Chronicity

8

Amy J. Barton

Introduction

The Centers for Disease Control and Prevention (2018a) indicate that six in ten adults in the United States have a chronic disease, with four in ten adults having two or more chronic diseases. Chronic diseases occur for a year or longer for which the client receives continual treatment and the disease(s) interfere with daily living activities. The most prevalent chronic diseases in the United States are heart disease, cancer, and diabetes (CDC 2018a). Further, of the $3.3 trillion spent on healthcare in the United States, 90% of that total is for people with chronic physical and mental health conditions (CDC 2018b). Merely the prevalence and cost of chronic conditions suggest the complexity associated with chronic care. Increasingly, across the globe, clients are experiencing more than one chronic disease, a phenomenon known as multimorbidity. Multimorbidity is "the coexistence of two or more chronic conditions, where each must be a noncommunicable disease (NCD), a mental health disorder, or an infectious disease of long duration" (The Lancet 2018, p. 391).

In contrast, chronicity is the experience of chronic disease over time. Martin and Sturmberg (2009) state:

> Chronicity is overtly conceptualized to encompass the phenomena of an individual journey, with simple and complicated, complex and chaotic phases, through long term *asymptomatic disease to bodily dysfunction and illness,* located in family and communities. Chronicity encompasses trajectories of *self-care and health care, as health, illness and disease co-exist and co-evolve in the setting of primary care, local care networks, and at times institutions* (p. 571).

A. J. Barton (✉)
Professor and Daniel and Janet Mordecai Endowed Chair in Rural Health Nursing,
College of Nursing, University of Colorado Anschutz Medical Campus, Aurora, CO, USA
e-mail: amy.barton@cuanschutz.edu

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Among the first to speak about illness trajectories were Glaser and Strauss (1968). A trajectory is the events throughout an illness shaped by the client's response to illness, interactions with others, and particular interventions (Reed and Corner 2015). Illness trajectories have been used as conceptual frameworks for research (Mackintosh and Sandall 2016), to identify study participants for research projects (Ruetsch et al. 2013), to redefine metastatic breast cancer as a chronic disease (Reed and Corner 2015), and to define functional decline (Huang et al. 2013). Trajectories have also been used at a policy level to inform service planning for end-of-life care (Canadian and Palliative Care Association 2013; Lynn and Adamson 2003; National Health Service Kidney Care End-of-Life Programme 2015). The key to trajectories in relation to the Quality Health Outcomes Model (QHOM) (Mitchell et al. 1998) is that they have been described as a phenomenon nested within "genetic, biological, behavioural, social, cultural, environmental, political, and economic contexts that change as a client develops" (Henly et al. 2011, p. S5). Trajectories have also been studied at the micro-, meso- (Mackintosh and Sandall 2016), and macro- (Canadian and Palliative Care Association 2013) levels. Managing trajectories from chronicity is critical to improving client outcomes—individuals, groups, and communities—and reducing healthcare costs. The QHOM provides a framework to discuss how these concepts interact with chronicity.

Chronicity: Linkages to the QHOM

Within the QHOM, it is clear that chronicity is experienced by the client as an individual with one or more chronic diseases (Fig. 8.1). Also, the impact on chronicity is experienced within the family and community aspects of the client concept. For the system, primary, acute, and public healthcare all have roles in managing chronicity to better outcomes. As such, interventions to facilitate improved outcomes can be through the care of the client experiencing chronicity at the individual and group (family) levels, or interventions can be directed at the system or organization within which care is delivered. Whether interventions target the client or the system, outcomes of care can be assessed at the individual, family, community, and organizational levels. Hence, chronicity is a fitting concept to explore within the QHOM.

Client

Client characteristics are essential to understanding the experience of chronicity. A potential framework for considering characteristics was created from a scoping review focused on client complexity attributable to multimorbidity. Five client characteristics and experiences noted from the literature are discussed further: health and social experiences, demographics, mental health, social determinants, and medical/physical health (Schaink et al. 2012).

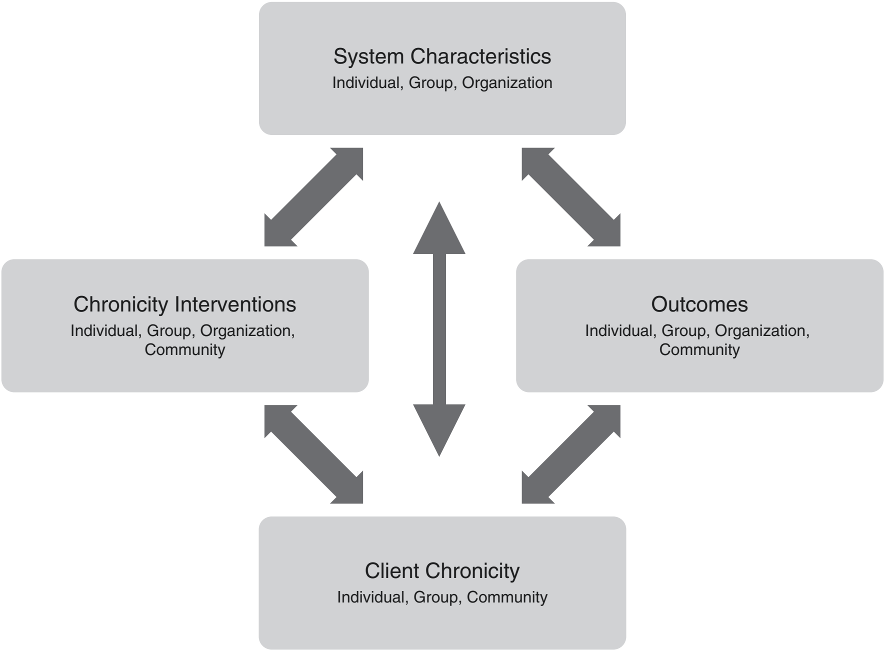

Fig. 8.1 Framework for chronicity

Client Characteristics

Health and Social Experiences

Health and social experiences encompass the utilization and cost of health services as well as challenges concerning self-care. For many clients with complex needs, the emergency department is an unavoidable point of care (Webster et al. 2015) that involves many resources and expenses. There are several dimensions within the healthcare system that require a better understanding to advance knowledge about chronicity and improve care. These include accessibility of care, continuity of care, client and caregiver access to information systems, and use of care teams (Bayliss et al. 2014).

Demographics

Within the United States, factors that influence complexity associated with multimorbidity include older age, frailty, female gender, racial and ethnic disparities, and lower education (Schaink et al. 2012). Globally, factors such as urbanization, industrialization, and aging are associated with the rising rate of multimorbidity. A recent study from Sweden (Vermunt et al. 2018) indicated that older age, women, those with a lower level of education, a manual occupation, and poor social network accounted for increases in the number of chronic conditions. Racial and ethnic disparities are widely reported. For example, using the Health and Retirement Study

(HRS) representative database on US middle-aged adults, Quiñones et al. (2019) found that compared to white adults, black middle-aged adults start with a higher level of chronic disease burden and develop multimorbidities 4 years earlier. Hispanic middle-aged adults accumulate chronic disease at a faster rate than white adults. Thus, the client's demographic characteristics are essential in understanding the experience of chronicity and the trajectory pattern that unfolds.

Mental Health

Individuals experiencing chronicity often develop challenges with mental health issues. The experience of chronicity can lend itself to social isolation. In older adults, the development of depression is common (Hegeman et al. 2017). Addiction or substance use might be present, as well. Alternatively, a history of adverse childhood experiences is linked with the occurrence of multimorbidity, even after adjusting for related social, behavioral, and psychological factors (Sinnott et al. 2015b). When chronic psychiatric illness occurs with chronic medical illness, outcomes deteriorate as evidenced by poor self-care, increased symptom burden and functional impairment, increased complications, and higher cost (Chwastiak et al. 2014).

Social Determinants

The social environment also influences the experience of chronicity. Caregiver strain and burden, low socioeconomic status, and poor social support are concerns noted in the literature (Schaink et al. 2012). The client's health literacy level, which requires the ability to understand and use health information, strongly influences chronicity (van der Heide et al. 2018) (see Chap. 7). Another social determinant is structural racism, defined as "organized systems within societies that cause avoidable and unfair inequalities in power, resources, capacities and opportunities across racial or ethnic groups" (Paradies et al. 2015; p. 1). A meta-analysis of 293 studies on the effect of racism on clients found associations between racism and poor mental and physical health.

Medical/Physical Health

One of the primary challenges associated with physical health with multimorbidity is the limited applicability of clinical practice guidelines. The interplay of risk factors, disease complications, and shared pathophysiology and toxicities among chronic conditions must be considered (Oni et al. 2014). Following guidelines for specific diseases can result in polypharmacy and inappropriate prescribing. Physicians in primary care settings were found to use interventions such as relaxing targets, using hunches and best guesses, and negotiating a compromise in stabilizing the client's multimorbidity disease (and chronicity) trajectory (Sinnott et al. 2015a). Montori (2019) cautions providers that care guidelines are intended to manage a disease, not a person. In addition to the community in which a client lives, the client's personal and social contexts are important aspects of treating "this client," not a client with "this condition."

Interventions

Several evidence-based models have been developed to guide interventions that improve client outcomes of chronicity. Table 8.1 briefly defines four models: the Chronic Care Model (CCM) (Wagner et al. 1996), the Innovative Care for Chronic Conditions (ICCC) Framework (Nuno et al. 2012), the Chronic Disease Self-Management Program (CDSMP) (Bodenheimer et al. 2002), and the Transitional Care Model (TCM) (Naylor et al. 2004). Table 8.1 also provides a synopsis of the four models as they relate to client and system in the QHOM, with interventions targeted at the micro-, meso-, and macro-levels (Serpa and Ferreira 2019). For the client, the microlevel is the individual, and the meso-level is the community. For the system, the meso-level is within a clinical unit or the organization, whereas the macro-level is societal policies and regulations.

Chronicity Interventions Focused on the Client

Interventions directed toward the client include self-management, care coordination, and prevention. Each will be discussed within the evidence-based care model in which it was derived.

Self-Management Support

Facilitating self-management skills within clients is the primary intervention associated with chronicity. Self-management is the evidence-based intervention promoted by the Chronic Disease Self-Management Program, CDSMP. This model is based on self-efficacy theory, where self-efficacy is enhanced through skill mastery, modeling reinterpretation, and social persuasion (Lorig 2015). The fundamental tasks associated with self-management include solving problems, making decisions, utilizing resources, forming a patient-provider partnership, and making action plans for health behavior change and self-tailoring (Grover and Joshi 2014).

It is important to distinguish between the structured skill building associated with a self-management program and routine patient education. Traditional patient education involves relaying medical facts and providing direction for various treatments. Montori cautions that providers must be mindful of the burden created by the addition of “medical errands” (Montori 2019). These errands are the disease-related tasks that clients are expected to complete with the goal of better health or symptom relief. Examples of errands include taking medications, changing diet, monitoring and transmitting symptoms, and preparing questions for provider visits. Often clients experiencing chronicity are assigned an errand workload that may exceed their capacity or that of their caregivers. Montori advocates for “careful and kind care for all” (Montori 2019, p. 769), where providers are tuned into individual clients’ needs and capabilities and work with them proactively to achieve care goals.

Table 8.1 Client and system interventions organized by evidence-based models of care

Model	Level	Client	System
The Chronic Care Model (CCM) organizes client-centered care through health system design, use of clinical information systems and decision support, self-management support, and community resources	Micro	Self-management support for an informed and activated client	
	Meso	Linking and using community resources	Delivery system design Decision support Clinical information systems Care coordination
	Macro		
The Innovative Care for Chronic Conditions model (ICCC) is an expansion of the CCM. It includes a focus on prevention, emphasis on quality of care, flexibility, adaptability, and integration. The model includes the importance of a favorable policy environment with interventions directed toward financing, legislation, and human resources	Micro	Informed, motivated, prepared client, family, community Emphasizes prevention	
	Meso	Raises awareness and reduces stigma Mobilizes and coordinates community resources	Uses healthcare personnel more effectively Builds integrated healthcare across settings, providers, time
	Macro		Coordinating financing across different phases of care Aligns sectoral policies to promote health Manages the political environment
The Chronic Disease Self-Management Program (CDSMP) is based on self-efficacy theory, includes peer teaching for specific conditions, and incorporates interventions concerning problem-solving, resource use, and action plans	Micro	Self-management support	
	Meso		
	Macro		

Table 8.1 (continued)

Model	Level	Client	System
The Transitional Care Model (TCM) is led by an advanced practice nurse and designed to facilitate coordination and continuity of healthcare as clients transfer between care levels within or across organizations	Micro	Identification of patient-specific concerns related to the transition process Medication adherence and persistence Assessing and supporting health literacy Utilization of remote patient monitoring Comprehensive plan of care	
	Meso		Advanced Practice Nurse Care Coordinator
	Macro		

Care Coordination

Care coordination is cited in several of the models as a client intervention for clients with chronicity. It is a care process based on a comprehensive plan of care that considers evidence and client preferences and values. An effective partnership with a care coordinator is characterized by the provider understanding and engaging with client preferences, improving client capacity, and decreasing client workload (Oni et al. 2014).

> Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care (McDonald et al. 2007, p. 5).

Given that patients experiencing chronicity see several providers, the coordination of care among providers is essential to streamline interventions, monitor reactions to treatment, reduce redundancies, and enhance the quality of life. See Chap. 11 for specifics on care coordination.

Prevention

One of the most effective chronicity interventions is to prevent diseases from happening at all. The Innovative Care for Chronic Conditions (ICCC) Framework includes prevention as a strategy at both the micro- and macro-levels and emphasizes coordination and integration. Prevention strategies include early detection and behavioral lifestyle changes. Typical areas of emphasis include increasing physical activity, healthy eating, and reducing or eliminating tobacco use (Grover and Joshi 2014). The ICCC Framework is designed for clients to be "informed, motivated, and prepared" (Epping-Jordan et al. 2004, p. 301) across the health continuum. The focus on population health requires strategies to improve health behaviors to avoid the development of chronic conditions.

Chronicity Interventions Focused on the System

The current healthcare system is designed with a focus on acute care problems and needs. To appropriately care for clients with chronicity, systems must transform from an episodic model of care delivery to one that focuses on continuity, communication, coordination, and integration.

Delivery system design concerns assembling an interprofessional team of providers, each practicing to the full extent of their scope of practice to address the various nuances of chronicity. Departmental barriers within organizations need to be removed so clients can successfully and seamlessly navigate the system as they receive care. Finally, community resources are included to provide linkages to needed services outside of the healthcare arena. Providers and care coordinators must view the client within his/her community context and connect with the resources to facilitate optimal health.

Chronicity Interventions Within Healthcare Organizations

The CCM provides a distinct set of interventions targeting healthcare organizations (Wagner et al. 1996). Implementation of the model begins at the systems level, whether in an acute care facility or primary care clinic. It requires an organizational commitment to a model that effectively manages the complexity of chronic care. A robust clinical information system is necessary to track clients with specific diseases and promote information exchange between providers and clients. Given that clients experiencing chronicity tend to see multiple providers, information among providers must be shared, problem lists must be consistent, and medications must be streamlined. Decision support incorporates care guidelines that are consistent with the evidence as well as client preferences. As previously mentioned, care guidelines that are typically focused on one condition are not optimal for clients experiencing chronicity. It takes a deliberate assessment of the client, symptoms, and potential interactions between diseases and treatments to use the best evidence when multimorbidity exists.

Chronicity Interventions Across Municipalities

The ICCC introduced interventions at the macro-level to address health policy issues concerning chronicity, especially in developing countries. The model's macroelements include the following: support a paradigm shift, manage the political environment, build integrated healthcare, and align sectoral policies for health (Grover and Joshi 2014). Managing the political environment is key to creating a system of care to support clients with chronicity. Even within the United States, the dialogue concerning whether insurance companies are required to provide coverage for preexisting conditions indicates that a “health for all” paradigm shift has not yet occurred. Further, systems are not aligned to support clients experiencing chronicity.

Recent emphasis on population health may contribute to looking beyond the walls of healthcare organizations, taking full advantage of community resources, and coordinating the care of clients experiencing chronicity within and outside of a traditional hospital or clinic. Although progress is occurring with the integration of behavioral health in primary care (Hunter et al. 2018), silos remain among specialty providers who treat disease-specific aspects of clients with chronicity. Once policies are aligned to support health across the life span, financing the healthcare system based on equity and effectiveness principles is essential (Epping-Jordan et al. 2004).

Implications and Future Directions

The prevalence of chronicity and the increasing occurrence of multimorbidity have prompted clinicians and researchers to explore complexity science as a more appropriate framework to inform work on chronicity. Complex adaptive care is client centered within a community context. It is an innovative and dynamic process that results in adaptability and empowerment (Martin and Sturmberg 2009). The complexity associated with multiple chronic conditions relates to the challenge that care protocols for individual diseases are not appropriate or effective for these clients. To meet their needs, clients must “(1) manage a high volume of information, visits, and self-care tasks, (2) coordinate, synthesize, and reconcile health information from multiple providers and about different conditions, and (3) serve as their own experts and advocates about health issues” (Zulman et al. 2015, p. 1065). A partnership between clients and their providers is essential to crafting practical, efficient, and reasonable solutions. The practice of complex adaptive care requires a provider to understand the client’s capacity for a myriad of medical tasks and connect with community resources that will facilitate an improved state of health.

The Department of Human Services convened experts who made 11 recommendations concerning clinical guidelines for individuals experiencing multimorbidity across 3 categories: improving the stakeholder technical process, strengthening substance and content, and increasing the focus on client-centeredness (Goodman et al. 2014). Within the technical process, recommendations included harmonizing or coordinating guidelines across related disease groups and including experts in the process. Concerning substance and content, guidelines should prompt the clinician about the possibility of comorbidities, consider issues with adherence to self-management protocols, and integrate preventive measures and care coordination. Finally, guidelines should be client centered and highlight the importance of shared decision-making.

The challenges of research and care for those experiencing chronicity are shifting from a single disease focus to multimorbidity. A framework such as the QHOM provides a broad approach to identifying systems issues and interventions that may improve the client’s outcomes. The study of chronicity as a health trajectory requires a measurement protocol that allows for the collection of variables over time, with the potential to note a pattern for clients, families, or populations (Henly et al. 2011).

Bayliss et al. (2014) call for the development of a partnership for collaborative action among healthcare providers, researchers, clients, caregivers, and community resources that are supported by payers and policy to advance understanding in the context of multiple chronic conditions. They recommend:

1. Establishing a measurement framework and prioritizing contextual factors at the individual, population, and system levels
2. Creating a national network of organizations to collect and disseminate best practices
3. Creating a public awareness campaign based on emerging research to empower further individuals experiencing multimorbidity
4. Activating an informed workforce to incorporate the vital contextual factors into practice and research
5. Fostering a supportive policy environment

The challenges of chronicity care and research will require interprofessional teams of dedicated clinicians and researchers to identify key factors and utilize qualitative and quantitative methodologies to advance the science.

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