Chronic Disease Self-Management

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Introduction

Approximately half of all US adults have at least one chronic health condition and over 25% live with two or more chronic diseases [1]. The most recent data (from 2016) demonstrate that the total costs of chronic diseases in the US, including economic productivity loss, totaled 3.7 trillion dollars [2]. Redesigning and implementing health care delivery systems in ways that support patient self-management improve outcomes and reduce costs [3]. The concept of *self-management* encompasses the reality that patients dictate their own chronic disease outcomes by their day-to-day decisions. In this chapter, we share specific and practical examples of self-management that can be celebrated and promoted by health systems.

Historical Developments

Health care systems were developed primarily to manage acute episodic care. The changing epidemiology of health care has forced a shift in focus to providing quality long-term chronic disease care. This shift has posed many challenges. One development in this changing environment is the patient-centered medical home (PCMH), which emphasizes comprehensive team-based care that is patient-centered [4]. The pillars of the PCMH are providing quality health care at lower cost, improved patient and staff satisfaction, and better health outcomes. To achieve these goals, patients must be empowered in the self-management of their chronic diseases.

Another major change to the landscape of chronic disease management is the growth of telemedicine/virtual care. Prior to 2020, some practices in the US were already providing telemedicine visits; however, reimbursement was still a barrier. The COVID-19 pandemic forced the Centers for Medicare and Medicaid Services (CMS) to quickly expand their reimbursement for telehealth visits. This expansion of virtual care has required patients to rely more on their own self-management and highlighted the importance of supporting and empowering patients.

Principles of Self-Management

Limitations of Physician-Directed Care

Western medicine developed to care for acute conditions by physicians specializing in separate body systems. In the 1960s, during a time of social restructuring such as the US civil rights movement and the Vietnam War protests, people began to push for holistic care over the course of a lifespan. Consistent with these ideals, Family Medicine emerged as a new specialty [5]. Continuity of care is a foundational tenet of the discipline and includes treating chronic conditions longitudinally [6]. This poses challenges for the physician, as good outcomes require high levels of patient involvement in their own care. Prescriptions from the physician may not simply be a medication or procedure but may include lifestyle changes, routine symptom monitoring (e.g., symptoms of hyperglycemia in a patient with diabetes), and attending recommended visits (e.g., for an annual diabetic eye exam with an ophthalmologist). The reality is that regular follow-through lies in the hands of the patient and can be impeded by competing physiological factors based on a patient's comorbid health conditions and personal psychosocial factors, such as mental illness or poverty. Physicians may be discouraged when patients do not or cannot follow advice that would likely lead to improved outcomes [7]. *Self-management* is a concept describing how the significant and constant patient influence on health outcomes can be supported to counteract barriers and work toward improving outcomes.

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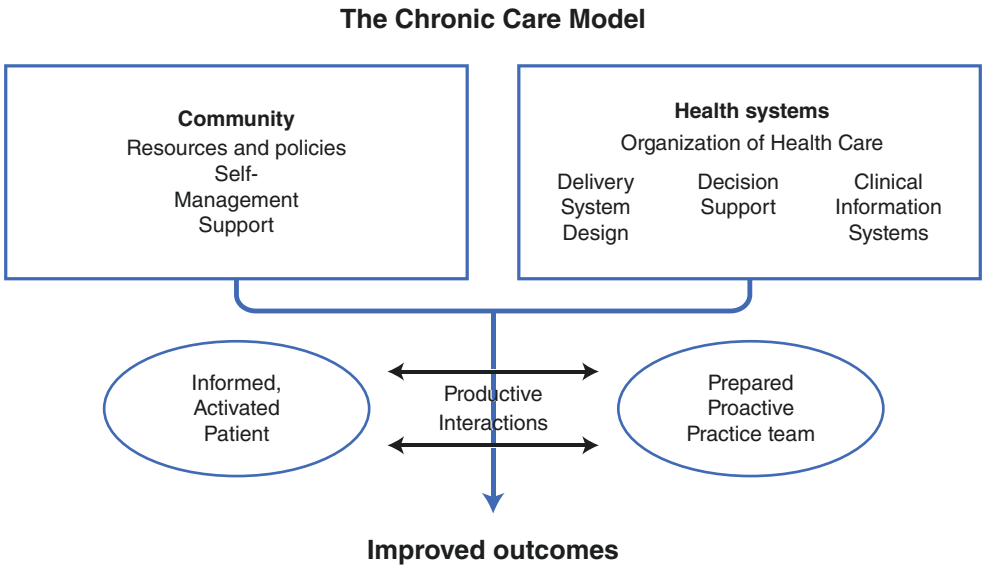

Fig. 5.1 The Chronic Care Model

Chronic Care Model

The Chronic Care Model (CCM) was developed by Ed Wagner, MD, MPH, at the MacColl Institute for Healthcare Innovation in the mid-1990s, to assist health care organizations in supporting high-quality chronic disease management (Fig. 5.1). The CCM was based on evidence showing the most improved chronic disease patient outcomes were tied to interventions that increased providers' expertise, educated and supported patients, improved care delivery (utilizing planning and team-based care), or used registry-based information systems [8]. Combining these interventions leads to even more improved patient outcomes [9]. The CCM does this, incorporating six critical areas of focus (Table 5.1) [10].

Limitations of the CCM include the costs of changing practices in this way, applying the model across multiple chronic diseases (as many of the studies focused on a single condition), and the practicality of a given health care organization applying this framework to its own specific practice conditions. While these topics require further research, the overall findings suggest the CCM improves health care outcomes [9].

Table 5.1 Six fundamental areas that form a system that encourages high-quality chronic disease management [10]

Area	Description
Self-Management Support	Encourage and support patients to be active participants in their care.
Delivery System Design	Ensure the care reaches the patient by communicating information in a way patients can understand, having case management available for complex patients, and planning regular follow-up by a team member.
Decision Support	Utilize shared decision-making by engaging in discussion with patients that provides evidence-based recommendations and elicits patient preferences.
Clinical Information Systems	Use patient and population data to identify at-risk groups and care gaps for proactive care, create reminders for providers and patients, enable communication between team members and patients for care coordination, and assess team performance.
Organization of Health Care	Foster a culture of high-quality care
Community	Help meet patient care needs by connecting them with available community resources and advocating for improved patient care policies.

Empowerment

Empowerment is the feeling that one can influence change and is critical to the successful practice of self-management. Empowerment is a main pillar of high-quality care in diabetes, a chronic condition that is often challenging to treat successfully [11]. Helping patients feel empowered encourages them to participate in their own health care. Empowerment means patients are confident they have a working understanding of a given medical diagnosis and relevant treatment options with the power to choose the direction of their care and management. The process to develop this requires resources that help with decisions and implement treatment. When challenges arise, patients should know where to find help.

Patients must have a foundational understanding of their medical diagnosis and treatment options prior to making any decisions regarding their own care. If a patient with hepatitis C facing administrative challenges to obtaining treatment does not first understand what hepatitis C is or its implications on her health, she cannot be expected to care about solving the challenges and obtaining the needed medication. Clinicians have limitations on their time and patients have

limitations on their medical knowledge that can hamper this understanding. Patients often do not know where to begin or what questions to ask. An asymmetry of knowledge and the relationship hierarchy that is inherent in the doctor-patient relationship can limit the ability to overcome this knowledge gap [12]. Implementation of delivery system design tools in the CCM can bridge this gap by having team members provide education on a given health topic pertinent to the patient. Team members include diabetic educators, pharmacists who review medication dosing and side effects, and asthma educators. Patient handouts, community presentations on a given health topic, and peer support groups can be helpful. One study found knowledge of osteoporosis and vitamin D intake improved after implementing patient education interventions such as a handout of calcium-rich foods, though further methods were needed to increase dietary intake [13].

Once patients feel confident that they are informed on a particular disease and treatment options, they should be reminded that they can choose their treatment path. Patients frequently feel they are a secondary member of their health care team, when in fact their participation is of primary importance. If a patient does not feel invested in the treatment, they are less likely to adhere to it [14]. Further discussions with the physician and utilizing decision aid tools may enhance the sense of empowerment. One such tool is bedsider.org, a website that facilitates decision-making regarding contraceptives [15]. Another is the Mayo Clinic's Statin Choice Decision Aid, which allows patients to visualize risk in terms of colored dots, with yellow dots showing the number of people with identical risk factors to the patient who will have a heart attack out of 100 people, once the patient has entered their own data such as age, gender, race, total and LDL cholesterol, smoking status, presence of diabetes, and blood pressure [16]. In a study of patient choice of diabetic medications, using a decision aid improved patient involvement in treatment decisions [17].

Challenges to treatment may arise, including psychological factors regarding the diagnosis (anger, frustration), comorbidities (depression, intellectual disability), or the involvement of multiple family members in the decision-making (e.g., children of people with cognitive impairment). In these cases, it is still important for the patient or their decision-maker(s) to feel supported and empowered. This may involve additional appointments, adequately treating concomitant diagnoses, and spending the time to bring in other members of the patient's team, such as family or a designated health care power of attorney.

Shared Decision-Making

Shared decision-making (SDM) is the process by which providers and patients together make decisions regarding the patient's health, considering both high-quality evidenced-based recommendations and patient values. This is the central tenet of the *Decision Support* part of the CCM and can be utilized as a general communication style between providers and patients, as it places priority on patient engagement in the conversation to promote a patient making value-congruent choices [18]. The Agency for Healthcare Research and Quality (AHRQ) has created a useful acronym for this approach, called the **SHARE** approach (**S**eek your patient's participation, **H**elp them explore/compare treatment options, **A**ssess their values/preferences, **R**each a decision, and **E**valuate this decision) [19].

While SDM can be of benefit in nearly every discussion between physicians and patients, some classic applications include:

- Screening for conditions where the balance of benefits and harms is equivocal, such as prostate cancer screening with a Prostate Specific Antigen blood test. This is now a grade C recommendation from the US Preventive Services Task Force for men aged 55–69 years [20]. Prior to ordering the test, a physician should go through the SDM process with a patient.
- Discussing treatment for any medical condition, as every option has the potential for side effects. SDM should be employed to assess the patient's understanding and comfort with both the possible side effects and the consequences of the condition remaining untreated.
- Discussing challenging situations such as end of life care.

One challenge to SDM is providing recommendations without being overly prescriptive. Conversely, one must avoid providing the treatments or screenings a patient wants without any evidence-based guidance [21]. Instead, SDM works toward a collaborative approach where the medical recommendations and the patient preferences contribute equally to a final decision.

Reasons to perform SDM include that ethically, it places value on autonomy. Furthermore, patients want to participate in decision-making [22]. SDM improves outcomes and reduces health care costs, due to more patient engagement in a decision, better follow-through with a plan, and less missed appointments or unfulfilled orders caused by a provider simply ordering something that was not agreed upon [23–26]. Limitations to SDM include competing requirements on a physician's time and low health literacy on the part of the patient.

Health Literacy

Health literacy (HL) describes a patient's level of understanding of basic health information. One study of college students showed that only 49% self-reported adequate health literacy [27]. According to a national survey of HL in 2003, which is one of the more recent surveys of its kind, only 12%

of US adults reported no difficulty with HL [28]. No matter how well-intentioned a clinician may be in informing and empowering a patient, this effort can be thwarted by providing information that is too advanced for the patient to understand. Understanding the HL level of one's audience is crucial to providing information in the most appropriate and user-friendly manner so that it can be utilized by patients to improve their self-management capability. Following are practices that can improve HL:

- Patients should have access to health information tools such as handouts that are concise and easy to read.
- Clinicians should utilize the Teach-Back method, where they invite patients to display their understanding of discussions with the provider.
- Patients can be encouraged to use the *Ask Me Three* method that empowers them to participate in their care discussion by asking specific questions of their provider ("What is my main problem? What do I need to do? Why is it important I do this?") [29].
- Clinicians should include decision aids in health management discussions with patients, as they provide easy-to-understand depictions of benefits and harms, often using graphics to help conceptualize the comparisons involved in each decision.

Practicalities of Self-Management

Managing Chronic Disease at Home

Patients carry out most of their chronic disease management outside of the medical office, in their daily decisions regarding lifestyle choices and medication compliance. Managing chronic disease successfully can be challenging for patients, as it is influenced by many competing community and personal psychosocial factors, from financial constraints to interpersonal or psychological stressors. The following are examples of tools that can simplify these processes for patients, from the day-to-day monitoring of their health to simplifying medication use instructions, thus allowing them to achieve their self-management goals.

One of the most prevalent chronic conditions is type 2 diabetes mellitus. In 2016 there were 26.6 million individuals in the US living with type 2 diabetes, at a total cost of 530 million dollars [2]. Diabetes is a chronic condition that demands a significant amount of self-management from those living with it, including blood glucose monitoring, dietary maintenance, medication administration, and, when applicable, insulin titration. While routine blood glucose monitoring is not necessary for non-insulin-treated type 2 diabetes [30], it is required for the safe management of insulin-dependent diabetes. Continuous blood glucose monitors are new devices that streamline self-management. They continuously measure blood glucose levels and transmit those readings to the patient's smart device, allowing timely action when indicated while avoiding multiple finger sticks. A systematic review is currently underway to determine the benefits of continuous glucose monitoring compared to flash glucose monitoring in the primary care setting [31]. A newer treatment for type 2 diabetes is a glucagon-like peptide 1 (GLP-1) agonist, such as semaglutide, dulaglutide, and exenatide. These medications empower patients with their own home self-management, lower A1c, and help with weight loss [32]. The GLP-1 agonists are once or twice weekly injections, which increase adherence compared to daily injections [33]. Other conveniently dosed treatments, such as once weekly basal insulin injections, are in development [34].

Another chronic condition that requires daily, as well as episodic flare-up, management is asthma. The asthma action plan is a tool that assists both pediatric and adult patients in the self-management of their asthma. This tool classifies the patient's symptoms into green, yellow, and red zones and has provider-prescribed, patient-specific actions for each zone. Asthma action plans increase the number of days spent in the desired green zone and decrease emergency department visits and hospitalizations [35]. Complimentary self-management education that includes self-monitoring of symptoms, a written asthma action plan, and regular review of asthma control decreases asthma morbidity in both adults and children [36]. Given their efficacy, asthma action plans are recommended for all patients with asthma by the Global Initiative for Asthma (GINA) 2021 Report, *Global Strategy for Asthma Management and Prevention* [37]. A sample asthma action plan template from GINA is shown in Fig. 5.2 [38].

Technological Advancements

Technological advancements through the emerging field of consumer health informatics provide helpful tools that assist patients with self-management. Online patient portals that make personal health records available via electronic platforms are a prime example of patients at the forefront of their own health and self-management. Patients now have access to their medication lists, blood work results, imaging reports, health prevention "gaps," clinic visit notes/documentation by their provider, growth charts, weight and blood pressure flow sheets, immunization records, and more. Additionally, patients can schedule appointments, ask questions, and

ASTHMA ACTION PLAN

Name: _____

Phone: _____

_____

Action plan updated: M _____ / D _____ / Y _____

Bring this action plan to your doctor/nurse at each visit.

Doctor's Contact Details: _____

Nurse/Educator Details: _____

In an emergency call: _____

OR CALL AN AMBULANCE IMMEDIATELY.

YOUR EMERGENCY CONTACT PERSON

Name: _____

Phone: _____

Relationship: _____

IF YOUR ASTHMA IS WELL CONTROLLED

You need your reliever inhaler less than 3 times per week, you do not wake up with asthma and, and your asthma does not limit your activities (including exercise) (If used, peak flow over ____L/min)

Your controller medication is: _____ (name) _____ (strength)

Take: _____ puffs/tablet _____ times EVERY DAY

□ Use a spacer with your controller inhaler

Your reliever/rescue medication is: _____ (name) _____ (strength)

Take _____ puffs if needed to relieve asthma symptoms like wheezing, coughing, shortness of breath

□ Use a spacer with your reliever inhaler

Other medications: _____ (name) _____ (strength) _____ (how often)

_____ (name) _____ (strength) _____ (how often)

Before exercise take: _____ (name) _____ (strength) _____ (how many puffs/tablets)

IF YOUR ASTHMA IS GETTING WORSE

You need your reliever more often than usual, you wake up with asthma, or you cannot do your normal activities (including exercise) because of your asthma (If used, peak flow between ____ and ____L/min)

Take your reliever/rescue medication: _____ (name) _____ (strength) _____ (how often)

□ Use a spacer with your controller inhaler

Take your controller medication: _____ (name) _____ (strength)

Take: _____ puffs/tablet _____ times EVERY DAY

□ Use a spacer with your reliever inhaler □ Contact your doctor

Other medications: _____ (name) _____ (strength) _____ (how often)

IF YOUR ASTHMA SYMPTOMS ARE SEVERE

You need your reliever again more often than every 3-4 hours, your breathing is difficult, or you often wake up with asthma

(if used, Peak Flow under____L/min)

Take your reliever/rescue medication: _____ (name) _____ (strength) _____ (how often)

Take prednisone/prednisolone: _____ (name) _____ (strength)

Take: _____ tablet _____ times every day

CONTACT A DOCTOR TODAY OR GO TO THE EMERGENCY DEPARTMENT

Additional comments: _____

_____

Fig. 5.2 Asthma Action Plan template from the Global Initiative for Asthma Implementation Toolbox [38]

request medication refills through their patient portal. Patients with diabetes who use their patient portals have improved glycemic control, although it is not clear whether the improved control is a direct result of using the patient portal or if confounding factors exist [39]. Such technology helps connect patients seamlessly to various aspects of their health care, allowing them to be more active and informed participants.

Electronic health tools can also be used for medication monitoring, allowing patients and caregivers to directly input symptom improvement, side effects, or other clinical outcomes. For instance, some patient portals allow patients to input their home blood pressure measurements into a flow sheet that is sent to their provider for review and medication adjustment. Patients generally find these tools to be a useful way to improve communication with their provider, and they improve health-related outcomes in frequent users [40].

Mobile/text messaging is used to promote health improvement and behavior change. Mobile messaging is an effective intervention for self-management of diabetes, weight loss, physical activity, smoking cessation, and medication adherence for antiretroviral therapy [41]. More studies are needed to determine cost-effectiveness of this strategy of promoting self-management as well as to inform the most effective mobile messaging intervention characteristics.

Numerous health mobile applications, known as apps, are available to consumers to assist in self-management efforts, usually for free or at low cost. These include weight loss apps (Noom, Weight Watchers, NutriSystem), physical activity apps (Map My Run, Fitness Buddy, MyFitnessPal, Nike Training Club), mental health apps (Moodkit, Talkspace, Calm, Headspace), and women's health apps (Ovia, Flo), to list just a few. While the use of apps has yet to show statistically significant improved health outcomes [42], they show great promise and evidence of their effectiveness in improving health outcomes is likely to grow.

Tobacco cessation counseling through telephone services, or quitlines, offers patients convenient and often free support for their self-management of tobacco cessation. Participating in multiple quitline counseling sessions improves long-term cessation for patients who smoke [43]. For example, QuitlineNC offers residents of North Carolina free, evidence-based tobacco treatment services. Printable resources are available on their website to keep in the office setting to encourage patients to call [44].

Suicide hotlines offer free and timely counseling and information through phone calls, virtual support, and text messaging. Their effectiveness has not been well studied given the ethical concerns surrounding randomized controlled trials for patients having mental health crises, though they may be helpful for young people [45]. Adolescents do engage with hotline services, suggesting that they are a good mental health self-management option.

Chat-based hotlines are a similar virtual support option that provide real-time communication between patients and trained professionals by utilizing mainstream chat applications such as WhatsApp and Facebook Messenger. Chat-based hotlines are an effective means of providing crisis and emotional support [46], with many patients preferring instant messenger applications over other modalities such as email, text messaging, phone calls, and in-person counseling. Positive and statistically significant mental health outcomes are noted regarding depression, anxiety, well-being, and suicidality. Chat-based hotlines have potential for providing additional support outside clinic walls in a medium that is mainstream and preferred by many consumers.

Peer Support

Peer support is an effective and cost-effective way to improve health outcomes [47]. Social support decreases morbidity and mortality, increases self-efficacy, and reduces use of emergency services [48]. Peer support is an effective means of reaching groups who would otherwise have little contact with the health care system [49]. The American Academy of Family Physicians Foundation developed *Peers for Progress*, an international collaborative learning network made up of peer support researchers, experts, and advocates. They have developed a toolkit that assists with developing a peer support program to help patients with their chronic disease self-management [50].

Group visits are another way that peer support promotes improved health outcomes in chronic disease management. For example, the University of North Carolina Family Medicine Center utilizes group visits for weight management and medication management of opioid use disorder. Additionally, they offer a longitudinal *Living Healthy* course, which supports patients with any chronic disease by helping them to develop action plans and thus take control of their own health. The program focuses on topics such as exercise, nutrition, stress management, and important questions to ask your provider [51].

Case Management/Population Health Services

Self-management needs ongoing support from the health care team; however, providing adequate support can be difficult for providers to fit into a busy clinic schedule, where the standard appointment time for primary care visits may not extend beyond 20 minutes regardless of the complexity of the patient's medical conditions. Care managers thus emerge as vital members of the clinical team, to help bridge care from the office to the community. Care managers provide additional support and services to patients such as moti-

vational interviewing, locating and disseminating resources, coordinating care, and addressing social barriers. Their services are a crucial component to providing patients with adequate support for their own self-management outside the clinic walls.

One example of a successful program is *Chronic Care Management (CCM)* at the University of North Carolina Family Medicine center in Chapel Hill. This program helps patients with chronic conditions in their own self-management via periodic check-ins that involve coaching through motivational interviewing; reminding patients of health maintenance items due; connecting patients to community resources; helping to secure appointments; helping to obtain durable medical equipment; case management; and coordination of care. The care managers in the CCM program serve as a conduit between the patient and the provider outside the clinic visit, which means fewer office visits, as patients can self-manage more at home. The CCM program reduces emergency department utilization and inpatient admissions for patients receiving its services [52]. Programs like this are increasingly important as payment models move from fee-for-service to value-based reimbursement.

Another successful model of care management is Community Care of North Carolina (CCNC), a partnership between North Carolina Medicaid and community primary care physicians in North Carolina that was developed with the goal of providing cost-effective, high-quality care for Medicaid recipients. This program improves the quality of care while reducing costs and utilization of health care resources by maintaining a focus on population health, care coordination, and quality improvement efforts [53]. Their Population Health Outreach and Care Coordination team comprises certified health coaches who work with patients on wellness coaching and disease management coaching, thus placing emphasis for patients on individual goal setting and taking control of their own health [54]. In July 2021, approximately 1.6 million Medicaid beneficiaries in North Carolina transitioned to a Medicaid Managed Care health plan. CCNC entered into agreements with the managed care health plans with the goal of providing a uniform approach to care management and quality improvement across all plans.

Future Directions

The COVID-19 pandemic sparked rapid change in health care delivery with the expansion of reimbursement for virtual visits. Telehealth is a safe and effective option for supporting patients in their self-management [55]. With ongoing technological advancements that support patients in managing their chronic conditions at home, health care delivery will likely continue to shift toward more virtual care, allowing providers to support patients safely and effectively in their self-management. The report *Implementing High-Quality Primary Care* from the National Academies of Sciences, Engineering, and Medicine (NASEM) recommends that the Centers for Medicare & Medicaid Services make permanent the expansion of reimbursement for virtual (not in person) and telehealth visits [56].

Current fee-for-service payment models do not support the wrap-around services of a patient-centered medical home. Care managers, health coaches, online patient portals (and the time spent by health care staff and providers managing the requests through the portals), and many other services are beneficial and necessary to support self-management by patients. The NASEM report presents multiple objectives that will support self-management by patients, including *Pay for primary care teams to care for people, not doctors to deliver services* [56]. Other recommendations include designing information technology that supports the continuous contact and relationships needed to promote patient self-management, interprofessional care teams, and research for continuous improvement. During the transition to alternative payment models, payors reimbursing with fee-for-service for primary care should shift toward value-based care by using a hybrid (fee-for-service and capitated) payment model that prospectively pays for team-based care, including care managers, and encourages investment in online patient portals.

Payment reform in our health care system must support the move toward increased patient self-management, given the many examples of benefits of the various methods described above, from implementing the Chronic Care Model to utilizing new and emerging technologies to promote patient engagement. New reimbursement systems and research to establish best practices will fulfill the promising potential of putting the patient at the center of their health care, a vantage point from which they can best understand their own health and most effectively foster positive change.

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