

PATIENT ENGAGEMENT & PATIENT ACTIVATION

Strategies for Supporting Self-Management Programs

*By Ricki Stajer, RN, MA, CPHQ
with program example by Stanley Tobias, MD, FACP*



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Introduction

Ask a care manager to identify what's arguably the most important predictor in patient outcomes and you're likely to get a simple answer: the patient. A growing body of evidence suggests that patients actively engaged in managing their own health are less likely to be hospitalized or visit the emergency room, more likely to model healthy behaviors, and generally report better healthcare experiences. What's more, it's not an all-or-nothing game—incrementally increasing patient activation yields significant results. This eBook examines the impact of patient engagement and patient activation, describes models for engaging patients, and explores the role of care managers in educating and activating patients.

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The Affordable Care Act and Patient Engagement

The Patient Protection and Affordable Care Act, often referred to as simply the Affordable Care Act, came into law in March 2010 with three primary goals:

- *Provide as close to 100% healthcare insurance coverage as possible, by making health insurance affordable and available to more people*
- *Provide healthcare insurance to all adults with income below 138% of the federal poverty level*
- *Stimulate the development of new innovative medical care delivery methods to lower healthcare costs*

With full implementation scheduled for Jan. 1, 2014, the Act was a call to action and the impetus to move from volume-based to value-based care. Accountable care organizations, medical homes, group appointments, nurse-driven clinics, bundled care and pay-for-performance payment programs, etc. are all examples of new care delivery models now in place in many systems. Of key importance under the ACA, was the recognition that patient engagement was a critical element in reducing healthcare costs and improving outcomes.

Sarah Kowitz, PhD, MPH, at the University of North Carolina, Gillings School of Public Health, writes that “patient engagement is a precursor to successful prevention and chronic disease self-management programs.” On the school's Peers for Progress Blog, she summarizes the results of several studies about patient engagement conducted between 2002 and 2017. Although different authors defined patient engagement in different ways, she concluded that the research agreed on the efficacy of patient engagement and patient activation as being “crucial components of prevention and chronic disease self-management programs.”

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Patient Engagement vs. Patient Activation

We see the terms patient engagement and patient activation often are used interchangeably and it is difficult to distinguish unique characteristics. The Center for Advancing Health in Washington, D.C., defines patient engagement as “actions individuals must take to obtain the greatest benefit from the health care services available to them.”

In a 54-page document entitled “Supporting People to Manage Their Health: An Introduction to Patient Activation” published in May 2014, patient activation is described as “the knowledge, skills and confidence a person has in managing their own health and health care.”

These two definitions, like many others found in the literature, point to patient engagement and patient activation as being two aspects on a continuum supporting full patient self-management.


Dr. Judith H. Hibbard, a senior researcher at the University of Oregon’s Institute for a Sustainable Environment and one of the developers of the Patient Activation Measures (PAM), notes the overlap of the two terms. PAM is a 13-question, 100-point, quantifiable scale determining patient engagement in healthcare.

In “What the Evidence Shows About Patient Activation: Better Health Outcomes and Care Experiences; Fewer Data on Costs,” Hibbard reports that patient engagement and patient activation are frequently used to mean the same thing, and are sometimes poorly defined.

Hibbard states that patient activation “emphasizes patients’ willingness and ability to take independent actions to manage their health and care” while patient engagement describes “a broader concept that includes activation; the interventions designed to increase activation; and patients’ resulting behavior, such as obtaining preventive care or engaging in regular physical exercise.”

Her examination of numerous peer-reviewed studies definitively found that individuals who scored higher on the PAM were much more likely to engage in preventive health-related behaviors such as healthy eating, screenings, immunizations, and check-ups. She also found that people who had low PAM scores were “also three times as likely to have unmet medical needs and twice as likely to delay medical care.”

Patients with chronic diseases who had high PAM scores were more likely to follow treatment recommendations, conduct routine self-monitoring and access regular chronic care services. Dr. Hibbard reported that these findings were consistent across patients with many different types of health conditions and across different countries including Canada, Norway, Denmark, Germany, the United Kingdom, Japan, and Australia.



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The Impact of Patient Engagement/Activation

Although there is no one commonly used definition for either patient engagement or patient activation, it is agreed that both involve imparting knowledge that results in a patient acquiring the skills, knowledge and confidence to manage their own health. Providers are grappling with the question of how to use patient engagement and patient activation techniques effectively: What type of support model would best benefit their patients? The answer lies in understanding the patient population in question.

But does educating patients truly enable them to self-manage health-related conditions and improve their health status and outcomes? Literature review described numerous examples of the power and success of patient self-management programs supported by strong care management and comprised of teams working continuously with complex, chronic disease patients.

What about patients who are basically well but have risk factors that are not addressed and will lead to a decline in wellness? Can they successfully manage their health and maintain their wellness status on their own?

Dr. Chris Feudtner, a pediatric physician at the Child Health Institute at the University of Washington in Seattle and a health services researcher who focuses on children with complex chronic conditions, addresses that question in a commentary in the *Western Journal of Medicine*.

Feudtner asked “What are the fundamental objectives of patient education?” He states that for patient education to be relevant, it must improve patients’ lives by achieving specific objectives, and that these objectives should be more than just improving a patient’s knowledge or even self-management skills.

Putting it simply, Dr. Feudtner argues that the objectives must matter fundamentally to the patient; in other words, based on outcomes with which the patient associates his or her wellness. Some examples might be objectives that focus on reducing anxiety related to being ill and improving self-esteem, activity levels, decision-making abilities and satisfaction with care.

Once objectives are defined, an appropriate model of care—which includes patient education—can be developed, and both the provider’s goals (e.g. increased adherence to therapies) and the patient’s outcome goals can be facilitated to support the overall objective of improving health.

Education Is Just One Step in Managing Illness

Evaluation of services like patient education suggest that education without follow-up is frequently not effective. For example, a recent survey done by the American Heart Association of 800 individuals identified as being at risk for or having a history of heart disease showed that almost 50% of those patients did not know what to do to manage their risk of disease.

Although 82% of those surveyed stated that they understood the link between high cholesterol and heart disease, only 47% had had their cholesterol levels measured in the past 12 months. In addition, these patients reported having discussions about cardiovascular risk with their primary care physicians; however on the survey, most said they did not know their personal medical risk issues.

Dr. Mary Bauman, a member of the American Heart Association's cholesterol advisory group, noted that even individuals with highest risk for heart disease and stroke did not have adequate knowledge of their situations.

In Dr. Baumann's opinion, patient education alone cannot engage patients in self-management. Patient education must reflect discussion of external risk factors such as family history, environmental factors, and lifestyle choices, so that the "most effective course of treatment" can be determined and tailored to his/her specific needs. The providers must validate that patients understand their risk factors and how to manage them effectively.

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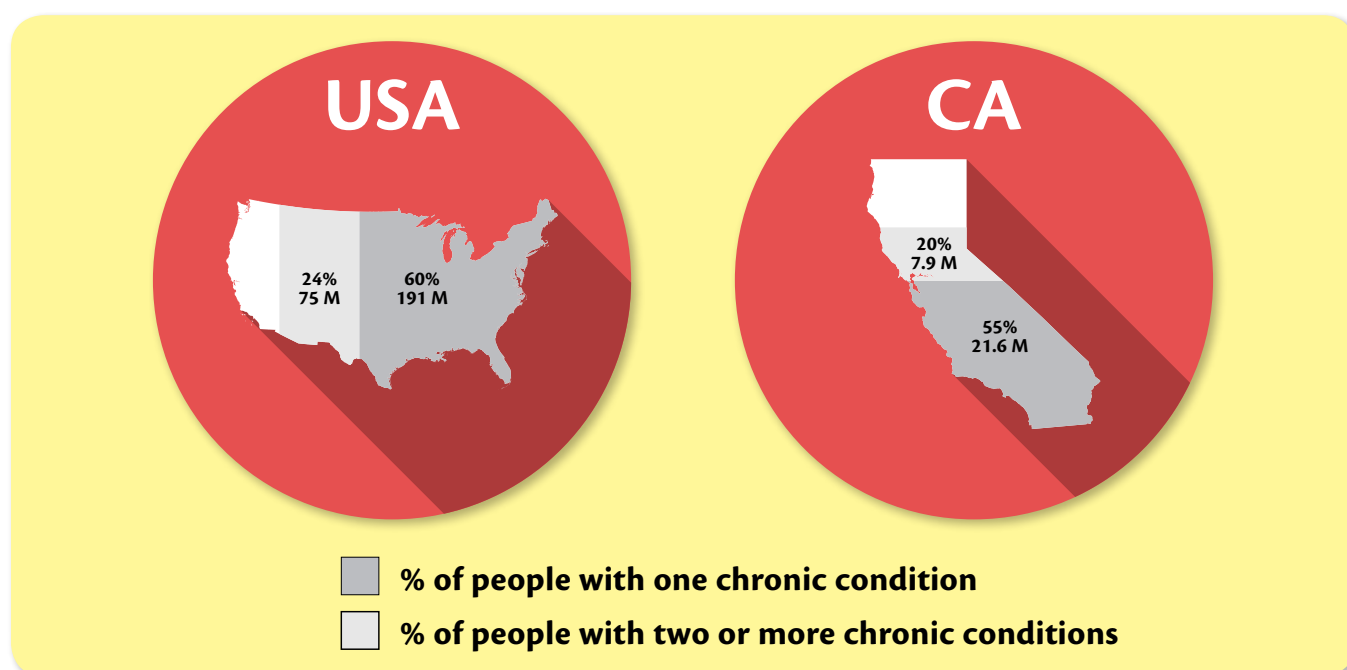
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Models for Engaging Patients

What models best support providing patient education that leads to goal setting, an understanding of what activities are required to meet goals and behavior modification to achieve positive health outcomes; in effect, what patient support model engages a patient to act positively for their own health interests?

First it is important to identify which patients need these types of programs. According to Partnership to Fight Chronic Disease—a national and state-based coalition of hundreds of patient, provider, community, business and labor groups, as well as health policy experts—in 2015 there were 191 million people (60%) in America with at least one chronic condition, and 75 million people (24%) with two or more chronic diseases. In California, 21.6 million people (55%) had at least one chronic condition, and 7.9 million people (20%) had two or more chronic diseases. On its website, FightChronicDisease.org/California, the partnership states “106,900 lives could be saved annually through better prevention and treatment of chronic disease.”



The Case Management Society of America (CMSA) emphasizes that the current medical model operates in silos and patients with more than one co-morbidity are treated by individual specialists, each treating the patient independently of other physicians' treatment plans. The CMSA also reports that 29% of individuals with a medical condition also have mental health comorbidities, while 80% of individuals with a mental health condition also have at least one general medical condition.

It is these medically complex high-risk patients who require support programs that integrate and coordinate their care plans and enable them to engage actively in their care.

A review of the literature identified two strongly evidence-based patient engagement or patient activation models:

Integrated Case Management Programs

The first is a comprehensive case-management supported model, either based directly in a physician's office or decentralized where patients are referred from the physician's office to a case management team in another location.

Often referred to as integrated case management programs, these programs are led by registered nurse and clinical social work case management teams. The nurse and social worker work directly with the patients and families to identify medical, social and behavioral

short and long-term goals. They develop actions plans with the patients mapping out the milestones toward accomplishing the agreed-upon goals.

The nurse case manager will monitor the patient's progress and make recommendations to the physician for additional interventions; the social worker will identify psychosocial issues that impede the patient progress and work with the patient and family to resolve these issues, often referring the patient to community resource services for additional support.

An excellent example of an integrated case management model is a program developed under a grant by the Centers for Medicare and Medicaid Innovation to the Pacific Business Group on Health (PBGH) in 2012. Called the Intensive Outpatient Care Program (IOCP), it focused on reducing healthcare costs for 27,000 high-risk Medicare patients through 20 Physician Medical Groups (PMGs) in California and Arizona. It expanded to include PMGs in Idaho, Nevada, and Washington.

The model embedded complex care managers in primary care teams to develop close relationships with medically complex patients, engage them in their care and ultimately reduce ED and hospitalization costs while improving the patients' quality of life. The role of the case manager was to understand the psychosocial barriers patients faced that prevented them from managing their own care effectively; work with the patient and family to problem solve the barriers; and, along with physicians, work "to change how patients managed their lives to reduce utilization and improve well-being." The teams consisted of registered nurse case managers and clinical social work case managers.

Key elements of the program included:

- *establishing trust relationships between case managers and patients*
- *creating a patient-centered action plan based upon shared goals developed by the patient and case manager*
- *comprehensive assessment including socio-behavior issues*
- *direct access to the case manager or other active team member*
- *case management support at transitions of care*
- *patient self-management support including medication management and behavioral change coaching*

The patient population targeted consisted of medically complex patients at high risk for hospitalization and/or frequent ED admissions. Data analysis results showed a reduction in healthcare costs by up to 20%. In addition, the Veterans' Rand 12 Item Health Survey (VR12), the Patient Health Questionnaire (PHQ) and the Patient Activation Measure (PAM) showed statistically significant improvements in patients' engagement in their own care and in physical and mental health.

An analysis done by Milliman shows reduced costs in care and:

- *3.6% increase in patient engagement*
- *33% reduction in depression symptoms*
- *3.4% improvement in mental health functioning*
- *4.1% improvement in physical health functioning*
- *21% reduction in the cost of care for high-risk patients enrolled for at least 9 months*

Better Choices, Better Health Programs

The concept of patient activation in a self-management health program is much older than the PAM assessment tool that is widely used today. Twenty-two years ago, in 1996, at Stanford University, Kate Lorig, RN, DrPH, and colleagues developed the Chronic Disease Self-Management Program, now evolved into Better Choices, Better Health (BCBH).

The BCBH programs are examples of the second evidence-based model in support of patient engagement/patient activation, or more commonly called a patient self-management program. BCBH programs consist of six-week workshops, held in community centers and led by two trained leaders, focused on people who have various chronic health problems. There are separate BCBH programs specifically for people with diabetes or arthritis.

These programs have shown to be so successful that Stanford University developed a separate Self-Management Center with similar self-management programs for cancer, chronic pain, and being a care giver. Better Choices, Better Health programs are available for health systems and providers to license and conduct independently and they have spread successfully across the country.

The National Council on Aging promotes three online Better Choices Better Health programs; Chronic Disease Self-Management Program (CDSMP), Better Choices, Better Health for Diabetes, and Better Choices Better Health for Arthritis.

Earlier this year, the *Journal of Medical Internet Research* published a peer-reviewed evaluation of the BCBH-Diabetes program completed by Ralph M. Turner, PhD, Kate Lorig, Dr.PH, et al. Diabetes mellitus patients who were recruited to a BCBH diabetes (BCBH-D) self-management program were followed against the same type of patients who did not participate in such a program. All participants were members of an Anthem-affiliated health plan, and were 18 years or older with Type 2 diabetes.

“Per patient, direct cost savings were \$815.”

Outcome measures included pre-and post-intervention utilization and costs—both diabetes-related and otherwise—including hospitalizations, ED visits and outpatient services with primary diagnosis of diabetes. The researchers found that the BCBH-D participant group had significant decreases in medical claims associated with hypertension and depression, while the non-participant group had significant increases in claims for healthcare services associated with renal disease, rheumatoid arthritis or osteoarthritis and musculoskeletal disorders.

In addition, the participant group had less all-cause ED visits and outpatient services compared with the non-participant control group. Per patient, direct cost savings were \$815.

Combining Coaching and Teaching

These are exciting examples of new models of care that support teaching and engaging patients in understanding and managing their conditions. Healthcare team members must learn to be coaches as well as teachers.

Comprehensive coaching is part of the evolution from didactic patient education done during a physician office visit, either by the patient or support personnel; to interactive, discipline-specific counseling; to the most recent generation of interactive and multi-disciplinary patient self-management programs.

The Institute for Healthcare Improvement (IHI)—the organization that created the Triple Aim, a framework for optimizing health system performance by simultaneously focusing on the health of a population, the experience of care for individuals within that population, and the per capita cost of providing that care—has a full complement of evidence-based resources available to healthcare providers to build self-management programs. All of them begin with the understanding that “patients with chronic illness need support, as well as information, to become effective managers of their own health.”

The IHI notes that to successfully help patients become self-managers, they need three things:

- *Basic knowledge about their disease*
- *Help to learn self-management skills*
- *Continuous support from their healthcare team members, their family, friends, and communities*

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Case Managers as Patient Educators

Where does case management and care coordination fit in this discussion? Again, the Affordable Care Act has pushed healthcare into a second curve of operations; from volume-based to value-based, patient-centered healthcare delivery. This movement clearly identifies care coordination, generally owned/supported by RN and social work case managers, as one of the key success factors in supporting patient-centered care.

The role of the case manager is to identify and manage high-risk patients. By today's definitions, the case manager is a teacher, coach, monitor, facilitator of patient information to and from the patient's physician and most importantly, a coordinator of care.

Care managers have always assessed, planned, implemented, and evaluated patient health status and resulting care; they are strong patient advocates who are focused on ensuring that care provided to patients is timely, appropriate, and aligned with the patients' personal goals and wishes. Care managers are also the "go-between" facilitators, focused on ensuring that the patient is receiving support from all elements of the continuum of care as appropriate to a situation. They are often the patient's voice, sometimes between the family and the patient, and also between the patient and the healthcare team. Their expertise includes disease management knowledge, financial resource knowledge, collaboration and negotiation skills, advocacy, planning, evaluation, and most importantly, patient alignment.

The American Association of Case Management defines case management as "a collaborative practice model including patients, nurses, social workers, physicians, other practitioners, caregivers and the community." Nurse and social work case managers often facilitate healthcare teams in complex chronic disease support models, such as the medical home model, the transitions of care model, and centralized or embedded case management/care coordination models within clinic models.

Evidence-based practice has proven that patient engagement leads to better patient health outcomes and that patients are most successful within self-management programs supported by a multi-disciplinary team working in collaboration with their primary care providers.

"... patients are most successful within self-management programs supported by a multi-disciplinary team working in collaboration with their primary care providers."

These types of programs have been developing over the past three decades and are easy to find for patients with congestive heart failure, diabetes, multiple chronic diseases, arthritis and most recently, for chronic pain sufferers. Other self-management programs are also being developed proactively in pockets across the country.

A New Patient-Engagement Strategy

Stanley Tobias, MD, FACR, a rheumatologist in Torrance, Calif, has developed the first stage of a patient-centered educational program for patients with fibromyalgia. Fibromyalgia is a chronic pain disorder estimated to affect 10 million people in the United States and approximately 3-6% of the world population. Roughly 75-90% of fibromyalgia patients are women, but it does occur in men and children and in all ethnic groups.

It is a young person's disease, often diagnosed in patients between the ages of 20 and 50, and it may occur in families, presenting among siblings or mothers and children. It is a chronic disease and the incidence increases with age; the American College of Rheumatology estimates that by 80 years old, 8% of the adult population has fibromyalgia.

People with this disease have diffuse muscular pain, diffuse tenderness when touched and chronic fatigue. Accompanying symptoms include stiffness, irritable bowel with recurring diarrhea and constipation, irritable bladder and urinary complaints, restless leg syndrome, vaginal pain and dryness, and painful menstrual periods. It is understandable then to recognize that they also have unrefreshing sleep, tension headache, depression and mood disorders, and difficulty in concentration and other cognitive functions.

A 2003 study published in the *Journal of Rheumatology* found that the total annual healthcare costs for fibromyalgia patients were more than twice as high as the costs for a typical insurance beneficiary. The Fibromyalgia Foundation also reports 2007 study results that 34% of these patients had between \$100 - \$1000/month out of pocket costs to see a fibromyalgia specialist. It is estimated that costs in the U.S. due to this disease are between \$12-14 million annually.

Having worked with fibromyalgia patients for almost 40 years, Dr. Tobias was used to hearing his patients report that their primary care physicians "could not help," "did not understand how much pain they were experiencing," or told patients the pain "was all in their heads."

At the same time, many primary care physicians would consult with Dr. Tobias and tell him that 1) they did not know what to do for these patients and 2) could not treat such complex patients within their 20-minute appointment times. It was obvious to him that both physicians and patients were frustrated, unhappy and dissatisfied. In addition, the patients were clearly suffering, physically and emotionally as they tried to deal with this difficult, complex, chronic disease.

Dr. Tobias knew by his own experience, that patients working together with their physicians and treatment teams experienced better pain control, dealt with fibromyalgia flare-ups quicker and more effectively, and reported feeling that they had a better quality of life. He recognized that a long-term approach, starting with education and building to patient empowerment was a key to efficacious ongoing condition management because fibromyalgia presents differently in each patient and therefore each patient requires an individualized management plan.

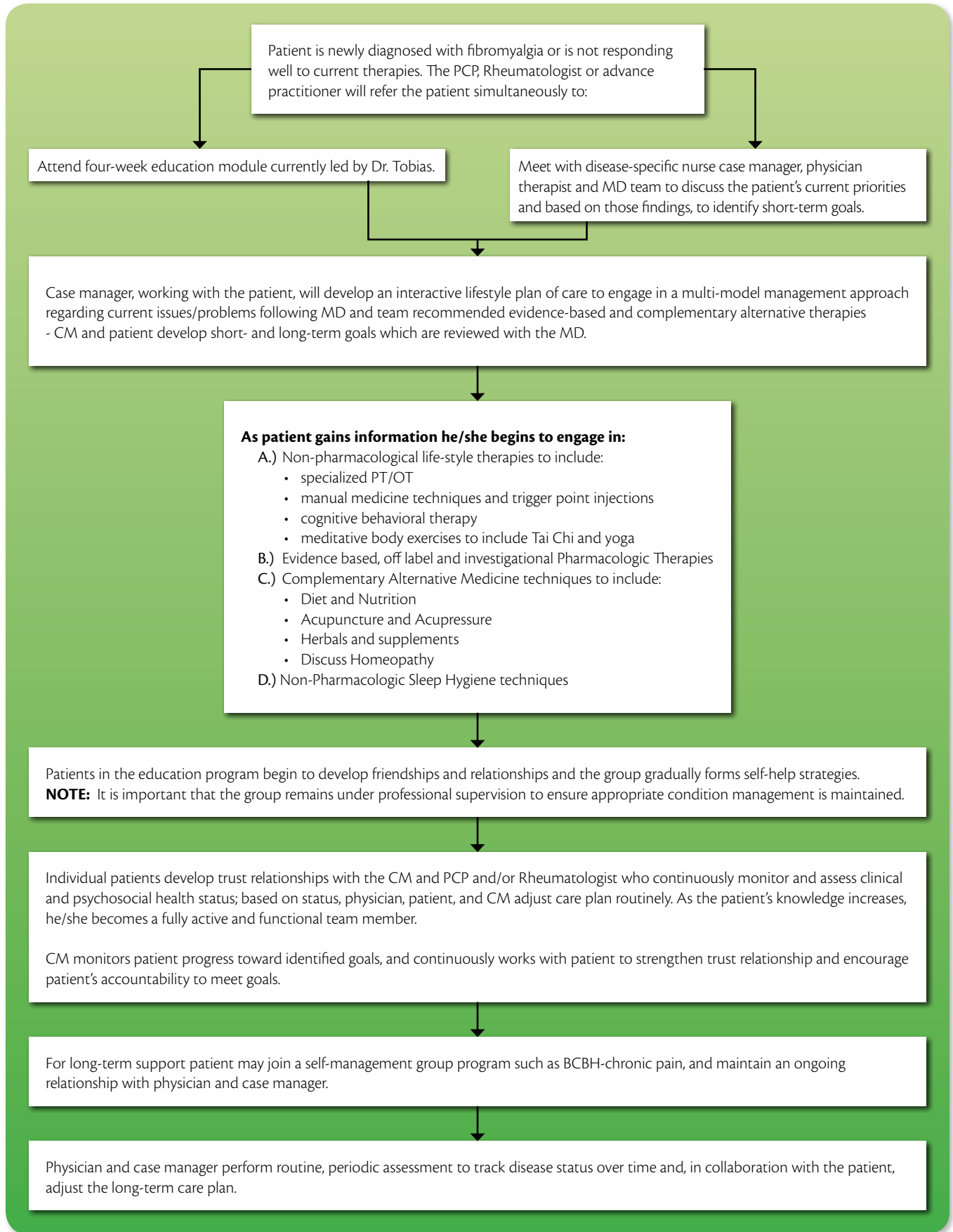
With the goal of supporting patients to become self-empowered and active participants in managing rather than being "victims" of their condition, he developed a six-week patient group education program; the first four weeks focus on the education module, the fifth week is a focused-topic workshop and the last week is a training session with ancillary team members, physiotherapy, nutrition, etc.

The education module teaches patients first how fibromyalgia affects them, explaining therapies, medication and emphasizing non-pharmacologic and life-style treatments for the disease. Each session of the education module has a one-hour didactic lecture and one hour devoted to open discussion; the second hour always runs over as patients engage fully in learning about their disease and what they can do to manage themselves.

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Dr. Tobias developed the following algorithm for physicians, case managers and patients to follow.



Dr. Tobias is in his fourth year of conducting this program. He has partnered with one of the main nonprofit hospitals in his area to hold the classes in their conference center. He works closely with the hospital's community education department and is working to present his program to the hospital's physician network group. Patient satisfaction surveys are overwhelmingly positive with written comments such as: "You have given me hope that I can live with this disease."

The most compelling indication of the program's success in improving patients' quality of life came by letter. The patient reported that she had suffered with fibromyalgia for many years with little understanding shown to her. "Thank you for the enormous amount of information you gave me, and for the validation of my diagnosis. I am comforted knowing the concrete facts of my condition." She went on to say that, with a new understanding about what strategies might be successful, she would continue in that direction and work toward utilizing more non-pharmacologic therapies. "I feel motivated and empowered to continue to fine-tune a treatment plan that is customized just for me."



Conclusion

It is commonly reported that 5% of the population in the United States currently generates 50% of the country's healthcare costs. Mostly these are elderly people with multiple co-morbid chronic diseases; but there is also a segment of the 5% of the population who are not seniors but are equally debilitated by complex and often chronic diseases. There are patients who are not in this high-risk category but who need support to maintain and/or improve their wellness status. For patients with complex medical needs due to multiple co-morbidities, the evidence points to comprehensive education-based self-management programs.

Whether the model is team-based coaching in a physician's office, or a community-based group approach, self-management programs have been proven to help these highest-at-risk patients attain better outcomes. These patients learn how to manage their health and—with a support system to back them up—change unhealthy behaviors and remain successful over long time periods. They reduce the number of times patients are forced to go to the ED or be hospitalized, which decreases their personal healthcare costs and increases their satisfaction with their healthcare.

Most importantly, more effectively managing their own health improves their quality of life. Activating patients and providing patients with the education, tools, and support to be confident and take accountability for their own health, is a win-win for all involved.

About the Author:

Ricki Stajer RN, MA, CPHQ, is a consulting associate with The Center for Case Management. She has held leadership positions in non-profit integrated delivery systems, overseeing areas such as quality management, performance improvement, and care management, as well as Transitional Care and Inpatient Rehabilitation units. She is a past member of the California Hospital Association's Advisory Board for Post-Acute Care Services and she recently retired as the Vice President of Care Coordination from PIH Health System in Whittier, California. PHI Health Hospital received the 2012 Franklin Award of Distinction awarded by ACMA/TJC for exceptional case management.

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