Pediatric Adherence as a Multidimensional and Dynamic Construct, Involving a Triadic Partnership

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Objective  The aim of this paper is to integrate and draw attention to research findings that support our conceptualization of adherence as being multidimensional, dynamic, and involving a triadic partnership.  Methods  A review of relevant articles found in Medline, PsychLit, and reference lists provided in pertinent articles was performed.  Results  Significant progress has been made in identifying disease-related and psychosocial correlates of pediatric adherence and in developing intervention programs to promote adherence. Both lines of work have proceeded without a unifying framework for conceptualizing and measuring pediatric adherence. We offer a model that views adherence as comprising three defining aspects: (a) multidimensional, in support of the complexity and interrelatedness of treatment components, (b) a triadic partnership, as in mutually influential exchanges within and among the caregiver-medical team, child–medical team, and caregiver-child relationships, and (c) dynamic in relation to the notion of changes in developmental adaptive capacity, contextual characteristics, and disease course.  Conclusions  Much work has yet to be done to validate, refine, and extend our model of adherence. Recommendations are offered for assessing each defining aspect, and a group-based methodology that accommodates longitudinal, prospective data is described.

Key words  pediatric adherence; conceptualization of adherence.

The successful management of childhood chronic illness poses formidable challenges not only for the patient and family, but also for health care professionals. For one, advancements in treatment have made it possible for many children with chronic illness to reach adulthood, thereby calling attention to changing developmental needs and family functioning. Families must adapt to emerging developmental needs to maximize children's capacity in relation to the demands of the illness. One challenge for health care providers is to ease this process of adaptation (Rolland, 1994). Second, optimal health is achieved when patients, caregivers, and health care providers collaborate in designing a manageable treatment program (Rapoff, 1999). This collaborative effort may be impeded when there are clashes of different views and discrepant beliefs about illness and treatment within the caregiver-child-provider relationship.

Less than optimal adherence is certainly a sign that something may be amiss: There may be a clinical paradox (the treatment regimen is suboptimal or ineffective); treatment recommendations may be too demanding or difficult to follow; and/or perhaps there is discord within the triadic partnership. The term triadic partnership refers to the therapeutic triangle in medicine that includes the caregiver, child, and medical team in facilitating adherence to treatment. A review of the psychological literature pertaining to the concept of pediatric adherence reveals that in the past two decades, significant progress has been made in identifying disease-specific and psychosocial factors that influence adherence to treatment for juvenile idiopathic arthritis (JIA) (Kroll, Barlow, & Shaw, 1999), type 1 diabetes (Johnson, 1993), asthma (Lemanek, 1990), cystic fibrosis (Gudas, Koocher, & Wypij, 1991), hemophilia (Van Sciver, D’Angelo, Rappaport, & Woolf, 1999).
Several published reviews describe the nature of relations among such correlates of adherence (Fielding & Duff, 1999; Kyngas, Kroll, & Duffy, 2000; La Greca & Schuman, 1995). Efforts have equally been directed toward developing intervention programs to promote adherence (Lemanek, Kamps, & Chung, 2001; Rapoff, 1999). Both lines of work have proceeded, however, without a unifying framework for conceptualizing and measuring adherence in pediatric populations.

Spurred by a lack of consensus on how to conceptualize pediatric adherence, we operationally define it as the manifestation of multiple treatment-related behaviors prescribed by a medical team, which is influenced by development and contextual characteristics, shaped by disease, and interpreted by the caregiver and individual child. Figure 1 illustrates our conceptualization of adherence. It evokes a view of adherence as being multidimensional (as opposed to unidimensional), involving mutually influential exchanges within and between three subsystems: caregiver–medical team, child–medical team, and caregiver-child, as represented by a triangle. It promotes the concept of adherence as being dynamic as opposed to static by incorporating the notion of changes in developmental adaptive capacity, contextual characteristics, and disease course. Integral to our definition are the requirements to: (a) compare manifested treatment-related behaviors as reported by caregivers (and children) with actual prescribed treatment and (b) approach the study of adherence from a developmental perspective. Without the first requirement, that is, comparison of reported behaviors with prescribed treatment, there is no telling what we are assessing. Without the second, there is no opportunity to prospectively observe periods of intrapersonal change and stability in treatment-related behaviors as a result of adaptive capacity, contextual characteristics, and disease course.

Prior to describing our model of pediatric adherence, it is worth noting how our model differs from previous models of adherence set forth by other authors. For instance, the Children's Health Belief Model (CHBM) espoused by Iannotti and Bush (reviewed by Rapoff, 1999, and Thompson and Gustafson, 1996) emphasizes children's perceived vulnerability to risk and the severity of the risk, as well as their perceived benefits of taking medication. In addition to these cognitive processes, the model includes the role of the environment in influencing children's health beliefs and behaviors (e.g., the caregiver's perceived benefits of the child taking medication). Although the CHBM identifies personal, environmental, and illness factors as affecting adherence, it does not integrate the role of developmental changes in children's health beliefs and behaviors. As well, it does not consider the influence of the medical team in shaping both children's and caregivers' perceived benefits and risks of treatment.

Leventhal's Self-Regulation Model (reviewed by Thompson & Gustafson, 1996) views children's ability to manage anxiety or distress evoked by the external environment as well as their self-appraisals (what they know and feel about themselves and specific health threats and outcomes) as motivating adherence. Culture and health care institutional factors are believed to influence skills and self-appraisals. However, the model affords very little understanding of how changes in development and disease course shape children's abilities and self-appraisals, and subsequent adherence. Social Cognitive Theory, originally proposed by Bandura (reviewed by Rapoff, 1999), emphasizes the role of children's behaviors, internal personal factors (cognitive, affective, and biological), and the external environment in affecting self-efficacy. In this model, too much emphasis is placed on children's belief in their capabilities to perform treatment tasks, without considering the role...
of development and its interaction with the environment in sustaining or improving self-efficacy. It also does not include changes in disease course as influential in self-efficacy. Although different in perspective, the Trans-theoretical Model of Change espoused by DiClemente and Prochaska in 1982 (reviewed by Rapoff, 1999) emphasizes an individual's progression through various stages of behavior change toward the maintenance of a desired health behavior. Both covert and overt activities tend to move individuals through this process; albeit, in relation to pediatric patients there is very little understanding of how development might play a role in moving children through the stages of change. Finally, while Applied Behavior Analytic Theory (reviewed by Rapoff, 1999), founded on principles of operant conditioning, emphasizes the role of the environment in shaping behaviors, it does not recognize children's developmental capacities in understanding the rules of reinforcement or in generalizing a learned rule of behavior.

More recently, Creer (2000) elaborated on the notion of self-management (synonymous with self-regulation) in reference to skills that children and families ought to perform in facilitating control of chronic illness. Self-management skills are determined by treatment demands, disease characteristics, age or ability of the child in relation to treatment tasks, beliefs of others, and the context within which behaviors take place. Although Creer acknowledges the role of development (changing abilities) and context (cooperation of family and interaction with health care providers), there is little integration of how these forces come together to influence self-management. In fact, in all of the models reviewed, there is a lack of attention paid to the fit (or misfit) in the development-context-disease regulatory system in influencing treatment-related behaviors.

The aim of this paper is to integrate and draw attention to research findings that support our conceptualization of adherence as being multidimensional, dynamic, and involving a triadic partnership. In describing our model of adherence, we take an inward to outward approach. That is, we first discuss the nature of treatment-related behaviors as being multidimensional, situated inside the triangle in Figure 1. In the second section of this paper, we consider the triadic partnership by focusing our attention on the three corners of the triangle, which represent the contribution of the three subsystems in the manifestation of treatment-related behaviors. Finally, we move outside of the triangle and focus on the dynamic nature of adherence, wherein we call attention to the influence of developmental adaptive capacity, contextual characteristics, and disease course, which are viewed along a continuum of changing values as represented by the intensity of shading in the figure. We offer recommendations on how to measure each defining aspect and end our discussion by proposing a program of research that adopts a longitudinal, prospective approach using a group-based methodology to empirically validate our model.

Defining Aspect 1: Multidimensionality

As illustrated in Figure 1, treatment plans for most chronic illnesses include several components, with different behaviors being executed on a regular basis to maintain optimal health. In addition, treatment components are interrelated, with the manifestation of behaviors in one component potentially affecting performance in others. It is worth noting that some studies have focused only on specific components (e.g., Bennett Murphy, Thompson, & Morris, 1997, and Reid, Dubow, Carey, & Dura, 1994, for type 1 diabetes; Chaney & Peterson, 1989; and Litt & Cuskey, 1981) for JIA. In this section, we describe the complexity and interrelatedness of treatment components.

Multiple Components to Treatment Plans

Consider what is required from children with type 1 diabetes: To maintain blood glucose levels as close to normal as possible, they must receive daily injections of insulin, follow dietary restrictions such as avoidance of concentrated sweets, engage in daily exercises (while balancing diet and insulin requirements), and monitor blood glucose levels through regular testing (Johnson, 1993). Children with cystic fibrosis also receive a complex treatment plan, including aerosol inhalants to relax and open airways; frequent postural drainage and chest percussions to prevent accumulation of excessive respiratory mucus in the lungs and to facilitate coughing; corticosteroids to decrease swelling; caloric supplements; and pancreatic replacement enzymes to control gastrointestinal malabsorption (Thompson & Gustafson, 1996). In treating JIA, pharmacological treatment is often required to control inflammation, minimize pain, and counteract side effects, as are regular exercises to strengthen joints and proper diet. For some children, orthopedic devices and specific medical procedures (hip/knee replacement, soft-tissue releases, tendon lengthening) may be recommended, thereby forming a fourth component to treatment (Wara & Emery, 1991).
Evidently, treatment programs place different demands on children and their caregivers, which may result in an uneven pattern of functioning across components. Treatments requiring lifestyle changes are often perceived to be problematic. Children with JIA, for instance, show greater difficulties with exercising or wearing orthopedic devices than taking medications (Barlow, Harrison, & Shaw, 1998; De Civita, Dobkin, Ehrmann-Feldman, Karp, & Duffy, 2003; Hayford & Ross, 1988; Rapoff, Lindsley, & Christophersen, 1985). Children with asthma report more difficulties in avoiding triggers and allergens compared with taking medications (Leickly et al., 1998). In their review of studies involving children with cystic fibrosis, Quittner, Espelage, Ievers-Landis, and Drotar (2000) report that taking medication is less problematic than engaging in chest physical therapy or following a specific diet. Likewise, children with type 1 diabetes report fewer difficulties with taking medications and performing glucose testing compared with exercising and following dietary restrictions (Glasgow, McCaul, & Schafer, 1987; Johnson, 1993). It appears that treatments resulting in immediate positive results are perceived to be less problematic, as in taking medication for pain relief or alleviating symptoms (La Greca & Schuman, 1995).

Interrelation of Treatment Components

The notion of multidimensionality also underscores the interrelatedness of treatment components. For example, refusing to wear splints in JIA may reduce range of motion and increase pain, as well as lead to deformity and permanent disability (Wara & Emery, 1991), thereby complicating medication and exercise regimens. Johnson (1993) describes how treatment-related behaviors in type 1 diabetes are intricately linked, with failure to follow dietary recommendations having negative implications for glucose management. In the treatment of cystic fibrosis, taking enzymes after a meal (as opposed to before or during) may lead to inefficient enzyme utilization and contribute to refractory malabsorption (Rusakow, Miller, McCarthy, Gershan, & Sлаingard, 1998).

Interestingly, some studies report weak associations among treatment behaviors (Celano, Geller, Phillips, & Ziman, 1998, for asthma; Glasgow et al., 1987; and Schafer, Glasgow, McCaul, & Dreher, 1983) for type 1 diabetes. In this body of research, however, the magnitude of correlations was dependent on the nature of the treatment task. That is, although the avoidance of asthma triggers was not correlated with taking medications, failing to take medications as prescribed was significantly correlated with missed appointments. While glucose testing was not correlated with performing exercises, it was significantly correlated with insulin injections and diet. Although these findings may be used to argue that some treatment components are unrelated, it is important to bear in mind that (a) the nature of some behaviors are more time-consuming and demanding for caregivers and children and (b) children and caregivers may be responsible for different components of treatment.

Let us suppose for a moment that the same person is responsible for all components of treatment. It may be that the initial intent is to follow the treatment protocol as recommended. However, with increased knowledge of the illness and its treatment, caregivers (and children) may make concessions to preserve quality of life. That is, they may selectively choose to perform treatment-related behaviors that provide immediate or more visible benefits and find alternatives to compensate for not completely engaging in those behaviors that require a lifestyle change, are more demanding in terms of time and effort, or interfere with normal developmental experiences. In a study by Deaton (1985) involving children with asthma, the parents’ decision whether to carry out treatment recommendations was based on their accurate knowledge of the illness and its treatment as well as their intimate understanding of their child’s needs. Higher levels of parental adaptiveness (defined as having knowledge of child and regimen and awareness of treatment choice) were associated with fewer disruptions in children’s activities. A study by Thomas, Peterson, and Goldstein (1997) involving adolescents with type 1 diabetes suggested that in socially challenging situations (peer related), finding acceptable compromises in carrying out treatment may increase quality of life without greatly endangering metabolic control.

Recommendations

Our conceptualization of adherence underscores the importance of assessing treatment-related behaviors prescribed by a medical team. Caregivers (or children), for instance, may have inaccurate knowledge of treatment recommendations (i.e., inaccurate doses or frequencies of therapies; levers et al., 1999). They may have been inadvertently careless about treatment, used treatment tools inappropriately (e.g., syringes, inhalers), or altered treatment according to symptoms without seeking medical approval (in asthma, see Celano et al., 1998, and Leickly et al., 1998; in JIA, see De Civita et al., 2003; in cystic fibrosis, see Gudas et al., 1991; in type 1
diabetes, Page, Verstraete, Robb, & Etzwiler, 1981; in hemophilia, see Sergis-Deavenport & Varni, 1983). Without access to prescribed treatment, we do not know whether reported behaviors (or their frequency of manifestation) reflect actual treatment or what the caregiver (or child) believed was recommended. As well, we will never be able to identify (and understand) the extent to which caregivers and children are selectively directing their energies in performing some treatment-related behaviors and actively compensating for not completely engaging in others.

To compare reported treatment-related behaviors to actual recommendations, researchers must ensure that data in medical charts are accurate and complete. One can develop standardized forms that stipulate components of treatment (specific for the illness under study) and their characteristics (e.g., type, frequency, and duration of therapies; caloric intake and foods to be avoided; surgery and follow-up treatments). Such forms could then be incorporated into the child’s medical chart prior to study recruitment and completed by health care providers following each visit. One could periodically review the forms to ensure compliance with established protocol (De Civita & Dobkin, 2003).

The reality that there are no accurate and affordable instruments for measuring the various treatment-related behaviors requires a multimethod, multiperson approach. Some examples of combining multiple methods are found in the works of Glasgow et al. (1987) and Celano et al. (1998). However, Glasgow et al. did not compare reported behaviors to actual treatment. Unlike Glasgow and colleagues, Celano et al. used pharmacy records to determine the extent to which reported behaviors corresponded to prescribed treatment. Levers et al.’s (1999) study on cystic fibrosis is an excellent example of how to integrate a multiperson perspective. They compared both caregiver and child reports of treatment-related behaviors with actual recommendations, using a validated questionnaire specifically designed for cystic fibrosis. Research by Johnson (1993) employed a 24-recall interview to elicit treatment-related behaviors from children with type 1 diabetes, with responses then compared with an ideal standard of treatment. More objective measures (e.g., drug assays, pill counts) can also be used, when feasible.

Defining Aspect 2: The Triadic Partnership

Another reason for weak associations among treatment-related behaviors may be that children and caregivers are solely responsible for specific components of treatment and share responsibilities for others. Not only does this introduce a confounding variable in explaining the manifestation of treatment-related behaviors, it equally draws a level of attention to the child-caregiver relationship not found in adult medicine. As illustrated in Figure 1, children, caregivers, and the medical team are each situated at a corner of the triangle. The triangle is used to symbolize the therapeutic system, which involves ongoing positive relationships (in terms of collaboration, communication, and helpfulness) between and within the three subsystems to facilitate treatment-related behaviors. The idea of using a triangle to represent the triadic partnership is not new. Researchers have used the triangle to conceptualize any treatment system involving families with children (Rolland, 1994). The difference lies in the subsystems represented within the triangle. In our conceptualization, we emphasize the medical team as opposed to only the physician, as children and caregivers must interact with different health care professionals. In this section, we describe issues specific to each subsystem that might influence treatment-related behaviors.

**The Caregiver and Medical Team**

Caregivers’ perception and interpretation of illness and its treatment may be influenced by their encounters with health care professionals. For instance, in a study by Worchel et al. (1995), physicians tended to underestimate the degree of interaction desired by parents, in terms of information about their child’s disease condition, interpersonal sensitivity, partnership building, and the ability to direct treatment. Interestingly, Henley and Hill (1990) found that while some parents felt that they had not received enough information regarding the psychosocial and future implications of cystic fibrosis, others preferred not to be exposed to all the facts. In a qualitative study by Barlow et al. (1998), some caregivers of children with JIA were frustrated and angry because their concerns were ignored during the early stages of diagnosis. Moreover, they felt that the information provided by health care professionals failed to satisfy their needs. Caregivers’ commitment to treatment recommendations may be strengthened when health care providers attend to their concerns and needs for support. Schroder, Crabtree, and Lyall-Watson (2002) found that mothers of children with JIA who felt supported by their child’s occupational therapist were more positive toward the splinting regimen. Hence, the ability of health care providers to adapt their clinical approach according to the needs of caregivers may alleviate the burden of caring...
for the child, thereby promoting the development of a positive partnership.

The Child and Medical Team

Studies show that children can falsify their self-reports of treatment-related behaviors (Delamater, Kurtz, White, & Santiago, 1988; Wilson & Endres, 1986). Kyngas and colleagues (2000) found that children lied about their behaviors to avoid being reprimanded by their medical team. These authors also noted that the behavioral actions of physicians perceived to be routine were linked to a lower manifestation of treatment-related behaviors. In a study by Bobrow, AvRuskin, and Siller (1985), adolescents with type 1 diabetes who perceived their physician to be encouraging and open to discussion were not more likely to engage in treatment behaviors. They also found that conflict within the parent-adolescent relationship negatively affected treatment-related behaviors. Bobrow et al. speculated that other issues stemming from the adolescents' interaction with caregivers during the period between visits might have dominated over the positive influence of the physician relationship. Therefore, health care providers need to be mindful that their positive influence may be overshadowed by difficulties within the child-caregiver relationship.

The Child and Caregiver

The involvement of caregivers in children's treatment will manifest itself in different ways across developmental stages. In early childhood, caregivers are completely responsible for ensuring that treatment recommendations are met and for monitoring physical symptoms. With increased developmental maturity and skill acquisition, children assume greater responsibility in carrying out treatment tasks for type 1 diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990), cystic fibrosis (Drotar & Ievers, 1994), JIA (Hayford & Ross, 1988), and asthma (McQuaid et al., 2001). When treatment tasks are shared, there may be disagreements with regard to who is primarily responsible for a particular component of treatment (Anderson et al., 1990; Hayford & Ross, 1988; McQuaid et al., 2001). Miscommunication between caregivers and children regarding treatment responsibility may compromise treatment-related behaviors. Health care providers may therefore benefit from knowing how treatment tasks are distributed within the family so that any disagreements about responsibility can be rectified.

Recommendations

A full account of the nature and the quality of transactions between health care providers, caregivers, and children cannot be appreciated from a unidimensional perspective. Although we may gain considerable insights into factors or issues that are specific to each subsystem, we need to go further and examine how they interrelate (and are often intertwined) to affect treatment-related behaviors. For example, Cohen and Wamboldt (2000) found that emotional overinvolvement in the caregiver-child subsystem negatively affected physicians' perception of their relationship with caregivers, and created difficulties in forming a partnership with them. Tates and colleagues (2000, 2002) conducted a detailed analysis of physician-child-caregiver communication patterns during a medical visit. They found that caregivers influenced the development of a partnership between children and their physician. That is, they restricted their child's participation in the medical encounter by interfering in exchanges between the physician and child, regardless of the child's age. In fact, even when the physician set the stage for the mode of interaction at the beginning of the visit favoring the child, caregivers dominated the role of respondent.

Analytic procedures to decipher the medical encounter involving health care providers, caregivers, and children would entail video-recording the clinic visit and then using a system of coding for sequences in turn-taking and style of communication, as illustrated by Tates and colleagues. Alternatively, researchers could audiotape individual interviews with caregivers, children, and health care providers about their relationships and code for issues specific to forming a partnership, as in Cohen and Wamboldt's (2000) study. Focusing exclusively on caregiver-child responsibility issues, validated questionnaires have been developed to assess the extent to which treatment tasks are assumed primarily by child or caregiver or shared in managing type 1 diabetes (Anderson et al., 1990), cystic fibrosis (Drotar & Ievers, 1994), and asthma (McQuaid et al., 2001). As shown by Barlow et al. (1998), the focus-group methodology is another approach that permits identifying issues specific to each subsystem and the formation of partnerships. Ideally, researchers should aim to determine the quality of the triadic partnership by (a) identifying and isolating specific issues believed to influence the quality of partnership within each subsystem, and (b) examining the interrelationship among the subsystems, allowing for the creation of a latent
variable that would represent the quality of the triadic partnership, as being facilitative or nonfacilitative of treatment-related behaviors.

**Defining Aspect 3: Dynamic**

Researchers have tended to focus on identifying the impact of point-in-time contextual characteristics (e.g., parental coping, family functioning) and developmental status (e.g., mastery, cognitive maturity) on the manifestation of treatment-related behaviors, without considering the possibility of change in context and development, their interactions, and eventual consequences on behaviors (Davis et al., 2001; Gudas et al., 1991; Hanson, De Guire, Schinkel, & Kolterman, 1995; Ott, Greening, Palardy, Holderby, & DeBell, 2000). Studies reporting on the impact of disease (e.g., disease duration, disease activity) do not provide an understanding of how disease shapes treatment-related behaviors over time (e.g., Johnson et al., 1992; Litt & Cuskey, 1981; Reid et al., 1994), by potentially affecting the transaction between development and context.

When a multidimensional, longitudinal approach is used to assess treatment-related behaviors, a dynamic perspective is often lacking. A few studies with repeated assessments of treatment behaviors related patterns of change to contextual characteristics and developmental status assessed at baseline (e.g., Hauser et al., 1990; Jacobson et al., 1990). This analytic approach assumes that early family environment and developmental status (e.g., levels of functioning in social, emotional, and cognitive domains) have an independent influence on changes in behavior beyond the influence of current environment and adaptation.

Development is an integral part of our conceptualization of adherence, as are context characteristics and disease course. As illustrated in Figure 1, each is placed along a side of the triangle to emphasize its changing nature over time. That is, development situated along the base of the triangle emphasizes a continuum in levels of adaptive capacity in relation to executing the treatment tasks. Although situated at the base of the triangle, it should not be interpreted as occurring in isolation from either contextual characteristics or disease course. In fact, the degree of adaptive capacity is always a product of contextual characteristics, which exert their own favorable or unfavorable influences. This transaction will undoubtedly be modified by the disease course, represented as a continuum of symptomatic severity. Concurrently, they determine the likelihood of demonstrating treatment-related behaviors.

In the following subsections, we describe the process of development as contributing to the degree of adaptive capacity, how the context influences this capacity, and how the disease course may modify the development-context interaction. We wish to note here that contextual characteristics apply to influences that occur in the family environment. We recognize that the family is embedded within a larger context that can either strengthen or undermine its influence on adaptive capacity. It is precisely the child’s exposure to influences outside of his or her family that makes understanding the magnitude of proximal influences pertinent.

**Development**

Too often discussions about development and its role in treatment-related behaviors center on developmental status, which refers to children’s level of cognitive, social, emotional, and physical functioning at a given time point. Chronological age is often used as a marker for developmental status, presumably because if functioning falls within normal limits, one would expect to observe differences in how children view and understand their illness and treatment (i.e., cognitive development; Thompson & Gustafson, 1996), take responsibility for treatment components (emotional development; Drotar & Levers, 1994), deal with peer pressure (social development; Kyngas et al., 2000), and effectively execute treatment tasks (physical development; Johnson, 1993; La Greca & Schuman, 1995). Age, however, may not necessarily be an accurate indicator of a child’s developmental acquisitions.

Theories of development postulate that children’s current cognitive maturity, social relations, emotional resources, and strengths, as well as physical abilities, cannot be adequately appreciated apart from their history. Developmental researchers explain that at each stage in development, children are confronted with specific developmental tasks, viewed as issues around which development is organized (Cicchetti & Tucker, 1994; Horowitz, 1987; Sroufe & Rutter, 1984). These issues are broadly integrative and span social, emotional, cognitive, and physical domains. A child’s level of adaptation is judged by how well he or she approaches and resolves specific challenges that are central to that period of development. The quality of resolution of each stage-salient issue is coordinated with prior development (across all domains), and reorganization of competencies occurs, which moves the child forward in his or her
development. Children therefore develop greater flexibility and organization of behavior as they successfully negotiate salient tasks such as trust and the formation of attachment during infancy, exploration and mastery of the environment in early childhood, self-regulation and initiative in middle childhood, and self-identity during adolescence. Inadequate resolution of a specific stage-salient issue in any particular domain will, however, arrest developmental progression. Less than adequate integration within that domain will occur and compromise organization across domains as hierarchical integration continues. This is because the child arrives at successive developmental stages with less than optimal personal resources to respond to the specific challenges of that period. Personal resources are those competencies that a child has acquired and can draw on to successfully negotiate later developmental challenges (Masten & Coatsworth, 1998). It is through this active process of dealing with stage-salient challenges (adequate or inadequate resolution) and subsequent integration and reorganization that children may come to demonstrate different competencies (in terms of levels of cognitive, social, emotional, and physical functioning) at similar ages. Hence, the use of age masks individual differences in adaptive capacity.

**Contextual Characteristics**

This active process of acquiring and refining competencies does not occur in a vacuum. Children negotiate salient developmental issues in relation to current environmental circumstances. Environmental influences can be either favorable or unfavorable to continued developmental progress (Masten & Coatsworth, 1998). Researchers have tended to identify and determine the magnitude of specific contextual influences, such as family support, cohesion, organization, and conflict (La Greca & Schuman, 1995; Kroll et al., 1999; Kyngás et al., 2000), on treatment-related behaviors, independent of children's pattern of adaptation. When both context and development are considered, high versus low family support, for instance, is no longer viewed as good or bad for adaptive capacity. Rather, the issue is one of determining what degree of family support will work optimally given the child's current adaptive capacity, and how this might change in the future as the child grows and/or family supports wane. For example, a child may show difficulties with treatment recommendations in spite of having shown no difficulties at an earlier assessment. Perhaps the child's previous level of adaptive capacity was adequate given a specific level of family support. Yet, as support diminished, the child became vulnerable in the face of treatment demands. According to developmental researchers, this mutual regulation of development and context takes place over time, because both adaptive capacity and contextual influences are likely to change in importance and, in so doing, influence one another accordingly (Cicchetti & Tucker, 1994; Horowitz, 1987; Masten & Coatsworth, 1998).

**Disease Course**

Rolland (1994) describes chronic diseases along four specific parameters—onset, outcome, incapacitation, and course. In our conceptualization of adherence, we view the course of the disease as most likely to play a modifying role in predicting treatment-related behaviors over time. Our rationale for focusing on disease course is linked to the idea of change underscored in our model. For instance, the type of onset and the eventual outcome of a disease are unchanging. The onset of disease can be either acute or gradual. The outcome can be fatal or possibly fatal or shorten the life span. Families are informed during the diagnosis phase about the type and the outcome of their child's illness. They are equally informed about the degree of incapacitation (disability) their child will experience. Brief interventions may be offered to support families through this vulnerable phase. However, once in gear, they must contend with the course of the disease (progressive, relapsing, or constant) and make adjustments accordingly. Although the illness may be initially classified according to its general form—for instance, cystic fibrosis seen as a progressive disease, and JIA and asthma as relapsing diseases—children with these illnesses can and do experience periods of stability in symptoms (and for JIA, periods of remission). Still, families do become strained by uncertainty in the recurrence of symptoms.

In our model, this view of disease course is enhanced by emphasizing the degree of severity in symptoms as one moves along the continuum from asymptomatic to symptomatic. A change in disease course may modify treatment-related behaviors by playing into the mutual regulation of context and development. For example, a 9-year-old boy enters a period of relapsing JIA, thereby experiencing high symptomatic severity. This change in disease course may render him more dependent on family supports. If familial conditions fail to change in response to weakening personal competencies, the risk for disengaging from treatment would be heightened. The probability of disengaging from treatment
can therefore occur at any point in time as a result of a misfit in the developmental-contextual-disease regulatory system.

**Recommendations**

Taking a dynamic perspective of treatment-related behaviors would require tracking developmental adaptive capacity, contextual influences, and disease course over time. The first step would be to create latent variables that capture the phenomena over time. Development, for instance, is viewed as a latent variable summarizing personal acquired resources in different developmental domains, as measured by social (e.g., peer functioning, academic functioning), emotional (ego control/resilience, depression, anxiety, self-esteem), cognitive (reasoning, knowledge of disease and treatment, appraisals, locus of control, coping), and physical functioning (motor skills, autonomy/independence). For each of these indicators, a criterion would be set according to developmental norms for children with chronic illness. For instance, a child meeting the criterion on a given indicator would receive a score of 1. Summing across these indicators would yield a total number of areas in which the child exhibited competent functioning. Because children can evidence competent functioning in diverse areas, this broad approach to assess developmental functioning allows for a global indicator of adaptive capacity, likely to vary within and between individuals over time.

Contextual characteristics would also be characterized in terms of being favorable or unfavorable. The context would be viewed as a latent variable, which summarizes qualities of the family environment as measured by different aspects of family functioning such as relationships (in terms of resourcefulness, cohesion, expressiveness, and conflict), support (in terms of praise, acceptance, instrumental, promoting personal growth, independence), and organization (in terms of supervision, household rules, regulations, task responsibilities). Here too the overall quality of the family context would be determined on the basis of selected criteria for families of children with chronic illness. Likewise, disease course would be represented by a latent variable, comprising indicators of health status specific to the disease under investigation.

**Translating Theory into Research**

Regression models that include only early assessments of the family environment and/or adaptive functioning in predicting patterns of treatment-related behaviors mask changes that may have occurred in these indicators, and their potential impact. As well, regression models that partial out variance in treatment-related behaviors due to early family environment and/or adaptive functioning when determining the impact of more recent assessments of these predictors may underestimate the enduring role of earlier circumstances and developmental functioning. Further, viewing these predictors as independent from one another misses the opportunity to examine their joint impact on behavior and how this joint relationship may change due to the disease course.

A more integrated view is needed to understand the dynamics underlying the manifestation of treatment-related behaviors over time. The key word is dynamic, in the sense that it emphasizes the importance of acknowledging the potential for change in treatment-related behaviors in response to developmental status, contextual characteristics, and disease course. We must see that assessments are therefore ongoing, beginning during the early stages of disease. In so doing, we can distinguish children whose difficulties in treatment first emerge in later years from those whose difficulties have persisted over time. We can then link such differences in treatment-related behavior patterns to the nature of the fit or misfit between a child’s adaptive capacity and contextual characteristics over time, while considering the influence of disease-symptomatic severity.

Once latent variables are created, the first statistical step would be to identify trajectories on the basis of manifested treatment-related behaviors, adaptive capacity, favorable contextual influences, and disease course. For instance, the quality of the triadic partnership as being facilitative would also be evaluated over time to identify distinct trajectories. The identification of trajectories would be accomplished by using the semiparametric group-based modeling strategy, outlined by Nagin (1999), which is easily incorporated into the standard SAS package. Rather than assuming the existence of different trajectories, this technique provides an empirical basis for determining the number of distinct trajectories that best fit the data, such as stable (good and bad) and changing patterns (recovery and desisting) in a specific phenomenon. It also provides a formal basis for estimating the proportion of children in each identified trajectory. For example, we could expect to identify a group of children who demonstrate consistently high levels of adaptive capacity and a second group with consistently low levels of adaptive capacity. In addition, there would be two other groups with variable
functioning: one group with increasing adaptive capacity, that is, a consistent later period of adaptive capacity (recovery), and another group with decreasing adaptive capacity, that is, a consistent earlier period of high capacity (desisting). In contrast to the semiparametric technique, traditional approaches for analyzing longitudinal data such as hierarchical and latent growth-curve modeling assume that a population is composed of a continuous distribution of patterns, and adjusts individual variability about the average. As such, these techniques are not well suited for addressing empirical questions that are categorical in nature and that require modeling small within-group variability.

The semiparametric methodology, with some modification, can estimate joint trajectories of different phenomena (Nagin, 1999; Nagin & Tremblay, 2001). Once trajectories of development, context, and disease have been identified, the second step would be to examine their relative overlap, providing for clusters of profiles. These clusters of profiles can then be examined in relation to trajectories of triadic partnership quality. Membership in the different profiles can be entered in logistic regressions to predict the manifestation of treatment-related behaviors. In keeping with a multidimensional approach, trajectories for treatment behaviors would need to be modeled for each component, as it is likely that different clusters of influences are operating. Researchers have successfully used the semiparametric methodology to estimate trajectories for a single phenomenon such as obesity (Mustillo et al., 2003) and problem behavior (e.g., physical aggression, opposition, hyperactivity; Nagin & Tremblay, 1999) from childhood through adolescence. Another work by Nagin and Tremblay (2001) examines the overlap in trajectories of two behaviors such as hyperactivity and physical aggression over the childhood and adolescence periods. (Readers interested in exploring this methodology can do so via http://www.stat.cmu.edu/~bajones/traj.html.)

Concluding Remarks

What we are advancing as a reconceptualization of adherence is not entirely new. It draws upon existing models of child adaptation in the context of chronic illness (see review by Thompson & Gustafson, 1996). What is novel is the application of knowledge that stems from the fields of pediatrics and developmental psychology to explain the manifestations of treatment-related behaviors. This new conceptualization introduces the notion of change and proposes a multidimensional approach in thinking about the manifestation of behaviors. It views children as moving through life along some specific developmental course with their personal trajectory being determined by what they bring in terms of adaptive capacity to every transaction. From this perspective, the nature of interactive exchanges among members of the triad is likely to change. In short, we must always think of the transactions that are constantly occurring between an ever-developing child and an ever-changing context in relation to the disease that is itself often dynamic. With this being said, it is worth noting that translating theory into research is a daunting task.

Our recommendations make clear the importance of tracking treatment-related behaviors, as well as the combined influences of developmental adaptive capacity, contextual characteristics, and disease course over time in a dynamic fashion. This would require a sophisticated system of data collection to reduce data loss. Although the creation of latent variables will reduce the number of variables in analysis, there is still a need to ensure a sufficient sample size to detect any significant associations. Researchers will face difficulties in recruiting and maintaining participation, coordinating data collection from different sites, and ensuring accuracy in data coding and entry. The systemic, large-scale, multifaceted, and ongoing nature of this research endeavor calls for collaboration both within and among research disciplines (e.g., pediatric psychology, pediatric medicine, developmental psychology, statistics). The wealth of knowledge that can be generated from this endeavor will, undoubtedly, refine and extend the proposed concept of adherence, as well as open new research vistas.

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