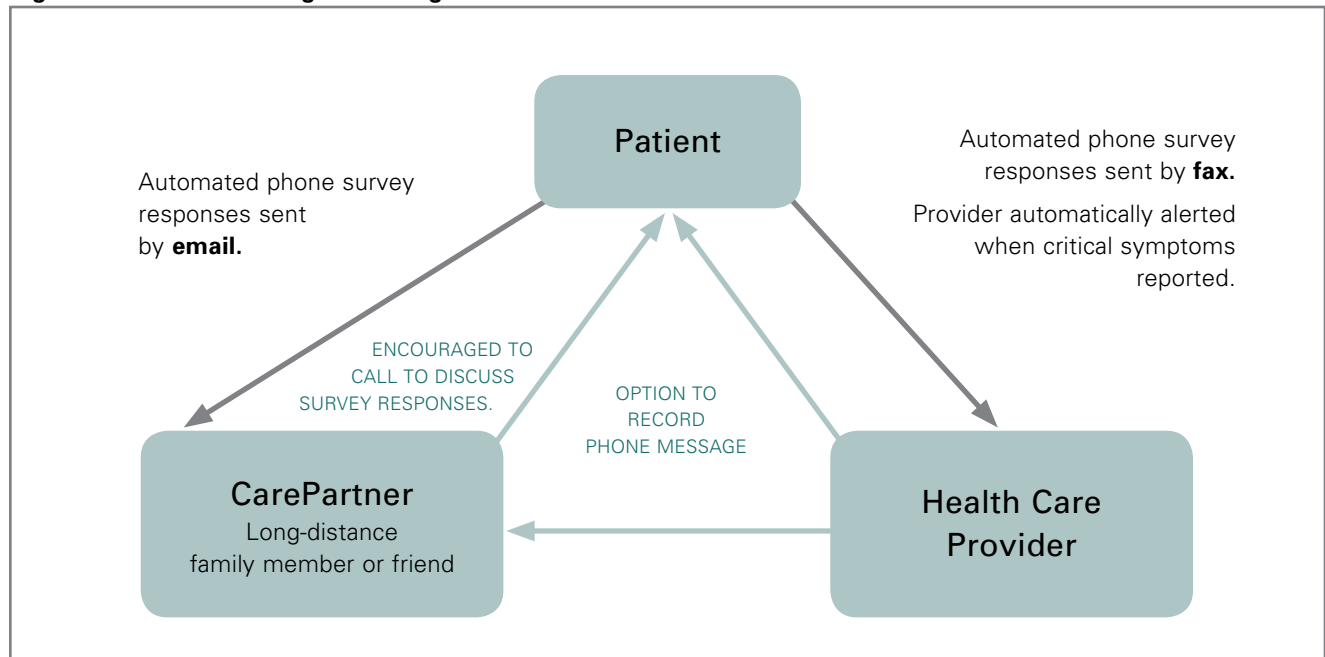
In the patient sessions, participants discuss similar material and identify specific ways family members can help with heart failure self-management. A newsletter with tips on reinforcing autonomy support strategies is mailed to participants several weeks after the session.

Patients in the autonomy support intervention decreased their sodium intake significantly more than those who participated in an educational program.

Monitoring Home-Testing and Symptoms: The CarePartner Program

The CarePartner program, developed by John Piette and colleagues at the University of Michigan, uses automated voice response telephone technology to connect out-of-home family members with chronic illness patients and their health care provider. Its basic features are illustrated in Figure 1. In this program, some of the assessment and support roles commonly provided by professional disease managers are performed by family members supported by automated technology. The initial CarePartner

Figure 1. CarePartner Program Configuration



program was developed and tested with heart failure patients.⁶³ At the beginning of the program, patients elect a family member or friend to serve as their CarePartner. CarePartners are given written and online information about heart failure management and advice on effectively influencing patient behavior using supportive statements and motivational interviewing.

During the program, patients are called weekly by an interactive automated telephone service to complete a health assessment. During those calls, patients report information about their symptoms (shortness of breath, swelling, fatigue), weight, fluid intake, medication adherence, and availability of their medication supply. Patients can also hear voicemail messages left for them by their CarePartner or clinical team. An email summarizing the patient’s responses is automatically generated for the CarePartner. The report highlights any concerning patient responses and suggests actions the CarePartner can take (see

Table 4) as well as a time frame for following up. The patient’s professional health care team receives automated faxes summarizing more urgent health problems such as significantly increased shortness of breath or weight gain. Professionals can access a Web site with information on the patient health assessment responses and can record phone messages for the CarePartner or the patient.

After a 12-week pilot study, 78 percent of patients reported that their CarePartner helped them to stay healthy, and 73 percent said that their CarePartner helped them to solve self-management problems. The effect of the program on heart failure patients’ health-related quality of life, hospitalization risk, and self-care behaviors is now being evaluated in a randomized controlled trial. The CarePartner program is currently being adapted for care of diabetes, depression, cancer, and for Spanish-speaking patients.

Table 4. Examples of Patient Responses to Automated Phone Assessment and Suggested CarePartner Actions

PATIENT RESPONSE	SUGGESTED CAREPARTNER ACTIONS
Do not have enough medication to last 2 weeks	<ul style="list-style-type: none"> • Recommend that patient call pharmacy right away for a refill
Drinking more than 2 liters of fluid a day	<ul style="list-style-type: none"> • Remind patient why it is important to limit fluids • Suggest that patient keep a log of fluid intake for 1 to 2 days
More body swelling than last week	<ul style="list-style-type: none"> • Remind patient to use support stockings if prescribed • Suggest patient call their physician to see if diuretic dose should be increased
Weight increased more than 3 pounds in last week	<ul style="list-style-type: none"> • Recommend patient call their health care provider within 48 hours

VII. Should Programs Focus on Certain Patients and Families?

Patient and Family Characteristics

Involving family in care is one way among many to support patients, and isn't equally easy or beneficial for everyone. The resources used by family programs might be best directed to those likely to get the most benefit. Although there is little research on the types of patients most likely to benefit from family involvement, it is possible to draw some conclusions based on program experience.

- Patients who want more support from family, and whose family members want to and are able to increase their involvement, are more likely to benefit from the program.
- Many family programs focus on patients with high support needs, such as those with uncontrolled or severe illnesses, or with more complex self-management regimens. Some patients have high support needs at certain times in the course of their illness, such as at the time of diagnosis; when making significant changes in self-management; when illness is worsening or flaring; or after major events like hospitalizations and surgeries.
- Other programs focus on patients in a maintenance phase of care, when short-term professional support services have ended and family can provide encouragement and help patients stay on track.
- There is no conclusive evidence that the age or gender of patients influences their likelihood of benefiting from family programs.
- If more than one family member is available, individuals can be selected based on their role

in the family (cooking or shopping for food, organizing activities, or taking a leading role in health decisions for the family).

- The quality of the pre-existing relationships between the patient and family member, and how the family functions as a whole, influence the success of family involvement. Many couple-oriented programs have found better patient health outcomes for couples who began the program with higher marital satisfaction.

Cultural Influences

Because culture influences family structure and relationships, it affects the family's approach to chronic illness care. For example, culture may influence who the patient lives with, who is considered "family," and the importance of extended family in the patient's everyday life.⁶⁴ Expected roles for the patient and others in the household—such as who cooks, who cares for children, or who makes medical decisions—may also be culturally defined. Family programs should consider how to culturally tailor content if participants share a particular cultural background.

Cultural background also influences how family members interact with patients' health care providers. Cultural norms may influence who takes the lead in communicating with the provider. When patients are from a cultural background different than that of their provider, family members can assist patients in communicating their needs and values to the provider. Similarly, patients who are not English-proficient might particularly benefit from programs that facilitate family roles in care.

VIII. Designing a Family Program

EFFORTS TO INCREASE FAMILY INVOLVEMENT do not need to be formal or extensive. Assessing family influences on patient care, helping patients set goals for increasing family support, or giving families simple tips for increasing support could all be accomplished during a clinic visit. However, many patients, families, and providers are interested in programs that give families more detailed roles, tools,

and guidance. The box below lists considerations for designing such family involvement programs.

It is important to plan the ways in which the family program will be integrated into the other care and support the patient receives from professionals. Other patient support programs, such as disease management and telephone care, are most successful when feedback is given on patient progress to

Considerations for Family Involvement Program Design

Which patients and family members will be included?

Will the program be integrated into other self-management support programs or stand alone?

Who will deliver the program?

- Health care professionals such as nurses, disease educators, nutritionists, counselors.
- Trained support group facilitator.
- Patient peers or family members.

What training does the program leader need?

What format will the program be delivered in?

- In person, by phone, in written materials, or some combination.
- Patients and family members participating separately.
- Patients and family members participating together, with couples participating in groups, or one couple at a time.

What behavior-support techniques will the program teach?

How will support skills be taught and practiced?

- Inclusion of case scenarios or role play.
- Assignment of "homework."
- Discussion of patient and family experiences.

Do program materials (handouts, videos, scripts) need to be adapted or developed?

Will "booster" sessions or materials be provided?

Will feedback be given to the patient's health care provider?

Do health care providers need training to help them communicate more effectively with involved family members?

How can practice environments be made more welcoming to involved family members?

providers and when they include mechanisms for provider action based on this feedback.^{65,66}

As we develop the concept of the patient medical home, more disease managers and case managers may be situated in practice settings. These support professionals should consider how to involve family in their work with patients.

Office staff might have legitimate concerns about family members who accompany patients, such as concerns about an increased burden on providers, or about complying with privacy rules. However, overly protective staff can make families feel unwelcome in providers' offices. Techniques to make families feel more comfortable might include educating clerical staff and medical assistants on the importance of family involvement in patient care, and designing

exam rooms with extra space and seating for family. Medical record forms could identify key family members' roles and allow patients to specify the type of personal information that may be shared with each family member. The **Institute for Family Centered Care** has many more suggestions for making health care settings welcoming to family members.

Evaluation of new programs is always important, and is particularly important for family programs since we lack extensive information on their effects. Plans for program evaluation should be built into the program design. The box below lists important areas to consider for program evaluation. The particular outcomes evaluated should be based on the pre-determined goals of each program.

Possible Elements of Family Involvement Program Evaluation

Patient and Family Participants

- Characteristics of patients and family members who participate and those who do not

Process

- Number of participants attending the sessions
- Reasons some people missed the sessions
- Whether the content and style of the program was delivered as intended
- Number of patients and families who dropped out, and why
- Whether family member use of targeted techniques increased

Patient Outcomes

- Health status
- Disease control
- Self-management behavior
- Perceived support from family
- Patient confidence (self-efficacy)
- Illness-related stress
- Depressive or anxiety symptoms

Family Member Outcomes

- Satisfaction with ability to help patient
- Stress related to patient illness
- Perceived burden related to supporting patient
- Changes in family member's health and health behavior

Relationship Outcomes

- Improved or strained relationship quality and interpersonal communication

Effects on Patient Clinical Care or on Health Care Provider Relationships

- Medical care utilization
- Length of provider visits
- Clinical processes completed
- Patient satisfaction with patient-provider communication and relationship
- Patient satisfaction with clinical care received
- Patient use of other professional support or ancillary services

IX. Future Directions for Family Involvement

PROGRAMS TO INCREASE FAMILY INVOLVEMENT are in varying stages of development. Changing patient demographics and needs will need to be addressed by future programs. Specifically:

- How can family members best support patients with multiple chronic illnesses?
- How can family members best support patients with low health literacy?
- How can advice for family supporters be tailored to cultural and gender-based differences in family roles?

Changing family structures and dynamics also pose challenges to increasing family involvement for many patients. More adults live alone or far from their extended family. Family members are juggling many roles at work or school, and caring for children and other relatives. As the prevalence of chronic illness increases, family members are often managing illnesses and disabilities of their own. Future family programs will need to be adaptable. Some questions to consider:

- Can telephone or Web-based programs help bridge distance gaps between family members?
- How can we best coordinate the efforts of multiple involved family members?
- How can family members provide mutual support for each others' health problems?
- How do we best help patients with negative family relationships that are affecting their chronic illness care?

Increasing strains on health care resources make it essential to provide family programs in a cost-effective way. Incorporating sessions for family into existing patient-support programs may help minimize extra costs. It is unclear how family involvement will affect the length of provider visits, frequency of phone calls to the physician, or utilization of other health resources. However if families can effectively support illness management over time, family support may be a low-cost adjunct to professional support, and allow patients to use more costly support resources less often. Questions to consider:

- How cost-effective are family involvement programs? How do family involvement programs increase or decrease provider work burden?
- Can programs carried out by phone, by video, or over the Internet increase family support for less cost and participant burden?
- How can family support programs be integrated with other treatment and support services?
 - Could family support supplant some types of professional support for some patients?
 - Could assessments of family support be useful in targeting professional support resources to those patients who need them the most?

X. Conclusion

Interest in family involvement is surging, and interventions to increase family support for chronically ill patients are being rapidly developed.

THE CARE OF MOST ADULTS WITH CHRONIC DISEASE HAS not actively addressed the roles and influences of family, even though family members are known to significantly affect chronic illness management. Family involvement in chronic illness care builds on the unique strengths of family members, including their intimate and sustained relationships with patients, their influence on patient daily routines, and their desire to help their loved ones. Interest in family involvement is surging, and interventions to increase family support for chronically ill patients are being rapidly developed. Content from thoughtfully designed programs based on health behavior theory can be used to guide new initiatives, but interventions must allow for adaptation to changes in patient needs, family relationships, and health care system structure.

The current environment offers several indications that interest in family involvement is likely to continue. These include increasing numbers of patients with chronic disease, the complexity of care, limited resources for care, and growing recognition of the positive effects of family support. Health care providers caring for children or the elderly have already recognized the benefits of a “family-centered” approach to patient care. The current proliferation in family support programs may herald a shift to a more family-centered approach to care for all patients with chronic illness.

Appendix: Tools and Resources

There are many patient resources for disease education and self-management support that can be shared with family members. However, there are few developed resources that give tips directly to family members about their support roles.

Resources for Caregivers

Resources aimed at caregivers of patients with more severe functional disability may be useful to family of other chronic illness patients, or may be adaptable for use in family programs.

For example, the [National Family Caregivers Association](#) offers online videos as part of its [Communicating Effectively with Healthcare Professionals](#) program. The program includes information for families on how to prepare for doctor visits, how to collaborate with health care providers, and how to adapt to different provider communication styles.

Web-based Resources for Patients and Families

Most publicly available materials addressing family involvement discuss diabetes care, but much of the advice is relevant to supporting adults with other chronic illnesses as well.

- [Tips for Helping a Person with Diabetes](#)
- [Tips for Helping a Person with Diabetes \(Spanish version\)](#)
- [Helping a Family Member Who Has Diabetes](#)
- [How to Involve Your Friends and Family in Your Diabetes Care](#)
- [Diabetes and Your Marriage](#)
- [Tips for Family and Friends on Managing Heart Failure](#) (A booklet version is available for order.)

Resources for Health Care Providers

The book *Family-Oriented Primary Care* by Susan McDaniel, Thomas Campbell, Jeri Hepworth, and Alan Lorenz provides practical advice on ways providers can include family issues in medical visits, and many examples of communication techniques for a wide range of family-related issues.

Program Materials

Developers of the three programs highlighted in Section VI have offered to share selected materials with those interested.

- [Couple-Oriented Education and Support Intervention](#)
Lynn Martire: martire@pitt.edu
- [Family Partnership Intervention](#)
Sandra Dunbar: sbdunba@emory.edu
Patricia Clark: pclark@gsu.edu
- [CarePartners Program](#)
John Piette: jpiette@umich.edu

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