

CHAPTER 8

Adherence

Susan Sochacki

► Introduction

Approximately 117 million Americans are living with at least one or more chronic diseases, requiring challenging treatments and multiple, lifelong medications (Brown et al., 2016). It is well documented that these staggering numbers present challenges for the U.S. healthcare system, including high healthcare costs and poor health outcomes in individuals with multiple chronic conditions (Parekh & Barton, 2010; Tinetti, Fried, & Boyd, 2012). Chronic health conditions cause fatigue, pain, and any number of physical limitations, which contribute to the burden of illness (Boehmer, Shippee, Beebe, & Montori, 2016). Additionally, chronic illness itself adds to a patient's treatment burden. Treatment burden is defined as treatment work, required by the patient, that impacts the patient's functioning and well-being (Eton et al., 2013). Because of the physical challenges of chronic illness and the burden of treatment it is challenging for many patients to follow the advice of care providers.

Patient adherence to treatment recommendations is a popular topic in recent healthcare literature. An underlying assumption in most studies of treatment adherence is that better

adherence leads to better outcomes (Chubak & Hubbard, 2016). Adherence, according to the World Health Organization (WHO, 2003), is defined as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a healthcare provider." The important part of this definition is that patients agree to the healthcare provider's recommendations and do not passively follow recommendations. It is important that all healthcare providers work with patients with chronic illnesses to ensure that there is clear understanding of the treatment regimen and that side effects and possible treatment outcomes are clear to patients and family members. Eighty-six percent of all healthcare spending in 2010 was for people with one or more chronic health conditions, with \$315.4 billion being spent on heart disease and stroke alone (Centers for Disease Control and Prevention [CDC], 2016a). In spite of this significant expenditure of dollars, adherence to medical recommendations remains poor across all chronic disease regimens, further increasing healthcare expenditures and preventing patients from achieving the full benefit of any intervention. In addition, most chronic disorders are treated

© Alpha/Shutterstock

159

160 Chapter 8 Adherence

with a plan of care that encompasses a variety of components, which may include medication, diet, and exercise. Therefore, patients are often asked to manage a very complex treatment regimen. Medication, lifestyle, and dietary nonadherence rates are estimated to range between 50% and 80% (Brown et al., 2016; WHO, 2003).

The relevance of adherence to the total wellness-illness continuum was first described in 1970 by Marston, a nurse. Marston considered adherence to comprise self-care behaviors that individuals undertake to promote health, to prevent illness, or to follow recommendations for treatment and rehabilitation in diagnosed illnesses. She is notable in the history of treatment adherence as the first reviewer of literature in the field (Greene, 2004). It may be helpful, however, to consider adherence as encompassing more than self-care behaviors; rather, it is behavior that is often shared, as patients cannot always implement their medical regimens without the participation of others, even though the delineation of responsibilities is not always clear.

The subject of adherence is multifaceted and complex, with patient, healthcare provider, and system dynamics contributing to poor adherence rates and suboptimal health. Nevertheless, it has been posited that greater health benefits worldwide would be realized with improved adherence to existing treatments than with the development of new medical treatments (Bosworth, 2010; WHO, 2003). To facilitate understanding of these complex issues, this chapter addresses factors that have an impact on adherence behavior. Theories that inform our understanding of adherence are discussed, and strategies to enhance treatment adherence are reviewed.

Goals for Healthy People 2020

Since 1979 the *Healthy People Initiative* has set disease prevention and health promotion objectives for the nation. Overall goals for *Healthy People* (Healthy People, 2016) are to help Americans lead healthy and long lives and to reduce health disparities. There are nearly 600 objectives

within 42 topic areas to be addressed by 2020, including 1,200 measures. While the shift away from a greater focus on individual behavior to improved healthcare infrastructure is reflected in the 2020 goals, many of the objectives in these documents relate to behavior-change goals for individuals. For example, for diabetes, many of the goals in *Healthy People 2020* refer to lifestyle changes and education to better manage the disease and avoid complications such as cardiovascular disease and death. Goals for *Healthy People 2020* include health behavior change, such as adherence to chronic illness regimens, and preventive behaviors such as screenings to detect risk factors for disease. As we near the 2020 deadline, the *Healthy People 2030* committee has been seated and is beginning the work of revising these health objectives to inform the next decade (Healthy People, 2016).

► Adherence and Chronic Illness

The predominant pattern of illness has changed from acute to chronic as science and technology have advanced. With that technology, treatment regimens have become very complex. However, because of changes in care delivery and insurance reimbursement, these complex regimens are often implemented with limited supervision, as the patient and/or family caregivers attempt to carry out these prescribed regimens at home. Therefore, healthcare providers must be concerned with the extent to which patients can implement the treatment plans that are recommended. Additionally, there must be more direct strategies to assess the patient's responses.

Patient responsibility for managing chronic conditions has increased; however, there is concern about adherence as it relates to medical outcomes and economic costs. For example, an individual who has type 1 diabetes mellitus (DM) may have a computerized insulin pump to deliver insulin that requires blood glucose testing 6–10 times per day. This requires understanding complex electronics

CASE STUDY 8-1

John Lang, a 74-year-old retired car manufacturer, is experiencing an acute exacerbation of shortness of breath. He was diagnosed with chronic obstructive pulmonary disease (COPD) 3 years ago and has a history of hypertension and type 2 diabetes. He has frequent upper respiratory infections and has had pneumonia three times since his diagnosis of COPD. He reports that he has been unsuccessful in his repeated efforts to quit smoking but has reduced his smoking to one to two packs per week, down from one pack per day. John's body mass index (BMI) is 36, and he admits that sticking to his diet is a daily struggle. His HbA_{1c} is 8.8%, and he says he faithfully takes his oral antidiabetic medication daily. John's wife is frustrated with his continued smoking and poor diet and asks the nurse for help.

Discussion Questions

1. What additional assessment might you perform?
2. What resources are available to John and his wife?
3. What questions might you ask to evaluate John's nonadherence to recommended health behavior changes?

and learning techniques that are difficult at best. Real-time continuous glucose monitoring has been available for several years, but its use in daily diabetes care is not widespread, though studies show that glycemic control is improved if worn consistently (Chiang et al., 2014; Patton, 2015). More than 90% of patients with diabetes have type 2 diabetes, which correlates with increased age, body weight, and family history (American Diabetes Association, 2015). A diabetic patient may, at some point, become a candidate for hemodialysis or renal transplantation because of complications. All of these treatment modalities require adherence behaviors to ensure maximal benefit, minimal disruption to daily routines, and most importantly minimal harm to the patient.

The changing healthcare environment has also had an impact on patient burden in chronic illness. Healthcare reimbursement has had a definite effect on health care as evidenced by earlier hospital discharges, shortened office visits, and increased home health referrals. Family members are assuming more responsibility for the continuing care of people with chronic illness. Approximately 34.2 million caregivers provide unpaid care to an adult older than age 50 in the United States (AARP Public Policy Institute, 2015). Family caregivers are performing tasks

that nurses typically perform. These tasks include management of medication, dressing changes, incontinence care, and even management of equipment such as feeding tubes and oxygen (Harvath, Lindauer, & Sexson, 2016), and often these tasks are in isolation. It is vital that healthcare providers ensure that patients and family members have appropriate resources to manage these complex care needs.

Healthcare researchers have examined adherence related to many different chronic illnesses for a number of years, and yet the problem persists. Chronic illness regimens can be exceedingly complex, and resources to assist individuals with chronic illness are often limited. Therefore, it is important that the healthcare professional understands the variables that affect the ability of the person to adhere to a treatment regimen.

History

In 2004, Greene described the use of the terms related to a patient's suboptimal following of recommended treatment regimens. He discussed how, in the early years of scientific inquiry of adherence, a variety of patients were labeled as "uncooperative, noncompliant, poorly controlled,

resistant, devious, incorrigible, and careless" (p. 330). The currently accepted term "adherence," however, recognizes the patient's active participation in and ultimate responsibility for his or her own health, implying patient empowerment to choose whether to follow health advice (Brown & Bussell, 2011). Healthcare professionals often make decisions about the effectiveness of treatments without knowing whether the patient has even followed treatment recommendations (Brown et al., 2016). It is important to be aware of a tendency among care providers to see adherence behavior as positive, admirable, and wise (the "good" patient) and nonadherence behavior as being negative, undesirable, and unwise (the "problem" patient). It seems probable that healthcare professionals who hold this view would be less likely to make concerted efforts to search out barriers to adherence, and simply attach the label of "nonadherent" to the patient.

Individuals with chronic medical conditions face a variety of stressful life circumstances involving a range of adaptation demands. They must deal with a loss of independence, the threat of disease progression, and the challenge of modifying their behavior to meet the demands of a prescribed regimen. Lifestyle modifications may become necessary and include, but are not limited to, dietary changes, use of medications, and change in physical activity. Adherence to these modifications has substantial implications for treatment success and decreased disease progression. For the patient with chronic illness, failure to adhere can result in increased disease complications, increased hospitalizations, and greater treatment costs, as well as disruptions in lifestyle, family dynamics, and coping skills (WHO, 2003).

Nonadherence to prescribed treatment is often hidden, so an important first step in improving adherence is to uncover nonadherence (Brown et al., 2016). Healthcare providers prescribe many different kinds of treatment regimens for patients with chronic illness. Because the most common intervention prescribed is medication, a look at adherence to medication is in order (Moral et al., 2015).

Prevalence

Ascertaining the true picture of nonadherence to chronic illness is difficult. Studies indicate that adherence rates in chronic illness are approximately 50% (Lee, Song-Song Lee, Xin, & Thumboo, 2017; WHO, 2003), with ranges of nonadherence rates estimated to be 20–40% for acute illness, 20–60% for chronic illness, and an incredible 50–80% for preventive regimens (Borowicz, 2010; WHO, 2003). In a study analyzing nearly 200,000 written e-prescriptions, only 78% were refilled, and only 72% of prescriptions for new medications were filled (Fischer, Stedman, Liu, Vogeli, & Shrank, 2010). Adherence rates were higher for prescriptions written by primary care specialists, especially pediatricians (84%), and for patients aged 18 and younger (87%) (Fischer et al., 2010). Self-reported adherence to cardiovascular medications in patients who have coronary artery disease is approximately 40%. Nearly 25% of patients are partially or completely nonadherent in filling prescriptions after hospital discharge for a cardiac event, and of the patients who are initially adherent, as many as 50% will discontinue antihypertensive medications within 6–12 months (Baroletti & Dell'Orfano, 2010).

Adherence is a key factor in the effectiveness of medication therapies but is particularly critical in the treatment of chronic conditions (Brown et al., 2016). There are a number of methods available to evaluate medication adherence. Patient self-reports are commonly used in primary care settings (Brown & Bussell, 2011). Simply asking patients if they are taking their medications as prescribed has obvious limitations. Patients often tell us what they think we want to know or are afraid to admit they are not following recommendations. Some healthcare practitioners use more objective measures such as pill counts and examining pharmacy-refill rates (Brown & Bussell, 2011). The danger here is assuming missing medication was actually taken by the patient. There are also biochemical measurements of serum drug levels that can help inform adherence. A combination of

these adherence evaluation methods is generally advised along with monitoring for the desired physiologic response (Brown & Bussell, 2011).

Adherence studies are typically disease-specific; that is, the study population is defined by the presence of a specific disease. However, more recent reviews of adherence behaviors in persons with chronic illness indicate that the nature and extent of adherence problems are similar across diseases, across regimens, and across age groups (Brown et al., 2016; Hamood, Hamood, Green, & Almog, 2016).

Studies examining adherence to prescribed medication in patients with chronic conditions demonstrates that patients are not following recommendations from prescribers. The data are staggering. Hamood et al. (2016) found that more than 20% of patients were nonadherent to all four prescribed cardioprotective medications after acute myocardial infarction. In a 2-year follow-up study of patients after stroke, 26.1% were found to be nonadherent to prescribed statin medication (Sjolander, Eriksson, & Glader, 2016). In a study of schizophrenic patients' adherence to prescribed medication after discharge, 36% were found to have missed more than 3 weeks of medications or more in the month after discharge (Abdel Aziz et al., 2016). Other disease-specific medication adherence rates include the following:

- **Epilepsy:** One study found an adherence rate of 34% (Paschal, Rush, & Sadler, 2013).
- **Hypertension:** One group reported 62% adherence when measured through electronic monitoring (Dunbar-Jacob, Sereika, Houze, Luyster, & Callan, 2012).
- **Tuberculosis (TB):** One report found an 80.6% adherence rate during the continuation phase of treatment (Tola et al., 2016).
- **Human immunodeficiency virus (HIV) medication in adults:** In one study 62% of adults reported 90% or better adherence to highly active antiretroviral therapy (HAART) medications (Ortego et al., 2011).
- **Asthma:** In one study, 63 of 182 patients (35%) had filled fewer than 50% of prescriptions for inhaled combination therapy, and

- **57 patients (88%) admitted low adherence after initial denial** (Gamble, Stevenson, McClean, & Heaney, 2009).
- **Glaucoma:** One study reported adherence rates of 71% (electronic monitoring), 77% (physician estimate), and 95% (patient self-report) (Okeke et al., 2009).
- **Stroke:** Of 15,192 stroke patients followed for 2 years, 73.9% were adherent to statin treatment after hospital discharge (Sjolander et al., 2016).

When looking at the prevalence of adherence in chronic illness, it is important to look at more than just adherence to prescribed medication. Patients with chronic illness have other elements in their treatment regimens that are often difficult to follow. In a study by the Juvenile Diabetes Research Foundation (2010), the use of continuous glucose monitoring devices declined in adults over time (from 7 days per month to 6.5 days per month by the sixth month). The decline was even greater in adolescents (6.3–3.3 days per week) and in children (6.8–3.7 days per week). Riaz and colleagues (2014) looked at dietary adherence in patients with type 1 diabetes and found that 58.5% were not adherent, and found that activity adherence in the same population was 59.4%.

In a study of no-show rates at a colposcopy clinic, researchers found that 12.3% of women at high risk for cervical cancer failed to attend a scheduled appointment (Luckett, Pena, Vitonis, Bernstein, & Feldman, 2015). Alves Vieira et al. (2015) found that in patients with phenylketonuria 56% of patients under age 13 and 77% of patients over age 13 had high phenylalanine levels, indicating that they were not adhering to the prescribed diet. Researchers looked at adherence among patients referred for endoscopic treatment for esophageal neoplasia and found a 72% adherence rate with follow-up endoscopy (Cassani, Slaughter, & Yachimski, 2016). Chan et al. (2015) studied follow-up visit rates in a renal palliative care clinic and found 30–50% of scheduled clinic visits were not kept. Most research demonstrates that adherence to

these adherence evaluation methods is generally advised along with monitoring for the desired physiologic response (Brown & Bussell, 2011).

Adherence studies are typically disease-specific; that is, the study population is defined by the presence of a specific disease. However, more recent reviews of adherence behaviors in persons with chronic illness indicate that the nature and extent of adherence problems are similar across diseases, across regimens, and across age groups (Brown et al., 2016; Hamood, Hamood, Green, & Almog, 2016).

Studies examining adherence to prescribed medication in patients with chronic conditions demonstrates that patients are not following recommendations from prescribers. The data are staggering. Hamood et al. (2016) found that more than 20% of patients were nonadherent to all four prescribed cardioprotective medications after acute myocardial infarction. In a 2-year follow-up study of patients after stroke, 26.1% were found to be nonadherent to prescribed statin medication (Sjolander, Eriksson, & Glader, 2016). In a study of schizophrenic patients' adherence to prescribed medication after discharge, 36% were found to have missed more than 3 weeks of medications or more in the month after discharge (Abdel Aziz et al., 2016). Other disease-specific medication adherence rates include the following:

- **Epilepsy:** One study found an adherence rate of 34% (Paschal, Rush, & Sadler, 2013).
- **Hypertension:** One group reported 62% adherence when measured through electronic monitoring (Dunbar-Jacob, Sereika, Houze, Luyster, & Callan, 2012).
- **Tuberculosis (TB):** One report found an 80.6% adherence rate during the continuation phase of treatment (Tola et al., 2016).
- **Human immunodeficiency virus (HIV) medication in adults:** In one study 62% of adults reported 90% or better adherence to highly active antiretroviral therapy (HAART) medications (Ortego et al., 2011).
- **Asthma:** In one study, 63 of 182 patients (35%) had filled fewer than 50% of prescriptions for inhaled combination therapy, and

- **57 patients (88%) admitted low adherence after initial denial** (Gamble, Stevenson, McClean, & Heaney, 2009).
- **Glaucoma:** One study reported adherence rates of 71% (electronic monitoring), 77% (physician estimate), and 95% (patient self-report) (Okeke et al., 2009).
- **Stroke:** Of 15,192 stroke patients followed for 2 years, 73.9% were adherent to statin treatment after hospital discharge (Sjolander et al., 2016).

When looking at the prevalence of adherence in chronic illness, it is important to look at more than just adherence to prescribed medication. Patients with chronic illness have other elements in their treatment regimens that are often difficult to follow. In a study by the Juvenile Diabetes Research Foundation (2010), the use of continuous glucose monitoring devices declined in adults over time (from 7 days per month to 6.5 days per month by the sixth month). The decline was even greater in adolescents (6.3–3.3 days per week) and in children (6.8–3.7 days per week). Riaz and colleagues (2014) looked at dietary adherence in patients with type 1 diabetes and found that 58.5% were not adherent, and found that activity adherence in the same population was 59.4%.

In a study of no-show rates at a colposcopy clinic, researchers found that 12.3% of women at high risk for cervical cancer failed to attend a scheduled appointment (Luckett, Pena, Vitonis, Bernstein, & Feldman, 2015). Alves Vieira et al. (2015) found that in patients with phenylketonuria 56% of patients under age 13 and 77% of patients over age 13 had high phenylalanine levels, indicating that they were not adhering to the prescribed diet. Researchers looked at adherence among patients referred for endoscopic treatment for esophageal neoplasia and found a 72% adherence rate with follow-up endoscopy (Cassani, Slaughter, & Yachimski, 2016). Chan et al. (2015) studied follow-up visit rates in a renal palliative care clinic and found 30–50% of scheduled clinic visits were not kept. Most research demonstrates that adherence to

chronic illness regimens is difficult for most and impossible for some patients.

Most adherence research in the psychiatric population is focused on medication adherence, but some researchers looked at appointment-keeping behaviors. Pantalano, Murphy, Barry, Lavery, and Swanson (2014) found that 42% of patients with a psychiatric disorder and 66% of patients with a dual diagnosis did not attend their first office appointment after discharge from a psychiatric unit.

Components of Adherence

Adherence has been conceptualized in the literature to include three components: initiation, execution, and persistence (Blaschke, Osterberg, Vrijens, & Urquhart, 2012). These authors were looking at medication adherence and identified initiation as being aware that a prescription was written, filling the prescription, and taking the first dose of medication (Blaschke et al., 2012; Gadkari & McHorney, 2010). Discontinuation is when a patient stops taking a medication. The time between initiation and discontinuation encompasses execution (defined as the regularity of dosing and the correspondence of behavior with prescribed regimen) and persistence (the time lapse between initiation and discontinuation) (Blaschke et al., 2012). For the purposes of clarifying the concept of adherence, and for quantification in research, these stages of adherence can be categorized as continuous actions (which include implementation and persistence) and discontinuous actions (which include initiation and discontinuation) (Lehmann et al., 2014). Continuous actions include both regularity and continuity simultaneously, whereas discontinuous behaviors bookend continuous action. Approximately 16% of patients with a new prescription do not commence treatment (Gadkari & McHorney, 2010), and half of patients stop treatment within the first year (Haynes, McDonald, & Garg, 2002).

Another component of nonadherence that is important to determine is whether nonadherence

is intentional or unintentional. Patients can purposely decide not to fill or take medication, not to follow diet and exercise recommendations, or to refrain from or engage in other behaviors that directly affect their health, but unintentional nonadherence should also be considered with any patient. Patients can unintentionally non-adhere to medications owing to forgetfulness, carelessness, poor health literacy, socioeconomic factors, and cognitive impairment.

Another factor in treatment nonadherence is the disruption of routines and schedules. Taking time away from work or other demands is not always possible. Medication intakes during evening, weekend, and holiday times have been shown to contribute to incorrect timing of doses as well as missing doses entirely. Most consistent medication intake occurs in the mornings, Monday through Thursday (96%), with the least consistent intake occurring on Saturday evening (82%). Correctly timed intake occurs most often on Monday and Tuesday mornings (61%), in contrast to Sunday evenings (33%) (Vervloet et al., 2013).

Another concept important to medication adherence is that of prospective memory—that is, the neurocognitive capacity to remember to do something at a later time. Prospective memory, a subcategory within the construct of episodic memory, declines with age and neurocognitive impairment. Research has demonstrated the importance of prospective memory for medication adherence in HIV infection, rheumatoid arthritis, and diabetes self-management, and it may be an important avenue for interventions to increase medication adherence behaviors across disease states (Zogg, Woods, Saucedo, Wiebe, & Simoni, 2012).

Managing chronic illness alone can be difficult and complex; therefore, some patients turn to family and friends to help with decision making, adhering to complex regimens, and simply to cope with the illness. Many researchers have studied the role of friends and family. Stephens, Rook, Franks, Khan, and Lida (2010) investigated both the negative and positive strategies spouses used to urge patients with

Type 2 diabetes to improve dietary adherence. Findings showed that cautioning the patient about the consequences of eating an inadequate diet was associated with poorer adherence, whereas encouragement to select healthier food choices was associated with better adherence. A study in the field of HIV describes the role that family and caregivers provide in complex regimens, and explicates how various types of stigma affect caring for an HIV-infected family member (Beals, Wight, Aneshensel, Murphy, & Miller-Martinez, 2006). Likewise, family support in adolescents suffering from asthma was positively associated with asthma control and improved quality of life (Rhee, Belyea, & Brasch, 2010). Sussman and colleagues (2016) studied patient perceptions of family and friends' involvement in their care, and found that 43.9% of the participants believed that their friends or family members were involved in their self-care almost every day, and 60.8% found the involvement to be a positive influence.

Families living with a member with a chronic illness strive for a flow, or routine in everyday life. Achieving this "flow" was found to be even more important than striving for life as it was before the chronic illness (Arestedt, Persson, & Benzein, 2014). To find a daily flow that works for a given family, it is important that family members find ways to be supportive of each other. Communicating thoughts and feelings helps members to concentrate on health and not on the illness (Arestedt et al., 2014). African Americans and Hispanics living with chronic illness were found to have additional family stressors. In a study by Saulsberry, Blendon, and Benson (2016), 24% of African Americans and 38% of Hispanics living with chronic illness had no form of health insurance or family health plan, leading to additional strain on family coping. Given that shared responsibility for family health exists, it seems reasonable to conclude that adherence-increasing strategies should be directed toward all persons involved in the regimen, and that there may be a need for explicitly discussing the division of responsibility among family members.

Factors Contributing to Adherence Behavior

Although nonadherence is increasingly recognized as a problem, there is no consensus about appropriate or effective methods to increase adherence. Some of the difficulty lies in the inadequacies of research on adherence, some lies in differing role expectations of patients and providers, and some relates to conflicting values. As healthcare professionals prescribe, teach, and counsel patients about medical regimens, they must be cautious in making assumptions about adherence behaviors in a given situation before imposing any specific strategy to the patient.

Individual Characteristics

Several patient characteristics that influence adherence have been examined, including demographic factors, psychological factors, social support, past health behavior, somatic factors, and health beliefs (Dunbar-Jacob, Schlenk, & Caruthers, 2002). More recent literature has examined ethnicity as an influence in adherence with diagnostic testing (Cook et al., 2010; Lockett et al., 2015). Lockett et al. (2015) found that patients who missed scheduled colposcopy appointments were more likely to be African American and Hispanic than white. Conversely, Cook and colleagues (2010) reported that Latina and African American women were 2 and 1.45 times more likely to receive Pap (Papanicolaou) smear screening, respectively, when compared with Caucasians. Data are mixed and no clear picture of ethnic demographics has emerged related to adherence. In 2015, 22% of persons 65 years and older were members of racial or ethnic minority populations such as African American, Asian or Pacific Islander, American Indian or Native Alaskan, or Hispanic (Administration on Aging [AoA], 2016).

Because of the many inconsistencies in studies that examine age and adherence behavior, no overall statement about these relationships can be made. According to Barnstein-Fonseca

and colleagues (2011), a variety of factors may potentially interfere with the ability of the older adult to adhere to a medical regimen. It is important to rule out cognitive changes, which may occur with aging, versus the busy lifestyle barriers that pertain to the middle-aged adult. As the baby boomer generation (1946–1964) continues to dominate the healthcare arena, they, too, are living with chronic illness (Eifert, Adams, Morrison, & Strack, 2016). It is estimated that in the year 2060, there will be 98.2 million persons over the age of 65, many of whom will be of a diverse ethnicity (AoA, 2016).

Psychological Factors. Intuitively, healthcare professionals believe that psychological factors may affect adherence behavior. Depression was found in 40% of patients with chronic rhinosinusitis leading to missed productivity and poor sleep (Schlosser, Gage, Kohli, & Soler, 2016). Depression may be related to poor treatment adherence. Depression has a negative effect on quality of life, causing increased economic burden. Presence of co-morbid depression in chronic illness is often associated with negative health outcomes (Schlosser et al., 2016). In patients with COPD, depression is associated with diminished quality of life, increased healthcare utilization, and even higher mortality rates (Panagioti, Scott, Blakemore, & Coventry, 2014). Depression has also been linked to a higher mortality rate in patients not following medical recommendations in acute coronary syndromes (Kronish et al., 2006) and HIV infection (Lima et al., 2007). It may be prudent to screen for and to treat depression in patients at risk for nonadherence.

Other psychological factors, such as ambiguity, hostility, and general emotional distress, as single factors, are not predictive of adherence behavior but may, in fact, be components of motivation (Dunbar-Jacob, Schlenk, & McCall, 2012). In a study of schizophrenic patients, lack of insight into their disease and persecutory delusions were major psychological indicators of nonadherence to medication following discharge from a psychiatric hospital (Abdel Aziz et al., 2016).

Social Support. Social support is a variable that has frequently been explored in adherence studies. When considering diet changes, as in diabetes, recommendations may include foods that some people are not familiar with or typically do not eat. Some marginalized persons may need help in adapting traditional foods and cooking methods to a diabetes-friendly diet (Vanstone et al., 2016). Changing the way you eat, and what you eat, means changing the way you live. If a person has limited health literacy or does not speak the dominant language, the marginalization is magnified. The diet modifications with diabetes are significant, and often ripple through most aspects of one's life. Even the most motivated person with significant support may have problems adhering to the diet. People who face some type of social marginalization are trying to make the same changes with fewer social resources. Adherence often is difficult or impossible (Vanstone et al., 2016).

Prior Health Behavior. It has been suggested that adherence to a particular healthcare regimen at a single point in time may predict subsequent adherence. In a 10-year study associated with the Lipid Research Clinics Coronary Primary Prevention Trial, initial medication adherence accurately predicted adherence throughout the study; however, this result did not extend to other health behaviors. In general, it was found that the more similar the initial behaviors were to the behaviors that needed to be developed, the greater the likelihood of adherence (Dunbar-Jacob, Gemmell, & Schlenk, 2009).

Somatic Factors. It has been postulated that the presence of symptoms may promote greater adherence with medical recommendations. For example, hypertensive individuals who are asymptomatic indicated that they could tell when their blood pressure was high and adhered to treatment at these times because of their belief that adherence relieved the symptoms (Chen, Tsai, & Chou, 2011). In another study involving individuals with lung disease, increased dyspnea predicted greater adherence with nebulizer therapy

(Laforest et al., 2013). In a study of patients with rheumatoid arthritis, those with only mild joint symptoms were more likely to demonstrate nonadherence to prescribed disease-modifying antirheumatic drugs (DMARDs) (Kumar, Raza, Gill, & Greenfield, 2016).

Patients who are severely ill with serious illnesses have presented with poorer treatment adherence, as relationships with care providers decline in the face of worsening health. These patients may become depressed, pessimistic, socially withdrawn, and hopeless or ambivalent about surviving, making adherence seem futile (DiMatteo, Haskard, & Williams, 2007). Illness-related symptoms may, therefore, be an important cue to following treatment recommendations.

Regimen Characteristics. Regimen type and regimen complexity have been linked to adherence behavior, with complexity being a more important factor (Dunbar-Jacob et al., 2009). Complexity includes multiple medications, frequent treatments, a variety of treatments (e.g., diet, exercise, and medications), duration of the regimen, a complicated treatment delivery system, and irritating side effects (Chesney, 2003). Complicated regimens lead to low adherence rates (Choudhry et al., 2011). This effect has also been well documented in the HIV literature, as patients with HIV/AIDS have extremely complex medication regimens (Chesney, 2003; Hinkin et al., 2002; Waldrop-Valverde, Jones, Gould, Kumar, & Ownby, 2010).

Economic Factors. Poverty, poor English-language proficiency, and limited access to health care are predictors of nonadherence (Peeters et al., 2011). The burden of financial costs alone may serve as a barrier to obtaining healthcare services, supplies, or medications needed to manage chronic illness. Another major barrier to adherence is a lack of resources, including inadequate or difficult transportation, inadequate availability of childcare, loss of time from low-paying jobs, and little job security.

Prescription medication can be very costly, especially for those with low socioeconomic status or those without prescription coverage. Medication nonadherence is related to avoidable hospitalization (Iuga & McGuire, 2014). Additional costs are incurred with increased physician services used, pharmacy costs related to therapy intensification, and diagnostic testing from advancement of chronic disease. Socioeconomic status has been found to be associated with poor adherence to oral hypoglycemic medications. Nearly 33% of patients in an urban area reported that multiple competing economic demands influenced their decision to stop taking their prescribed medication (Blackmon, Laham, Taylor, & Kemppainen, 2016).

Health literacy may also contribute to problems in managing chronic illness regimens. In some studies, limited health literacy has been associated with poor adherence to antiretroviral medications (Waldrop-Valverde et al., 2010; Wolf et al., 2007) and with better adherence to other HIV medications (Paasche-Orlow et al., 2006).

Some barriers to adherence are clearly related to an ineffective healthcare system for chronic disease management. There is decreased availability of primary care services, particularly in inner cities and rural areas, to groups such as migrant workers, new immigrants, the homeless, and those with AIDS. In addition, the maze of governmental and third-party payers' policies and regulations often deny provider reimbursement for preventive or educational services, making these services less available to patients. How this will change in the future, as the United States shifts to better insurance coverage and better chronic disease management, remains to be seen.

Cultural Factors. More attention is being given to the ways in which culture influences health behaviors and the interactions of patients with healthcare providers. Cultural influences affect the way adults and children experience, interpret, and respond to illness and its treatment. Because of changing demographics and the influx of immigrants into the United States, studies examining the behaviors of different cultural

groups appear quite often in the literature. Some of these studies explore the dimension of being a member of a minority group who has a health problem. Language issues affect the utilization of health care and the ability to form relationships with healthcare professionals. Different cultural norms may also interfere with adherence behaviors. Abdel Aziz and colleagues (2016) studied schizophrenia patients in the United Arab Emirates and found that patients who sought out faith healers were more likely to be nonadherent to prescribed medications. Latinos have also been described as seeking health care late, if at all, and then using folk healers and medications for illness (Ransford, Carrillo, & Rivera, 2010). Some of the delay in healthcare utilization relates to insurance issues, language barriers, and immigration status.

It will become increasingly important for healthcare professionals to interpret the effect of culture and ethnicity on adherence behavior. One issue that confounds the link between health behavior and culture is socioeconomic status. There is a need to distinguish whether poor adherence is related to ethnic, cultural, or socioeconomic factors, as opposed to the interaction of these factors.

Patient-Provider Interactions

Of all the variables associated with nonadherence, patient-provider interactions have been highlighted as being extremely important. Recent studies have focused on the relationship between provider and patient as a way of encouraging health behavior change (Chan et al., 2015; Hall et al., 2016; Harvath et al., 2016; Levy & Signorelli, 2014). Importantly, the topic of self-management is discussed in primary care consultations infrequently, as maintaining the self-other relationship remains a prime objective for both patients and professionals (Blakeman, Bower, Reeves, & Chew-Graham, 2010). Enabling the patient to self-manage his or her condition threatens the medical hierarchy and may create tension in the patient-provider relationship.

Patients and providers are likely to have different perspectives about chronic illness, its treatment, and the relative merits of adherence behavior. The patient lives with the disease, and treatment is only one aspect of that individual's life. Living with treatment consequences is vastly different from offering advice, counsel, education, or exhortation about healthcare recommendations. Patients, on the one hand, ask for help from healthcare professionals because they feel ill, they are worried, they are responding to others' recommendations, they need evidence to validate claims for entitlement benefits, and so forth. Providers not only often fail to recognize nonadherence in their patients, but they also contribute to it, by prescribing complex regimens, failing to fully explain the benefits, and failing to consider the financial implications of what they prescribe (Brown & Bussell, 2011).

Ethics and Adherence Behavior

Adherence to recommendations for health behavior is an increasingly important ethical issue in healthcare cost containment, because conflicts arise when healthcare resources are limited and decisions about the best use of time, money, and the energy of providers must be made. However, economic and ethical issues in adherence differ. Whereas economic issues are concerned with the most efficient distribution of resources, ethical issues are concerned with the most equitable distribution (Guindo et al., 2012). Bosworth (2010) believes that strategies that promote and improve a patient's active and effective self-care are both ethically and economically significant.

There is also concern about providing resources to help those persons with chronic disorders in developing countries, where treatment nonadherence is very high (WHO, 2003). Ethical issues center on reciprocal rights and responsibilities of caregivers and patients, use of paternalism and coercion by caregivers, autonomy of the patient, relative risks and benefits of proposed regimens, and the costs to society

of nonadherence. Again, the focus on the patients' active participation with their healthcare professionals appears to raise ethical concerns (Guindo et al., 2012). This brings up the question of whether health care directed solely by the practitioner without input from the patient is ethical and whether nonadherence should rest only upon the shoulders of the patient.

Theoretical Underpinnings of Adherence Behavior

Theoretical frameworks and conceptual models provide direction for healthcare professionals by guiding the assessment and providing structure for the interaction between patient and provider. The emphasis is on translation of theories and models into effective practice interventions. Models for understanding individual health behavior can be useful only if they are based on empirical research and can be used to create effective interventions. This linkage relates to the current mandate for translational research and evidence-based practice. Brief reviews of behavioral models that are currently used are presented here.

Health Belief Model

The health belief model (HBM), developed by Hochman and colleagues (as cited in Rosenstock, 1974), was devised to explain health-related behaviors, especially preventive health behaviors, and contains a cluster of pertinent beliefs and attitudes (Becker & Maiman, 1975). The original model was subsequently modified to include general health motivation (Becker, 1976), and then modified again to include sick-role behaviors. The HBM's major proposition is that the likelihood of an individual taking recommended health actions is based on (1) the perceived severity of the illness, (2) the individual's estimate of the likelihood that a specific action will reduce the threat, and (3) perceived barriers to following recommendations. The HBM continues to be used to explain the relationships of attitudes and

behaviors to adherence behavior, specifically in regard to perceived susceptibility, perceived severity, and perceived barriers (Jerant, Fiscella, Tancredi, & Franks, 2013). Recent studies utilizing this model as a theoretical foundation to inform interventions have yielded significant (mostly moderate to large) improvements in adherence behaviors (Jones, Smith, & Llewellyn, 2013; Petley et al., 2016; Tola et al., 2016). The authors concluded, however, that intervention success did not appear to be related to specific HBM constructs, as the HBM was not used in its entirety, nor were health belief outcomes measured in some studies.

Foot, LaCaze, Gujral, and Cottrell (2016) studied adherence to medication across multiple health conditions and found that those who believed their medications were necessary for their current and future health were more likely to adhere to even complex medication regimens. The same research study found that individuals who held strong 'concern beliefs' were more likely to be nonadherent. This study helps inform how patients choose a particular behavior through a cost-benefit analysis, in which the benefits (better health) are balanced against the perceived cost (pain, loss of work, financial cost) (Foot et al., 2016).

Health Promotion Model

A nursing model that evolved from the HBM is the health promotion model (HPM) (Pender, 1996; Pender, Murdaugh, & Parsons, 2001). Pender conceptualized health as a goal and believed that only the desire to be healthy leads to engagement in health promotion activities. Pender organized the concepts under the framework of individual characteristics and experiences, behavior-specific cognitions and affect, and behavioral outcomes. The Health-Promoting Lifestyle Profile is an instrument that assesses health promotion behaviors; it has been translated and validated in Spanish as well as English (Kwan, Berggren, & Dahlborg-Lyckhage, 2010; Walker, Sechrist, & Pender, 1987) and continues to be used and adapted (D'hooghe, Nagels,

De Keyser, & Haentjens, 2013; Padden, Connors, Posey, Ricciardi, & Agazio, 2013; Tucker et al., 2014). Studies using the HPM have found that low income and low education negatively impact involvement in health promotion activities (Harley et al., 2014; Smylie et al., 2014).

Common-Sense Model of Self-Regulation

The common-sense model of self-regulation (CSM) was developed from two prior models. One of its antecedents, the common-sense model, was developed by Leventhal, Meyer, and Nerenz in 1980 to explain how individuals coping with illness-related events and how this shapes coping and adherence. Early studies using this model were conducted primarily on individuals with asymptomatic illnesses. In brief, an individual's processing of illness-related events depends on four dimensions: cause (what was responsible for the illness), consequences (how things will change because of the illness), identity (being able to identify the illness), and timeline (the course of the illness). In 1987, Leventhal, Glynn, and Fleming identified a feedback mechanism to a behavioral model and called it the self-regulation theory. The dimension of control-cure was examined as part of the illness representation (Leventhal et al., 1987).

These two models are now combined into one model known as the CSM (Leventhal, Brisette, & Leventhal, 2003). The combined model (CSM) was designed to describe dynamic interactions among the variables controlling health behaviors in response to current or future threats to health (Leventhal, Phillips, & Burns, 2016). Studies using this model have shown that beliefs about illness do affect coping (Gould, 2011; Snell, Hay-Smith, Surgenor, & Siegert, 2013). In an analysis of published research, researchers failed to find evidence that the use of the CSM to design interventions positively impacted adherence (Jones, Smith, & Llewellyn, 2016). The CSM model is, however, useful in understanding adherence. Patients

with chronic illnesses often do quite well initially keeping up with prescribed treatment regimens; however, healthcare providers must help patients transition from initial performance behaviors to making these changes a part of their daily behaviors.

The Theory of Reasoned Action and the Theory of Planned Behavior

The theory of reasoned action (Fishbein & Ajzen, 1975) and the theory of planned behavior (Ajzen, 1985) have intention as a main component. According to these theories, individuals engage in health behaviors intentionally, based on attitudes toward a behavior and social influence. The theory of planned behavior adds a component to the model called "perceived behavioral control," the model called "perceived behavioral control," which captures the extent to which a person has control over any given behavior. Both of these theories have been useful in the examination of preventive behaviors, such as engaging in exercise programs (Lee, Chiang, Hwang, Chi, & Lin, 2016; Martin, Oliver, & McCaughy, 2007), food choice (Ackerman & Palmer, 2014), condom use (Gredig, Niderost, & Parpan-Blaser, 2006), and avoiding binge drinking (Norman, Armitage, & Quigley, 2007), where intention has been found to be an important component of engaging in the desired behavior. Rich and colleagues found that attitudes, subjective norms and perceived behavior control were predictors of adherence intention, and intention was a predictor of treatment adherence behavior (Rich, Brandes, Mullan, & Hagger, 2015). These theories have also proved valuable in assessment of physical activity in chronic illness regimens (Eng & Martin Ginis, 2007) as well as in assessment of HAART adherence in patients with HIV infection (Vissman, Young, Wilkin, & Rhodes, 2013). Additionally, these theories have also been used to predict which treatment options should be recommended by substance abuse providers in outpatient treatment facilities (Roberto, Shafer, & Marmo, 2014).

CASE STUDY 8-2

Mr. W is a 58-year-old African American college history professor with type 2 diabetes. He was diagnosed 3 years ago and lost weight and started an exercise program after diagnosis. During the last year, he has gained some weight back and is no longer exercising daily. He admits to you that with some changes at work, he is extremely stressed. He starts every evening with a martini, relaxes after his long day, and then has a big dinner. His blood sugars are out of control, and you are concerned that he will have to start insulin injections.

Discussion Questions

1. Would you, the healthcare provider, label Mr. W. as nonadherent? Why or why not?
2. Suggest several lifestyle modifications that may benefit Mr. W.
3. How might Mr. W's perspective of his illness differ from that of his provider?

Cognitive Social Learning Theory

Cognitive social learning theory attempts to predict behavior that is dictated by outcome and efficacy expectancies. This theory combines environment, cognition, and emotion in the understanding of health behavior change (Bandura, 2004). Three necessary prerequisites to altering health behavior are the recognition that a lifestyle component can be harmful, the recognition that a change in behavior would be beneficial, and the recognition that one has the ability to adopt a new behavior (self-efficacy) (Schwarzer, 1992). To effect any change, then, each individual must be able to self-monitor and self-regulate health behavior. This aspect of self-regulation has led to a variety of self-management strategies to cope with illness. The additional component of self-efficacy, defined as the patient's expectations or confidence in his or her ability to perform a recommended action, has also promoted research to test efficacy-enhancing strategies important in health behavior change. Self-efficacy has been found to be an important predictor of self-management behaviors in the treatment of AIDS (Johnson et al., 2006), cardiac disease (Hiltunen et al., 2005), depression (Sussman et al., 2016), and diabetes (Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013). Cognitive social learning

theory has also been applied to the development of a community-based parenting program in a rural community (Singla & Kumbakumba, 2015) and has been used as a predictor of clinician behavior in diabetes management (Presseau et al., 2014).

Transtheoretical Model of Change (Stages of Change)

The stages of change (transtheoretical) model (TTM), developed by Prochaska and DiClemente (1983), is an eclectic model that aims to examine and predict the process of change. This model contains three constructs: the stages of change, the processes of change, and the levels of change. Its underlying premise proposes that people are at different stages in their intentional desire to adopt certain health behaviors with or without assistance. The model also proposes that interventions should be matched to each categorical stage of change. Although presented hierarchically, the process of change is considered to be a spiral, with relapse from a healthy behavior placing an individual in a position to move backward toward contemplation of the healthy behavior. The model also incorporates self-efficacy and decision making as key factors in the process

of change, but these factors have an impact at different stages of change. The stages include the following:

- Pre-contemplation: no intention of changing behavior
- Contemplation: considering future action
- Pre-action: has a timetable for action
- Action: involved in behavior change
- Maintenance: after change is adopted; relapse is a possibility

The stages of change model of health behavior was initially applied to the treatment of addictive behaviors. Currently, research on behavioral change in chronic illness has embraced this model. Clinical interventions have been proposed at each stage. Wilson and colleagues (2016) applied each construct of the TTM to patients with chronic lung disease and found that the model accurately predicted physical activity in the subjects. The use of motivational interviewing (MI) has been examined as a means to move patients to an action phase of readiness (Pantalon et al., 2014; Moral et al., 2015), although critics warn that there is no theoretical link between the MI and the TTM.

Lee-Lin, Nguyen, Pedhiwala, Dieckmann, and Menon (2016), in a longitudinal examination of mammography screening data, found that behavior change occurs in stages, can be cyclic and not linear, and that it may be easier to move people up one stage at a time, which fully supports the tenants of TTM. They found that patients in all study groups moved up in stages over time, as many as 65% in one group. In a study measuring physical activity in overweight and obese adults, researchers found the TTM accurately measured plan of change behaviors in the subjects (Romain, Bernard, Hokayem, Gernigon, & Avignon, 2016).

Three-Factor Model

With decades of research on behavior change and adherence behaviors to review, consistent findings across meta-analyses and large-scale studies have

led to the identification of a three-factor model for clinical action to promote patient adherence. The three factors are information, motivation, and strategy (DiMatteo, Haskard-Zolnierak, & Martin, 2012):

- Providing information to patients and ensuring their understanding are essential to treatment adherence, but insufficient to ensure adherence. Essential elements in providing useful information to patients include clinician-patient communication, accurate clinician recall of information, adapting information to compensate for any extant cognitive deficits, and shared decision making.
- Patient motivation for adherence is ignited by the patient's belief in the efficacy, appropriateness, and feasibility of any treatment, and is strengthened by "informed collaborative choice" (p. 81). Motivation requires ongoing reinforcement to be maintained.
- Strategy refers to a patient's ability to adhere to the treatment, whereby identification and overcoming of obstacles improve his or her capacity for adherence. Commonly encountered barriers include medication cost and side effects, cognitive deficits, inability to perform ongoing difficult lifestyle changes, mental health, and highly complex treatment regimens.

Ecologic Perspective

Broadening adherence beyond individual and/or patient-provider (dyad-level) considerations to include system-level factors can expand intervention options to improve the modifiable aspects of adherence. Such factors include the clinicians' patient load, available consultation time, provider training, and policies and regulations (Berben, Dobbels, Engberg, Hill, & De Geest, 2012). Such multilevel attention, including individual-, micro-, and macro-level implementation, can support individuals' success in caring for themselves and their families.

In summary, many models have been used to study adherence behavior in chronic illness. It is

important to have a theoretical basis for proposed interventions; however, more research needs to be accomplished to evaluate the effectiveness of theory-based interventions.

Measuring Adherence Behaviors

Several widely used methodologic approaches focus on adherence, and it has been suggested that adherence assessment should always focus squarely on adherence as a behavior—not on its predictors or its consequences (Morisky & DiMatteo, 2011). Primary methods include self-report, practitioner report, observation, physiologic measures, medication monitoring, and electronic monitors.

When a treatment is prescribed, the efficacy of that recommendation hinges on the follow-through by the patient. If a prescribed treatment does not appear to be working, clinicians often change medication dose, question the diagnosis, or take a more (sometimes harmful) aggressive approach. What is sometimes missed in the face of an apparently ineffective treatment response is an assessment of the degree to which the patient adhered to the prescribed action (Brown et al., 2016).

Measuring patient behavior is complex, and different methodologies exist for different contexts and diseases. Important aspects of choosing appropriate measurement methods include the need for accuracy, comprehensiveness, ease, and minimal cost of administration (Brown & Bussell, 2011).

There is no gold standard to measure medication, lifestyle, or dietary adherence, and current evidence suggests several strategies other than disease outcomes may be used to capture treatment adherence to medication (Brown et al., 2016; Brown & Bussell, 2011; Desroches, Lapointe, Ratté, Gravel, Légaré, & Turcotte, 2013; Lehmann et al., 2014). Electronic monitoring is often used as the reference method for determining medication adherence (Erdine & Arslan, 2013; Park, Howie-Esquivel, & Dracup, 2015). Polypharmacy in chronic disorders adds

another variable when observing and measuring medication adherence. Each measurement is prone to some error, usually consisting of a bias toward an overestimation of adherence (Lehmann et al., 2014). However, using a combination of methods to measure a specific adherence behavior is recommended to increase accuracy and reliability of the results, compared with a single method of measurement (Brown & Bussell, 2011; WHO, 2003).

An assessment of the patient's overall well-being and psychological structure is essential to attain a better understanding of his or her adherence behaviors. A systematic assessment of the patient includes the patient's family, sociocultural and economic factors, health literacy, beliefs, attitudes, and an understanding of the proposed treatment. Likewise, attention should be given to the patient's perceptions of the illness threat, the efficacy of recommendations, and the patient's ability to carry them out. There should be a determination of the "rightness" of the prescriptions for the particular patient, including an estimation of the relative harm or benefit that is expected. This assessment allows the nurse to determine which aspects of the regimen management are most likely to achieve adherent behavior, are most important in attaining therapeutic goals, and require the most learning to attain the desired behavioral change. Although the following questions from Hingson and colleagues are nearly four decades old, current literature did not yield a significant or better replacement. The following questions should be asked in an adherence-oriented history (Hingson, Scotch, Sorenson, & Swazey, 1981):

- Have you been taking anything for this problem already?
- Does anything worry you about the illness?
- What can happen if the recommended regimen is not followed?
- How likely is it that you will not follow the recommended regimen?
- How effective do you feel the regimen will be in treating the disorder?

- Can you think of any problems you might have in following the regimen?
- Do you have any questions about the regimen or how to follow it?

Indirect Measures

Self-Report. Patient self-reports of adherence behaviors are the simplest and least expensive method of gathering adherence information and are feasible in virtually all care settings. Self-reports also allow the collection of more detailed information on the circumstances surrounding poor adherence than any other type of measure (Dunbar-Jacob et al., 2009; Park et al., 2015). Self-report data may be elicited through simple questions; through a more complex, structured interview schedule; or through a validated questionnaire. Common self-report measures include medication and symptom diaries, structured questionnaires, and interviews.

Self-reported adherence behavior has come under scrutiny because this methodology is believed by many to be invalid and unreliable (Brown & Bussell, 2011). A patient's self-reported adherence may be inaccurate for many reasons. While patients who report nonadherence tend to report their behavior accurately (Bosworth, 2010), some may honestly not remember whether they took their medications, may be unaware that they are not following recommendations, or may have misconceptions about their dosing schedule (Bosworth, 2010; Brown et al., 2016). A study of women with breast cancer found that 88% of the women self-reported completing all of their prescribed oral anticancer medication during 6 months of treatment, but objective assessment found only 78% adherence (Addeo et al., 2015).

Other reasons for nonadherence may include economic factors, lack of resources, or the patient's discomfort with admitting nonadherence to healthcare providers. In any event, it is incumbent for the provider to be able to assess whether a patient can and is willing to follow a recommendation. Toward this end, researchers recommend asking questions in a

nonjudgmental, consistently blame-free manner to elicit valid responses about regimen adherence (Brown et al., 2016).

Studies have attempted to evaluate and define the accuracy of self-reported adherence. Many of these studies have compared patient reports with pill counts, electronic monitoring, drug levels, or biologic markers in body fluids. Most have found that individuals overestimate their adherence (Garfield, Clifford, Eliasson, Barber, & Willson, 2011; Shi et al., 2010).

Despite its inherent problems, self-reports are still the measure most commonly used in adherence assessment. Self-reports have the potential to provide the most accurate record of what a patient has done, as long as the patient can remember taking the medication and is motivated to be absolutely truthful about what is remembered (Morisky & DiMatteo, 2011). Thus, establishing trust within the patient-provider relationship and developing strategies to enhance recall are essential to obtain accurate information.

Observation and Clinical Judgment. Direct observation of the patient is rarely possible, making it an impractical method of assessing adherence. Theoretically, this method would be an ideal way to provide evidence of adherence behavior; however, individuals often "play to an audience," and the knowledge that someone is watching affects behavior. Direct observation is thought of as a passive method of medication distribution; it limits patients' active participation in treatment and is inflexible to adaptation in real-life contexts (Erdrine & Arslan, 2013).

An example of this behavior for an individual with asthma is the demonstration/return demonstration of the correct method of using metered-dose inhalers (MDIs). Patients with asthma are assessed on their ability to carry out the instructed regimen. Although nurses assess patients' behavior in carrying out tasks related to their health care, the assumption cannot be made that this activity will continue at home.

Clinical judgment of patients' adherence to medication regimens has also been shown to be poor, with rates of adherence to cystic fibrosis

medication ranging from 50% to 60%, compared to 36% when measured via electronic monitoring (Daniels et al., 2011). Clinician assessment of medication adherence is often incorrect, with overestimation being more common than underestimation (Brown & Bussell, 2011).

Monitoring. Other methods for measuring medication adherence (drug-dosing recall, pill counts, and pharmacy refills) have indicated similar rates of adherence (DiMatteo, 2004; Dunbar-Jacob et al., 2002). Each method has potential limitations, including errors made during pill counts, failure to document dosage modifications in the medical record, and not knowing if the patient actually took the medications once dispensed by the pharmacy (Atkinson et al., 2016).

Pill counts, pharmacy-refill monitoring, and MDI canister weighing can all be used to measure medication adherence. In studies that use pill counts, the subject is given a vial each month that contains a certain number of tablets, and this vial is exchanged for a new one each month. The medication left in the container can be compared with the number that was supposed to be left if the medication were taken. This can also be accomplished when patients bring all prescription medications in their original containers to each office visit. Similarly, when a patient requests a refill from the pharmacy, the time of the request is compared with the expected date of refill if the medication was taken as prescribed. Such methods do not take into account whether patients are sharing medications with others or "dumping" pills prior to refill. MDI canister weighing is used with patients who have respiratory illnesses. The canister is weighed before it is given to the patient and then reweighed at specific times during treatment. Some MDI medications come with dosage counters on the vial, but there is always the possibility that the patient is not actually using the medication.

Although some medication-monitoring methods appear highly accurate, they may overestimate adherence behavior (Jentsch, Camargos, Colosimo, & Bousquet, 2009; Rapoff, 2010).

Berg and Arnstein (2006) further suggest that asking a patient to bring in the medications for a check of pill count may, in fact, be offensive and counterproductive to building rapport between patient and provider.

Electronic monitors are the newest technology for the assessment of adherence behaviors. The most commonly used of these devices is the electronic medication monitor. Electronic monitors may also be used to capture heart rate and muscle movement with exercise adherence (Sylvia, Bernstein, Hubbard, Keating, & Anderson, 2013) or to monitor nasal continuous positive airway pressure adherence for patients with sleep apnea (Fox et al., 2012).

Electronic monitoring is undergoing rapid development through the use of electronic sensors and mobile/wireless technologies. With this technology, microprocessors are placed in special bottle caps or blister packs and can monitor the date and time of day for each manipulation of the drug container and provide information on drug-taking behavior for days or weeks. Knowing the pattern of pill taking (or not taking) can be useful in evaluating clinical responses (or lack thereof) or side effects, and can provide guidance for interventions specifically tailored for each patient (Park et al., 2015). Electronic monitors have been used to assess medication adherence in many studies and typically provide lower estimates of adherence than self-report data (Park et al., 2015).

An innovative use of technology was reported in a pilot trial to monitor lung transplant recipients' adherence to self-care behaviors—namely, a Pocket Personal Assistant for Tracking Health device (Pocket PATH) (De Vito Dabbs et al., 2009). This mobile, hand-held device significantly improved self-care behaviors of monitoring vital signs, medical regimens, health habits, and communicating important changes to the transplant team between scheduled visits, as compared to standard pencil-and-paper methods.

Direct Measures

Physiologic Measures. Physiologic measures of adherence include serum drug levels, heart

rate monitoring, muscle strength, urine analysis, cholesterol levels, and glycosylated hemoglobin levels. The advantage of physiologic methods is that these measures are not dependent on the patient's memory or veracity.

Of all of the physiologic measures, measurement of drug levels is the most commonly used. Although drug-level measurements offer a greater degree of accuracy than self-reports and clinician reports, there are some difficulties with this type of assessment. First, these measures do not reflect the level of adherence (Brown et al., 2016) but merely identify the status of the chronic disease. Second, although biomarker assays offer a direct and objective approach to the measurement of adherence, this method is neither affordable nor available for every drug. Third, physiologic technologies are often unable to detect dosage levels. Biomarkers are defined as characteristics that are objectively measured as indicators of normal biologic, pathogenic, or pharmacologic processes for the National Institutes of Health, 2012). Biomarkers might include laboratory tests that assess the status of a chronic illness, such as viral loads and electrolyte levels, or other samples for direct medication concentrations such as blood, urine, or hair samples (Park et al., 2015). Finally, accurate detection of nonadherence through drug-level testing offers no explanation or insight into the reasons for nonadherence (Park et al., 2015).

In the end, no single measure of adherence can compete with the accuracy of a multimethod approach that combines feasible self-reporting and reasonable objective measures within a professional clinician/patient relationship built on trust and respect (Brown et al., 2016). Assessment should also lead to a determination of the proper focus of adherence-increasing strategies. The notion of adherence as self-care may be too restrictive in situations in which adherence with medical regimens cannot be achieved without the assistance of others. For instance, the combination of significant physical disability and chronic illness makes the conceptualization of adherence as self-care ability

inappropriate. In such instances, a social support network may be the most important influence on adherence and, therefore, should become the focus of adherence-increasing strategies. However, the nurse should carefully assess the impact of social support on adherence. Although social support—by significant others or through support networks—may help patients cope with chronic illness and reinforce adherence behaviors in some populations, this relationship may not hold true for all individuals. Some persons do not always want or cannot always receive tangible help from others.

► Interventions to Enhance Adherence Behavior

The complexity of the variables associated with adherence should not deter the healthcare professional from working with the patient to achieve maximum possible integration of optimal health recommendations. To accomplish maximum adherence, those who use adherence-increasing strategies have a responsibility to ensure the patient's safety and comprehension. For the nurse, who frequently serves as a liaison between the patient and physician, communicating with either or both is often necessary before matters are sufficiently clear to select and begin specific adherence-increasing strategies. Enhancing adherence behaviors is not as simple as telling patients what to do and then telling them again when the desired effect is not achieved. It is important to look at all aspects of the patients' perspective about the prescribed treatment. The regimen must be doable, with minimal side effects, and produce a positive desired effect, and it has to be worth the effort for the patient (Atkinson et al., 2016). Understanding and respecting the social, cultural, and psychological factors that influence adherence behaviors may enhance efforts to manage the problem of nonadherence.

Furthermore, the patient or caregiver simply may not understand, or remember, instructions. If patients lack the knowledge or skills to undertake a recommended behavior or treatment, they will not do it. Instructions related to treatment regimens need to be reinforced continually over time to enhance adherence behaviors.

It is generally believed that adherence increases when patients actively participate in learning and are involved in deciding how to implement prescribed regimens. However, insistence by the healthcare professional on a preconceived or stereotyped notion of the most desirable level of participation may be inappropriate. A mismatch between an authoritarian provider and an assertive, active learner may influence adherence adversely. Conversely, the provider who expects an active involvement process by the patient can overwhelm a passive and nonactive learner.

The power differential between patients and providers constitutes an important aspect of adherence behaviors. When arrogance and resistance are left behind, caring and empathy step in to allow the patient to be consciously informed about the treatment regimen and empowered to make the decision to adhere (Levy & Signorelli, 2014).

Enhancing a patient's motivation requires careful assessment of his or her readiness to make and maintain behavioral changes. Building skills requires that the patient be ready to learn tasks such as reading food labels, selecting appropriate food in restaurants, and incorporating the taking of medications into his or her daily routine, often multiple times per day. In other words, patients must learn new strategies to help them adopt and maintain new behaviors, especially when their daily routines are significantly altered (Barnestein-Fonseca et al., 2011; Hall et al., 2016).

There is universal agreement that it is important for patients with chronic illness to follow evidence-based provider recommendations (WHO, 2003). To enhance adherence to treatment, healthcare professionals can employ a variety of strategies. Strategies are educational,

behavioral, or organizational. WHO (2003) has suggested adopting the use of the "five A's" to assist patients with self-management of their chronic disease: assess, advise, agree, assist, and arrange. Advising the patient of the importance of treatment adherence, establishing agreement with a treatment plan, and arranging adequate follow-up are necessary steps for healthcare professionals who are interested in providing treatment adherence interventions to their patients. Additionally, four phases of treatment adherence have been identified—contemplating, initiating, maintaining, and sustaining long-term behavior—with each phase having different barriers and facilitators (Bosworth, 2010). Discrepancies between a patient's stage of treatment adherence and a provider's intervention may yield nonadherence owing to a patient's lack of readiness for the intervention. The interventions suggested in this chapter are adaptable within these frameworks.

Education and Coaching

Educational interventions should be developed based on an assessment of the patient's level of knowledge, cultural background, and individual goals. Educational information should be presented in manageable segments, with additional information and reinforcement being provided at subsequent meetings. The nurse should focus on key issues in the management of the regimen and should select the most important aspects necessary for health maintenance. Difficult skills should be demonstrated, and then the patient is allowed to practice and perform a return demonstration. Difficult skills should also be reviewed each time the patient visits.

Health literacy is an important part of patient education that all healthcare providers should consider. Health literacy is defined as the patient's ability to obtain, process, communicate, and understand basic health information and services needed to make appropriate health decisions (Zhang, Terry, & McHorney, 2014). When patients are adequately informed and clearly understand what they are asked to do,

they are better able to share in the decisions that affect their health, and can be more adherent to the regimens that they are a part of creating.

Health literacy should be a concern for all healthcare providers. Miller (2016) found that health literacy interventions were effective in improving patients' levels of health literacy by 22% and adherence to treatment by 16%. Nurses can be instrumental in ensuring that health literacy is assessed and that interventions are in place to address any information gaps.

Health numeracy is another skill that must be part of any healthcare education plan. Health numeracy is the capacity of an individual to assess, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information so as to make effective health decisions (CDC, 2016b). Examples of numeracy include being able to understand food labels; manage weights, portions, and size estimations; and interpret blood sugar or blood pressure readings (CDC, 2016b).

While health numeracy is discussed less than literacy in the literature, it is a skill of equal importance when self-management, family involvement in management of a loved one's health, and adherence behaviors are at stake (Gaglio, Glasgow, & Bull, 2012).

Often patients rely on family members to interpret complex regimen details and may feel embarrassed about their challenges with health literacy (Zhang et al., 2014). Therefore, when educating those with chronic illnesses, family members or significant others should be involved in the educational session. Emphasis in teaching needs to be directed toward not only knowledge of the disease, but also the skills needed for the regimen (Morello, Chynoweth, Kim, Singh, & Hirsch, 2011; Zhang et al., 2014). In addition, the regimen should be simplified as much as possible, using terms that are part of everyday conversation and not medical jargon.

Given the recognition of the prevalence and complexity of managing chronic illness, nurses are increasingly being trained in

coaching techniques. Health coaching, whether carried out by nurses or by other healthcare professionals, utilizes multiple consultations between the participant and coach to improve disease management (Melko, Terry, Camp, Xi, & Healey, 2010). Coaching has been effective in improving patient adherence to colposcopy follow-up (Luckett et al., 2015), hypertension treatment (McGillicuddy et al., 2015), anticoagulant serum testing (Levy & Signorelli, 2014; Shaha et al., 2015), oral anticancer treatment (Hall et al., 2016), TB treatment (Tola et al., 2016), and rheumatoid arthritis treatment (Kumar et al., 2016; Lee et al., 2017). Health coaching utilizes MI and cognitive-behavioral therapeutic techniques to improve self-efficacy. Wong-Rieger and Rieger (2013) have identified the following health coaching principles as being most often utilized:

- The patient is the best source of information for personal behavior change strategies.
- Education is provided when the patient is ready.
- Goals are aligned with the patient's vision of health and personal values.
- Emphasis is placed on how to change behavior, not why current behaviors exist.
- Plans are established for how to deal with setbacks.
- The coach reinforces accountability using the patient's own values and stories.
- Only the patient is able to choose goals that are the most motivating.
- Priorities are established by balancing long-term vision and what is most salient in the patient's present life.
- Patience and belief in the patient are critical to establish trust in the coaching relationship.
- Coaches guide patients in linking behavior change to their life purpose.

Nurses play a vital role in coaching. Shaha and colleagues (2015) found that patient adherence to oral anticoagulation therapy was enhanced when nurses were part of the development of the educational process and the tools. Nurses were surveyed about what should be included in the

educational sessions, and they were instrumental in the final large-font tools, with color-coded charts, and the inclusion of a mechanism for documentation. These tools were used during coaching sessions to increase adherence to anticoagulant medications.

Strategies such as MI have also been used successfully by healthcare professionals who are advocating health behavior change. Motivational interviewing is an interview style designed to promote behavior change. It is defined as "a set of targeted communication skills to motivate patients to change their own behaviors in the interest of their health" (Moral et al., 2015, p. 2). Through the utilization of four core principles, practitioners can harness the spirit of MI and guide patients toward greater self-motivated change: resist the righting reflex, understand the patient's motivation, listen with empathy, and empower the patient (Moral et al., 2015). Using MI is not simply a series of techniques, but it also aims to create a spirit of collaboration and to encourage a sense of personal resources (Patton, 2015). Motivational interviewing was originally developed for the treatment of addictions but has since been modified for use in different contexts, including adaptation to the healthcare setting. This technique has been used effectively to realize better treatment adherence through improving BMI, cholesterol, and systolic blood pressure (Lane, Hood, & Rollnick, 2008); to improve medication adherence in elderly patients being treated with polypharmacy (Moral et al., 2015); to improve appointment-keeping behavior in patients with psychiatric disorders (Pantalon et al., 2014); to improve antihypertensive medication adherence (Insel, Einstein, Morrow, Koerner, & Hepworth, 2016); and to improve self-monitoring of blood glucose in type 2 diabetes (Ong, Chua, & Ng, 2014; Patton, 2015). Motivational interviewing has a focus on strengthening the patient's own commitment to change and may be a factor in improving adherence.

Abilities beyond knowledge and comprehension are required as well. Therefore, educational goals must be broader than solely the acquisition

of knowledge if adherence is to result from the intervention. The outcome of adherence depends on participation of the learner beyond simply listening, reading, or assimilating information. That is, clinicians should encourage patients' participation in their own care. Flexible self-care regimens enable people to exercise a larger degree of autonomy than is incorporated in standard regimens, even when these regimens are adapted to some extent for individuals. The flexibility of instructions, such as "If you have this sign or this symptom, then try this activity," allows people some freedom to make informed choices, and having choices fosters independence and a better quality of life (Jimenez, 2017; McWilliam, 2009; Moral et al., 2015).

Behavioral Strategies to Enhance Adherence

Behavioral strategies attempt to directly influence specific adherence behaviors through the use of various techniques. These strategies may be used either as single interventions or in combination to achieve the desired results. Cognitive-behavioral techniques such as goal setting and self-monitoring, and behavioral techniques such as cueing, chaining (associating new behaviors with established ones), positive reinforcement, and patient contracting are examples of strategies that have demonstrated a positive impact on adherence behaviors (McGillicuddy et al., 2015; Rains, Penzien, & Lipchik, 2006). Interventions employing education with behavioral support with continued contact over several weeks or months via phone, mail, and/or video have shown the greatest success in increasing medication compliance across conditions such as hypertension, hyperlipidemia, heart failure, and myocardial infarction (Jones et al., 2016; Ma, 2016; McGillicuddy et al., 2015; Viswanathan et al., 2012).

Tailoring

At a minimum, the outcome of patient participation with the nurse in developing an adherence

culturally based home remedies in conjunction with or instead of prescribed treatment, producing profound effects on their treatment outcomes. Knowledge was a major problem in this study. As an example, participants were told to avoid salt and lose weight but they did not know how.

Healthcare professionals need to recognize that their belief system, values, and attitudes toward healthcare management are also culturally determined and may be responsible for ideologic or philosophical differences (McWilliam, 2009). The emphasis on self-care in Western medical systems is ideologically consistent with the value

of individual enterprise in Western cultures (Anderson, Tang, & Blue, 2007). Persons of other cultures, however, may find the value of self-care to be foreign.

► Outcomes

There has been a blossoming interest in documenting the evidence of particular strategies to improve health outcomes. Evidence-based practice guidelines for a variety of physiologic and behavioral interventions are now readily available to all

Evidence-Based Practice Box

Purpose

The purpose of this study was to determine if pharmacy-provided medication review and reconciliation, together with follow-up outpatient primary care physician visits, reduced hospital admission rates.

Method

The participants were divided into two groups: group 1 patients were seen for hospital follow-up visits by physicians only during a 5-month period, and group 2 patients were evaluated jointly by the same physician group and a pharmacist.

Sample

The study enrolled 236 patients into group 1 (physician alone) and 98 patients into group 2 (physician and pharmacist). Both groups were evaluated simultaneously during the 5 months of the study. Inclusion criteria were (1) age 50 and over, (2) taking five or more medications, and (3) having more than one chronic disease.

Intervention

Participants in group 1 were seen by a physician only during their follow-up appointment scheduled at time of discharge. Participants in group 2 were seen by a physician and a pharmacist during follow-up appointment scheduled at the time of discharge. Pharmacists performed medication reconciliation, comprehensive chart review, assessment of accuracy of medication therapy, and monitoring of medications from an evidenced-based chronic disease management approach.

Results

Differences in size of groups were due to availability of pharmacists for this study. Nine of the patients (9.2%) in group 2 (physician and pharmacist) were readmitted to the hospital within 30 days of discharge, compared to 46 patients (19.5%) from group 1 (physician only). The difference was statistically significant at $p = 0.023$.

Implications for Nursing

Coordination of care during transition of care periods plays an important role in the management of chronic illness. Innovative strategies between acute care and primary care providers are essential to decrease the risk of readmission. Based on this study, a collaborative team approach to transitions in care can improve patient care, decrease costs, and empower patients in self-care.

Source: Arnold, M. E., Roys, L., & Fullis, F. (2015). Impact of pharmacist intervention in conjunction with outpatient physician follow-up visits after hospital discharge on readmission rate. *American Journal of Health-System Pharmacology*, 72(11), 536-542.

Study Questions

1. How does adherence to treatment regimens affect patients with chronic illness?
2. What are the components of adherence to prescribed treatment? Discuss.
3. Because treatment nonadherence is so prevalent, think of examples from your own practice. How would you address nonadherence?
4. What factors contribute to nonadherence?
5. What are the ethical issues that arise when healthcare providers attempt to address poor adherence? Discuss this question from an ethical framework.
6. How do economic factors influence adherence?
7. Think of a particular culture. How would you address adherence within the rituals, norms, and accepted practices of that culture?
8. What role do healthcare providers play in patient adherence? What is their responsibility in addressing adherence with their patients?
9. How do theoretical models inform your understanding of adherence?
10. Identify five interventions that healthcare providers can do to have a positive impact on adherence in patients with chronic illness?

healthcare practitioners (through the Agency for Healthcare Research and Quality, National Guideline Clearinghouse [NGC]). This means that what we recommend to patients is based on evidence of efficacy. Nevertheless, we continue to face the challenge of helping patients follow recommendations. No matter the quality of our interventions, they will be beneficial only if patients actually use them. It is up to healthcare professionals to more effectively assess whether patients can do what we suggest, and then to evaluate the outcomes.

► Acknowledgment

Thanks to Jill Berg, Robynn Zender, Lorraine S. Evangelista, and Jacqueline Dunbar-Jacob for their previous work on this chapter in earlier editions.

References

- AARP Public Policy Institute and the National Alliance for Caregiving. (2015). *Caregiving in the U.S.* Washington, D.C.: Author.
- Abdel Aziz, K., Elamin, M. H., El-Saadouni, N. M., El-Gabry, D. A., Barakat, M., Alharyas, F., & Moselhy, H. F. (2016). Schizophrenia: Impact of psychopathology, faith healers

- and psycho-education on adherence to medications. *International Journal of Social Psychiatry*, 62(8), 719-725.
- Ackerman, C. L., & Palmer, A. (2014). The contribution of implicit cognition to the theory of reasoned action model: A study of food preferences. *Journal of Marketing Management*, 30(5), 529-550.
- Addeo, R., Iodice, P., Maiorino, L., Febraro, A., Incoronato, P., Pisano, A., . . . Del Prete, S. (2015). Acceptance and adherence of oral endocrine therapy in women with metastatic breast cancer: Exacampania group study. *Breast Journal*, 21, 326-328.
- Administration on Aging. (2016). *A profile of older Americans: 2016*. Retrieved from https://www.giaging.org/documents/A_Profile_of_Older_Americans_2016.pdf
- Aillinger, R. L., Martyn, D., Lasus, H., & Lima Garcia, N. (2010). Populations at risk across the lifespan: Population studies: The effect of a cultural intervention on adherence to latent tuberculosis infection therapy in Latino immigrants. *Public Health Nursing*, 27(2), 115-120.
- Ajzen, I. (1985). From intention to action: A theory of planned behavior. In J. Kuhl & J. Beckman (Eds.), *Action control: From cognition to behavior* (pp. 11-39). Heidelberg, Germany: Springer.
- Alves Vieira, T., Nalin, T., Correa Krug, B., Matzenbacher Bittar, C., Oliveira Netto, C. B., & Doederlein Schwartz, I. V. (2015). Adherence to treatment of phenylketonuria: A study in southern Brazilian patients. *Journal of Inborn Errors of Metabolism & Screening*, 3, 1-7.
- American Diabetes Association. (2015). *Living with type 2 diabetes program*. Retrieved from <http://www.diabetes.org/biabetes-basics/type2>