

Reference:

DiMatteo, M. R., & Sin, N. L. (2011). Family adherence in health care regimen. In M. Craft-Rosenberg & Shelley-Rae Pehler (Eds.), *Encyclopedia of Family Health*. New York: Sage.

## **FAMILY ADHERENCE IN HEALTH CARE REGIMEN**

Fostering healthy behaviors and managing chronic medical conditions are essential family actions. In 2009, nearly half of all Americans had a chronic medical condition, according to the Robert Wood Johnson Foundation (please see Anderson, 2010, in the Further Readings section). Effective management of chronic conditions may require adherence to a variety of health behaviors, including exercise, dietary modification, daily disease monitoring, keeping medical appointments, and taking prescription medications. Adherence can be essential to good health outcomes.

### **Adherence to Medical Treatment**

The term “adherence” (also called “compliance”) involves accurately implementing a health care recommendation or treatment prescribed by a health care professional. Faithful adherence for many chronic disease conditions is remarkably low. Based on a meta-analysis of 569 studies of adherence, *at least* one in four patients is non-adherent to their physicians’ advice (DiMatteo, 2004). For some conditions and treatment recommendations, non-adherence is much higher.

Non-adherence has many serious implications for health outcomes and medical expenses. Symptoms can be exacerbated, unexplained relapses can occur, and functioning and well-being can be impaired. Subsequently, medical decisions may be misinformed and result in improper

changes to the medical treatment or unnecessary tests. For example, a physician who is unaware of patient non-adherence may increase or change medication in light of an ineffective clinical response, not realizing that the initial dosing was never followed. Non-adherence contributes to an increase in emergency room visits, a greater risk of hospitalization, and higher medical costs (Sokol et al., 2005). The New England Healthcare Institute estimates the yearly cost of drug-related problems, including non-adherence to medications, to be approximately \$290 billion in the United States.

The likelihood of adhering to a health care regimen varies based on a number of factors, according to the DiMatteo (2004) meta-analysis. For instance, the average rate of adherence ranges from 65% for sleep disorders to over 88% for HIV. Age is also associated with adherence: the average adherence rate for adults is higher than for children (77% vs. 71%). Furthermore, people are more likely to adhere to medication regimens than to regimens that require health behavior changes (such as diet, exercise, glucose monitoring, and physical therapy).

Families can help, or hinder, the achievement of its members' health behaviors and adherence to treatment. This entry discusses the social and psychological factors in families that can affect an individual's adherence to medical recommendations. Here, "family" is defined as a household unit that includes parents or guardians, adult and pediatric children, relatives, and other individuals living in the home. A family shares norms, habits, and experiences that can influence and shape the health of its members.

### **Family Psychosocial Factors Affecting Adherence**

Adhering to a medical regimen is rarely an individual matter. Family members are often required to communicate with medical professionals, understand and accept treatments, monitor health status, and perform essential activities to implement a prescribed regimen. When children experience acute or chronic illnesses, their parents, siblings, and extended family members frequently assume significant responsibility for their care. As individuals enter adolescence, complex developmental challenges affect adherence. Among adults, family responsibilities, pressures, and interpersonal dynamics can either support health-promoting efforts or provide numerous opportunities for intentional and unintentional non-adherence.

### **Family Dynamics**

Managing an illness can be psychologically and physically demanding. Thus, positive family interactions and supportive family attitudes are conducive to adherence. Patients in cohesive families (i.e., warm, accepting, and emotionally healthy) are more likely to be adherent; those in conflict-ridden families with negative emotional interactions tend to be less adherent. In pediatric diabetes, for example, high stress contributes to poor glycemic control both directly, by affecting metabolic functioning, and indirectly, by leading to poor adherence and ineffective regimen management.

Family size can affect adherence. For adults, being married or living with others promotes adherence, perhaps due to the support, reminders, and accountability from a household member. Larger households, however, place greater demands on parents; they are often required to balance limited energy, resources, and time between an ill child and those who are well. Research suggests that the more people living in a household, the lower a child's adherence.

Moreover, the attitudes and behaviors of siblings may have a profound impact on a chronically ill child's treatment adherence.

### **Social Support**

Support from family and friends can promote adherence in all age groups by enhancing the health care recipient's optimism and self-esteem, ameliorating depression, and reducing stress. Although emotional support is important for adherence, practical social support—such as reminders about medical appointments and assistance with the regimen itself—has a slightly stronger impact. Family members are more likely to provide practical support to health care consumers, whereas peers tend to provide emotional support and companionship. Overprotective families may socially isolate the patient and thus inadvertently contribute to poor adherence; companionship from peers can protect against social isolation.

### **Perceived Severity**

Parents' perceptions of the severity of their children's conditions affect their willingness and ability to adhere to required care, according to DiMatteo, Haskard, and Williams (2007). For less serious conditions (e.g., sore throat, middle ear infection), parents are more adherent when they believe their children are in poorer health. Conversely, for more serious diseases (e.g., cancer, end stage renal disease, diabetes), children judged by their parents to be in poorer health have *worse* adherence. When a child is severely ill with a serious disease, parents may be less adherent due to denial, doubts about treatment efficacy, or a desire to protect the child from uncomfortable medical interventions. Adult health care recipients show a similar pattern: among

those diagnosed with more serious diseases, individuals in poorer health are less adherent than those in better health.

### **Parental and Child Beliefs**

Parents' beliefs about their children's medical conditions and treatments are vital to adherence. For many chronic illnesses, mothers and children who perceive relatively greater benefits and fewer barriers to treatment are more adherent. Parents and adolescents who have high perceived self-efficacy (i.e., believe they are capable of completing the regimen tasks) are more adherent than those with low self-efficacy. However, parents of a sick child are less likely to be adherent if they do not agree on the treatment strategy or if their beliefs are not congruent with those of the physician. Parents are less adherent when they question the diagnosis, when they are unfamiliar with the physician, or when they distrust the physician. Furthermore, some parents believe that their child will "outgrow" a chronic illness (such as asthma) and may stop adhering when the child is asymptomatic.

### **Communication with Health Professionals**

Effective communication between health professionals and care recipients (and caregivers) involves sharing information, asking and answering questions, collaborative decision-making, shared treatment planning, empathy, and understanding. Effective interactions and communication with their child's physician lead parents to be more adherent to their child's treatment. Psychosocial concerns associated with health (such as family norms and attitudes that conflict with the prescribed regimen) are essential to raise in the medical visit. Although many parents believe that such discussion with their child's physician is important, they are often

reluctant to raise these concerns. Observations of the family's situation and frank discussion of psychosocial issues are essential to meeting their needs for support and care.

Decades of research show that interactions between physicians (and other health professionals) and their adult patients are generally not effective enough to promote adequate adherence. Physicians often fail to provide sufficient medical information and tend to be vague in their instructions and recommendations. Many adults leave their physicians' offices without understanding the regimen and its purpose well enough to be adherent.

### **Age-Specific Adherence Problems**

#### **Adolescents**

Compared to younger pediatric patients, adolescents are at a greater risk of non-adherence. An adolescent may not have yet developed the expected skills and maturity to assume responsibility for managing a chronic illness. Parents and health professionals must carefully evaluate an adolescent's competence because premature transition of regimen responsibilities from parent to child can lead to non-adherence. Adolescents are also more likely than younger children to test the boundaries of their health and to be skeptical of the long-term benefits of treatment that is unpleasant in the short-term. Some may refuse to take medication in front of peers and abandon treatments that threaten their ability to "fit in." Adolescents facing multiple risk factors may be particularly vulnerable to non-adherence. For example, adolescents with end stage renal disease who were non-adherent to immunosuppressive treatment tended to be depressed, lacked social support, had low self-esteem, and had difficulty communicating to family members and medical professionals.

## **Older Adults**

Older adults face special challenges that affect their willingness and ability to adhere to medical recommendations. Older adults are more likely than younger adults to be socially isolated, limited in mobility, lacking adequate financial resources, and struggling with sensory and cognitive impairments (e.g., poor hearing, eyesight, memory) that affect adherence. Mental health problems, particularly depression, are also more prevalent among older adults. Research indicates that the pessimism, social isolation, and cognitive deficits that accompany depression can contribute significantly to poor adherence.

Physicians communicate differently to older people than to younger ones. They give older patients relatively less information, less choice in their care, and less guidance about the procedures of the physical examination. Due to time limitations or the constraints of the physician-patient interaction, older patients fail to discuss as many as half of their medical and psychosocial symptoms. Some older individuals rely on caregivers and family members to help with their medical visits and treatment regimens, but the presence of a third person (such as a spouse, adult child, friend, or hired caregiver) can dramatically alter the dynamics of the medical visit. When a companion is present in the examination room, older patients raise fewer topics, are less responsive on the topics they do raise, are less expressive and assertive, and are less likely to engage in joint decision-making. Physicians tend to speak to the third person, excluding the health care recipient from the conversation. Under some circumstances, a companion can facilitate the medical interaction, such as by asking the individual questions, prompting the individual to speak, and encouraging the individual to be active in medical decision-making.

## **Recommendations**

Families can exert a powerful influence on a person's health behaviors, treatment adherence, and chronic disease management. The process of medical care should take into account each patient's family context when providing information to patients. Treatment recommendations and their purpose should be clearly understood, and participation of relevant family members in medical decisions should be encouraged. The concerns of family members should be addressed, including fears, beliefs about the treatment, and family norms and attitudes about the disease and the treatment regimen. Providers should address patient/caregiver commitment (such as by asking, "How will you take your medication?") and ask how the family is managing the chronic illness of its member. Input from chronically ill children and their well siblings can be very important to care, and adolescents should be assisted in their transition to independent care of their illnesses. Adults' challenges in coping with the added responsibilities of chronic illness in the family should be assessed, and providers should listen carefully for signs of family stress and conflict. Potential depression in family members should be assessed and treated, and guidance in obtaining resources for coping (such as community support groups) should be offered. Attention should be paid to the experience of potentially vulnerable older health care recipients.

### **Conclusion**

An individual's health outcomes are strongly influenced by his or her family context. Families can have a powerful effect on the management of chronic illness by influencing a person's commitment, motivation, and ability to follow recommended medical treatments. To ensure optimal health behavior and adherence to medical regimens, health professionals should be aware of and address issues of concern for patients and their families.



*M. Robin DiMatteo*

*Nancy L. Sin*

*See Also* Chronic Illness and Family Management Style; Communication in Families Related to Health and Illness; Family Attitudes Toward Health; Family-Centered Care; Role of Families in Health Promotion

### **Further Readings**

- Anderson, G. (2010, February). *Chronic care: Making the case for ongoing care*. Robert Wood Johnson Foundation. Available online at <http://www.rwjf.org/pr/product.jsp?id=50968>
- DiMatteo, M. R. (2004). Variations in patients' adherence to medical recommendations: A quantitative review of 50 years of research. *Medical Care*, *42*, 200-209.
- DiMatteo, M. R., Haskard, K. B., & Williams, S. L. (2007). Health beliefs, disease severity, and patient adherence: A meta-analysis. *Medical Care*, *45*, 521-528.
- DiMatteo, M. R., & Martin, L. R. (2002). *Health psychology*. Boston: Allyn and Bacon.
- Drotar, D. (Ed.). (2000). *Promoting adherence to medical treatment in childhood chronic illness: Concepts, methods, and interventions*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Johnson, S. B., Perry, N. W., & Rozensky, R. (Eds.). (2002). *Handbook of clinical health psychology, Volume I: Medical disorders and behavioral applications*. Washington, DC: APA Press.

Martin, L. R., Haskard-Zolnierrek, K. B., & DiMatteo, M. R. (2010). *Health behavior change and treatment adherence: Evidence-based guidelines for improving healthcare*. NY: Oxford University Press.

New England Healthcare Institute. (2009, August). Thinking outside the pillbox: A system-wide approach to improving patient medication adherence for chronic disease. Available online at [http://www.nehi.net/uploads/full\\_report/pa\\_issue\\_brief\\_\\_final.pdf](http://www.nehi.net/uploads/full_report/pa_issue_brief__final.pdf)

Roter, D. L., & Hall, J. A. (2006). *Doctors talking to patients/patients talking to doctors: Improving communication in medical visits* (2nd Ed.). Westport, CT: Praeger.

Sokol, M. C., McGuigan, K. A., Verbrugge, R. R., & Epstein, R. S. (2005). Impact of medication adherence on hospitalization risk and healthcare cost. *Medical Care*, 43, 521-530.