Chapter Objectives

1. Explain the chronic illness experience from individual and family perspectives.
2. Examine special family concerns associated chronic disease management.
3. Describe ways nurses prepare families to satisfy various member needs associated with a family member’s chronic illness.
4. Identify the continuing and episodic individual and family stressors and experiences as members live with uncertainty.
5. Use family focused care to support and overcome barriers when child and adult members have a chronic illness.

Chapter Concepts

Care coordination
Chronic illness
Collaboration
Family health routines
In-time
Non-normative
Normative
Off-time

Chapter Introduction

This chapter considers the complex care needs linked with chronic illness and the diverse ways families experience them over time. Nurses are often well-prepared to address the needs of acute conditions, but many are less familiar with those that occur when living with chronic conditions for years or even decades. Acute illnesses have rapid onset of symptoms and the symptoms are often short-lived. The suffering with an acute illnesses can overwhelming and life-threatening,
but these conditions can also be short lived and persons can resume usual prior activities and maintain their lifestyle. Although some acute conditions are traumatic, disrupt family life, and cause family members great stress, many conditions are temporary and resolved rather quickly. On the other hand, chronic health conditions are typically expected to last more than a year, often have no cure, and self-management needs can change over time as the condition leads to other complicating factors. Chronic disease is defined as health problems that require ongoing management over a period of years or decades (World Health Organization, 2002). Chronic conditions are things like asthma, diabetes, cerebral palsy, multiple sclerosis, and cancer.

This chapter describes skills and actions to consider when giving care to those with chronic conditions. The family perspective of chronic illness is addressed by including a case study of Theresa Zimanske and her family. In this chapter, Theresa’s family story is presented through many years of life. The case provides ways to consider the multiple stressors associated with a rare chronic disorder over time. Theresa’s son was born with a rare genetic condition. The family’s chronic illness experience begins soon after birth, extends through a prolonged process of diagnosis and disease progression, and continues even after death. This family’s story shows how the diagnosis was merely the beginning of an experience that saturated many aspects of the family’s life. Chronic conditions change, require different forms of attention, and result in new family challenges. This chapter shows some ways family unit problems are paired with an individual’s chronic illness. Examples of ways nurses can think family and provide family focused care are described and examples provided.

**Using Family Focused Perspectives to Manage Chronic Illness**

Chronic conditions invade activities of daily life, require unusual attention, and often intrude into every aspect of individual and family life. Many chronic conditions, like diabetes,
can be self-managed with medications and lifestyle changes and individuals can live active mostly healthy lives for many years. However, if the disease is ignored or poorly managed then complications occur (e.g., neuropathy, heart disease, kidney failure, blindness). Other chronic conditions (e.g., multiple sclerosis, amyotrophic lateral sclerosis, lupus) become progressively worse over time. Conditions, like asthma, can mean a mostly normal life if risk factors are controlled, but severe exacerbations can cause the condition to become life-threatening. Care and management of chronic conditions is ongoing, challenging to some aspects of individuals’ and family units’ lifestyle, stressful, filled with uncertainty, and expensive. Additionally, most chronic disease management occurs outside the purview of health care professionals.

Although most nurses agree that family is important in chronic care management, students’ formal education often fails to clearly explain ways to include the family unit. Nursing education needs to clearly demonstrate ways knowledge and skills are applied to practice. Application to practice can be taught through opportunities to practice skills related to family nursing. Students need to have adequate opportunities to practice in safe supportive environments and to reflect with peers about the meanings of experiences. Students enter nursing at various ages, different life stages, and with diverse prior life and family experiences. Examination of personal bias and assumptions is necessary. Taking time to examine the affective aspects of thinking family are equally important as knowledge development and skills for practice. Taking time to reframe critical thinking and clinical judgment considering emotional responses, personal belief systems, ethical or moral choices, and health equity are important. Students need time to identify clinical competencies in terms of personal responses to situations as they reflect on alternative care approaches needed with various family members, family units, and over time.
Often chronic illness is primarily addressed in relationship to caregiver support for parental care of infants, toddlers, youth, teens, or dying persons. Many chronic conditions last a lifetime and require different forms of adaptation as maturity and individuals age. Some nurses might think family when care roles are for the elderly if a condition such as Alzheimer’s occurs. However, attention to the needs of those aging with chronic illness conditions and what occurs as these persons outlive longtime caregivers is less often considered. Family unit and needs of adults living for decades with a chronic condition are altered over time. Developmental changes of aging siblings, parents, grandparents, or spouses alter support systems and influence resource availability. Chronic illness is not a point in time, but a family life over years of time. The meanings of high quality life for multiple member households when a member has chronic illness vary. Yet the ongoing demands can deplete resources and abilities to cope. Students need opportunities to weigh meanings attached to living with chronic illness and understand how the needs of an individual affects routines of multiple members. Nursing concerns and system matters potentially linked with chronic care needs are addressed using the Family Health Model (Denham, 2003).

**Chronic Illness: Scope of the Problem**

In 2005, the percentage of the population 75 years of age and over was 6% and it is projected to increase to 12% by 2050 (NCHS, 2007). In 2005, only 12% of those 45-54 years of age reported living with a chronic condition, but 44% of those 75 or older reported a chronic condition that either created a disability or limited their abilities to perform usual activities of daily living (NCHS, 2007). Chronic conditions produce cumulative physiological damage over time, but damages can also be emotional, cognitive, social, and vocational. An aging population and longer life expectancy means that an increased prevalence of chronic diseases and conditions
associated with aging (e.g., disabilities, limitations in activity) can be expected. Activity and self-care limitations due to chronic physical, mental, or emotional conditions interfere with life quality and functional capacities. These things not only prevent aging persons from engagement in valued and meaningful activities, but they also affect the lives of those supporting and caring for them in the family household. Chronic conditions often require specialty medical services (e.g., primary care, home care, rehabilitation, long term care, specialty services), ongoing health education, and various forms of support. Chronic illness means families face new demands when a member has a chronic illness, situations that call for adjustment and adaptation (Patterson, 1988). Needs vary depending on the type of chronic illness, but some conditions require vast amounts of family energy and attention.

Students need to learn what it means to think family when individual members whether young or old are diagnosed with chronic conditions. They need to understand about the ongoing lifestyle demands and the various forms of supportive care that might be needed. Students must be able to differentiate the ways diagnosis of chronic conditions can dramatically alter family life. Chapter eleven provides students with scenarios to consider what is happening within the family as the clinical condition of a child changes. It is important that they also understand that some similar changes occur in families when a member is an adult. The importance of coordinated care that includes multiple medical care providers can be disruptive to family life and households. Opportunities to reflect about family situations following clinical experiences could be useful in helping students compare and contrast their responses to situations. Students need skills to recognize family strengths, commendations for positive actions, and abilities to listen to what might be painful family stories before they assume they know what is needed or
take action. Helping students build *think family* skills linked with reflective practice can equip
them to thoughtfully weigh collaborative decision making, goal setting, and planning care.

**References**


Davis.


from: [http://www.cdc.gov/nchs/data/hus/hus07.pdf](http://www.cdc.gov/nchs/data/hus/hus07.pdf)