

Chapter 2

Conceptualizing Adherence

Abstract In this chapter we review theoretical constructs that have proved crucial to our thinking and approach to pediatric adherence. This is not meant to be a comprehensive review of current theories, but a selective examination of some key points. Constructs familiar from the adult literature are considered from the perspective of family-centered care, which entails recognition of the different roles the family plays in helping manage a child's chronic illness. In later chapters these key concepts will further inform discussion of the roles of parents and healthcare providers in fostering children's adherence and eventual attainment of autonomous and independent self-care skills.

Theories are explanatory systems that provide a way to bring together diverse aspects of a subject in a way that can help foster understanding of the big picture. They “organize experience, generate inferences, guide learning, and influence behavior and social interactions” (Gelman and Legare 2011). Many parents (and clinicians) are influenced by “folk theories” of why people do or do not adhere to their medical regimen—unexamined and untested beliefs that arise from the culture and personal experience. Theories based in science provide a corrective view to these beliefs, ground an understanding of *why* people struggle with adherence, and suggest or open ways to help improve adherence and illness management more generally.

One challenge of applying theoretical models of adherence to children is that all of the main models have been developed with adults in mind. Rapoff (2010) therefore cautioned against extrapolating conclusions about children's adherence from adult-based models. In contrast to adults, who manage an estimated 95–99% of their own chronic illness care themselves (Funnell 2000), children do not manage illness independently. Pediatric illness management is complicated by the fact that multiple players are involved, by developmental changes that can make adherence a moving target, and by interactions between development and parenting, which has to be adapted accordingly. In addition, complexities arise in the interaction between the family and their healthcare providers. For example, in working with a teen and her parents, it can be difficult to know who the provider should speak with about which health-related issues.

When children are younger, parents have sole responsibility for illness management, but as the child gets older, management responsibility shifts increasingly to

the child. Pediatric adherence can therefore be seen as involving a *transaction* between parent and child, in which child behavior and parenting practices influence each other reciprocally (Sameroff 2009). The ways in which parents and their children interact has a tremendous impact on whether and how well the child's illness is managed.

The transactional nature of pediatric adherence is one of the main complications in trying to extrapolate from adult models and concepts of adherence. Adult models of health behavior and adherence highlight concepts such as *beliefs*, *goals*, *intentions*, and *motivation* as important drivers of adherence behavior, yet when applied to pediatrics, the question repeatedly arises of *whose* beliefs, goals, etc. should be the focus of consideration—the child's or the parent's (Schwartz and Drotar 2006)? Or consider the model of *patient-centered care*, which has become one of the cornerstones of modern illness management, within which “patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care—and their wishes are honored (but not mindlessly enacted) during their health care journey” (Epstein and Street 2011). How can a provider be patient-centered in this sense with a 4-year old, or even a 10- or 12-year old child? Whose wishes are to be honored?

The solution is that, in pediatrics, it is not enough to be patient-centered; instead, care must be *family-centered*. This means taking both child and parent perspectives into account. But what should be done when parent and child perspectives diverge, when the parent wants one thing and the child another? How are parent-child differences in beliefs, goals, and values to be navigated and negotiated? Obviously development plays a role. Early in development, the parent perspective dominates, but over time the child perspective becomes increasingly important, eventually eclipsing the parent at the time of transition into adulthood. Even so, this leaves open a long stretch of developmental time—let's call it adolescence—when there can be as much conflict as cooperation, and goals may clash (Schwartz and Drotar 2006). What should be done when parent and child perspectives diverge, when the parent wants one thing and the child another?

In the sections that follow, we selectively review conceptual models of important factors that underlie adherence. Sections are organized to roughly follow the process of adaptation individuals often go through from disease diagnosis to initiation of health-related behaviors (Fig. 2.1). We first review *stress/and coping* models that describe how individuals adapt to a new disease. We then discuss the importance of disease- and treatment-related *knowledge* as a necessary foundation for illness management, and the ways in which *health beliefs* of both patient and parent affect their understanding and utilization of their knowledge. Health beliefs in turn influence the *goals* individuals set for themselves, which serve as action plans for subsequent adherence behaviors. *Self-regulation* models describe the capabilities that underlie goal-striving—namely, the individual's ability to exert self-control such that future goals can be attained. These factors in turn help determine a person's underlying *motivation* for engaging in adherence behaviors that may have no immediate benefits but are critical for long-term health.

Fig. 2.1 Hypothetical model of the process of adaptation, from initial coping to adherence



Stress and Coping Models of Illness Adaptation

When a child is first diagnosed with a chronic illness, it is often a shock to the family; and in many cases diagnosis is experienced as traumatic, especially if the caregiver or child fears the child may die or be seriously harmed. High rates of post-traumatic stress symptoms have been reported in parents of children diagnosed with cancer (Kazak et al. 1998) and type 1 diabetes (Cline et al. 2011; Landolt et al. 2002). Less severely, about one in three children develop a diagnosable adjustment disorder at diagnosis (Cameron et al. 2007).

For most children with a chronic illness and their families, the shock dissipates but a sense of chronic stress remains. As we noted in the Introduction, many illnesses require complex and intrusive daily management; others, such as asthma and sickle cell disease, have recurrent (and sometimes unpredictable) symptom flares; and still others (e.g., cystic fibrosis) result in substantial functional limitations and disability.

The recognition that a chronic illness becomes a chronic stressor to which the child and family adapt is at the core of *stress and coping models* of illness adjustment (e.g., Thompson and Gustafson 1996; Wallander and Varni 1998). Also important is the idea that the condition requires “continual readjustment” and “repeatedly interfere[s] with the adequate performance of ordinary role-related activities” (Wallander and Varni 1998). Adjustment requires the child and family to manage emotional responses, consider social implications, and marshal resources both within and outside the family for managing the disease and maintaining (or returning) to “life as normal” as far as possible. It also requires children and families to “change and reprioritize ... goals in order to incorporate new goals related to [illness] management” (Schwartz and Drotar 2006).

Children and their families draw on their resources to cope with illness. In Wallander and Varni's (1998) model, these so-called *resilience factors* include a person's competence and skills, family environment, social support, practical resources, and "stress-processing factors such as cognitive appraisal and coping strategies." At the same time, pre-existing or co-existing *risk factors* interfere with or complicate children's and families' abilities to cope and manage the illness. Important risk factors include disease-related disability, reduced ability to complete activities of daily living, and psychosocial stressors (Wallander and Varni 1998). An important contribution of stress and coping models has been to identify modifiable risk factors that can be targeted for intervention.

More recent models of coping with chronic illness have focused on the dimension of *control* (Compas et al. 2012). *Primary control* (or active coping) refers to efforts to change the source of stress or one's reactions to it, whereas *secondary control* refers to efforts to accommodate to the stressor. *Disengagement* or passive coping refers to avoidance or lack of any coping attempts (Rudolph et al. 1995). Not surprisingly, disengagement or avoidance coping has been associated with poorer adherence (e.g., Reid et al. 1994).

In a recent review, Compas et al. (2012) noted that secondary coping has the strongest support in terms of child adjustment to illness, and they suggested that the uncontrollable nature of many illnesses requires adaptation rather than active attempts to control the disease. This finding is consistent with the burnout often seen among children and youth who attempt to maintain tight illness control and sheds some light on why children and youth with better adherence sometimes have worse psychosocial adjustment. It may also shed light on a point made over a decade ago by La Greca and Bearman (2001): "What may appear to be 'nonadherence' to a health care professional may actually be the family's way of adapting the regimen to accommodate the child's quality of life." In other words, poor adherence when an illness is especially difficult to control may sometimes be the most effective coping strategy, at least in terms of maximizing immediate quality of life. The fact that adherence and quality of life are often at odds may be the most challenging aspect of maintaining good illness control. As noted by Schwartz and Drotar (2006) in discussing a hypothetical youth with diabetes, "if prioritizing and working towards her health-related goals compromises her ability to pursue and achieve other personally salient goals, then she may feel that her [chronic health condition] is affecting her quality of life and adaptation."

Illness and Treatment Knowledge and Health Literacy

Managing a chronic illness requires a new set of knowledge and skills to carry out health behaviors correctly and consistently. As noted by many authors (e.g., Adams et al. 2004; Hood et al. 2009), medical regimens have become increasingly complex, and often stretch the abilities of patients and their families. After diagnosis, physicians and other healthcare providers focus on patient and family education,

although there is some question of whether enough time is spent for families to truly learn and understand the condition and its treatment for many illnesses (Turner et al. 2009), especially as diagnosis is often a time of such high stress, which can limit parents' ability to actively engage in learning.

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (US Department of Health and Human Services 2000). Recent reviews of health literacy in the pediatric domain (Abrams et al. 2009; DeWalt and Hink 2009; Yin et al. 2009) suggest the following main points:

1. Health literacy involves a complex set of skills that include reading, math (numeracy), multimedia, problem-solving and interpretive skills.
2. Health literacy is closely associated with general literacy, and with socioeconomic and cultural factors that are themselves related to literacy (see Chap. 8)
3. Health literacy “*must be considered in terms of parents' or caregivers' health literacy as well as the children's own health literacy* (which is evolving as children grow, learn, and develop)” (Abrams et al. 2009; emphasis added)
4. Low parent health literacy is associated with worse child health outcomes, especially for younger children
5. Low health literacy among adolescents is associated with greater general risk-taking behavior but there is no evidence of an association with worse adherence
6. Overall, low health literacy is associated with worse adherence, BUT
7. Interventions to improve health literacy have been shown to improve health *knowledge* but at best have weak and indirect effects on health *behavior*

Regarding the last point above, a recent meta-analysis of interventions for pediatric nonadherence reported negligible-to-small effect sizes for education-only interventions ($d=0.16$, 95% CI=0.10–0.22; Kahana et al. 2008). Education is an important component of interventions for adherence, however. A second meta-analysis (Graves et al. 2010) found that interventions that combined educational with behavioral approaches had more potent effects on health outcomes ($d=0.74$, 95% CI=0.55–0.94) than either type of approach alone ($d=0.16$, 95% CI=0.02–0.30). Moreover, Graves et. found that educational approaches resulted in better long-term health outcomes on follow-up. Taken together, these findings support the notion that education is necessary but not sufficient for adherence to medical recommendations (DeWalt and Hink 2009).

It is also important to recognize that knowledge is different from the ability to use that knowledge successfully. For example, caregivers in the National Cooperative Inner-City Asthma Study demonstrated good knowledge of asthma (M=84% correct answers on an asthma information quiz), but when presented with hypothetical problem situations most offered at least one solution that was “potentially dangerous or maladaptive” (Wade et al. 1997). Interventions that focus on teaching illness-specific problem-solving skills (e.g., Grey and Berry 2004) are likely to be more effective than interventions focused on increasing knowledge.

Many factors play into families' understanding of disease and illness. Healthcare providers are used to taking for granted the empirical basis for most of what they do—clinical guidelines and best practice recommendations are based, to the degree possible, on the best available scientific evidence. Many laypeople do not think this way, however. It must be acknowledged that there is a lot of distrust of medicine and “Big Pharma.” For example, a recent Pew poll found that only one quarter of U.S. adults have a lot of confidence that new medicines have been carefully tested before being made available to the public, half had “some” confidence, while the last quarter had little to no confidence (<http://www.pewforum.org/2013/08/06/chapter-4-views-about-todays-medical-treatments-and-advances/>). Many people use alternative therapies despite the lack of an empirical basis. A National Science Foundation survey from 2001 found that 88% of respondents agreed that “there are some good ways of treating sickness that medical science does not recognize” (Science and Technology: Public Attitudes and Public Understanding; <http://www.nsf.gov/statistics/seind02/c7/c7s5.htm#c7s512a>), and all indications are that use of alternative therapies has only increased since that time.

Health Beliefs

Adjustment and coping attempts and adherence all rely on the child and family's beliefs about the illness, its controllability, treatment, and their own capabilities. According to Helman (1981) in a classic article:

Faced with an episode of ill-health, patients try to explain what has happened, why it has happened and decide what to do about it. The shaping of the illness and the behavior of the patient—and of those around him—will depend on the answers to six questions:

- What has happened?
- Why has it happened?
- Why to me?
- Why now?
- What would happen if nothing was done about it?
- What should I do about it or whom should I consult for further help?

How the questions are answered, and the behavior that follows, constitutes a 'folk model of illness'.

In other words, patients (and their families) will attempt to come to an understanding of what the illness is and what it means to them.

The *Health Belief Model* (HBM; e.g., Janz and Becker 1984) posits that people's adherence will be influenced by their beliefs that the illness poses a true threat to their health, that the treatment is effective and its benefits outweigh its costs, and they are capable of doing what they need to do to manage the illness. The HBM has a substantial amount of empirical support in the adult literature and has been

one of the most influential theories of health-related behavior. But to the degree that pediatric adherence results from an interaction between the child and his/her caregivers, the question arises, *whose* health beliefs should be considered (La Greca and Mackey 2009)? This question is especially important as child and parent health beliefs are not always correlated (Charron-Prochownik et al. 1993).

Parent Beliefs Parent health beliefs have a significant impact on children's illness management. Adherence tends to be poor when parents are concerned about medication safety or side-effects. One study of children with asthma and their parents looked at the difference between parents' perceived necessity of medication and their concerns about adverse effects or dependency (Kelly et al. 2007). Adherence increased as the differential between perceived need and concern widened, and adherence was lowest when concerns exceeded perceived necessity. Minority parents were more likely to have concerns about medication, as were parents who reported using alternative therapies. An even more dramatic demonstration of the importance of parent beliefs can be seen in the recent recurrence of diseases such as measles (declared to be eradicated in the U.S. in 2000) due to caregivers' erroneous beliefs about the safety of vaccines (Diekema 2012).

It should also be kept in mind that most children have multiple caregivers, not all of whom may agree about the meaning of the illness or importance of treatment. For example, we often hear anecdotal reports of multigenerational families in which a grandparent undermines the parent's attempts to manage a child's illness by expressing doubt about the need for the prescribed treatment, or a preference for a more traditional alternative medicine approach.

Child/youth beliefs The relation between children's health beliefs and adherence is much less clear. A systematic review of the relation between children and youth's health beliefs and adherence (Haller et al. 2008) found conflicting results, with about half of studies showing an association and half showing no association. Methodological differences may account for some the discrepancies, but as the authors note, "Unmeasured factors such as parents' role in affecting adherence behaviors more than beliefs may potentially explain this difference."

Indeed, few studies have examined both child and parent health beliefs and their relation to adherence within a single study. Bush and Iannotti (1990) adapted the health belief model for children (the Children's Health Belief Model) and used the model to predict children's (age 8–14 years) expected medicine use for common (acute) health problems. They first examined child health-belief predictors and then repeated the analysis entering caregiver variables, thus accounting for the effect of caregiver beliefs. Surprisingly, caregiver beliefs accounted only for a small (although statistically significant) amount of additional variance, although it should be noted that the outcome was *expected* medication use, not actual use. (They could not measure actual use because they used a sample of children without chronic illness requiring regular medication management.) It seems plausible if not likely that parents' beliefs would have a much stronger effect on whether medicines are actually taken or not.

Studies of youth with type 1 diabetes have generally shown positive effects of youth health-beliefs on adherence (although see Urquhart et al. 2002). Skinner and colleagues have consistently found relations between perceived treatment effectiveness and better diabetes self-care (diet, exercise, blood glucose monitoring, and insulin administration; Skinner and Hampson 1998; Skinner and Hampson 2001; Skinner et al. 2002). Perceived threat of diabetes has also been found to be associated with better adherence (Skinner et al. 2002), but possibly only when the costs of following the diabetes regimen are seen as low (Bond et al. 1992). Interestingly, Bond et al. found that metabolic control was worst when perceived threat and perceived cost were both high, suggesting that perceived threat may be a risk factor for poor illness control when youth struggle with management tasks. Studies of youth with asthma have also generally shown positive effects of health-beliefs in the expected directions (Buston and Wood 2000; Rich et al. 2002; Zebracki and Drotar 2004).

Many of the studies examining health beliefs in children have methodological limitations (Haller et al. 2008), especially regarding differences in measurement of the relevant constructs (Rapoff 2010). A promising measure of youth health beliefs is the Beliefs About Medication Scale (BAMS; Riekert and Drotar 2002), a 59-item scale that assesses a number of important constructs of the HBM: Perceived Threat (severity and susceptibility), Positive Outcome Expectancy (i.e., benefits), Negative Outcome Expectancy (i.e., barriers), and Intent. In the validation study of 133 adolescents with asthma, HIV, or inflammatory bowel disease, the BAMS accounted for 22% of the variance in self-reported medication adherence. Three subscales were positively correlated with adherence and the fourth approached significance. A shorter version of the scale has also been developed to assess caregiver beliefs (Naar-King et al. 2006) and presumably could be re-adapted for use with children.

Health beliefs, as measured by the constructs of the HBM, may not be good predictors of adherence or illness control for minorities, although few studies have examined this directly. Patino et al (Patino et al. 2005) found no relation between health beliefs and adherence or glycemic control in a sample of youth with a relatively high proportion of minorities (Black and Hispanic youth). However, they did find that perceived susceptibility to diabetes was much higher and perceived severity of the illness was lower compared to the findings reported by Bond et al. (1992), suggesting that this sample saw themselves as more vulnerable but perceived the consequences of diabetes as less bad.

Overall, research findings indicate that both parent and youth health beliefs have an effect on children's adherence. Studies are needed that examine the concordance between parent and child health-beliefs and their effect on illness management. In line with this, a recent study by Herge et al. (2012) found that higher concurrent youth and parent self-efficacy for diabetes was associated with better adherence. Better understanding of health beliefs may open up new avenues for intervention, although to date interventions that have changed health beliefs have had minimal impact on adherence behavior (Stecher and Rosenstock 1997).

Goal Setting

Health beliefs strongly influence the goals people set for themselves (or for their children, or for their patients), and goals in turn drive *intentions*, or the plans and effort expended in the pursuit of goal attainment (Ajzen 1991, 1996). Intentions are seen as proximal indicators of a person's readiness to perform a behavior (Ajzen 2005) and have been shown to account for 20–30% of the variance in health behavior in adults (Gibbons 2008).

Goal-setting is often the first step in developing a plan for behavior change. For example, a physician will set glycemic goals for a child with newly diagnosed diabetes, and an overweight youth will set weight-related goals for himself. More proximal behavioral goals in these examples might be determining the number of glucose checks the first child performs, and setting up a walking schedule and dietary targets for the second child.

However, in line with the theme of this book, goal-setting is complicated by involving multiple actors. Goal discrepancies between the child, parent(s), and healthcare providers are common. Children and their parents often have competing goals—parents tend to be more focused on illness management, whereas children focus on immediate quality of life, such as their social lives, school performance, and extracurricular activities. Health-related goal setting may place pressure on a child to alter her standards for herself in other areas of her life, such as “not having to be the best soccer player; not having to get As on every test” (Schwartz and Drotar 2006). As one can imagine, this sort of reorientation of goals and standards can entail a significant sense of loss for the child. Goal-discrepancies between parents also occur.

Children and families also may have different goals from healthcare providers. In general, healthcare providers see disease management as the primary goal, whereas families will often prioritize goals “to maintain normalcy and enhance well-being” in the family (Rehm and Franck 2000).

Some examples of differing goals between patients, parents, and healthcare providers include:

- A parent does not want a 9-year old child to know she may be infertile as a result of treatment
- A parent wishes her diabetic child to have an insulin pump for better glycemic control, whereas the child does not want to wear a device that others could see.
- A parent wants her child to have life-prolonging treatment (e.g., chest physical therapy for CF) that the child resists because of time and discomfort (Rapoff 2010)
- The parent of a child with type 1 diabetes prioritizes minimizing hypoglycemic lows whereas the physician is focused on reducing hyperglycemia (Marteau et al. 1987)
- The parents of a child with terminal illness prioritize prolonging life, whereas the medical team prioritizes minimizing suffering (Wolfe et al. 2000)

Competing views on the relative importance of different goals often result in misunderstandings and conflict—between the child and parent, or between the healthcare provider and the child or family (Schwartz and Drotar 2006), even if the provider is not aware of the conflict. As Schwartz and Drotar note, and as we discuss later in this volume, “discrepancies among invested parties will likely be minimized when there is collaboration and agreement about what goals are important and how to achieve them.” Even when agreement is not achieved, simply improving communication among the relevant parties can greatly increase chances for adherence success (DiMatteo 2000).

It is also important to recognize that people often have competing goals themselves, requiring them to prioritize goals, and patients will often prioritize non-health-related goals over health-related goals. Thus “understanding and respecting patients’ non-health-related goals” (Schwartz and Drotar 2006) is necessary for providers who wish to best help their patients with adherence. If providers are unaware of these competing motivations, they will be unable to discuss pros and cons with their patients. Using a motivational interviewing-style approach (see Chap. 4) may prove especially helpful here, as providers can point out the youth’s own competing goals and highlight the discrepancy between them, which has been shown to help motivate behavior change. On the other hand, simply telling patients what they *should do* is very likely to backfire, as we discuss later in this chapter.

Self Regulation

Attaining health-related and adherence goals requires self-control—i.e., inhibiting an impulse to engage in some desirable behavior (such as eating a restricted food) in the interest of a goal whose benefits may be far in the future. The human animal is simply not wired to do this. Evolution predisposes us to “eat now because there may be famine tomorrow.” Greater uncertainty of receiving the long-term benefit contributes to this tendency to favor immediate reward (Mischel and Ayduk 2004).

Nonetheless, people are often able to delay gratification and work toward goals that are far in the future. *Self-regulation* refers to a person’s attempts to control impulses and adapt immediate behavior in the interest of attaining a long-term goal or goals (de Ridder and de Wit 2006). Models of self-regulation focus on two linked processes: setting goals, and then striving to achieve them. Successful self-regulation depends on multiple factors including having goals that are personally meaningful, a belief in one’s ability to attain the goal (termed *self-efficacy*; Bandura 1997), and the skills necessary to problem-solve difficulties, overcome barriers, and cope with frustration and other emotional responses.

One may ask whether it is *self-regulation* when it is the parent who is largely in control of health management. We believe the answer is yes, as in these instances the child has to conform—to self-regulate—in response to the parent’s wishes or demands. When a child is unable to do this, significant behavior problems result, often requiring intervention by a behavioral specialist. Still, as we will see, the issue



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