Treatment Adherence in Adolescence

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Quality health care outcomes depend upon patients' adherence to a variety of treatments including medication, medical device use, and lifestyle management such as diet and exercise. Adherence refers to the degree to which an individual follows disease management activities as directed by their health professional. The empirical study of adherence now spans more than 50 years in the scientific literatures of psychology, medicine, and public health. Nonadherence has been found to be a pervasive threat to health and well-being and imposes an appreciable economic burden estimated at 290–300 billion dollars per year (DiMatteo, 2004a; New England Healthcare Institute, 2010). More than 240 million medical visits per year are wasted due to nonadherence (Haskard-Zolnierek & DiMatteo, 2009) and both providers and patients often remain unaware that a major cause of poor health outcomes is poor adherence (DiMatteo, Haskard-Zolnierek, & Martin, 2012).

While adherence behavior is not itself a health outcome, adherence is significantly related to both acute and chronic disease outcomes. Meta-analysis shows substantial and statistically significant outcome differences (26 %) between high and low adherence in all disease realms. Among pediatric (including adolescent) patients, adherence is significantly more strongly related to health outcomes than it is for adults. The difference in risk of a poor health outcome is 33 % greater with poor adherence than with good adherence in samples of children and adolescents; for adults, this risk difference is only 23 % ($z=2.64, p<0.01$) (DiMatteo, Giordani, Lepper, & Croghan, 2002).

Adolescent Nonadherence

The challenges of treatment adherence have been studied extensively in adult populations, but less so in child and adolescent care. In a meta-analysis of 569 empirical studies of adherence spanning the history of adherence research to that time, DiMatteo (2004a) found four times as many studies of adult populations (18 and older) as pediatric, and only a portion of the pediatric studies involved only adolescents. Since 2004, the corpus of studies of adolescent adherence has grown appreciably, however, with a recent search producing over 900 empirical research references, 162 of which were published in the year 2010 alone.

Adolescent nonadherence typically takes a number of forms. Although parents are likely to be in charge of filling/refilling medication prescriptions, scheduling medical appointments, and transporting the patient to treatment, adolescents themselves are likely to be expected to take

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responsibility for various health actions including testing blood sugar levels, taking insulin injections, following a prescribed diet or avoiding prescribed foods (e.g., those containing gluten), doing specific exercises for a sports injury, and following a daily asthma treatment regimen to avoid a breathing crisis.

The prevalence of nonadherence across a wide variety of diseases, regimens, and patient populations averages 25%, although in some disease conditions such as the complex management of diabetes, nonadherence can be 50% or more. In meta-analytic work with stable estimates, there is a significant trend for (401) studies of adults to yield higher adherence (76.8%) than (116) studies of pediatric patients (70.6%) (t(515) = 2.84, p = 0.005). Among adult patients, there is no relationship between age and adherence (83 studies, r = 0.01, d = 0.02), but among pediatric patients (41 studies, r = -0.06, d = -0.12) adherence is lower among adolescents than it is among children (p < 0.10) (DiMatteo 2004a).

Treatment nonadherence in pediatric populations is estimated, in further studies, to be about 50–55% (Rapoff, 1999); among children with asthma followed in a specialist clinic, medication adherence was about 70% (Phelan, 1984). Based on structured interviews and daily phone diaries, more than 50% of adolescents with cystic fibrosis reported doing less than their prescribed airway clearance regimen and 30% indicated that they were not doing any of their prescribed regimens (DiGirolmo, Quittner, Ackerman, & Stevens, 1997). In a study of prescription medication adherence among adolescents, complete adherence to the prescription was only 36.2% (Chappuy, Treluyer, Faesch, Giraud, & Cheron, 2009). Between 50 and 60% of children and adolescents with adherence problems were found to underuse their prescribed medication (while less than 10% overused it) (Chmelik & Doughty, 1994; Coutts, Gibson, & Paton, 1992). Among adolescent patients with adequate functional health literacy, 35.7% were categorized as adherent, but only 23.5% of those with marginal/inadequate health literacy were categorized as adherent (Murphy et al., 2010). Twenty-five percent of adolescents with type 1 diabetes reported mismanagement behaviors such as missing insulin shots (Kovacs, Goldston, Obrosky, & Iyengar, 1992; Weissberg-Benchell et al., 1995). In asthma treatment, the average overall adherence rate among African-American adolescents (measured as daily mean percent of prescribed inhaler puffs) was only 31.5%. Adherence also decreased over time, from 42% at the start of the study to only 20.2% of prescribed puffs after a year on treatment (Rohan et al., 2010).

Simmons, Logan, Chastain, and Cerullo (2010) found variability in adherence as a function of the treatment regimen. Among adolescents who were recommended a medication change, 53.1% were fully adherent; 87.5% were fully adherent to obtaining additional recommended tests. Of participants prescribed physical therapy, 100% were fully adherent to continuing if they had already started, but only 75% began; 90.9% were fully adherent to use of a TENS unit, but only 60% were fully adherent to an independent exercise program. Adherence to psychological recommendations varied as well: 85.7% of adolescents were fully adherent to continuing treatment with their current therapist; but only 46.7% were fully adherent to beginning cognitive behavioral therapy (Simmons et al., 2010).

Understanding Treatment Adherence in Adolescent Patients

The empirical literature on treatment adherence in all age groups has documented a wide variety of factors that influence the degree to which patients follow medical recommendations. Researchers have offered empirical evidence for the contribution of dozens of intra- and interpersonal, environmental, disease-related, and regimen-related factors. Practical applications of this research are somewhat limited, however, because there are so many causes of nonadherence. It is critical to understand these causes in a workable conceptual framework in order to design successful programs to advance adherence among adolescents. DiMatteo et al. (2012) describe the Information, Motivation, Strategy (IMS) model which distills the findings of the

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complex literature into three main elements for understanding adherence. According to the IMS model, patients of all ages are non-adherent for three straightforward classes of reasons: (1) They do not understand what they are supposed to do (e.g., information transmittal and gathering are lacking; they have not participated in the decision-making process; their communication and rapport with their health professionals is limited), (2) they are not motivated to follow their treatment (e.g., they do not believe that the benefits outweigh the costs; their social network and/or cultural environment do not support the behavior), and (3) they do not have a workable strategy for following the treatment (e.g., they do not have help; practical barriers stand in the way). In the following section of this chapter, we examine the specific challenges in treatment of chronic illness among adolescents in the context of this model, attempting to understand three categories of factors related to adolescent nonadherence. We also examine the effectiveness of adherence-enhancing interventions in the context of this model.

Information

The communication of information between health professionals and their patients is a primary element essential for the achievement of treatment adherence; patients cannot follow treatments they do not fully understand. Communication is essential for a realistic assessment of patients' knowledge and understanding of their regimen, and communication is essential for building trust in the therapeutic relationship. In a recent meta-analysis, the relationship between physician–patient communication and treatment adherence was found to be higher (borderline significant) in pediatric practice (average $r=0.24$) than in the care of adult patients (average $r=0.18$) ($t(101)=1.75, p=0.08$). Further, training to improve physician communication showed significantly more improvement in patient adherence when pediatricians were trained (average effect size $r=0.27$) than when non-pediatricians were trained (average effect size $r=0.10$) ($t(19)=3.42, p=0.003$) (Haskard-Zolnierek & DiMatteo, 2009).

At the most basic level, recall of recommendations is essential, although studies have shown the majority of adults (e.g., Kravitz et al., 1993) as well as children and their parents (Ievers et al., 1999; Lewis, Pantell, & Sharp, 1991) fail to recall what they are told about disease management during their medical visits. Patients and caregivers need the opportunity to ask questions and have them answered, to clarify information they are given, and to “teach back” to their health professionals what they have learned. All patients, including adolescents, need the chance to participate in the decision process and to determine how they will follow their treatment (Golin, DiMatteo, & Gelberg, 1996). When patients and their doctors share similar beliefs about patient participation (that is, when patients are motivated to participate and their physicians allow them to do so), patient outcomes tend to be more positive and patients are more satisfied (Jahng, Martin, Golin, & DiMatteo, 2005). Patients are also more adherent to physicians who answer their questions (DiMatteo et al., 1993) and patients are typically willing to follow treatment recommendations only for health professionals they trust and who provide satisfactory interpersonal quality of care (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992).

Whether patients understand and can follow their treatment is related strongly to their health literacy, which has been found to be a major factor among HIV-infected adolescents (of whom almost 15% were found to have inadequate or marginal health literacy). Among the 85% of participants with adequate functional health literacy, only 36% were categorized as adherent, and among those with marginal or inadequate health literacy, only 23.5% were categorized as adherent (Murphy et al., 2010). Adjusting for age and education level, viral load, and self-efficacy to adhere to medication regimens, however, adolescents' own health literacy was not significantly associated with their medication adherence (Murphy et al., 2010). But, as Janisse, Naar-King, and Ellis (2010) found among high-risk adolescents with IDDM, parental literacy/reading...
comprehension was significantly related to treatment adherence among adolescents on an intensive insulin regimen (Janisse et al., 2010). Parents with low health literacy struggled to help their children adhere to increasingly complex diabetes treatment regimens, leading the authors to suggest that families may benefit from more intensive diabetes education or different approaches to teaching diabetes management skills (Janisse et al., 2010).

Essential elements of improving communication involve strengthening physician–family interactions and the relationship between the adolescent and health professionals; the goal is to help understand the adolescent as well as the disease (Drotar, 2009; Simmons et al., 2010). Drotar (2009) studied both parents’ and children’s perceptions of their pediatricians’ behavior in the management of pediatric chronic illness treatment management, and correlated the providers’ communication behavior with treatment adherence. The findings showed that discrepancies between the needs of parents and their children, and inconsistencies in physicians’ behavior while explaining treatment procedures, were related to limitations in the children’s adherence to treatment. Further, understanding and implementing complex treatments, such as for diabetes, can be challenging to even the most motivated parents and their adolescents (Rudy, Murphy, Harris, Muenz, & Ellen, 2009).

**Motivation**

Probably more than in any other age group, adherence among adolescents is affected by issues of motivation. The motivations of the adolescents themselves as well as of their parents, siblings, and peers can have strong effects on commitment to a treatment regimen, and ultimately on its fulfillment (Wysocki, Greco, & Buckloh, 2003). Motivation for treatment adherence is built upon a number of factors (DiMatteo et al., 2012). These include the following: (1) belief in the treatment (the necessity of it, and its value), (2) the perceived costs of the treatment (particularly in terms of potential losses of social status, cultural norm maintenance, and peer acceptance), and (3) attitudes about the illness (i.e., its meaning) and treatment (i.e., expectations that the benefits outweigh any costs) and about the self in relation to disease management (self-efficacy). Beliefs, attitudes, motivations, and their resultant commitment to treatment may be particularly difficult to achieve for an adolescent patient, because he or she is embedded within a social system comprised of influential family members as well as peers who may not support the regimen (or with whom the adolescent is resistant to share the issues of care). Further, adult caregivers and parents may struggle to bridge the differences in attitudes and beliefs between the adolescent and all of the adults with whom they deal.

Models of health behavior and general behavior change (e.g., the Health Belief Model, the Theory of Planned Behavior) (Martin, Haskard-Zolnierek, & DiMatteo, 2010) posit beliefs and attitudes as the building blocks of commitment to action. Commitment requires belief in potentially negative and serious consequences of not acting, the expectation that the benefits of acting will outweigh the costs (broadly defined) of doing so, a synchrony between the beliefs and desires of the individual and his or her social (including cultural) environment, as well as the individual’s belief in his or her own ability to act (i.e., self-efficacy). These models suggest that, clinically, it is vital to know the patient well, and to identify and manage realistic treatment goals and expectations for therapy.

In the case of adolescent care, it is also vital to know the adult caregivers. Understanding what patients and their parents/guardians expect and believe, what they are influenced by, and what they can be inspired or prompted to do allows for health professionals to support adolescent motivation to adhere to treatment.

Chronic illness management can challenge the self-esteem of some adolescents (Friedman et al., 1986), who may become frustrated and view themselves as “defective” because of their illness; such feelings can potentially contribute to significant emotional distress (Rudy et al., 2009). Adolescents may view their illness and treatment regimens as forcing an unwanted dependence on their parents (Rudy et al., understand to their condition their medications, the effect of medications to their body, the health condition might be ignored to be likely to their medication). Dyslexia, cystic fibrosis, celiac disease, and “diabetes” are all conditions that can be challenging to live with and can potentially have a significant impact on a young person’s life.

The goal of pediatric chronic illness management is to help understand the adolescent as well as the disease, to help them to be able to act, and to be able to adhere to treatment. (Each otheradolescent may need to be treated differently, and what is best for one patient may not be best for another.)
their parents, guardians, and health professionals (Rudy et al., 2009). Sometimes, in an attempt to understand the full meaning and implications of their condition, adolescents might stop taking their medications as an experiment to determine the effect on their health or well-being. Not all medications produce immediate results, however, so their benefits may not be at all obvious; and the health consequences of not following treatment might also be delayed (e.g., celiac disease, cystic fibrosis). Some consequences might not be noticed at all, or might not be clearly connected to nonadherence. Distal future outcomes might be ignored completely, because adolescents are likely to have some difficulty with focused commitment to the future (Ingerski, Baldassano, Denson, & Hommel, 2010). The belief that treatment is not necessary to their current interests and goals may severely limit some adolescents’ commitment to disease management (Ingerski et al., 2010).

For many adolescent patients, the perceived stigma of being ill is one of the major factors limiting active adherence to treatment (Wysocki et al., 2003). The developmental period of adolescence is one in which the struggle to “fit in” and to be accepted by peers is a primary concern. The everyday management of a chronic disease (such as with blood sugar testing and insulin injections by the diabetic, or the avoidance of popular foods such as pizza by the patient with celiac disease) can be a source of embarrassment and “differentness” leading the adolescent to avoid social stigma by avoiding the treatment regimen (Friedman et al., 1986; Salamon, Hains, Fleischman, Davies, & Kichler, 2010). Some adolescents may even have difficulty with management of their disease within certain social contexts because of direct peer pressure and actually being singled out for criticism because of their condition (Wysocki et al., 2003).

The sociocultural norms of adolescence (including expectations that adolescents have for each other regarding dress, activities, and behavior) may carry a great deal of weight in an adolescent patient’s decisions about health action and treatment adherence (Hampson, Glasgow, & Toobert, 1990). These cultural norms can affect responses to treatment plans as well as perceptions of the meaning of illness and the sick role, and the acceptability of seeking and accepting advice from adult caregivers (Hampson et al., 1990; La Greca, Bearman, & Moore, 2002). For adolescents, friends and peer group members may be the strongest influences in their lives and in their commitment to care (La Greca et al., 2002). Thus, culture not only refers to racial and ethnic identification but extends to the broader adolescent culture, underscoring the need for health professionals who work with adolescent patients to fully understand adolescent culture (both broadly and regionally), perhaps working with psychologists who are experts in adolescent treatment (Christian & D’Auria, 1997). Providers should identify the important individuals and influences in the adolescent’s life, and examine their understanding of, beliefs about, and influences on the patient’s treatment and adherence (La Greca et al., 2002; Thomas, Peterson, & Goldstein, 1997). Concerns about norms and adolescent culture should be discussed with the patient and his or her caregivers in an effort to increase awareness of the factors that can affect the success of medical recommendations (Christian & D’Auria, 1997).

Adolescents with chronic disease can face daily challenges of social pressure, especially when their medical condition makes them appear different from their friends (Christian & D’Auria, 1997; La Greca & Hanna as cited in La Greca et al., 2002). For the diabetic, for example, the complexities of dietary adherence and invasive activities such as blood glucose testing and insulin injection are potentially significant issues that can derail adherence (Thomas et al., 1997). Promoting patient adherence requires health professionals to determine the degree to which their adolescent patients feel their disease affects their friendships, and to try to find ways to deal with these challenges (La Greca et al., 2002).

Although the findings are mixed, some research suggests that by being generally supportive (though not necessarily helping directly with treatment), peers can help to motivate adolescents to be adherent to chronic disease management. In a review by La Greca et al. (2002),
data suggested that adolescents perceive the support of their friends to be more important in certain areas (e.g., meals and exercise) than in other areas of management (e.g., insulin injections and blood testing). Friends may also be helpful with emotional reactions. Bearman and La Greca (2002), however, did find that friend support, although not related to overall treatment adherence, was related to higher adherence for blood glucose testing. These findings argue for the importance of identifying the specific areas of disease management in which friends can be most supportive, and facilitating that support with education and encouragement. Providers should respectfully address patients’ beliefs (including their concerns about the role of peers), and should serve as both partners and persuaders, working together with adolescent patients to arrive at mutually agreed-upon courses of action and using the strength of the therapeutic relationship to facilitate the adolescent’s commitment to the treatment regimen. Identification of the “stage of change” at which the adolescent is approaching the treatment, and working with the patients’ beliefs, attitudes, subjective norms, and cultural context, providers can help the patient to develop and maintain a commitment to long-term disease management (Prochaska, DiClemente, & Norcross, 1992).

**Practical Barriers**

Practical barriers can represent some of the most common challenges to patient adherence. At the simplest level, a medication’s bad taste has been found to limit adherence among children and early adolescents (Ingerski et al., 2010). Economic challenges may limit the affordability of treatment (Rohan et al., 2010) and combined, with other pressures such as difficult parental work schedules, can result in parents’ failures to obtain on-time refills of medications. In a study of adolescents with inflammatory bowel disease who were taking oral medications, the most commonly reported barriers included forgetting (87.8%), being away from home (47.3%), interference with an activity (44.6%), refusal/defiance (17.6%), not feeling well (16.2%), and running out of the medication (16.2%). Intensive treatments (such as for HIV, diabetes, CF) may be quite demanding and difficult for adolescents and families to manage (Ingerski et al., 2010). Orban et al. (2010) found that the most frequent stressors reported by adolescents receiving treatment for HIV were related to medication-taking (Orban et al., 2010), even despite the availability of clinic support services for adhering. These services, however, tended to focus more on tangible aspects of adherence such as medication reminders; in fact, some efforts such as passive coping strategies made youth feel helpless and frustrated, increasing depression and reducing adherence (Orban et al., 2010).

Treatments for chronic disease interfere with the lives of adolescents in major ways. Medication schedules can disrupt normal routines and both school and after-school schedules. Dosage frequency influences adherence to prescriptions, with more frequent dosing resulting in lower adherence; average adherence was 73% for once daily regimens, 70% for twice daily, 52% for thrice daily, and 42% for four times a day regimens (Chappuy et al., 2009). Researchers have found that adherence to complex and intrusive treatments such as dietary modification, glucose monitoring, and physical therapy is even lower than adherence to medical regimens in adolescents (Rapoff, 1999). Length of treatment also influences adherence. In one study with children treated for was significant days than f the barrier A meta-an for patients’ available when pa (DiMatteo, 2001) found that adherence. In a assessed average c tus and the sig among cs to be 1.3 from the risk of n w. Furthermore such that was as: care of: r=-0.11 greater tional energy. Sho individual examples were admin and a 378 M.R. DiMatteo and T.A. Miller

**Strategy**

Even with a full understanding of the disease and treatment, strongly held commitment, the best of intentions, and supportive norms, individuals may still fail to adhere to necessary health behaviors because they encounter practical difficulties. Patients can only do what they are capable of doing within their resource limitations; those resources can range from affordable treatments to organized and supportive families to well-developed habits. Thus, the third element of achieving adherence involves identifying the barriers that adolescent patients face in following their treatment and assisting them to gain the necessary resources and supports to solve their strategic challenges.
of the most sick. At the same time, the economic aspect of treatment with mental work to obtain the dy of adolescence who most commonly forget their medications (Orban et al., 2001). Of course, long-term chronic disease management is likely to produce even lower adherence (World Health Organization, 2003).

One of the most important factors in patients’ ability to follow treatment involves the degree of practical support available to them to deal with the barriers encountered (Sherbourne et al., 1992). A meta-analytic review of the literature from 122 studies found a significant positive relationship of patients’ adherence with the practical support available to them; adherence was 27% higher when patients had practical social support (DiMatteo, 2004b). Social networks affect adherence. In a meta-analysis, DiMatteo (2004a, 2004b) assessed 40 studies of adult patients in which the average correlation between subjects’ marital status and their adherence was only 0.05. However, among nine samples of pediatric patients, the average correlation between parents’ marital status and children’s treatment adherence was significant ($r = 0.15$). The risk of nonadherence among children with unmarried parents was found to be 1.35 times higher (standardized relative risk from the binomial effect-size display) than the risk of nonadherence among children and adolescents with married parents (DiMatteo, 2004b).

Furthermore, this meta-analysis showed a trend such that a greater number of people in the family was associated with lower adherence in the care of pediatric patients (median $r = -0.22$; mean $r = -0.17$). A likely explanation would involve greater competition for both physical and emotional resources including parental attention and energy in larger families.

Shorter duration of hospital stays and limits on physician time spent with patients have significantly shifted care to families and increased the need for family responsibility in treatment management for children and adolescents. For example, cancer medications that, in the past, were given to children in hospital may now be administered by parents at home. Certainly there are advantages to home care for pediatric patients, including the comfort and familiarity of setting and availability of relatives and friends. However, although some families are able to administer treatments effectively, not all are capable of taking on the organization and planning necessary to manage treatment responsibly (Riekert & Drotar, 1999). Some families may have difficulty independently caring for medical symptoms (such as of asthma) and instead rely on health care providers in clinic or emergency room visits (Rohan et al., 2010).

Emotional Distress and Family Conflict

Stress and emotional distress, in the patient and in the family, can be significant barriers to adherence (Cox & Gonder-Frederick, 1992). Depression and distress can be common in medical patients, and are associated with diminished health status (Sherbourne, Wells, Meredith, Jackson, & Camp, 1996) and increased health care utilization (Manning & Wells, 1992; Simon, Ormel, VonKorff, & Barlow, 1995). In a meta-analysis, the relationship between depression and nonadherence was substantial and significant (DiMatteo, Lepper, & Croghan, 2000). Compared with nondepressed patients, the odds were three times greater that depressed patients would be non-adherent, suggesting the importance of recognizing depression as a risk factor for poor outcomes among patients who might not be adhering to medical advice. In the Medical Outcomes Study, a longitudinal study of 1,198 patients with chronic medical diseases (hypertension, diabetes, heart disease), patients who were distressed about their health, used avoidant coping strategies, or reported worse physical and role functioning were less likely to adhere in general (Sherbourne et al., 1992). Blotcky, Cohen, Conaster, and Klopovich (1985) found that subjective distress was significantly related ($r = -0.48$) to refusal of treatment among children with cancer. Brownbridge and Fielding (1989) found adherence to be significantly lower in the care of children with end-stage renal disease when the main caregiver was depressed ($r = -0.45$).

There is a negative relationship between adherence and family conflict (including dysfunctional family interactions, the anger of a healthy sibling, and family pathology); an average $r$ effect size of $-0.21$ indicated that poorer adherence was
associated with greater family conflict and that the odds of nonadherence among patients in higher conflict families were 2.35 times higher than among those in families with lower levels of conflict (DiMatteo, 2004b). Effective communication about decision-making autonomy is also critical. Miller and Drotar (2003) documented the relationship between discrepancies in mother and adolescent perceptions of diabetes-related decision-making autonomy, diabetes-related conflict, and regimen adherence; discrepancies between mothers' and their adolescents' perceptions of decision-making autonomy were related to greater maternal report of diabetes-related conflict. In particular, mothers reported greater conflict with their adolescents when the adolescents reported that they were more in charge of decisions than their mothers believed that they were (Miller & Drotar, 2003).

In a meta-analysis, DiMatteo (2004b) found that the odds of adherence are three times higher if patients come from cohesive families than if they do not (r = 0.27). Higher levels of mother-reported spousal support were associated with less conflict and with greater adherence to treatment (Lewandowski & Drotar, 2007). This latter study was important because it demonstrated that the spousal support mothers receive may play an important role in the health care behaviors of their adolescents (Lewandowski & Drotar, 2007). DeLambo, Ievers-Landis, Drotar, and Quittner (2008) examined associations between observations of the quality of family relationships and reported adherence to medical treatments for older children and adolescents with cystic fibrosis. Based on children's reports of treatment adherence, the positivity of the observed family relationship quality predicted reported adherence to airway clearance and use of aerosolized medications among child and adolescent patients (DeLambo et al., 2008).

**Family and Adolescent Control: Responsibility for Illness Management**

Adherence to medication and other treatment regimens for children and adolescents depends, to a great extent, on the help of parents/guardians and other family members (DeLambo et al., 2008). With the onset of adolescence, there are often changes in the allocation of treatment-related responsibilities among adolescent patients and their caregivers. Yet, although adolescents can be given increased responsibility for their care compared to what they had as children, research shows that adolescents need help from their parents as well as scheduled support and help from their health professionals. Data suggest that there are predictable differences in treatment-related expectations for adherence behaviors among children versus adolescent. For example, children age 7–10 will likely have different and fewer responsibilities compared to those 11–15 years of age (Modi, Marcie, Slater, Drotar, & Quittner, 2008; Walders, Drotar, & Kercsmar, 2000). Yet, the division of illness-related responsibilities between an adolescent and his or her parents/caregivers needs to be optimal and reflect the adolescent's unique abilities (Lewandowski & Drotar, 2007; Miller & Drotar, 2003). There is no significant relationship between adolescent chronological age and the ability to take responsibility for asthma management (Walders et al., 2000). This study shows that when caretakers reduce their involvement in asthma management based on their child's chronological age, they might operate under the false premise that adolescents are consistently able and/or willing to take on increasing accountability for asthma management (Walders et al., 2000).

It is, therefore, necessary for families to help, and for parents to supervise. Yet, one study of cystic fibrosis patients found that by age 15, adolescents were completing nearly 90% of their daily treatments on their own—although this was often done at the cost of poor adherence (Modi et al., 2008). In addition, adolescents who spent more of their treatment time supervised by their parents had better adherence (Modi et al., 2008). Walders et al. (2000) examined family management patterns among African-American adolescents with asthma. They found a relationship between caretakers' overestimation of adolescent responsibility for important self-care tasks and increased nonadherence and functional morbidity (Walders et al., 2000). These studies demonstrated that parents and adolescents need anticipatory guidance on how and when to transition...
Responsibility for daily treatment regimens and that family interventions are essential for improving adherence among adolescents with chronic illness (Modi et al., 2008).

Should adolescents make their own decisions about their treatments, and take complete responsibility for them? Probably not. Lewandowski and Drotar (2007) found that adolescent decision-making autonomy did not help adherence; it was not necessarily a good thing to have adolescents making their own decisions about care. Instead, decision-making responsibility and disease management were better negotiated and agreed upon by parents and their adolescents. A discrepancy in expectations about who will make decisions is a problem; parent/adolescent conflict can lead to resistance to adherence. In diabetes treatment, increased levels of mother–adolescent conflict have been found to be associated with poorer treatment adherence and mother-reported diabetes-related conflict and disagreements about decision-making autonomy predicted poor glycemic control (Lewandowski & Drotar, 2007).

One study examined decision-making competence in a sample of parents and their adolescents with type 1 diabetes (Miller & Drotar, 2007). Parent–adolescent communication during a problem-solving task was assessed, along with the adaptiveness of adolescent decision-making, adherence to treatment, and metabolic control (Miller & Drotar, 2007). Parent–adolescent communication was associated with adherence to treatment, but not with the quality of adolescent decision-making (Miller & Drotar, 2007). Poorer decision-making was associated with lower adherence (measured by parent report), and decision-making competence did not mediate the relationships between parent–adolescent communication and adherence (Miller & Drotar, 2007).

**Parent–Adolescent Collaboration**

Data suggest that full responsibility by parents may not be the best course of action for adolescent care, for several reasons. In some research, parents made significant errors in the timing of medication and some even encouraged premature discontinuation of medication because symptoms “seemed” to improve (Dawson & Newell, 1994). Parents with low health literacy have been found to struggle to help their children adhere to complex treatment regimens (Janisse et al., 2010). Family habits have sometimes been found to jeopardize adherence to the treatment regimen (Nock & Kazdin, 2005). In order to optimize the efficacy of asthma management, for example, researchers suggest that family-based treatment plans should be collaboratively developed between physicians and family members (Walders et al., 2000). Effective illness management requires good communication between adolescent, parents, and health professionals in order to have an appropriate and effective division of illness-related responsibilities.

**Validated Interventions to Improve Adolescent Adherence**

Several interventions to improve adolescent adherence have been shown to be effective; each emphasizes at least one component of the IMS model, and most are multifactorial—incorporating some combination of all of the factors. Interventions that target, in an integrated way, the many elements that affect patient adherence are most likely to be successful (DiMatteo et al., 2012).

In a pilot study with ten adolescents with type 1 diabetes and HbA1c levels greater than 7%, Salamon et al. (2010) assessed a cognitive–behavioral intervention geared toward challenging and restructuring negative social attributions that can contribute to nonadherence. One hour intervention sessions to boost understanding and motivation were combined with three weekly phone calls that focused on cognitive restructuring and on problem-solving training to improve strategizing (Salamon et al., 2010). Problem-solving that was geared toward dealing with social situations (in which adolescents likely experience the greatest pressure to be nonadherent) was the most helpful.

Nock and Kazdin (2005) used a brief adjunctive intervention (called PEI training) which provided parents of adolescents with knowledge, motivation, and tools toward the goal of
overcoming conduct problems and barriers to treatment participation. PEI therapists helped parents develop specific plans to overcome each barrier through the use of a change plan worksheet (Nock & Kazdin, 2005). When parents received the training, their adolescents had better attendance at treatment sessions and showed greater adherence to treatment recommendations.

Dean, Walters, and Hall (2010) conducted a comprehensive search of the literature and reviewed 17 studies that offered empirical data on interventions to improve long-term medication adherence in children and adolescents with chronic disease. They examined educational interventions, behavior interventions (that may have also included education), and educational approaches combined with another intervention. Of seven (primarily) educational interventions, only one (Jay, DuRant, Shoffitt, Linder, & Litt, 1984) targeted adolescents only, and found that an educational intervention with peer counselors significantly increased adolescent girls’ adherence to their oral contraceptives for 1–2 months, although the significant effect did not last over the 4 months of the study. Four studies involved both children and adolescents, but did not allow separate analyses. Three of these four were with asthma. One study (Hughes, McLeod, Garner, & Goldbloom, 1991) found that home visits and education about asthma management did not affect adherence as measured by medication diary, but did lead to significantly better asthma control. Another (Farber & Oliveria, 2004) provided single-session education with video and discussion, and found adherence significantly higher in the intervention group, but only for preventer medication (not the rescue bronchodilator). The intervention group had lower rates of corticosteroid undertreatment. In the treatment of HIV in children and adolescents, home visits involving education and strategies to resolve adherence barriers resulted in significantly greater self-reported adherence as well as increased dose frequency (Berrien, Salazar, Reynolds, & Mckay, 2004). In this review, there were seven studies using behavioral interventions, five of which were with both adolescents and children (not separated) and one studying only adolescents. In the latter, behavioral management (including advice with contingency contracting, advising about problems, goal setting, development of habits and routines, and family involvement) prevented missed doses of tuberculosis medication (as self-reported in face-to-face interviews) significantly more often than both control treatment and an intervention to improve self-esteem (Hovell et al., 2003). Of the five studies of children and adolescents, all showed significant improvements in adherence to some or all medications when the intervention involved behavioral management. These behavioral interventions included monitoring and goal setting, reinforcing medication-taking with rewards, contingency contracting, problem-solving, and linking medication taking with established routines to establish habits. Van Es, Nagelkerke, Colland, Scholten, and Bouter (2001) found that adolescents with asthma demonstrated better treatment adherence if they received both education and group therapy exploring treatment and disease-focused issues including their attitudes, coping skills, and management of peers. (Two other interventions cited by Dean et al. (2010) showed no benefit of education combined with cognitive behavioral therapy or stress management.) No studies were found to demonstrate the effectiveness of intervention to reverse nonadherence among young people once nonadherence has been established.

### Future Research on Interventions

Currently validated interventions exist to promote adherence among adolescents with chronic disease. The empirical data available so far is limited but does suggest that multifaceted interventions work better than do single-issue interventions. The best combination of elements to produce the greatest improvements in adherence with the greatest efficiency is not yet evident, but it does appear that a combination of education, information, methods for increasing motivation, and problem-solving strategies and supports may offer the greatest opportunities for success (Dean et al., 2010). While there is no clear message...
from the literature about why various factors may be effective, some of the more theoretical and empirical work in adult adherence notes that multifaceted solutions, targeting many factors that affect adherence, may be essential. Future research attention to intervention studies should seek to determine the mediating and moderating factors of successful interventions, so that effective elements can be preserved in exportable interventions that can be used on a wide scale. Further, as Dean et al. (2010) conclude, some studies do not provide data for calculation of effect sizes that are necessary for meta-analyses; meta-analytic work is essential to moving this field forward. Also, many studies combine data from children and adolescents, making it difficult to determine the unique effectiveness of interventions for adolescent populations. Thus, future research should focus on adolescents, and in publication should offer as much data as possible for extracting or calculating effect sizes, in order to allow meta-analyses of the growing literature on adolescent adherence to treatment.

Clinical Implications

Research on the challenges of adolescent treatment adherence suggests some important clinical recommendations. First, it is essential for medical teams (consisting of physicians, nurses, nurse practitioners, physician-assistants, pharmacists, case managers, etc.) to coordinate their efforts and share information toward the goal of helping patients achieve adherence. Second, clinicians on the medical team should regularly ask patients and their families about adherence. Assessing adherence accurately is central to the enhancement of treatment choices and to the prediction and optimization of health outcomes (Sherbourne et al., 1992). Assessing adherence accurately is not easy, of course (Hays & DiMatteo, 1987), but there exist many methods to collect accurate self-reports from patients in ways that encourage truthfulness (see measures in DiMatteo, Hays, & Sherbourne, 1992). Third, clinicians on the medical team should help family members work together in treatment management, helping each member of the family to be clear about their responsibilities in the treatment regimen. Discrepancies between parents’ and adolescents’ perceptions of disease-related decision-making autonomy can contribute to nonadherence; identifying and solving these discrepancies can be a potentially important area for clinical intervention (Miller & Drotar, 2003). Fourth, as Dean et al. (2010) note, there is no research to date offering effective interventions to reverse adolescent nonadherence once it becomes habitual; until evidence-based offerings are available, preventing nonadherence should be a clinical priority. Finally, the medical team should approach adherence in an organized fashion, with a focus on three broad elements of care: providing information, building motivation, and assisting with strategy. Working on these goals in the context of effective communication can result in substantial and significant improvements in adherence and, ultimately, in better adolescent health care outcomes.

References


