Families of Patients with Chronic Illness

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- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a physician, behavioral health professional, or Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
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Faculty

Alice Yick Flanagan, PhD, MSW, received her Master's in Social Work from Columbia University, School of Social Work. She has clinical experience in mental health in correctional settings, psychiatric hospitals, and community health centers. In 1997, she received her PhD from UCLA, School of Public Policy and Social Research. Dr. Yick Flanagan completed a year-long post-doctoral fellowship at Hunter College, School of Social Work in 1999. In that year she taught the course Research Methods and Violence Against Women to Masters degree students, as well as conducting qualitative research studies on death and dying in Chinese American families. (A complete biography appears at the end of this course.)

Faculty Disclosure

Contributing faculty, Alice Yick Flanagan, PhD, MSW, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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The division planners and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience

This course is designed for physicians, nurses, social workers, marriage and family therapists, and any healthcare professionals involved in the care of patients with chronic illness.

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Social workers completing this intermediate-to-advanced course receive 10 Clinical continuing education credits.

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Course Objective

The purpose of this course is to increase the knowledge base of social workers, physicians, nurses, marriage and family therapists, and other allied healthcare professionals who work with patients with chronic illness and their families, in order to effectively address the impact of chronic illness on the entire family system.

Learning Objectives

Upon completion of this course, you should be able to:

1. Differentiate between the key terms involved in discussions of chronic illness.

2. Discuss the major assumptions of crisis theory and their application for families with patients experiencing chronic illness.

3. Discuss the major assumptions of family systems theory and their applications for families with patients experiencing chronic illness.

4. Explain the Family Adjustment and Adaptation Response (FAAR) Model and its application for families with members who are chronically ill.

5. Describe the impact of chronic illness on the patient and the role of the patient's developmental stage in affecting the meaning and impact of chronic illness.

6. Describe the types of demands experienced by the family system when a family member is diagnosed with chronic illness.

7. Describe the variations of coping responses.

8. Identify and explain factors that influence how families respond to the diagnosis of chronic illness.

9. Articulate the role of gender in family adaptation to chronic illness.

10. Discuss the role of spirituality and religiosity in family adaptation to chronic illness.

11. Distinguish between the terms "caregiving" and "caregiver," and define the concept of caregiver stress.

12. Discuss the role of culture, race, and ethnicity in family caregiving.

13. Utilize various types of assessments and interventions for the families of patients with chronic illness.

INTRODUCTION

Chronic physical illness impacts both the patient and the entire family system. The patient with the illness is profoundly affected in the biologic, psychologic, and social functioning arenas. Those persons in the immediate social context of the patient, such as family members, are also affected in multiple ways. Family members are affected emotionally, cognitively, and behaviorally and are often faced with changing their day-to-day routines, plans for the future, and feelings and meanings about self, others, and life. Meyerstein described the impact of chronic illness in the following way [1]:

> Patient and family members wander in unfamiliar territory, facing strange hospital environments, foreign "medicalese," and confusing procedures. Family members are thrown off their familiar path and have difficulty finding their way back. While the detour has different meanings for individual family members, sustaining one's spirits and preserving identity in the face of illness is a challenge.

This course focuses on chronic physical illness in general and does not cover mental illness. It is possible to take a noncategorical approach because the impact psychologic, social, financial, and emotional of chronic illness can be generalized to families experience all types of chronic illnesses [48]. The unique characteristics and features of mental illness evoke a different set of reactions from family members, friends, and society than physical illness. In addition, the mental health system is different from the general health system and warrants separate attention.

The first section of the course reviews key terms and concepts and highlights three theoretical perspectives: crisis theory, family systems theory, and the Family Adjustment and Adaptation Response (FAAR) Model as they apply to families who have patients with chronic illness. The second section describes how chronic illness impacts the patient. It is important to have an overview of the patient's subjective world as it is affected by chronic illness because it will ultimately impact the patient's family. Each member responds to chronic illness differently, and, therefore, the social realities of mothers, fathers, and siblings in coping with chronic illness will be described. Gender and spirituality/religiosity will be discussed as variables that affect family coping with chronic illness. The third section examines the areas of family life that chronic illness impacts, the concept of caregiver stress, and how variables such as gender, culture, race, and ethnicity color family perceptions and responses to chronic illness. The fourth section focuses on assessments for nurses, social workers, marriage and family therapists, and other service providers when working with patients with chronic illness and their families. The final sections cover interventions for families and the role of interprofessional collaboration and practice.

The premise and goal of this course is to arm nurses, social workers, healthcare professionals, and other service providers with knowledge and skills to help educate patients and families about the social and familial dynamics of chronic illness. Chronic illness is not just about symptom management; it is about the journey that families and patients undertake when they first learn about the diagnosis, cope with the symptoms, and ultimately, make life meaningful despite the illness.

KEY TERMS, CONCEPTS, AND THEORIES

ILLNESS, DISEASE, AND DISABILITY

The terms "illness" and "disease" are frequently employed interchangeably; however, there is a distinction, particularly in relation to the life experiences of families of patients with chronic illness. The terms actually tap into a potential gap between the view of the service provider and that of the patient [2]. "Disease" refers to the problem as viewed by the practitioner or service provider in terms of symptoms and, ultimately, the diagnosis [3; 68]. Diseases are conceptualizations or constructs based upon a culture within the practitioner's community and discipline (e.g., medicine, social work, physical rehabilitation). "Illness" refers to the human experience and the lived social reality of the manifestation of symptoms, suffering, and process of adaptation that patients and family members make in light of the disease given the patient's functional impairments [3; 4; 68]. Individuals and families have illness beliefs, which are cognitions or explanations that help make sense and meaning of the reality of their illness and the existential questioning of death, vulnerability, and mortality [125; 132]. Similarly, when service providers refer to "disease course," they are talking about the progression of the disease and the characteristics and phases of the symptoms. Meanwhile, an "illness trajectory" encompasses psychosocial issues, such as managing the medical regimen, adapting to potential restrictions due to the disease, altering one's lifestyle, learning to live with the stigma associated with the disease, and adjusting to the social and financial impact of the disease [5].

The term "disability" refers to a medical condition that affects an individual's physical functioning and structures, which my extension impairs their movement, senses, or activities [87]. A disability also has both physical and social ramifications; therefore, there is a relationship between a chronic illness and a disability [88]. However, not every chronic illness is a disability nor can every disability be traced to a chronic illness [87]. This course will explore family members' chronic illness experience.

ACUTE AND CHRONIC

What is the distinction between an acute illness and a chronic illness? Acute illnesses involve a sudden onset of symptoms that are related to the disease process itself. Patients with acute illnesses require short-term care and usually improve upon receiving care [141]. The symptoms usually end shortly with almost complete recovery, resumption of prior activities, or death [3].

In the past, many types of conditions would have rapidly killed patients, but because of technologic and pharmacologic advances, patients with chronic illnesses, such as intellectual disability, multiple sclerosis, cerebral palsy, paralysis of extremities, cancer, diabetes, dementia, respiratory illnesses, acquired immune deficiency syndrome (AIDS), and stroke, live longer. However, because chronic illness tremendously affects patients' functioning and daily activities of life, and because of increased life expectancies, chronic illnesses may be viewed as long-term visitors who do not inform their hosts how long they plan to stay [3; 6]. With many families, chronic illness becomes part of the patient's and family's identity.

The definition of chronic illness has always been nebulous. Miller offers one definition: a state caused by a nonreversible pathologic condition, which cannot be corrected by medical intervention and ultimately results in an altered health state with a lingering disability that cannot be easily treated [7]. The Centers for Disease Control and Prevention defines a chronic condition as lasting for one or more years and one that requires continual medical treatment and/or that limits activities of daily living [169]. Other researchers have provided similar definitions [157].

The National Center for Health Statistics highlights four dimensions of chronic illness [6; 8]:

- **Time period**: An illness is chronic if it is prolonged (i.e., generally more than 12 months in duration).

- **Lifestyle**: An illness is chronic if it is long-term and affects and interferes with the patient's functioning in the physical, psychologic, or social arena.

- **Quality of life**: An illness is chronic if the symptoms of the illness do not resolve spontaneously and begin to affect the normal activities, roles, and routines of the patient and the patient's family.

- **Symptom management**: An illness is chronic if it involves symptom management. Due to the incurable nature of the chronic illness, symptoms are persistent and long-term, and the patient will be left with residual effects of the condition. Ultimately, the goal is to manage the symptoms on a daily basis.

The Australian Institute for Health and Welfare has identified the following common attributes of chronic conditions [142]:

- Development of the condition may be long with no visible signs of symptoms
- Complex factors contributing to causality
- Functional impairment
- Possible other health conditions that result

In general, chronic illnesses are slow in progression and lengthy in duration [143]. Given the nature of the illness, there is usually variability and fluctuation in symptom severity over time, profoundly affecting the family and the course of the patient's life [193]. Because so many different types of conditions fall under the heading of chronic illness, and the nature and social perception of each individual condition varies, it is important not to make sweeping generalizations. For example, the family of an AIDS patient will experience tremendous negative social stigma compared to a family who has a patient diagnosed with multiple sclerosis. This course attempts to provide an overview of how chronic illness, as a long-term visitor, affects family life and to provide a foundation for nurses, social workers, and other healthcare professionals to intervene.

HOW MANY ARE AFFECTED BY CHRONIC ILLNESS?

It is estimated that 60% of adult Americans suffer from a form of chronic illness [2; 8; 169]. An estimated 150 million Americans have been diagnosed with a chronic condition, and of these individuals, an estimated 100 million have more than one chronic condition [156]. Approximately 40% of American adults have two or more chronic conditions [169; 170]. Those with five or more chronic conditions comprise approximately 12% of the adult population in the United States. Given the developmental life cycle, elders will inevitably have to confront illness. Of older Americans, it is estimated that 80% have a chronic condition [195]. However, chronic illness is not merely associated with the elderly. Approximately one-third of persons in the United States 18 to 44 years of age experience chronic illness [2]. It is estimated that more than two-thirds of all deaths are caused by one or more of the following chronic diseases: heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes [196]. Between 2021 and 2022, the lifetime prevalence of depression, a chronic condition, increased to 21.7%, which translates to 54.2 million adults in the United States. In the same period, the rate of diabetes also increased to 11.5%, affecting 31.9 million adults [194].

Approximately 18 million children have some form of chronic illness. The majority of these children are not cared for within institutional settings but live with parents or guardians, which means that caregiving is provided within the home [9]. More than 75% of healthcare costs in the United States may be attributed to chronic illness [8]. For heart disease and stroke alone, total costs were estimated at $329.7 billion in 2014 [126]. The Centers for Disease Control and Prevention estimates that chronic conditions are responsible for a total annual cost of $4.1 trillion in healthcare costs in the United States [169]. It is projected that by 2030, healthcare costs associated with chronic illness will grow to $42 trillion [170; 197].

WHY THEORIES?

Theories are logical systems of concepts that provide a framework for organizing and understanding observations. They are intended to offer comprehensive, simple, and dependable principles for the explanation and prediction of observable phenomena. Theories provide explanations and direction for how the service provider will proceed during various phases of the change process. They define the problem, the etiology of the problem, and, ultimately, guide assessments and interventions. All families experience a crisis at the onset of chronic illness; therefore, the first theoretical perspective to review is crisis theory.

CRISIS THEORY

There are two types of family crises: maturational (i.e., transitional or developmental) and situational. Maturational crises refer to universal crises that are associated with the normal developmental stages of the individual or the family, which occur at major life transitions. These life transitions include adolescence to adulthood, middle-age to old-age, birth of a child, school entry, children leaving home, and retirement [10]. These are predictable and universal life-stage events that can be anticipated and for which families can prepare accordingly.

Situational crises, on the other hand, are unpredictable. They are typically major sudden interruptions for the individual or the entire family system. They originate from three different sources: (1) material or environmental (e.g., fires, natural disasters); (2) personal or physical (e.g., loss of limb due to accident, diagnosis of an illness); and (3) interpersonal or social (e.g., death of a loved one) [11]. Inevitably, the crisis causes anxiety and disequilibrium, which can trigger anxiety and feelings of helplessness and despondency, and the individual or the family must learn to cope [158]. The crisis situation is short-term or time-limited.

A crisis can be viewed in one of two ways: as a threat or as an opportunity [12]. It can be viewed as a threat because the crisis could have negative ramifications or consequences on psychologic health and social well-being. It can also affect quality of life. Self-esteem and problem solving are correlated with quality of life; yet, when a crisis hits, problem solving may be temporarily hampered, which then leads to a sense that one's quality of life has been disrupted [13]. However, from an opportunity perspective, an individual or a family who is in crisis is more vulnerable and, consequently, may be more receptive to interventions, which can then lead to growth [12]. Family crisis interventions are often successful because the growth and opportunity that may occur during crisis can break the normally rigid boundaries of the family system, making the family and its members more open to change [127].

A closer look at the major tenets of crisis theory and a brief case study will illustrate this theoretical perspective. This course provides only a basic overview of crisis theory.

Major Assumptions and Tenets of Crisis Theory

The major assumptions of crisis theory are [14; 159; 229]:

- Crisis situations are normal. They are not an illness and are not pathologic. They occur throughout the normal life spans of individuals, families, groups, communities, and nations.
- Crises are initiated by some sort of hazardous event. This is defined as a finite, stressful blow. It may be either a single catastrophic event (e.g., earthquake) or a series of stressful events that build up a cumulative effect.
- The impact of the hazardous event disturbs the individual's homeostatic balance or equilibrium (i.e., state of stability). This hazardous event then places the individual in a vulnerable state. In an attempt to regain equilibrium, the individual will use his/her existing repertoire of coping and problem-solving strategies.

If these strategies are not successful, his/her upset or stress increases. The individual may seek new strategies to deal with the crisis.

- If the problem continues and cannot be resolved, the tension peaks, and a precipitating factor can bring about a turning point. The individual's repertoire of problem-solving skills is not adequate to take care of the stress. This is the state of active crisis.
- During the course of the developing crisis situation, the individual may perceive the initial and subsequent events as a threat, a loss, or a positive challenge.
- Each of these perceptions regarding the crisis elicits an emotional reaction. A threat elicits anxiety. A loss may evoke feelings of depression and grief. A challenge may bring forth some anxiety, but there will also be an undercurrent of hope and expectation.
- A crisis may reactivate some earlier unresolved conflict, which will exacerbate the crisis situation.
- All crises follow a series of predictable stages, which can be mapped out.
- Crisis situations are temporary in nature. The total length of time between the initial blow and the final resolution of the crisis may vary. Crisis situations, by definition, are time-limited, usually lasting up to four to six weeks.
- During the resolution of the crisis, the individual tends to be open to help. Therefore, minimal interventions can yield maximum results.
- During the reintegration phase, new coping and adaptive styles are learned which helps the individual to cope more effectively with other situations at other times. However, if help is not available, maladaptive patterns may be adopted.

In general, crises can be characterized as temporal and episodic [229].

The tenets of the theory should then flow into the intervention. Therefore, the ultimate goal of crisis intervention is to help individuals return to their level of functioning in the precrisis state [15]. Roberts developed a seven-stage crisis intervention model, which encompasses the following [16]:

- Stage 1: Assess the client's level of danger to himself/herself

- Stage 2: Establish rapport

- Stage 3: Identify the major problems to work on

- Stage 4: Explore feelings

- Stage 5: Explore alternatives

- Stage 6: Develop a concrete, solutions-focused action plan

- Stage 7: Follow up with the client

Crisis intervention is based on a problem-solving orientation, where the situation is immediately assessed. The type of assistance is decided upon and a concrete plan of action is implemented. When the client's equilibrium appears to be achieved, the practitioner should reinforce those techniques used by the individual or family unit that helped promote adaptation and coping [17].

CASE STUDY 1

Patient Y is a married woman, 76 years of age. She emigrated from China to the United States with her husband 53 years ago. They have three children: a daughter who lives near them; a son who lives in the same city; and a son who lives out of state. They also have eight grandchildren. Patient Y is a homemaker. She and her husband have lived in the same neighborhood, in the same house for more than 40 years. Patient Y speaks little English and depends on family members to translate for her when the need arises. Recently, she became ill, complaining of dizziness, shortness of breath, being tired all the time, and loss of appetite. During a visit, her daughter noticed that she looked pale and had lost strength in her left arm. She convinced her mother to go to the hospital and accompanied her; Patient Y was diagnosed as having had a mild heart attack and was admitted to the hospital for tests and observation. On the second day following hospitalization, Patient Y suffered a second, more serious heart attack and was admitted to the intensive care unit (ICU). Her condition was guarded and other family members were notified, including the son who lived out of state.

The hazardous event in this case scenario is the onset of the illness and the symptoms. It usually occurs when the family receives news of the diagnosis. Rolland's trajectory phases of illness chronicle the natural history of chronic diseases [18]. Rolland's first phase is the crisis stage, which includes the onset of symptoms, learning about the diagnosis, and the initial adjustment period. During this stage, the patient and family assimilate the news of the diagnosis, attempt to comprehend the meaning of the disease, and begin grieving the loss that the disease will bring. Eventually, there is a movement toward acceptance and gradual equilibrium in the family system. In crisis theory jargon, the hazardous events in this case study are the initial diagnosis of the first attack, and later, the diagnosis of chronic heart disease and Patient Y slipping into a coma. Patient Y's family will learn of the diagnosis and begin to comprehend the enormity and gravity of the situation.

Although visiting in the ICU was strictly limited, a family member was allowed to stay with Patient Y most of the time due to her anxiety about hospitals and the staff's limited ability to converse with her. Patient Y continued to refuse to eat, and IVs were maintained. Her condition was guarded, although she insisted through her husband and children that she was fine and just wanted to go home to prepare for Thanksgiving.

The younger son was contacted due to the seriousness of his mother's condition and arrived the night after her second heart attack. The daughter organized the family to take turns being with Patient Y, and the grandchildren and other extended family members provided transportation, cooked, cleaned the home, and met her basic needs.

After three days in the ICU, Patient Y was transferred to the telemetry unit. The crisis situation began taking its toll on the family. The younger son argued with his sister that his mother should be allowed to go home to familiar surroundings, familiar foods, and family care. He was angry about his mother's condition and blamed his father and siblings for not taking better care of her. Patient Y's husband ignored him and refused to discuss any future plans with him or the other children. The long days and nights and his worry about his wife were obviously affecting this quiet man whose wife had always looked after him and dealt with the children.

The daughter took over and met with physicians and the hospital social worker and organized family resources to assure her father's care. She arranged for a family member to always be present with Patient Y and arranged with the hospital to allow the family to bring more familiar foods to her mother. She quietly and competently mobilized family resources to meet new and different demands and began gathering information about available resources for when (and if) her mother was able to leave the hospital, in spite of her father's denial and her brother's unrealistic optimism.

Crisis theory is helpful in normalizing the crisis event and the responses evoked by Patient Y's illness. In this case study, the son's anger and the calm, methodical, and systematic responses of the daughter are not viewed in a pathologic perspective. Instead, they are viewed in light of the crisis and from the perspective that a range of emotions and reactions are normal. The range of responses on the part of the patient and/or family members may include: (1) a biophysical response (e.g., the patient's experience of pain and discomfort); (2) the range of emotional responses (e.g., anger, sorrow, shock, loss, helplessness, anxiety about welfare of children, spouse), fear of death, and other emotions; (3) the cognitive response (e.g., fears, belief systems about how illness will affect the future); and (4) the behavioral response (e.g., the patient and the family's adjustment to medical regimen, hospital rules if hospitalized, assimilation of diagnosis) [10]. Because of the crisis event, the family system freezes, requiring an altering of family functions and roles. In this case scenario, the daughter's role was redefined as she mobilized the family to meet the various demands of her mother's illness. The grandchildren assumed various caretaking roles including cooking, cleaning, and transporting Patient Y's husband to and from the hospital. Because the stress was a threat to the ongoing functions of the family, its members mobilized its energy to establish new equilibrium.

FAMILY SYSTEMS PERSPECTIVE

Practitioners should not view "families as mere adjuncts to the patient, [as] it will perpetuate the tendency for healthcare professionals to identify families as generally dysfunctional, to marginalize the family's role in care" [160]. Therefore, family systems theory helps to understand the course of the illness within the context of the whole family's beliefs and dynamics. Family systems theory is based on von Bertalanffy's theory [19]. von Bertalanffy argued that systems are a set of interrelated elements but that each of the elements is distinct from the environment in which it is embedded. Energy from the environment will inevitably permeate the boundaries of the system. The family is then viewed as in a continual state of change given that the family will always be interacting with the environment [19]. Family systems theory is quite detailed and this course provides only an overview of the theoretical perspective.

Basic Assumptions of Family Systems Theory

A system refers to a set of elements in a patterned relationship to each other. Therefore, a family system consists of a group of individuals who are characterized by marked transactional patterns and dynamics of relationships between them [20; 21; 161; 230]. These transactional patterns are the focal points as they influence which members act and how they behave [21]. The family is a dynamic system of interdependent parts, and the family system is constantly characterized by change [22; 230]. Change impacts both the individual and the entire family system. For example, family members' emotional states are interdependent, and the overall family emotional climate will affect the ill member's health and well-being [193; 198].

Within this family system there exists family structure and family functioning. Family structure is defined as the organizational patterns or characteristics of the family [21]. Boundaries mark who is in and who is out. The boundaries are semipermeable, so the family system can change and adapt to normative transitional forces (e.g., births, marriages, deaths, divorce). Boundaries also ensure differentiation of the subsystem [21]. Boundaries in families are also marked by generations; that is, all family systems have generational boundaries. Generational boundaries refer to the differences in communication, roles, privileges, and responsibilities between members within different family generations [23]. It is important to remember that culture, race, and ethnicity influence these boundaries. For example, some ethnic groups, such as Latino families, incorporate nonfamily members into the family structure [24]. Some family structures are more highly organized (e.g., the structures of Asian families) where there are clearly defined generational boundaries and roles [25; 161].

Subsystems include those members who are part of the larger family system on either a temporary or permanent basis, all with specific roles [21]. Subsystems may be organized by gender, power, past history, or interests [21]. Family subsystems might include marital dyad, parental unit, the parent-child unit, and grandparents.

Family functioning refers to the connections of the members within the family system. Level of cohesion and flexibility, problem-solving styles, behavioral controls, and affective expressions are elements that characterize family functioning [20]. The family seeks homeostasis or stability given the dynamic and changing nature of the family system. However, disequilibrium is normal, and a family can grow as a result of it, but homeostasis restores equilibrium [22].

All families have rules and roles. Family rules are the expectations for behavior that shape and direct how families function. These rules can be either implicit or explicit. Rules may be manifested in the routines and daily activities of family life. Family roles refer to the beliefs that define how each member should behave and the specific function that each individual plays [23; 161]. For example, a mother may assume the primary responsibility of caretaker and nurturer [22]. It is important to remember that the family roles are not only defined by needs or family origin, but also by culture, race, and ethnicity.

The family is indeed a unique system. On one hand, the system strives for togetherness, which helps maintain closeness, harmony, and a sense of responsibility for each other [26]. Yet, simultaneously, each member of the family strives for individuality by attempting to achieve personal goals and responsibilities [26]. Family systems theory argues that when there are changes in the environment, there will inevitably be changes (not necessarily negative) within the family structure [23]. Therefore, healthy family systems have clear boundaries between the subsystems as well as flexible rules and roles to promote individuality, but still maintain healthy generational hierarchies and promote growth and adaptability [25].

When families experience stress, such as when a family member is diagnosed with chronic illness, the homeostasis of the system is interrupted as the forces of togetherness and individuality may come in conflict. For example, the mother may have to forfeit her personal goal of returning to a career, or she may find that most of the emotional and logistic work of caregiving falls on her—working to maintain

the patient's medical regimen, care for the patient, and navigate between continual hospitalizations and home life [160]. The goal of togetherness is achieved, but at times to the detriment of personal individuality [22]. Chronic illness can also affect family roles. The eldest child may assume the role of a coparent, helping his/her siblings, while the parents deal with the patient's regimen and care. In addition, chronic illness often affects boundaries. Boss coined the term boundary ambiguity for a chronically ill family member who may be physically present but psychologically absent [27]. A parent diagnosed with dementia, for example, may not be available either emotionally or psychologically for the family. The family system must deal with the ambiguity of the role of the ill parent. This is further exacerbated by feelings of loss and mourning, with no closure, since the physical presence of the ill family member will continually activate these feelings.

Family coping behaviors as they relate to family boundaries can also be understood by two concepts—engulfment and balancing/boundary setting [28]. These two concepts can be viewed along a continuum, with engulfment on one end and balancing/boundary setting on the other end. They are not meant to be viewed as absolute, distinct entities whereby an individual's behavior can be clearly classified in one of the two categories. Rather, caregivers often exhibit mixed responses and at times, shift from one end of the continuum to the other [28]. Engulfment occurs when the caregiver subordinates his/her needs and activities to that of the patient with chronic illness [28]. The caregiver is so involved that the physical and psychologic suffering of the patient becomes entwined with the caregiver's. On the other end of the spectrum are balancing/boundary setting, where there is psychologic distance or separation between the caregiver and the patient. In addition, some families also find that they come together to meet the challenges by dividing up the tasks that need to be completed and finding resources and learning new caregiving skills [160].

CASE STUDY 2

The family in this case consists of a mother, a father, and three children: a daughter 39 years of age; a son, Patient J, 38 years of age; and a daughter 32 years of age. Patient J has recently made contact with his family after an absence of 16 years. During this time, he has lived in another state and has had no contact with his father and older sister. He has been in touch sporadically with his mother and younger sister, although without the knowledge of his father and older sister. Nine years ago, Patient J was diagnosed with HIV and 11 months ago was diagnosed with AIDS. His health is deteriorating, and he will most likely be unable to care for himself within a few months. Patient J has been in a stable relationship for about seven years, and his partner is both willing and able to care for him throughout the course of his illness. Patient J would like to reconcile with his father and older sister and move back to his hometown. His partner, a successful writer who works from their home, is willing to accompany him. They have purchased a home approximately six miles from Patient J's family home and have arranged to transfer his medical treatment to a local physician. All of this has been accomplished with the assistance of Patient J's younger sister and mother, both of whom are eager to have the patient near them but are apprehensive about the reception he will receive from his father and older sister.

In this scenario, we see how the diagnosis of HIV and AIDS has estranged Patient J from both his father and older sister. Although Patient J has made repeated attempts to bridge the gap, his attempts have been rebuffed. The patient's mother and younger sister have worked to bring him home, with much disapproval from his father and older sister. We can imagine the conflict that must have transpired within the marital dyad and perhaps between the two sisters. We can also see how AIDS has affected the lives of Patient J and his partner. Patient J's partner, who is committed to him, has taken on the responsibility of providing the day-to-day care for the patient. He is also willing to sacrifice his professional writing career, deciding to relocate with Patient J to their new home.

THE BEST OF BOTH WORLDS: FAMILY ADJUSTMENT AND ADAPTATION RESPONSE (FAAR) MODEL

Derived from the family systems perspective, the FAAR Model has been developed specifically for understanding family response and coping with stressful life events [29; 199]. It encapsulates elements of both crisis and family systems theory.

The FAAR Model argues that all families experience a pileup of demands, stressors, and strains. Stressors are acute and isolated events that cause changes in the family system, while strains are ongoing tensions [162; 231]. Families attempt to maintain equilibrium or homeostasis by employing their resources and coping behaviors to deal with the demands and stressors of the illness [29; 30; 232]. The resources and coping behaviors may be viewed as the family's protective factors [30]. Tangible resources might include finances, while intangible resources are the psychologic inner strengths. Stressors might include daily minor disruptions of the day, unresolved family strains, and normative and non-normative events [30].

How families accomplish a sense of equilibrium is a function of how they perceive and ascribe meaning to the stressors they experience and the resources they have available to cope with the stressors [20; 30; 162; 232]. There are three levels of meanings. First, situational meanings refer to the family's appraisal of its resources and coping behaviors and its appraisal of the stressor [30]. The second level of meaning involves the family's identity; that is, how the family views itself as a family unit [30]. The third level of meaning consists of the family's worldview, which refers to how it sees its family system in relation to the larger system (i.e., community, society) [30]. Overall, how a family recovers from the crisis will be a function of the number of demands, appraisal and meaning-making of the crisis, and the resources used [162]. This model is strength-oriented and is consistent with the person-in-environment perspective [163].

In summary, how families engage their repertoires of tangible and intangible resources and coping skills to deal with the stressors and the meanings they ascribe to illness event will influence family adaptation [30; 231]. The goal of practitioners who utilize the FAAR model is to facilitate the family's resources and coping behaviors in order to restore balance within the family system. It assumes that practitioners will take a proactive approach in working with families and that families have the strengths to deal with the stressors [30].

According to the FAAR Model, there are three phases that families travel through when the news of chronic illness hits [199].

Adjustment Phase

This is a relatively stable period of time during which families attempt to meet the normal demands and minor stressors of life with their existing resources and coping behaviors. Resources are either tangible (e.g., money) or intangible (e.g., self-esteem) and may come from the individual, the family, or the community. Coping behaviors are the specific things that families do to deal with stress and restore family equilibrium [29].

Family identity and its worldview remain intact during this phase. A family identity is its sense of oneness that makes it feel distinct and separate from other families [29]. A family identity formulates through the routines, rituals, and values that are maintained and reinforced [29]. A worldview is a family's perception of and orientation toward the world [29]. It encompasses religious and cultural beliefs and other belief systems that serve as a guide for how to deal with and understand the changes around them [29]. Family identity and worldview are influenced by the meanings that families attribute to life's demands and stressors and affected by the family's existing resources and coping behaviors.

Crisis Phase

A hazardous event (e.g., news of the chronic illness) threatens the existing equilibrium of the family system [162]. This is not necessarily a pathologic phase since crisis can bring growth to families. It is a time when families are most open to help.

Adaptation Phase

As the crisis besets a family, it feels vulnerable, stressed, and uncomfortable. Consequently, the family will attempt to restore stability or homeostasis by obtaining new resources, coping skills, and problem-solving skills to handle the stressors evoked by the family member who is diagnosed with chronic illness [162]. The family must ascribe new meanings to the event. Family identity may change as routines, rituals, and roles change to deal with the crisis. In addition, a family's worldview might also change. For example, in cases of chronic illness, Patterson maintains that families who may have had a high internal locus of control may move towards a balance of external and internal loci of control. The family realizes that it cannot control all aspects of the world around it [29].

It is important to remember that this phase may not necessarily be a one-time phase: instead, a family may cycle in and out of the crisis and adaptation phases, depending upon the nature of the crisis [29].

IMPACT OF CHRONIC ILLNESS ON THE PATIENT

The problems associated with chronic illness will ultimately color the various domains of the patient's life, including the physical, psychologic, economic, and social dimensions. Although these domains overlap and are not necessarily discrete entities, they will be presented as such in this course. Impact of chronic illness is never static; it is an ever-changing process that influences how the patient accepts the disease, copes, manages, and integrates and adjusts to the illness [200].

DOMAINS OF THE PATIENT'S LIFE AND CHRONIC ILLNESS

Some have compared the coping and adjusting required of patients with chronic illness and their families to a job, with the requisite duties, skills, and knowledge. One of the duties involves managing social relationships with family, friends, employers, coworkers, and health providers to ensure healthy outcomes [233]. Patients benefit from skills to maintain schedules and routines in order to accommodate medical regimens. Knowledge about how to manage the symptoms of the chronic condition is also required.

Physical Domain

Functional Status

This refers to the patient's ability to continue functioning in his/her daily activities, such as self-care, going to work or school, participating in recreational activities, and continuing with activities that the patient enjoyed prior to the chronic condition [31].

Physical Symptoms

Because of the nature of chronic illness and its long-term symptoms, the patient is continually reminded of his/her condition [3]. The symptoms include both the symptoms related to the chronic illness and the side effects from the treatment that is prescribed [31]. The predictability of symptoms also affects patients' psychosocial well-being [234].

Schirm argues that symptoms are continual symbols for the patient [31]. They may serve as a reminder of the patient's eventual death, and on a more abstract level, symptoms symbolize psychosocial loss, such as helplessness, grief, and powerlessness [31]. Ultimately, how a patient perceives the symptoms will affect the course of the illness. The symptoms of a chronic illness also impact one's perception of their present and future biographical accounts. Biographical continuity and disruptions result from social adjustments, changes to social identities, and evolving self-concept over the course of the chronic illness [235]. Patients who are resigned to their symptoms will passively accept them, while those who view their symptoms as challenges will engage forcefully and actively to combat them [31].

Psychologic Domain

Grief and Sorrow

Loss, sorrow, and the ensuing grief are characteristic in patients coping with chronic illness [6]. There is grief of the loss of a body part and of physical functioning [32]. Variables such as age, gender, health before the diagnosis of the illness, and the patient's existing social support influence what types of losses will be experienced [6]. Both the patient and family members grieve and mourn over the loss of the person who once was and the personality and traits associated with that person [33]. Olshansky termed this chronic sorrow because, although the patient may have accepted the diagnosis, the feelings of grief and loss continue to wax and wane throughout the course of the illness [34]. Others terms employed include ambiguous, symbolic, living, and symbolic loss [236]. These losses can be situated at two points in time—before and after the onset of the illness. The loss of what once was encompasses "physical (in)dependence, relational connection, images of self, and trust in institutions," while losses of what will never be involve family planning and career dreams [236].

Fears

Patients with chronic illness experience a variety of fears due to the uncertainty of the prognosis of their illness, difficulties understanding medical jargon, having to adapt to medical regimens and new schedules, and feeling a loss of control over their lives. Pollin highlighted eight fears that a patient with chronic illness experiences [6; 35]:

• Loss of control
• Loss of self-image
• Loss of independence
• Stigma
• Abandonment
• Expression of anger
• Isolation
• Death

Other patients may experience fears and anxiety about their own future, that of their children's future, and the effect of the illness on relationships [36]. Concerns about their own sense of attractiveness may also affect their outlook, sense of self-esteem, and body image [32; 36]. Body image, for example, is an unconscious mental representation of one's body and is influenced by a host of factors including attitudes, sensory and physical sensations, and interpersonal interactions, all of which are affected by chronic illness [32].

Stigma

Stigma is the devaluation of a person due to an attribute, such as chronic illness [128]. In general, people seek to enter a social relationship in which both partners are perceived to bring a benefit and not a social cost. Because patients with illnesses of any kind may be stigmatized as not credible and abnormal, it may be difficult to maintain or obtain friendships and other relationships [128]. For those with a concealable chronic illness in which the symptoms are predominantly invisible, family, friends, coworkers, and the general public may believe the individual is exaggerating the illness [237]. This may result in the patient withdrawing and becoming more socially isolated [237].

Interpreting and Reinterpreting Meaning

When patients learn of the diagnosis, their worldview collapses. They wrestle to answer questions, such as: "Why did this happen?" "Why me?" and "Who or what is responsible for this?" [31]. Foley asserted that, generally, individuals ascribe various meanings to illness or suffering, including [37]:

• Punishment (i.e., having done something to deserve punishment)
• Testing (i.e., testing one's faith or character)
• Bad luck
• Nature merely taking its course
• Resignation to the will of God
• Acceptance of human condition (e.g., pain, suffering)
• Personal growth (i.e., suffering helps one grow, makes them a better person)

- Denial
- Minimizing (i.e., downplaying the severity of the illness or prognosis)
- Divine perspective
- Redemption (i.e., finding peace in suffering)

Economic Domain

Chronic illness is not only an emotional drain but is also a financial drain on patients and family members. Because of the debilitating effects of the illness, patients may find themselves giving up their jobs. Some may find it necessary to give up their home and return home to their parents [36]. Even if the patient has health insurance, there are often out-of-pocket expenses that are not covered by insurance. A 2022 study using a dataset from the 2016 to 2018 Medicare Current Beneficiary Surveys focused on the "big four" chronic conditions: cardiovascular disease, cancer, diabetes, and chronic lung disease [238]. In this study, those with one of these conditions spent 15% higher out-of-pocket costs and were 56% more likely to spend 20% or more of their annual income on health-related costs compared with those without one of these four conditions. Finally, the patient's family may also experience loss of income, particularly those family members who have to forfeit their jobs to assist with caregiving activities [31]. The sense of economic instability may rise given looming medical bills and, at times, substantial out-of-pocket expenses [201].

Social Domain

Because of their limited functional abilities, some patients with chronic illness may decrease their level of participation in social activities, thereby altering their social network relationships [38]. Developmental tasks, such as attending school, developing and maintaining friendships, finding a mate, having children, or moving to the next phase of their career, may also be affected [36; 202]. With certain illnesses, such as AIDS, family and friends may withdraw from the patient. Because the issue of mortality is inevitably linked with chronic illness, not only do patients confront this issue, but

their friends and social network systems become uncomfortable with the idea of their own mortality [38]. Consequently, they may withdraw. This is particularly important because loneliness has been shown to be a precursor of depression, particularly among older women [164].

THE DEVELOPMENTAL LIFE CYCLE

Developmental transitions are normal aspects of life, and accomplishing developmental tasks may bring about stress. However, the uncertainty of chronic illness compounds these difficulties; it influences how the patient views his/her chronic condition and ultimately affects the family system [6; 20]. Chronic illness inevitably sets a different tone for the individual and the family.

Childhood

During childhood years, particularly around 6 to 11 years of age, school becomes a primary context for developmental acquisitions, including both formal knowledge and social skills. Success in the school environment aids in the development of self-mastery, which is a crucial developmental task of this life cycle [39]. A child who is chronically ill may not be able to attend school to learn and to play with peers. The child may have frequent hospitalizations, adhere to strict medical regimens, and/or comply with rules that restrict his/her movement [40; 202]. The child feels isolated, knowing that he/she is different from others in the peer group, which can in turn affect the child's self-esteem. In one meta-analysis, researchers found that children with chronic illness tended to have lower self-esteem scores, particularly girls compared to boys [129]. In a study with school age children from 19 different European countries, children who had a chronic illness had lower ratings of school experience, which was correlated with lower ratings of life satisfaction [239]. The child's adjustment to illness is highly dependent on the coping skills and adjustment of those around him/her, such as parents, sibling, and friends [39]. Indeed, one of the most vital tasks of a chronically ill child is to effectively handle and cope with other's responses.

Adolescence

Adolescence is characterized as a period of confusion and turmoil. Boice noted that one of the main developmental tasks for the adolescent is the search for identity, and those adolescents who achieve a sense of identity will experience well-being—a sense of knowing where they are going and feeling a comfort level with their body. In their search for identity, adolescents wrestle with the perception that they are different from their peers [41]. Social acceptance is one of the major concerns for adolescents. However, often the chronically ill adolescent is isolated from other teenagers and spends a large amount of time with adult caregivers and healthcare professionals. In a study with 3,207 adolescents, those who had a chronic condition were less likely to report positive social connectedness across different contexts (e.g., with family, friends, school) compared with their counterparts with no chronic illness [240]. This is one reason adolescents with chronic illness often welcome returning to school. In a study of adolescents with cancer, participants reported that returning to school represented "being on the right track" to recovery, rebuilding friendships, and regaining their sense of identity [165]. Rejection by and isolation from peers may contribute to even greater stress [41]. Indeed, studies have found that when chronically ill adolescents have frequent peer contacts during their illness, psychosocial outcomes are improved [42; 43; 44]. And when their healthy counterparts have increased interactions with adolescents who are chronically ill, prejudicial attitudes held by the healthy peers decrease [42].

Adolescence is also a period marked by tremendous biologic changes. Chronic illness may impair biologic processes or affect the timing of the process of puberty [41]. It has been documented that adolescents who are chronically ill express more anxiety about their height and weight [41]. Chronic illness diagnoses at this age may have change patients' body image, which can impact their sense of identity, sense of belonging, and future plans [203]. Providers should discuss with patients how their chronic illness affects their current and future biographies [203].

Adolescents typically want more freedom, and this is no exception for those with chronic illness. Parents may give adolescents increasing responsibility for managing their illness, depending on his or her level of self-efficacy [130]. Research indicates that children who are expected to do household chores despite their illness exhibit higher levels of health self-efficacy and self-management [130].

Early Adulthood

The emphasis during the early adulthood years is on finding a place in a vocational niche, finding their personal identity, establishing intimacy with others, and selecting goals for life. College-age students with invisible chronic illness navigate multiple identities in order to fit in, for fear of being socially rejected. The pervasive myth that these individuals are faking or exaggerating their illness or are lazy often impedes them from disclosing their illness, so much so they were willing to risk their long-term health [88]. In one study, patients who had a chronic illness reported struggling with establishing their identity [131]. Participants tended to feel threatened by how others might respond to them and that they had limited social status as a result of their chronic illness [131]. Others may struggle with a changed body image or loss of physical function that they have to adjust to or struggle with being less independent [166].

Intimacy with others entails interactions with others, which in turn are affected by one's own perceptions of oneself as competent and valuable [6]. Chronic illness may interrupt this process of achieving intimacy and the life one had envisioned [166]. Again, the illness may force patients to isolate themselves. Patients in early adulthood who have achieved relationships prior to the diagnosis of the illness now struggle with maintaining levels of intimacy with spouses and children. Some wrestle with whether they should have children or additional children [6]. For those who have to give up jobs or careers, they may feel unproductive and unsuccessful [45].

Middle Age

According to Erikson, one of the major developmental tasks during the middle-age years is generativity versus stagnation. The tasks of generativity involve productivity and giving back to society [46]. However, patients with chronic illness who are navigating this developmental stage may feel unanchored, grieve over missed opportunities, and feel anxious about impending death [6; 45].

Older Adulthood

In older age, the major developmental task as defined by Erikson is achieving integrity versus despair. This involves a review of life accomplishments and acceptance of one's life [46]. Major issues include dealing with loss and developing a point of view regarding death. In this stage of life, chronic illness can be especially debilitating, both physically and psychologically. Participation in leisure activities may be limited by chronic illness symptoms and often requires adaptation (e.g., additional rest, modifications) [241]. However, elders with chronic illnesses also are very resilient. They view resilience as a unique skill in managing physical and emotional challenges [167].

This section provides only a snapshot of the many variables that affect the coping and adjustment processes of patients with chronic illness. It does not do justice to their courage or to the pain, frustration, and unique challenges that they experience. The reader is encouraged to listen to patients' stories in order to provide more effective psychosocial interventions.

IMPACT OF CHRONIC ILLNESS ON FAMILIES

All families go through normal challenges that are related to life cycles and situational stressors. However, families living with chronic illness confront a new set of demands related to that illness [20]. The effects and meanings of the illness have an dynamic interplay on the patient and all family members [204]. This section focuses on the various demands that challenge families with chronic illness and explains the factors that influence how families react to chronic illness. This includes caregiver stress, gender, culture, race, and how ethnicity affects caregiving and caregiver stress.

STRESSORS AND STRAINS ON FAMILY LIFE

Patterson and Garwick argue for systemic analysis and the need for longitudinal studies on families experiencing chronic illness. They maintain that it is difficult to disentangle the stressors and demands that existed prior to the diagnosis of the chronic condition from the stressors and demands that emerged as a result of the chronic illness. However, it is the multiple demands that these families experience that nurses, social workers, and other healthcare professionals should address. Patterson and Garwick coined the term "pileup of demands" to describe these cumulative stressors and demands [20]. Parents of children and youths with chronic illness often assume the responsibility of managing their children's medication regimen, dealing with any emergencies that might arise, and supervising educational, social, and recreational activities [205]. These responsibilities are in addition to typical day-to-day responsibilities of family life. When symptoms of the illness are unpredictable and when new medical regimens are introduced, family roles, tasks, and responsibilities will inevitably be renegotiated [232].

In a study with 17 families affected by chronic illness, participants described how stressors varied at different phases of the illness and healing [168]. The first phase of chronic illness is described as the "fight" or adversarial stage, during which the family member learns of the illness. This stage involves acknowledging the illness and the stressors that emerge as a result of dealing with the illness. The second phase involves family members coming to terms with the illness and redefining family life. The third phase involves the day-to-day living of the illness. Often, families have to re-invent routines in order to minimize the impact of the illness on the family system. Phase four focuses on maintaining the social relationships within the family so everyone feels supported. The final phase is figuring out how to move the illness to the background of family life

[168]. A qualitative study found that families initially felt that their family life fell into disarray because routines were disrupted and, often, controlled by the patient's needs [206].

Financial Stressors and Strains

Patients with chronic illness and their families often experience financial strains due to frequent physicians' visits, hospitalizations, and medical and therapeutic treatments. For those families who are uninsured and without access to proper medical care, there are tremendous ramifications in terms of the disease course and the quality of life [47]. In the first half of 2022, 27.4 million Americans were uninsured, 8.3% of the total population [242]. This is lower than in 2021, during which 9.2% of the population, or 30 million Americans, were uninsured [242]. In the first quarter 2023, the uninsured rate reached its all-time low (7.7%) [243]. However, racial/ethnic minorities remain more likely to be uninsured than their White counterparts. In 2022, 27% of Hispanic Americans and 12.9% of Black Americans were not insured [242].

For those families who may be adequately covered, a family member may have to leave his/her employment in order to care for the patient, as full-time nursing care is often not economically feasible [20]. Nearly 75% of family caregivers who retired early to take care of an ill family member stated they would have continued in the workforce if their life situation had not warranted them leaving [244]. Family demands related to care may either preclude a family member from receiving a promotion or result in the loss of a job [49]. Having to take time off from work, leave work early, and/or arrive late to work also results in occupational stress [244]. Medical visits, therapy, special equipment, medicines, and other specialized services are part of the financial demands associated with chronic illness [49]. For those families who are already financially stressed, chronic illness may place them at additional risk of draining their resources [49]. It has been shown that financial resources are a crucial predictor to family coping and adjustment to chronic illness [50]. The amount of financial resources has implications for access to and quality of health services.

Day-to-Day Demands

The effects of chronic illness on families may be examined from a "task perspective" [51]. This perspective involves listing the activities and tasks of the primary caregiver in order to understand the demands of caregiving. The list usually includes an exhaustive array of tasks that must be accomplished on a daily basis. Some of the activities are intimate, such as assisting with the patient's personal care and hygiene. Other tasks are more practical, such as shopping, making meals, running errands, doing laundry, housekeeping, and helping with the patient's paper work [51]. In families that include chronically ill children who cannot attend school regularly, the households have to consider the logistics for homeschooling [245]. In a national survey, all types of carers reported on average 2.1 hours a week in providing some type of care related to the health of the family member [171]. An estimated 21% attended their family member's appointments. In total, 32% indicated they had trouble paying for medications, and 41% felt they did not have adequate information about the family member's illness or maintenance regimen. Caregivers often talk about experiencing role strain, which is influenced by feeling "in the middle" when making decisions about the care of the chronically ill family member; a "burden of responsibility" in assuming a multitude of tasks; and a "changed identity" due to new roles related to caregiving [52]. Family routinization has been found to be the main coping strategy for family members who provide caregiving [133; 134]. Non-caregiving family members (e.g., siblings) will also assume new responsibilities and may feel partially responsible for keeping the family together [207].

In addition to assisting with the patient's activities of daily living, Coffey found that caregivers also assume an advocacy role, which entails three elements: vigilance and taking over; negotiating and taking a halt; and tenacious information seeking [9]. While fighting for services and care for the patient was found to be a large part of the advocacy role, taking a halt was equally important. This meant that the caregiver was firm about calling a halt to care when he or she felt that the patient had had enough of a certain medical treatment or intervention. Also

important was the need to be assertive in obtaining health information so as to make the best and most informed choices for the patient. Caregivers struggled to balance the fine line between worrying that they might alienate healthcare providers and wanting to ensure the best care for the patient [9].

Social Demands

When families have a family member with chronic illness, their social spheres will inevitably be affected. Particularly for those families who provide care for the ill family member, there is a loss of family privacy, reduced spontaneity of life, time taken away from other family members, such as children, and potential loss of work opportunities [20]. Families may feel socially isolated and limited in their ability to go out or travel. When the ill family member is a child, parents may feel uncomfortable relying on a babysitter or other untrained caregiver [245].

The responsibility for caring for a patient with chronic illness, particularly a child, can strain marital relationships. Marital satisfaction can be compromised because the communication process between the spouses may be hampered, and there is less "down time" together [53; 205]. Lower marital satisfaction was related to increased treatment compliance and less maternal contact, indicating that parents find themselves in a difficult situation, in which they must sacrifice either their relationship or the care of the chronically ill child [53]. Parents are often involved aspects of the patient's life they usually would not be, often feeling responsible for protecting the normalcy of the patient's social development [202]. For those whose spouse or partner became ill, some felt the illness made them partnerless and became an unwelcomed intruder in the relationship [246].

The level of marital satisfaction is ultimately affected by the wife's perceived support from her spouse. Mothers of young children who are chronically ill, for example, expend a lot of time and energy in caring for and coordinating the regimen of the sick child. Assistance from the spouse has been identified as a major predictor of marital satisfaction [49].

Siblings in a family system are also affected. Studies have shown that siblings of a chronically ill family member are vulnerable to adjustment problems, low self-esteem, poor peer relations, anxiety, depression, and lower health-related quality of life [54]. In some cases, parents may underestimate the overall functioning of the healthy sibling(s) in part because they use the frame of reference of the unhealthy child [135]. Some siblings may take on parental roles [247]. Siblings may feel caught by being a caregiver and defender of the ill family member, and may feel jealous, frustrated, resentful, and neglected [53; 207]. They may perceive injustices as a result of different expectations, rules, and parental attention and indulgences for the ill sibling [136]. Parents may have less physical and emotional time to spend with siblings to help them adjust to the effects of chronic illness on the family system, and consequently, the healthy sibling(s) receive less attention [247]. In addition, the degree to which the siblings are affected is also influenced by the severity of the condition [54]. They also miss out on a normal sibling relationship and companionship [136].

Healthy siblings will either internalize or externalize their emotional experiences in response to their chronically ill sibling. Examples of internalizing their emotions include withdrawing, becoming "invisible" to alleviate their parents' burden, loneliness, and separation anxiety. Separation anxiety most likely stems from frequent separations from parents who are caring for the sick sibling. Examples of externalizing emotions include intense anger, restlessness, hyperactivity, academic problems, and aggressive behaviors [136].

There is research that indicates that healthy siblings may not be as socially competent as their peers without ill family members. However, a variety of factors play a role in social adjustment, including gender, age, social support, and contact with other children [208].

Psychological Demands

Both the patient and family mourn over the loss of what could have been—the hopes, dreams, and possibilities of the ill family member. It has been argued that living with and caring for a patient with chronic illness requires a continual navigation of emotionally charged routes for families [6]. The family continues to experience a loss of "what could have been," as Olshansky described in the concept of chronic sorrow [34]. Boss and Couden also term this as ambiguous loss that results because the ill family member is still physically present but perhaps psychologically absent [55]. With illnesses where the diagnosis has yet to be confirmed or the prognosis is unclear, both the patient and family members may feel as if they are riding an emotional roller coaster [55]. There may also be ambiguity about the roles, rules, and boundaries in the family system as a result of the patient's illness [55]. This ambiguity may be particularly true in the early stages, when family members are in denial and physicians express optimism [6]. Then there are the concerns and anxieties about the future and the pressures of constant decision making [20]. Chronic sorrow may be triggered by many factors, including missed developmental milestones, chronicity of the illness, uncertainties related to the future, missing school, hospital readmissions, and the realization that the family member will need a guardian in the event a parent passes away [172; 209].

Another emotion that is ever pervasive is worry, or, as Coffey terms it, "living worried" [9]. It is a type of worry that is characterized as being present focused, but also projected in the future. For example, families worry about who will care for the patient if they are no longer able to provide care. However, this worry is not a passive emotion; rather, it is tinged with hypervigilance, where families are continually on guard observing for: changes in symptoms and health status; how the illness is affecting siblings; and how the illness is affecting the patient's social functioning in other areas, such as school [9]. Ultimately, this continual worry and hypervigilance can cause physical and emotional exhaustion [245].

These demands are further colored by what Rolland terms the "psychosocial typology of illness" [47]. Instead of purely biologic criteria in categorizing illness, Rolland argues that the nature of the chronic illness has certain psychosocial demands on families. Rolland conceptualized the typology along five points [47; 125]:

- **Onset**: This can be categorized as either acute or chronic illnesses. For acute illnesses, families experience the emotional and day-to-day demands in a more compressed fashion. However, with chronic illness, the period of coping, adjustment, and family reorganization is extended.

- **Course**: A chronic illness can be progressive, constant, or episodic. An example of a progressive chronic illness is Alzheimer disease. Families who have a patient with a progressive chronic condition continually refine and organize their roles to adapt to the illness. Family caregivers continually juggle the demands of life with negotiating the care of the patient. A chronic illness that is constant means that the occurrence of the initial event (i.e., illness) is followed by a relatively stable biologic course. An example of a constant chronic illness is a heart attack. The initial illness and diagnosis are followed by shock and crisis. However, families adjust and equilibrium is restored. A chronic condition that is episodic is characterized by periods of crisis that occur whenever the symptoms flare up followed by equilibrium, which is restored when the crisis abates. An example of an episodic condition is asthma. Families live with a ghost that periodically comes back to haunt them. Families require flexibility to navigate between two forms of family roles and organization-one when the symptoms exacerbate and one when the symptoms diminish.

- **Outcome**: Outcomes for chronic illnesses can be fatal (e.g., terminal cancer), can shorten the patient's life span (e.g., heart conditions), or may not necessarily affect the patient's life span (e.g., arthritis). The outcome of the illness affects how families grieve or mourn. When death is imminent, families may emotionally detach themselves from the patient. They may also experience a range of emotions (e.g., anger, sadness) that are at times consuming and distract the family system from engaging in the practical tasks that are integral to family functioning and organization. When loss is not necessarily at the forefront, families have to work on bringing normalcy back to the family system. Rolland notes that family members could take on an "it could happen" mentality, which breeds overprotection on the part of healthy family members and powerful secondary gains for the patient.

- **Incapacitation**: The degree of disability affects role reallocation in families. A patient who is diagnosed with Alzheimer disease impairment will be cognition-oriented. Family members may find that they have to provide more caregiving activities compared to a condition that leaves a patient disfigured but with cognition and movement intact.

- **Uncertainty**: The level of unpredictability of the course of the illness will affect family coping and adaptation.

Although families with a member who has a chronic illness will experience stress, challenges, and loss, it is important to remember that post-traumatic growth may occur. The concept of post-traumatic growth comes from positive psychology, which acknowledges the resiliency of the human spirit and that positive change that can follow negative events [137]. Meaning making and available social supports are predictors of post-traumatic growth for those with chronic illness [210]. Researchers observe that positive and negative affective states do not occur in a linear fashion. Instead, growth and loss operate independently and affect the well-being of the individual members and the entire family system [137]. Most families do function and adapt well despite the stressors. Positive functioning is often contingent upon available support and family connection [211].

TYPES OF COPING RESPONSES

Freud first talked about the unconscious mechanisms of coping. His discussion of defense mechanisms, such as denial, repression, rationalization, and projection, were unconscious ways in which individuals managed stress and anxiety. By the 1970s, the research moved into examining conscious coping strategies [56]. Lazarus was one of the first to develop a theoretical perspective about coping as a conscious process [57]. He first defined stress as consisting of three components: (1) primary appraisal, the process of perceiving the stress as a threat to oneself; (2) secondary appraisal, the process whereby one brings to mind the potential response to the threat; and (3) coping, which is the process of carrying out the response(s) to deal with the stress. This is not necessarily a process whereby each stage is experienced in an unbroken, linear manner. For example, if a family initially learns of a child's diagnosis of a serious illness, family members may initially be in shock, but may realize that they have a full array of coping resources, allowing them to reappraise the situation and perceive the threat as less threatening [58].

Lazarus identified two types of coping. Problem-solving coping is concrete and task-oriented [57]. It involves doing something to alter the source of stress [58]. Emotion-focused coping is targeted at reducing or managing the emotional distress that is triggered by the stressful event [58]. Both types of coping are utilized in stressful situations. However, Folkman and Lazarus found that problem-solving coping is used when individuals feel that something constructive can be done, while emotion-focused coping is used primarily when individuals perceive the stressful situation as something that must be endured or persevered [59]. Folkman and Lazarus later highlighted eight different coping styles that again fell

into two major headings: problem-focused coping and emotion-focused coping. Problem-focused coping consists of problem-focused strategies and the seeking of social support. Emotion-focused strategies consist of eight subdimensions [59]:

• Wishful thinking

• Distancing

• Emphasizing the positive

• Self-blame

• Tension reduction

• Self-isolation

• Seeking social support

• Self-control

Individuals who are self-compassionate are able to view stressors in a less threatening manner and ultimately are more likely to use cognitive reframing strategies and less likely to employ avoidance coping strategies [173]. In a study in which parents of children with chronic illness were interviewed, many parents reported using cognitive strategies (e.g., reframing, passive appraisal) [211].

Some patients and family members may utilize avoidant coping strategies (e.g., disengagement), and it is important to not simply categorize these strategies as negative or dysfunctional. In some cases, a break from the stressor is required. For parents with a child with chronic illness, distractions are associated with good psychosocial outcomes and positive emotional coping (e.g., gratitude and positive meaning making) [248].

Dyadic coping is a coping process that involves partners' interactions and influence on appraisals, communication, and coping [249]. In other words, how each individual appraises the stressors and copes are contingent on how the other partner copes. With chronic illness, each member of the dyad appraises the event, and, together, discuss the stressor and explore how to help each other reduce and cope with the stress [249]. In a 2024 study, when a couple employed dyadic coping strategies to deal with the onset of the chronic illness, both partners experienced greater well-being, felt closer to each other, and experienced higher levels of sexual satisfaction [249].

Cultural variations in coping have been discussed in the literature. Culturally based worldviews and values affect how individuals respond to stress. Collectivistic values emphasize interpersonal relationships (i.e., family or other social support networks) and whether these relationships affect coping. For example, in one study, Chinese caregivers relied primarily on family-related coping strategies. These strategies focused on obtaining help and support from immediate family members rather than assistance from outsiders [212]. This type of coping should not be labeled as pathologic, as it fits within cultural norms of collectivism, filial piety, and familialism. Values that focus on independence might dictate that individuals from Western cultures use coping strategies such as being assertive, disclosing vocalizing feelings and thoughts, confronting others, and actively problem-solving [60]. Western frameworks, however, do not capture the full nuances of the coping strategies of individuals from communal and collectivistic cultures (i.e., Asia, Latin America, and Africa). For example, forbearance, perseverance, and sacrifice are characteristics that are highly valued in collectivistic cultures. Consequently, individuals from these cultures may cope by not disclosing their problems to others because they do not want to burden others [60]. Helping professionals should therefore not immediately label these strategies as resistance to or denial of the problem and attribute pathology. Helping professionals should be alert to the possibility that more serious psychologic, social, and mental health problems might be being masked [60].

Religious coping refers to the process of harnessing one's religious or spiritual beliefs to deal with life's adversities. Calling upon a higher power, God, or the sacred for hope and providence moderates the stressors associated with challenges [250]. Religious coping among ethnic minorities (particularly African Americans) has also been discussed in the literature [61]. Culver et al. found that African Americans and Hispanics used greater levels of religious coping and humor than whites [62]. Furthermore, they were less likely to use venting compared to their white counterparts [62]. In a comprehensive review of the literature, Latino caregivers who had children with

a chronic illness tended to use religion/spirituality, support from their family network, alternative healing practices, and information about the illness to cope [174].

Hill's model of coping specifically addresses families' adaptation to a family member's illness [63]. The model was initially developed to understand how mothers coped with their children's diagnoses of sickle cell disorders; however, it is also useful in understanding the coping styles used to adapt to a family member's chronic illness. Hill proposed five different coping strategies [63]:

- Embracing the medical model: This strategy focuses on acquiring information about the illness.

- Achieving mastery: This mechanism emphasizes managing the symptoms. It is characterized by day-to-day survival rather than trying to understand the situation.

- Normalization: This strategy focuses on reducing stigma and establishing a sense of control.

- Positive reframing: This coping style emphasizes reframing the loss to acknowledge the ill family member's other positive strengths or attributes.

- Religion: This strategy focuses on how the stressful situation is part of spiritual growth.

These different types of coping styles overlap with Lazarus' and Folkman's initial conceptualization of coping styles.

FACTORS INFLUENCING HOW FAMILIES WILL RESPOND TO CHRONIC ILLNESS

Variations exist in how families respond to the consequences of chronic illness. These variations are influenced by nature and characteristics of the condition, resources, illness phases, family life stage, and gender [20].

Nature and Characteristics of the Illness

Some research indicates that how a family adapts depends more on the characteristics of the illness than on the initial diagnosis. These characteristics include:

- Degree and type of incapacitation (e.g., sensory, motor, cognitive)
- Extent of visibility of the condition
- Prognosis or life expectancy (e.g., is the outlook negative or positive; is it a terminal illness)
- Course of the illness (e.g., constant, relapsing, or progressive)
- Amount of home treatment, outpatient, and inpatient medical treatment and the expertise needed for the patient
- Amount of pain or other symptoms experienced

Resources

Families possess three types of resources [20; 64;213]:

- **Personal Resources**: This refers to the family's inherent resources for dealing with the challenge of chronic illness. These resources include their socio-economic status, level of coping skills, self-efficacy, positive emotions, courage, being kind to oneself, sense of mastery, and their own physical health.

- **Social/Familial Resources**: This refers to the availability of social support networks in families, including confidantes, friends, and extended family members. Social support is an important moderating variable. The extent of an individual's or family's social support system can buffer stress. How a family responds to chronic illness will be impacted by its social support system, which includes family, friends, neighbors, and community resources. Familial resources refer to the organization of the family, such as clarity of rules and expectations, routines for daily family tasks, clear generational boundaries, and good communication.

- **Community Resources**: This refers to the quality of relationships that families have with professionals who are providing care and other services to the ill family member. Families who are familiar with navigating the medical and social service delivery system and have interactions with professionals who are well-trained, professional, reliable in scheduling, and sensitive to family dynamics are better able to mitigate the strain of chronic illness.

Illness Phases

Neither illness nor family coping is static; rather, it is dynamic. How a family responds to chronic illness is also a function of the phase of the illness as each phase of the illness has specific demands and transitions, and families will require different strengths, resources, and reorganization to meet these psychosocial demands [47]. Illness phases, as conceptualized by Rolland, can be delineated into three periods: crisis, chronic, and terminal phases [47].

- **Crisis Phase**: This time period includes the symptomatic period prior to the diagnosis and the initial period of coping and adjustment after the diagnosis. Families in this phase must learn to cope with the symptoms related to the condition, navigate the medical and healthcare system, and manage the day-to-day responsibilities of caring for the patient. In addition, patients and family members begin to make meaning of the illness.

- **Chronic Phase**: This phase is characterized as the "long haul," which includes the day-to-day activities and tasks related to caring for the patient and the family's attempt to maintain a semblance of normalcy. Family members reallocate roles and work on maintaining individual autonomy in the family system and not letting the illness define them.

- **Terminal Phase**: This period is marked by the imminence of death, and family members struggle to deal with issues of separation, mourning, and resuming family life after the loss.

Family Life Stage

Rolland as well as Carter and McGoldrick assert that there are distinct family roles, goals, functions, and transitional points at various stages of the family life cycle [47; 65]. Carter and McGoldrick highlighted eight phases of the family life cycle, where each phase heralds a distinct marker with its associated inherent stressors [65]. Chronic physical illness adds a new dimension and hue to these normal developmental stressors. At times, chronic illness will propel the family system into a new stage: a family anticipating the birth of a new child with new hopes and dreams that hears about an ill family member will be forced to deal with loss [47].

Families who have a family member with a chronic illness have different needs, strengths, and resources at various points in the family life cycle. In a family with young children, for example, when one of the parental figures is diagnosed with a debilitating disease, the impact on child-rearing tasks can be affected in several ways. In many ways, one parent is lost to the chronic illness; the other parent is also "lost" because his/her presence may be diminished by new caregiving roles [47]. In some cases, an older child may take on a caregiver role or assume more adult responsibilities. Spousal relationships can change as one inevitably has to become the carer and the reciprocal relationship can no longer be maintained [175]. In addition, a "new" family member (i.e., chronic illness) becomes part of the family system [47; 175]. During later stages, a chronic illness may have less impact on the parent dyad, but new anxieties emerge about the future welfare of their ill child [175].

Absent a chronic illness, parents who have raised their children and are ready to launch them into the world will renegotiate their roles and dreams in order to accommodate the exits [65]. Spouses will plan how they will be using their free time since they no longer have child-care responsibilities. However, if a family member is diagnosed with a serious chronic illness, parents may need to revise their "launching plans." For example, parents may have to re-examine the issues of autonomy and individuation and revisit the notion of caretaking as the patient becomes more dependent [47]. The case of Mr. and Mrs. P below illustrates this situation.

Case Study 3

Mr. and Mrs. P have long anticipated their retirement years. They have plans to travel the country in the RV they purchased last year and have spent many evenings studying maps and brochures about campgrounds. With their two children grown and relatively stable, they look forward to having time to devote to each other and to their shared interest in travel. Their friends tease them about their pending "second honeymoon" and are planning a surprise retirement party for Mrs. P, who will retire from her career as an elementary school teacher in one week, at the end of the school year. Mr. P has been retired for two years. Both are eagerly anticipating the freedom that Mrs. P's retirement will allow and have been caught giggling together on more than one occasion. Future plans include taking their two grandchildren to the Grand Canyon and Disneyland, but they first plan to spend six months alone just going wherever they please and getting used to the RV lifestyle.

Neither has anticipated the total disruption to their lives that the telephone call from the hospital brings. Their daughter has been involved in an auto accident and has suffered severe brain damage. She is currently in a coma in intensive care and the prognosis is not good. Their son-in-law asks if one of them can pick up their 7-year-old grandson from school and take him to a neighbor who sometimes babysits for the parents. They decide that Mr. P will do this and then meet Mrs. P at the hospital.

Later in the evening Mr. and Mrs. P, their son-in-law, and their other daughter meet with the neurologist who is attending their injured daughter. The neurologist reports that the damage is extensive and, at best, they can expect several weeks of hospitalization followed by months of rehabilitation. Suddenly, everyone's plans have changed and the future no longer seems so carefree.

Role of Gender

Gender is another important variable that influences how a family responds to chronic illness. The term "feminization of care" refers to the notion that most women are caregivers and expected to provide caregiving duties [66; 176]. Traditionally, women are socialized to be natural caregivers in many cultures [251]. Wives, daughters, and even daughters-in-law are expected to provide care to family members [251]. When fathers are primary caregivers, they tend to be given the positive label of "responsible caregivers," but this same positive attribute is not given to female caregivers because this role is expected of them [252]. Women who work full-time are more than four times as likely as men who work full-time to be primary caregivers to elderly parents [67]. The competing demands of balancing full-time work, caring and nurturing their own children, and maintaining their own homes contribute to the caregiving stress and burden on women. According to Short, adult daughters are more likely to care for their frail elderly parents, and they provide 33% of the long-term care; 75% reside with the frail elderly parent to provide the care, and on average, the majority provide some sort of care and assistance every day for at least four hours [69]. The caregiver burden may also threaten women's financial security as a result of their having to leave the workforce [138]. Women typically do more hands-on caregiving tasks and spend more hours providing caregiving compared with men [139].

Because of the prevailing belief that women are more involved as caretakers when a family member is chronically ill, fathers have received less empirical attention. However, men are assuming more caregiving responsibilities. A study conducted using three national datasets of young adult caregivers found that over half of the caregivers were men [70]. Furthermore, there do not appear to be gender differences in the amount of caregiver burden experienced [214]. Katz and Krulik found that fathers had more difficulty than mothers adjusting to their child's physical limitations due to a chronic illness [71]. Fathers also disclosed experiencing tremendous stress in having to assume greater financial responsibility due to the costs of medical treatment, physicians' visits, and hospitalizations, particularly if the mother had to give up her job to assume caregiving responsibilities. Goble's qualitative study of fathers who had a chronically ill child indicated that finances were a continual stress [72]. Some fathers had to work overtime and some stated that they lived from paycheck to paycheck and were lucky to make ends meet.

Fathers have also reported feeling like the forgotten parent because they are frequently not as involved as the mothers [73]. However, they also felt conflicted by the desire to spend more time with their chronically ill child and the need to work because of the additional medical expenses. Work also helped the fathers to forget about the stresses and bring some normalcy back to their lives [74]. Around the world, there appears to be a common denominator in how men handle the stressors of chronic illness. Men are more likely than women to express wanting to be in control and to be reluctant to talk about feelings related to the changes of the chronic illness [253].

The fathers also disclosed that they felt closer to their wives and experienced a lot of support from them [72]. However, there was no down time to merely relax and have fun with their wives. One of the fathers in the study stated that he missed being in a husband-wife relationship and that having a chronically ill child was like running a business. Everything was scheduled down to the minute, except relaxation time as husband and wife [72].

In a 2016 qualitative study, some instances of caring were identified as more "masculine" (e.g., lifting the patient). Men in this study also described how the illness provided an opportunity to emotionally express themselves and seek emotional support [176].

Role of Beliefs: Religiosity and Spirituality

Shaw and Halliday observed that belief systems are central to understanding how families respond to crises and adversity [75]. Belief systems are defined as strongly adhered-to ideas that have been either learned through socialization or shared through time to connect people in a meaningful manner [75]. Families have belief systems (whether secular or religious/spiritual) about health and illness, the healthcare system and practitioners, and the meaning of adversity [75]. During a crisis, these belief systems will be triggered, which will then influence family responses.

Religion and spirituality influence adjustment and coping for chronic illness and can enhance existing pathways of coping, adjustment, and health, while also giving meaning and purpose to the caregiver and the patient [177]. Religiousness or religiosity is defined as personal belief in God or a higher being, often times encapsulated in organizational and institutional practices, such as church attendance, church membership, or an organized religion [76]. It is an external expression of faith [77]. Spirituality is broader and defined as a personal philosophy, which could include religion as well as culture, where a person strives to search for meaning and believes that power extends beyond himself/herself [76; 77].

Religion can assist with coping with stressful situations (i.e. chronic illness) in a multitude of ways [77]:

- How the illness is interpreted: Is the illness part of God's plan? Is God to blame?
- How the coping process is shaped: For example, religion could provide fortitude.
- How and whether the coping process can influence religion: A highly stressful situation can lead a person to religion.

Pargament identified three types of religious coping [78]:

- Self-Directing Style: The individual who uses this coping style does not involve God in the process at all.
- Collaborative Religious Coping Style: The individual and God work together to solve the problem.
- Deferring Style: The individual waits passively for God to intervene.

In later studies, Pargament et al. hypothesized that there might be an additional religious coping style, called "Plead," in which the individual petitions to God for a miraculous intervention to bring about the identified outcome(s) [79]. The individual refuses to accept the status quo. Other studies have indicated that pleading may not be adaptive since it has been associated with greater levels of psychologic distress [80].

One qualitative study found that Chinese family caregivers pray and rely on the belief in a higher power to give them inner strength [212]. Children may also demonstrate these religious coping styles. Pendleton argued that children display declarative religious/spiritual coping whereby they command God to intervene [140]. They may also demonstrate petitionary religious/spiritual coping (i.e., asking or pleading with God to help) or collaborate religious/ spiritual coping (i.e., offering to do something in exchange for God helping and intervening).

In a 2022 literature review, five themes emerged in the relationships between religion/spirituality and chronic illness [254]:

- Religion and spirituality are related to better health outcomes.
- Religion and spirituality provide comfort, solace, and hope, which in turn promotes resiliency.
- Religion and spirituality offer emotional support in the form of religious communities and friends who become the patient's anchor and strength.

- Religion and spirituality appear to be positively related to medical treatment or intervention adherence. They may also give patients motivation to continue with the treatment.
- Religion and spirituality seem to be the fabric for many racial, ethnic, and cultural groups, and patients draw hope from their religious and spiritual beliefs and identities.

For the family caregiver, religion and spirituality influence the motivation to provide care [251]. Overall, religion and spirituality are powerful determinants to health and well-being for both patients and family members.

CAREGIVER STRESS AND BURDEN

The terms "caregiving" and "caregiver" have been employed in this course rather ubiquitously. At what point do we define a person as a caregiver? After all, family members provide both concrete assistance and mutual support to each other as a part of normal family interactions [81]. Biegal et al. maintain that caregiving in the context of chronic illness extends beyond the traditional tasks and services offered by family members [81]. Caregiving in these situations is "the increment of extraordinary care that goes beyond the bounds of normal or usual care" [81]. Because it extends beyond what is normally provided, one of the emotional consequences that a family may experience is stress or burden.

There are two types of family caregivers. A care provider is one who performs and carries out practical tasks such as shopping, doing housework, cooking, and caring for the patient's hygiene [82]. A care manager refers to family members who arrange for and/or coordinate the caregiving services of other professionals or lay people [82]. Socioeconomic status and the extent of the patient's illness will play a role in determining whether a family caregiver is primarily a care provider or a care manager [82].

Others define caregiving as the behavioral expression of the commitment to caring, which is the affective component of an individual's commitment to the welfare of another [83]. Yet in a study conducted by

Ayalong, caregivers distinguished between the terms "care" and "caregiving" [84]. Care was a reciprocal activity, while caregiving was something one had to do (i.e., an obligation), although it could be viewed in a positive manner. Whatever definition is used, the literature converges on a single point-families experience caregiving stress, which might ultimately lead to caregiving burden when a family member has a chronic illness.

Caregiver stress results when the demands of providing care for an ill family member are perceived as exceeding the resources available [82]. These resources may include what was discussed earlier-personal, family/social, and community resources. Caregiver stress can result in depression, anxiety, feelings of helplessness, and burden.

The concept of caregiver burden received much empirical attention in the 1980s, and most of the research has focused on impaired elderly patients. Recently, however, the literature has used this concept with other populations as well. Generally, caregiver burden has been defined as the range of physical, psychologic, social, and financial strains or problems experienced by a caregiver in which a family member has a disability [85; 255]. It is perceived negatively by the caregiver [82]. The concept has been broken down into two categories: objective burden and subjective burden. Objective burdens refer to the emotions stemming from providing specific caregiving tasks and the time spent on these tasks [86]. Subjective burdens encompass the emotional, psychologic, and social impact involved in providing care [86; 255]. Not surprisingly, caregivers who provide more activities of daily living and perform more tasks related to the management of the patient's health tend to experience more anxiety symptoms and poorer health [215]. Overall, the concept of caregiver burden has not been consistently operationally defined and measured in research [255]. Some have advocated shifting the term from "caregiver burden" to "caregiver resilience" and focusing on providing caregivers restorative services, such as respite care and problem-based home visiting [256].

ROLE OF CULTURE, RACE, AND ETHNICITY IN CAREGIVING AND CAREGIVING BURDEN

More recently, there has been a concerted effort in research literature to examine the role of culture, race, and ethnicity in caregiving and caregiving burden. In part, three factors or trends have contributed to a more systematic cross-cultural examination in this area. First, the United States is becoming increasingly multicultural. Demographic trends indicate that ethnic minorities are rapidly growing. By 2060, it is estimated that the African American population will increase to 74.5 million and the Hispanic population will increase to 119 million [144].

Second, the number of older adults in the United States is projected to grow to 27.7 million by 2040 [266]. Chronic illness is often associated with older adults. In addition, certain chronic illnesses, such as heart disease and hypertension, are found in exceedingly higher rates in African American populations [89]. Consequently, it is crucial to examine the role of culture, race, and ethnicity and its impact on caregiving.

Finally, caregiving burden is a highly subjective experience. Meanings of experiences are inextricably embedded in cultural values and belief systems, and therefore, it is safe to surmise that perceptions and patterns of caregiving, as well as the outcomes of caregiving (e.g., burden or stress) might be mediated by culture. In many cultures, there is social expectation that the family (specifically women) will assume caregiving responsibilities. It is a cultural imperative or a social expectation [257].

The hypotheses about the role of culture, race, and ethnicity can go in either direction. One can postulate that certain cultural values and beliefs, such as familism and collective versus individualistic orientation, as expressed in Asian and Hispanic communities, the extended family structure, as expressed in African American families, and the role of filial piety, may promote a higher level of caregiving concern [251]. This is the case also in Turkish

and Moroccan cultures in which the eldest daughter or wife of the eldest son is expected to provide care [251]. Therefore, these cultural values and characteristics might provide a buffer against caregiving stress [82; 90; 91]. A recurrent theme in research with ethnic/racial minority participants was that caregiving is perceived to be embedded in the fabric of life [146; 251]. However, one could also argue that the additive force of traditional cultural norms as well as the adoption of new Western norms may result in internal conflict in the area of caregiving [91]. For example, many Asian immigrants in the United States may have been socialized and influenced by traditions such as filial piety. However, as they acculturate to Western values and belief systems, their expectations about gender roles may alter. In traditional Korean families, for example, it is expected that the elder son's wife will provide care for her parents-in-law when they become frail. However, because of acculturation, these daughters-in-law may find caregiving burdensome [91]. While they have been taught the importance of filial piety, they may be influenced by the more egalitarian gender roles in the United States. Role blurring and confusion are even more pronounced in multicultural families. Families from collectivistic cultures tend to provide caregiving because interdependence is inextricably woven into their cultures; individualistic cultures tend to provide caregiving out of necessity [147]. It is also plausible that when immigrants from collectivistic cultures acculturate, they will adopt views about caregiving that are more similar to those from individualistic cultures.

HISPANICS/LATINOS AND THE CAREGIVING EXPERIENCE

Lim and Luna identified four potential cultural values in the Mexican culture that may help us to understand how Mexican cultural values and belief systems color the caregiving experience [92]. These four cultural values include: emphasis on the family unit; emphasis on the family over the individual; specific gender role expectations; and emphasis on existential suffering.

The family is very important in Mexican culture. It is the basic source of emotional support, and interdependence is valued [92; 93]. Children are socialized early on to carry out family responsibilities and esteem family unity [93]. Because interdependence is emphasized, the extended family structure is relied on for support [93]. Therefore, one could postulate that Mexican American families view caregiving in a positive light as it is an extension of family life, with individual needs relegated to the needs of the family. Elderly family members are highly revered for their wisdom and often live with their family [148]. However, one could also argue that the emphasis on interdependence could lead to high levels of caregiver stress and burden because caregivers ignore their needs in favor of the ill family member [92]. The themes of familismo and marianismo emphasize close-knitted family ties and bonds and the expectation of feminine nurturing [258]. These are motivators for Latina caregivers, who perceive provide care as an essential part of being a good role model. However, this can be at the expense of their own health and well-being. For example, in one study, more than 20% of Latina caregivers indicated they were eating fewer than two meals per day and nearly 25% did not exercise regularly [258]. This was further confirmed in a study by Cox and Monk [94]. Yet, despite the high levels of reported caregiving stress and familiarity with formal services, the caregivers opted not to use formal services. They rarely even disclosed to friends or close family members about any stress [94]. Hispanics tend to have higher family systems-related resources [216]. Although this is a cultural strength, external resources have been found more beneficial in alleviating stress.

Other studies have indicated that caregivers of Hispanic descent are more likely to decrease their work hours or quit their job entirely in order to provide care for an ill family member [178]. Similar patterns have been noted in third-generation Asian Americans, who, along with Hispanic caregivers, exhibit the greatest number of caregiving hours [178; 179].

The focus on the collective over the individual is related to the cultural value of family orientation [92]. In this orientation, the individuals' well-being and identity are intricately linked to the collective reference group (i.e., family unit). Caregiving tasks are distributed among family members, and therefore, the social support network acts as a buffer against the caregiving burden [92; 148; 217]. However, Tirrito and Nathanson found that female caregivers in Hispanic, Asian, and African American families with an extended family network were experiencing comparable levels of role strain and stress as caregivers from nuclear white families [67]. Similarly, other findings have shown that, although the extensive social network system provided support to Hispanic families, the actual instrumental assistance (i.e., running errands, cooking) provided by relatives was minimal [92]. It is important to remember that Hispanic families are heterogenous, and it is important for providers not to assume that Hispanic caregivers have extensive family support [216].

Gender role expectations are highly demarcated in Mexican American families. Men perform tasks and duties related to the outside world, while women perform tasks related to the family. In terms of caregiving, a "good" man will care for his family, although this is often related to financial or material support [257]. Furthermore, there is an expectation that women will provide the caregiving duties, and daughters appear to be the first choice of caregiver across racial/ethnic groups [92; 178]. When men perform caregiving tasks, they are most likely to help with transportation [148]. There is some indication that Latina daughters assume caregiving responsibilities earlier compared to their white counterparts [95].

Finally, the cultural characteristic of enduring suffering is another value associated with Mexican American culture. In part, existential suffering is rooted in Catholicism [92]. This cultural trait may influence the caregiving experience both positively and negatively. The caregiving process may be perceived as self-sacrificing and a source of pride, even as

the caregiver may be reluctant to seek help from community services or assistance from family and friends [92]. In addition, the caregiver may keep silent about any stress or sense of isolation experienced. A study conducted by Calderon and Tennstedt found that Puerto Rican caregivers were more likely to cope with the stressors associated with caregiving by employing strategies such as resignation, denial, and respect. They turned to their Catholic faith and asked God to give them strength [96].

In a study conducted with Latina and white female caregivers, cultural values and acculturation appeared to play a role among Latinos in their decisions to institutionalize elder family members [95]. Those Latina caregivers who had positive views toward caregiving and were less acculturated were more likely to play a role in the decision to delay institutionalization. Cultural values of familismo, where the family is emphasized over the individual, respecto, where respect for older persons is emphasized, and dignidad, which is the value of maintaining dignity and not asking for help, may all contribute to caregiving decisions, such as not wanting to institutionalize a family member [95]. However, practitioners should not assume that all Hispanic/Latino families will be willing to care for their elders. Those Latino caregivers who had less positive views of caregiving institutionalized their elderly family members more quickly than either their white counterparts or those who had more positive views of caregiving [95].

AFRICAN AMERICANS AND THE CAREGIVING EXPERIENCE

African Americans are more likely than other ethnicities to extend caregiving to relatives outside their immediate families [97]. Caregiving in African American families tends to be wider in scope and assumed by adult children, friends, and members of an extended family network [84; 218]. Given this, there is a stereotype that African Americans are less likely to use nursing homes for their elders. Yet, African American adults 85 years of age and older are more likely to reside in nursing homes compared to whites [98].

The decision to provide care is embedded in the sociocultural context stemming from historical oppression and slavery, which required mutual support and sharing of resources in order to survive. The preservation and maintenance of this cultural value of family and filial obligation has been transmitted over the generations to combat day-to-day racism and discrimination [259]. Groger and Mayberry examined African Americans' attitudes about filial obligations toward elder [98]. African American college age students and young adults had the most stringent expectations about filial obligations. They rejected the idea of nursing homes. In particular, they declared that they were willing to put their careers on hold to care for their family members. The young adults were similarly passionate, yet they qualified this by noting the role of the elders' needs versus the family's ability to meet those needs. African Americans from the middle-age group were the ones who actually experienced the demands of providing caregiving to elderly family members while balancing raising their own children. Nursing home placement was considered the last resort. Other intermediate options such as homecare services were weighed. African American elders understood the realities of caregiving as they had experienced it. They also understood firsthand the burden of caregiving, yet they asked for small things, such as not being ignored and being visited. They wanted to be independent and valued their children's help, but they did not want to be a burden [98]. In a 2017 study, African American caregivers averaged 11 hours more per week in caregiving activities post-stroke compared with their white counterparts [180].

Studies have found that African American caregivers reported less caregiving burden compared to their white counterparts [98; 99]. Some have postulated that the lower levels of burden can be explained by the African American family structure. One pattern among African Americans is that extended family members share households for both economic and cultural reasons, such as beliefs about connected-ness [100]. Studies indicate that African American families often have an extended network of family members, relatives, friends, and other individuals who assist in providing care [218]. These norms may reduce the stress and strain associated with caregiving [100]. Indeed, Dilworth-Anderson et al. found that the majority (74%) of the structures were collectivist in that they were formed by two or more caregivers [100]. It is plausible, however, that the expression of burden is expressed differently in African American caregivers than in white caregivers, and it is important to note that much of the measurement employed in research includes standardized scales that may not adequately capture differing expressions of burden [96]. Calderon and Tennstedt found that African American caregivers described the caregiving experience through somatic complaints and feelings of frustration and anger [96]. As with Puerto Rican caregivers, resignation was the most frequently expressed mode of coping among African American caregivers. They viewed caregiving as part of their fate and part of God's will [96]. African American caregivers may use the church for their emotional support, as religion and their church family are often central to their lives [149]. White caregivers employed more active and hands-on techniques, such as relying on formal services to mitigate the day-to-day logistics of caregiving, and found other outlets, such as gardening or other hobbies [96].

It is important to remember that although caregiving may be part of African Americans' sociocultural tradition, unique sociocultural and environmental stressors can impact the caregiving experience. African American caregivers experience an interaction of racism/discrimination, cultural norms, and financial burdens/concerns that contributes to caregiving stress [260]. For example, they may face challenges in accessing services due to institutional and/or discriminatory barriers and related stress. Financial stress complicates caregiving for ill family members [260].

ASIAN AMERICANS AND THE CAREGIVING EXPERIENCE

Traditional Asian beliefs and values are centered around Confucian thought, which focuses on harmony, unity, and family [101]. In traditional Chinese culture, for example, one way to maintain harmony is to adhere to the hierarchical structure of the family. Therefore, there are specific prescribed roles for men and women; men have more authority than women. Women's roles are primarily circumscribed in the home and in child-rearing activities [101]. Children are expected to obey their parents and demonstrate filial piety and to repay their parents for all the sacrifices they have made for them [102]. Filial piety is defined as a set of obligatory behaviors and expectations closely tied to family relationships; it is characterized by children respecting and obeying their parents and families honoring ancestors [219]. This belief system extends to providing physical, emotional, and material/financial care to parents and elders [212]. In families who adhere to Confucian principles, caregiving is allocated to daughters-in-law. If there is no daughter-in-law, the role goes to unmarried daughters, then to married daughters, and finally extended female family members [146]. Filial piety is believed to act as a buffer against caregiver stress and to improve the perception of caregiving [181; 182].

The concept of filial piety also applies to Korean culture. As noted, the eldest son and his wife typically assume caregiving tasks when the eldest son's parents become old and frail. The son is to fulfill his financial obligations to his parents; however, it is the daughter-in-law who is to execute the day-to-day caregiving activities because caregiving is congruent with the cultural gender role expectations of Asian women performing domestic and nurturing tasks [90; 103]. Given this cultural expectation, Lee and Sung hypothesized that Korean caregivers (primarily daughters-in-law) of frail elderly parents would display greater filial obligations, and white caregivers (primarily daughters) would have access to more formal services. Therefore, these variations of norms and values would produce differential responses toward caregiving [90]. They found that the white caregivers reported closer relationships with the care recipient and higher gratification from the caregiving compared to their Korean caregiver counterparts. Korean caregivers showed higher levels of filial responsibility and utilized greater extended family support, while white caregivers displayed lower levels of filial obligation and employed more extensive formal services. The level of overall caregiving burden was lower for Korean caregivers, which was associated with higher levels of filial responsibility and the use of extended family support. However, the level of emotional burden was much higher compared to white caregivers, and this may be because Korean caregivers are primarily daughters-in-law, who ultimately experience less gratification with caregiving [90]. Studies also show that when elderly parents perceive their children are exhibiting filial piety, their well-being increases along with their health status [150].

Chao and Roth found somewhat similar results in a qualitative study of 31 Taiwanese women, 23 to 58 years of age, who were primary caregivers to their parents-in-law [104]. A major theme that emerged was the "just doing," which encapsulated the caregiver's sense of duty, sense of dealing with trials, and sense of filial piety, which was viewed as a lifelong commitment [104]. Therefore, the amount or degree of caregiving was not the issue, but rather, how the caregiver interpreted the nature of her role. In cultures characterized by filial piety, caregiving is seen as a reciprocal expression of love [212]. Clearly, cultural norms influenced perceptions of caregiving.

One might hypothesize that as the individuals become more acculturated, they demonstrate less filial piety. However, research indicates that highly acculturated individuals continue to exhibit high levels of filial piety [183]. Consequently, the family system, may serve as a barrier to seeking formal and community assistance [102]. This may further be compounded by the Japanese cultural value of shikata ga nai, which refers to the view that the situation cannot be helped and nothing else can be done [102]. Asai and Kameoka further argue that

it may not necessarily be filial piety that influences the Japanese to provide caregiving, but rather the cultural value of sekentei [105]. Sekentei refers to social dignity, reputation, and social appearance in public [105]. It taps into the notion of individuals behaving in a certain way because of one's concern about the public eye on behavior. In terms of caregiving, sekentei comes into play because individuals are concerned about what others may think of them if they do not provide caregiving [105]. The notion of saving face (i.e., avoiding public or community criticism) surfaced in a study conducted with Korean caregivers [103]. Coupled with the desire for family harmony and saving face, these cultural values impede caregivers from seeking formal services for chronically ill family members; instead, they opt to provide care within the home [103].

In Filipino culture, which is highly influenced by Catholicism, caregivers may view the caregiving experience as a part of God's plan [102]. Again, as mentioned earlier, the reliance on God and the emphasis on quiet endurance may color caregiving both positively and negatively. Filipino caregivers look towards God for support and do not view caregiving as a burden. However, this silent perseverance may impede Filipino caregivers from seeking formal and community assistance.

The counterpart to filial piety as exemplified in Filipino culture is the concept of utang na loob, which refers to a debt of gratitude within relationships [102; 261]. Children are indebted to their parents because their parents raised them. Therefore, children are expected and socialized early on to care for their parents until their parents' deaths [102; 261]. Filipino women expressed a sense of duty that stemmed from gratitude over what their parents had sacrificed. Caregiving is viewed as part of the life cycle. Because of the gendered role expectation on women to be caretakers and nurturers, they feel that when their parents inevitably require care, they will be the ones to assume this role [261]. Again, it is plausible that these cultural values may provide a buffer against caregiving burden and stress.

The perceptions of the caregiving experience are colored by cultural factors and the social environment. In many cultures affected by delayed marriage, divorce, and migration for work, the ability of family structures to provide care has been impacted [256]. As the United States becomes increasingly multicultural, it is important for nurses, social workers, marriage and family therapists, and other healthcare professionals to explore and identify specific cultural factors that influence the caregiving experience and help-seeking behaviors, as well as potential outcomes, such as caregiving stress and burden. It is also important to remember that there is tremendous diversity within groups, and therefore, the themes presented above should not be generalized to every individual and family with which the helping professional comes into contact. Factors such as level of acculturation, age-of-immigration, educational level, and socioeconomic status contribute to the heterogeneity among groups.

ASSESSMENTS FOR FAMILIES OF PATIENTS WITH CHRONIC ILLNESS

Catching a glimpse of human response and experience is the essence of the assessment process. Nurses, social workers, marriage and family therapists, and other allied healthcare professionals need ways of recognizing and organizing cues in order to effectively assist patients with chronic illness and their families [106]. Assessing the impact of chronic illness is vital for two reasons. First, caregivers can prove to be valuable allies when working with the patient. Consequently, the assessment phase provides an opportunity for healthcare professionals to build rapport with families and patients. Second, caregivers experience specific demands, which have been highlighted throughout this course. The literature shows that continued feelings of caregiver strain or burden lead to greater risk of serious health and mental health outcomes [106]. Therefore, it is important for healthcare professionals to know how to intervene.

QUALEY'S THREE-STAGE ASSESSMENT

A general framework of the assessment process is highlighted below, using Qualey's three-stage assessment process when working with family caregivers [107]. Within this framework, basic problem-solving skills are identified [108].

Pre-Problem Assessment Phase

During this phase, the helping professional tries to empathize with and truly understand what the caregiver is experiencing. This phase builds on the therapeutic relationship between the helping professional and the family caregiver. During this time, the caregiver is asked about resources that are required, such as Medicare, home care, or social services.

Problem Assessment Phase

To define a problem accurately, it is important to help caregivers express their problems or needs as specifically as possible. Often, problems are expressed in global terms [108]. In addition, it is important to focus on the present, as opposed to the past. It is not beneficial to dredge up numerous examples of problematic behavior. Clients often have a tendency to bring up a host of problems, shifting from one problem to another. Therefore, the helping professional should help the caregiver identify and focus on a single problem.

The Family Caregiver Alliance National Center on Caregiving recommends that practitioners explore the following domains [151]:

• Background of the patient and caregiver
• Caregiver's perception of the patient's daily functional abilities
• Caregiver's beliefs and values
• Physiologic, psychologic, financial, and social effects of caregiving on the caregiver
• Care needs of the patient
• Resources available

Although it is beyond the scope of this course to review religion and spirituality assessments, practitioners should also evaluate the family caregiver(s) use of religion and spirituality as a pathway for coping as well as if the chronic illness as a stressor has facilitated a religious/spiritual crisis [184].

Solution/Evaluation Assessment Phase

Healthcare professionals can educate caregivers in how to problem-solve. Hepworth et al. delineated the following steps [108]:

1. Acknowledge the problem
2. Analyze the problem and identify needs
3. Employ brainstorming to generate possible solutions
4. Evaluate each option realistically
5. Implement the option selected
6. Evaluate the outcome of the problem-solving efforts

Emotionally focused medical therapy is based on the premise that practitioners build healthy and respectful communications in families. From this perspective, the following open-ended assessment questions may be useful [262]:

• What has each of your experiences been with the illness?
• What does your illness do to you? How does it work?
• How do you think that your illness experience has impacted you (e.g., emotionally, mentally)?
• What is your extended family's experience with illness in general?
• What are your cultural beliefs around health and illness? If these are different for each of you, how do you support one another in light of these differences?
• What are the main issues your illness has caused for you? Beside yourself, who would you say worries most about your health? What worries him, her, or them?
• Who are the members in your support system who have done the most to assist you (emotionally, mentally, physically) throughout this experience? What have they done?
• How do you notice that your physical symptoms impact your emotions, thinking, and behavior?

- How have each of you coped with this illness?

- In what ways has this illness had an effect on your relationship?

- What was your relationship like before the diagnosis? In what ways may your relationship have changed since your diagnosis?

- What gives you hope or strength when things get hard?

- Has your health experience influenced your thoughts about spirituality? If yes, how has your spirituality influenced your health experience?

The next section discusses the various tools and instruments that can be utilized during the assessment process to identify how chronic illness affects families. In addition, several standardized instruments for measuring caregiving strain, burden, and related mental health outcomes such as depression and anxiety will be discussed.

GENOGRAMS

Genograms are excellent assessment tools that visually represent family chronology and family patterns. They provide healthcare professionals the ability to map the family structure and to note and update the family picture as it forms and alters [109; 125; 263]. Genograms give both the clinician and the family member(s) a sense of the relationships among family members by highlighting the roles of family members. The focus is on the interactions and transactions of family members. It removes the scrutiny on any one individual [263]. This can be extremely helpful in identifying the caregiver(s) of the ill family member and the specific tasks they assume. If the caregiver is experiencing strain, then identifying the roles and tasks of the caregiver in the presence of other family members may help them to realize the extent of caregiving provided and offer to take on some of the responsibilities. Healthcare professionals may ask the following types of questions [109]:

- Who helps out when needed?

- To whom do family members turn for assistance?

- Who would you say is the caregiver or caregivers for the patient? What types of tasks and activities are provided by the caregiver(s)?

- Who in the family can take on and adapt to new roles easily?

- Who in the family is seen as the strong one? The dominant one? The submissive one?

- Who is close to the patient?

Life events and crises, both maturational (e.g., births, deaths, a family member leaving for college) and situational (e.g., job loss, chronic illness) may be tracked on a genogram. It is also important to take into account the family's developmental life cycle [125; 151]. This provides a sense of historical continuity and gives a picture of the effect that changes have on the family system [109; 264]. In terms of chronic illness, the clinician can explore these issues with family members by asking the following types of questions [109]:

- How did the family react when symptoms emerged? When a diagnosis was given?

- Who took it the hardest? The easiest? How did personality styles correlate with this?

- How did each family member react and respond to the patient?

- What types of stressors and demands were experienced by each family member?

Genograms can go beyond the immediate, nuclear, and extended family and examine other networks, such as fictive kin, neighbors, community, friends, school, work, religious/spiritual supports, and other social supports [263]. A genogram can offer an objective view for practitioners to see the transactional nature of caregiving for a particular family [264].

SOCIAL NETWORK GRID (OR MAP)

Another visual tool employed to assess a family's degree of social support network is the Social Support Network Map [110]. This assessment tool can be utilized with the primary caregiver of a patient with chronic illness. To conduct this assessment, the helping professional assists the caregiver in identifying family members in the immediate and extended

family system, friends and neighbors, formal organizations, and other community services whom the caregiver perceives as supportive, particularly in his/her role as a caregiver. When working with children who have assumed caregiving tasks, a social network map can provide a useful, visual tool for articulating challenging concepts, such as the complexity of family dynamics, nuclear and extended family relationships, and other social supports [185]. This tool may be used to launch discussion with caregivers about their needs and the resources available to them for help. Social network mapping assesses the following types of issues [110]:

- Who provides social support
- The types of support provided and available
- Gaps in relationship resources
- Opportunities for reciprocal exchanges
- Presence of negativism and stress that produces criticism
- Barriers to using available resources
- Priority of social support in relation to other challenges

STANDARDIZED INSTRUMENTS

Standardized instruments or measures are also viable assessment tools for healthcare professionals. Standardization refers to the process whereby the same procedures are applied across a set of situations so that the results from administering an instrument can be compared and interpreted [111]. Standardization yields findings where one knows that the differences in responses are a reflection of the respondents versus the process of administering the instrument [111]. Standardized instruments have established psychometric properties, which indicate the degree of an instrument's validity and reliability. Such instruments can be useful in clinical practice because they provide a quick means to identify needs that help guide individualized care and interventions [200].

Table 1 lists and describes some standardized instruments that tap into variables related to families and chronic illness. This is not an exhaustive list; other instruments may be helpful [232; 265].

INTERVENTIONS FOR FAMILIES

Because chronic illness can vary over time, the medical regimen prescribed to the patient, the prognosis, and the functional capability of the patient will inevitably vary as well. This unpredictability undoubtedly causes stress for every member of the family system. Chronic illness involves a life-long commitment from all parties—patients, their caregiver(s), and their family members. Consequently, it is imperative that physicians, nurses, social workers, marriage and family therapists, and other healthcare professionals have an understanding of the various types of interventions that can help families and caregivers mitigate the stress brought on by chronic illness. This section is meant to provide some general guidelines for healthcare professionals who work with families that include a member with chronic illness.

PROVIDING INFORMATION

Families who have members with chronic illness require information. This sounds simple, but it is crucial for healthcare professionals to realize that chronic illness is a new and unanticipated event to the family. Therefore, families need concrete information targeted to various timelines [222]. At the initial diagnosis, the family may be overwhelmed and struggling to come to terms with the illness. It may also be grappling to understand new medical jargon and trying to assimilate a tremendous amount of information in order to make decisions about medical care plans. Over time, some family members may be required to take on more responsibilities related to the medical care. This requires practitioners to teach family members necessary skills and to provide support when they feel uncertain about these new responsibilities [153]. At this juncture, the helping professional should assist in enhancing communication between the primary physician and the family [112]. Technical information about the illness, prognosis, and care regimen should be conveyed.

COMPILATION OF STANDARDIZED INSTRUMENTS FOR FAMILIES WITH PATIENTS WITH CHRONIC ILLNESS	
Instrument/Measure	**Description**
Caregiving Issues	
Caregiver Strain Index (CSI)	A 13-item instrument used to measure strain among caregivers of physically ill and functionally impaired older adults. Good internal consistency with Cronbach's alpha of 0.86.
Caregiver's Burden Scale (CBS)	A 29-item scale designed to assess feelings of burden experienced by caregivers of elderly persons with senile dementia.
Caregiver Well-Being Scale	The Caregiver Well-Being Scale measures caregiver well-being from a strengths-based perspective by assessing caregivers' basic human needs and satisfaction with activities of daily living.
Caregiver Reaction Assessment	A 24-item instrument employed to measure a caregiver's reactions to caregiving for elderly family members with a variety of chronic illness. Measures both positive and negative reactions.
Revised Scale for Caregiver Self-Efficacy	A 15-item instrument used to measure confidence in one's ability to carry out issues related to caregiving. It measures three specific areas: self-efficacy for obtaining rest and help, dealing with disruptive patient behaviors, and handling upsetting thoughts related to caregiving. Reliable, with Cronbach's alpha greater than 0.80 for all three subscales.
Caregiver Burden Inventory	A 24-item instrument that asks the caregiver to respond to various demands of care and how it affects one's time, physical health, and social and emotional development.
Mental Health Outcomes	
Center for Epidemiologic Studies—Depressed Mood (CES-D)	A 20-item scale to measure depression in the general population. Very good internal consistency with Cronbach's alpha of 0.85 with the general population.
Self-Rating Anxiety Scale	This is a 20-item instrument comprising elements found in anxiety disorders.
Perceived Stress Scale	This is a 10-item instrument utilized to measure the degree to which one appraises situations in one's life as stressful. Cronbach's alpha is 0.78, indicating respectable reliability.
Social Support	
Multidimensional Scale of Perceived Social Support (MSPSS)	This is a 12-item instrument designed to measure perceived social support from three sources: family, friends, and a significant other. It has excellent reliability with Cronbach's alpha of 0.91.
Social Support Questionnaire	This scale asks about people in the individual's environment who provide help or support. The scale first asks the individual to list people who provide the support, and then to indicate his/her level of satisfaction.
Social Support Behavior Scale	This is a 45-item instrument used to access five types of social support: emotional, socializing, practical assistance, financial assistance, and advice/guidance.
Financial Burden	
The Economic Hardship Questionnaire	This is a 12-item instrument that measures how the household has been affected by financial challenges.
The Family Burden Interview Schedule	This instrument does not solely measure financial burden; it also measures how an illness affects family routines, interactions, leisure, and health and mental health. This is a 24-item instrument that has been demonstrated to be valid and reliable.

Source: [115; 116; 117; 118; 119; 120; 121; 122; 123; 124; 152; 186; 220; 221] — *Table 1*

Healthcare professionals should be sensitive to the fact that this information may need to be relayed on several occasions. Information and education should be communicated in a lay-friendly and non-hurried manner [222]. During this time, the helping professional may want to begin to coordinate a list of resources and referrals [112].

Over the course of the illness, caregivers and family members continue to need information about how to efficiently care for the patient. The types of information may range widely. Lubkin and Larsen, for example, note that healthcare professionals can provide general information about human development to family members. It is beneficial for caregivers and family members to understand normal changes that are part of human development and the life cycle, changes that are specifically related to the illness, or possibly, an interaction of both [82]. Egocentrism, for example, is a part of adolescence. Chronic illness can magnify this as the adolescent receives a great deal of medical and parental attention, and the adolescent can become overbearing [41]. Yet, simultaneously, an adolescent may believe that he/she is the only one with these problems and feel that no one can empathize [41]. Social isolation may occur. Therefore, it becomes a complicated issue to determine whether a particular behavioral change is the result of normal human development or illness-related.

Technical information related to the daily care of the patient should also be relayed. Family members may have to be taught how to lift and move patients around without hurting themselves or the patient and how to administer medications [82]. Family members should be reminded and educated about the physical consequences of the illness. Patients, for example, may experience fatigue as a result of the medications and/or the illness; however, some family members may become frustrated with the patient and interpret the patient as being lazy and taking advantage of the sick role [82]. Healthcare professionals should be fully knowledgeable about resources on both the local and national level to assist families in coordinating care for both the patient and themselves. Resources and services include places to access special equipment, legal and financial information, respite care, counseling, and support groups [82].

EXPLORING THE MEANING OF CHRONIC ILLNESS AND AMBIGUOUS LOSS

The emphasis is to provide an opportunity for family members to explore their feelings of loss, sorrow, mourning, and grief. Interventions also focus on helping families to accept the ill family member's lost physical functioning and capabilities [32].

Boss and Couden argue for the importance of helping families deal with ambiguous loss [55]. The goal is not necessarily to eliminate this sense of loss, but rather, to increase family tolerance and coping. Interventions are both structural/short-term and solutions-focused as well as psychodynamic [55]. After identifying the loss, the family would work collaboratively to make decisions regarding day-to-day care and activities. Operating from this lens, depression, which is commonly experienced among caregivers, may also be viewed as symptomatic of ambiguous loss. Therefore, practitioners can help encourage caregivers to not assume all the burden of responsibility, but rather to delegate and distribute the work. This may mean obtaining respite assistance [55].

One of the more difficult tasks is for family members to understand and make sense of the ambiguous loss [55]. They can begin by looking at their own family's socialization, spiritual and religious values, and mentality of thinking and viewing the world optimistically, and by evaluating the family's beliefs about mastery [55].

SELF-CARE FOR FAMILY MEMBERS

In order to prevent burnout, family members and caregivers should learn to take care of themselves. Caregivers often experience a host of conflicting emotions, including guilt, sadness, anxiety, and exhaustion. They often feel that they should not express negative feelings, believing that it will adversely affect the patient [82]. Healthcare professionals should routinely ask caregivers how they are feeling and coping, and then validate their experiences and feelings.

Caregivers should also be encouraged to obtain respite care. Respite refers to any type of service, either informal or formal, that offers relief and assistance for family members to cope with the challenges of chronic illness [113]. Informal respite assistance may include extended family members, neighbors, and friends who might periodically help with meal preparations, transportation, or house-keeping. Formal respite consists of in-home respite or out-of-home respite. In-home respite care involves a paid companion who spends time with the patient and helps with the patient's care, while out-of-home respite care includes adult day-care centers and community recreational services [113].

Mindfulness interventions may also be beneficial for caregivers. These approaches teach caregivers to be aware of what is occurring at the moment without any judgement and to focus on regulating emotions. In a study to evaluate the effectiveness of an online mindfulness intervention, the level of caregiver burden was decreased after eight weeks of weekly, one-hour mindfulness practice and self-compassion training [187].

In collectivist cultures, one's identity is intertwined with the ill family member, and how the ill family member fares also affects the caregiver [188]. As such, interventions may target the patient and caregiver simultaneously [188].

FAMILY THERAPY

Based on family systems theory, family therapy can be a useful intervention to assist families in acknowledging and accepting the patient's illness as well as the treatment plan and prognosis [112]. It can help the patient and family understand the illness narratives created by the patient and how this story has affected the family system. The goal is to help each member co- and re-author the illness narrative(s) [223]. It can help families develop coping skills to manage the challenges of the continual stressors related to chronic illness and identify maladaptive family patterns, such as enmeshment, triangulation, overprotectiveness, and rigidity [112; 125]. Role expectations can be clarified among family members, and lines of communication can be opened,

and at times, restored, if certain family members feel overloaded with caregiving responsibilities [82]. Furthermore, assuming a caregiving role for an elderly parent may resurrect previous developmental issues [154].

PSYCHOEDUCATIONAL GROUPS

Psychoeducational groups were first used in families with members who had schizophrenia; however, they have been adapted for use with other clinical populations. Psychoeducational groups typically involve a didactic and support component, whereby family members (i.e., caregivers) convene for 10 to 12 structured sessions, on a biweekly basis [114]. It assumes that the caregivers are experts and each member can help each other [155]. The didactic component focuses on both cognitive information and behavioral change. Caregivers, for example, listen to a series of mini-lectures that focus on disease etiology, treatment, and management [114]. Problem-solving skills and coping strategies are often discussed. Caregivers are encouraged to use these newly learned skills and apply them at home. The support component of the psychoeducational groups provides a forum for family members to talk about various issues that may come up in the caregiving situation. Facilitators and other family members provide validation and recognition of feelings. Ultimately, when family members feel confident about providing care, their quality of life improves [153]. Psychoeducation that encompasses active participation and learning appears to be more effective compared than psychoeducation interventions solely involving lectures. The use of role playing, practicing of skills, completion of assignments, and group discussions provide a forum for participants to be actively engaged and where they can practice new communication and problem-solving skills [267]. In terms of the research evaluating the effectiveness of psychoeducational groups for caregivers, the findings are mixed. In one study, nurse-facilitated psychoeducational groups for caregivers resulted in no improvements in perceived caregiver burden [189]. But a separate study found participation in distance or in-person psychoeducational groups was associated with improved caregiver distress and

burden [190]. A 2023 meta-analysis of 13 trials of Internet-based psychoeducation for caregivers living with an individual with dementia, psychoeducation interventions were effective in reducing depression and stress [268]. However, there was no effect on quality of life, anxiety, and burden.

SELF-HELP GROUPS

Support and self-help groups focus on a specific client population (e.g., patients diagnosed with cancer) and related caregiver needs. These groups are facilitated either by volunteers or healthcare professionals. They may vary but will provide information regarding the illness and disease process and symptom management, normalize members' experiences, provide emotional support around caregiving, encourage advocacy, or a combination of these services [82; 191]. Trust is a key element for these types of groups [192]. Such groups can also help to improve members' outlook on life, feelings of optimism, and self-esteem [224].

The installation of hope is vital for caregivers so they can look toward the future [269]. Caregivers are often isolated, and therefore, when they come to a support group, they realize that they are not alone, which is known as universality. The imparting of information is also key, as caregivers in the group exchange information and learn from each other. Altruism is the desire to help others, and caregivers in a support group can feel good that they were able to play a role in helping another groups member. Existential factors, such as loss and death, are inevitable, and support group members can provide comfort and support to their fellow caregivers. Finally, group cohesiveness can provide group members with a sense of belonging, which can be empowering and nurturing. Ultimately, the benefits from support groups can be powerful for caregivers [269].

MACRO-ORIENTED INTERVENTIONS

Findley argues that part of their social justice advocacy role for social workers and other service providers is to challenge issues of marginalization when working with families and family members who have been diagnosed with a chronic illness [145}. This is particularly the case for racial/ethnic minorities and those who are further marginalized based on their socioeconomic status, sexual orientation, gender identity, and other factors that contribute to health disparities. It is important to advocate reducing or eliminating barriers that prevent families and patients from receiving the care and support that they need. Practitioners can also work to promote evidence-based interventions and guidelines to ensure greater collaboration between patients and their family members at the various levels of care [145].

INTERPROFESSIONAL PRACTICE AND COLLABORATION

Chronic illness is a multifaceted and complex issue for the patient and the patient's family. It is estimated that patients with chronic illness consistently visit an average of four to nine different healthcare professionals [225]. To facilitate more efficient and greater quality care, it is vital that care plans be synchronized and carefully coordinated among practitioners. This requires that practitioners have broad knowledge informed by a biopsychosocial perspective, with competence in the medical facts of the illness condition, family systems, spirituality/religiosity, marriage and couple therapy, developmental theories, and social work and case management skills. Because it is impossible for a single practitioner to be highly competent in all of these areas, interprofessional collaboration (IPC) is key.

IPC is characterized as a process whereby multiple service providers representing different professional fields work together to provide comprehensive services to clients/patients in order to coordinate high-quality services across settings. The World Health Organization defines interprofessional collaboration as occurring "when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care across settings" [226]. It requires professionals to alter the way they practice—moving from working in a silo to working in a collaborative and trusting manner. Efficiency, cost containment, and measurable outcomes are key to IPC. In the case of chronic illness, including the expertise of psychologists, dieticians, and exercise physiologists can be key [270].

The core features of IPC include sharing, interdependency, communication, and mutual trust and respect [227]. Because of the complexity of chronic illness, the ideal is to have one shared care plan and document that is easily accessible by all providers [225]. Unfortunately, barriers to effective referral, costs to patients if their insurance does not cover certain types of providers, and lack of understanding of IPC are impediments [270].

A systematic review of clinical trials studies on the role of interprofessional collaboration on chronic illness found that interprofessional collaboration improved the quality of coordinated care and ensure that care provided was patient-centered [228]. However, there is not sufficient evidence that interprofessional collaborations improved medication adherence or decreased mortality. Another systematic review and meta-analysis found that IPC was effective in reducing the number of hospital stays, patients' blood pressure, and cholesterol level [271].

CONCLUSION

Education is an empowering form of intervention. Often, families are overwhelmed and need guidance in pointing them in the direction where they can obtain information and resources. Nurses, practitioners, and other healthcare professionals are encouraged to review and look into these resources as a means of continuing their own education as well as a place to direct families for additional resources.

RESOURCES

Families have a range of resources to tap when attempting to gather information. This section highlights some national organizations as well as material and resources that may be found on the Internet. Service providers can use these as a starting point when working with families.

Alzheimer's Association
https://www.alz.org
The Alzheimer's Association, a national network of chapters, is the largest national voluntary health organization committed to finding a cure for Alzheimer's and helping those affected by the disease.

American Cancer Society
https://www.cancer.org
The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

American Diabetes Association
https://www.diabetes.org
The American Diabetes Association is a nonprofit health organization providing diabetes research, information, and advocacy.

American Society on Aging

https://www.asaging.org

Brings together researchers, practitioners, educators, business people and policymakers concerned with the physical, emotional, social, economic, and spiritual aspects of aging.

California Caregiver Resource Centers

https://www.caregivercalifornia.org

A network of 11 centers that provide resources for family caregivers of adult patients who are affected by chronic and debilitating health conditions.

Caregiver Media Group

https://caregiver.com

Caregiver Media Group is a leading provider of information, support, and guidance for family and professional caregivers. They publish Today's Caregiver Magazine, the first national magazine dedicated to caregivers. They also sponsor caregivers.com, a website that includes topic specific newsletters, online discussion lists, back issue articles of Today's Caregiver Magazine, and chat rooms.

**Center for the Study of
Chronic Illness and Disability**

https://chhs.gmu.edu/research/research-centers/CCID

The CCID is an interdisciplinary research center at George Mason University. Founded in 2007, it works to promote research to improve the lives of people with chronic illness and disability.

Eldercare Locator

https://eldercare.acl.gov

The Eldercare Locator is a public service of the Administration on Aging, a division of the U.S. Department of Health and Human Services, and is administered by the National Association of Area Agencies on Aging and the National Association of State Units on Aging.

Family Caregiver Alliance

https://www.caregiver.org

Founded in 1977, the Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. It is now a nationally recognized information center on long-term care.

Genograms

https://www.therapistaid.com/therapy-guide/genograms

This site provides information about communication patterns and the basics of genograms.

**Juvenile Diabetes Research
Foundation International**

https://www.jdrf.org

Juvenile Diabetes Research Foundation International is the world's leading nonprofit, nongovernmental funder of diabetes research. JDRF was founded in 1970 by the parents of children with juvenile diabetes—a disease that strikes children suddenly, makes them insulin dependent for life, and carries the constant threat of devastating complications.

KidsHealth

https://kidshealth.org

KidsHealth is a doctor-approved health information site providing information about children from before birth through adolescence.

National Association for Home Care and Hospice

https://www.nahc.org

NAHC is the nation's largest trade association representing the interests and concerns of home care agencies, hospices, home care aide organizations, and medical equipment suppliers.

National Caregivers Library

https://cpfamilynetwork.org/resources/resources-guide/national-caregivers-library-2

The National Caregivers Library is dedicated to improving the lives of caregivers of the elderly, disabled, and chronically ill by creating a highly accessible resource where caregivers can better learn the process of caregiving, receive help in managing their fears and concerns, and obtain resources for help with all aspects of caregiving.

Implicit Bias in Health Care

The role of implicit biases on healthcare outcomes has become a concern, as there is some evidence that implicit biases contribute to health disparities, professionals' attitudes toward and interactions with patients, quality of care, diagnoses, and treatment decisions. This may produce differences in help-seeking, diagnoses, and ultimately treatments and interventions. Implicit biases may also unwittingly produce professional behaviors, attitudes, and interactions that reduce patients' trust and comfort with their provider, leading to earlier termination of visits and/or reduced adherence and follow-up. Disadvantaged groups are marginalized in the healthcare system and vulnerable on multiple levels; health professionals' implicit biases can further exacerbate these existing disadvantages.

Interventions or strategies designed to reduce implicit bias may be categorized as change-based or control-based. Change-based interventions focus on reducing or changing cognitive associations underlying implicit biases. These interventions might include challenging stereotypes. Conversely, control-based interventions involve reducing the effects of the implicit bias on the individual's behaviors. These strategies include increasing awareness of biased thoughts and responses. The two types of interventions are not mutually exclusive and may be used synergistically.

FACULTY BIOGRAPHY

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