

Longitudinal Research in Pediatric Psychology: An Introduction to the Special Issue

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This issue of the *Journal of Pediatric Psychology* (JPP) includes articles submitted for a special issue on “Longitudinal Research in Pediatric Psychology.” In the Call for Papers, we sought empirically oriented manuscripts that employed longitudinal designs and theoretical, methodological, or statistical papers relevant to longitudinal research. Examples of potential topics were provided in the Call and included: (a) familial, peer, and/or other contextual predictors of subsequent change in health-compromising behaviors in typically developing children or change in health-related behaviors and processes in children with chronic illness, (b) the impact of chronic illness on normative development or the consequences of varying developmental trajectories for subsequent health-related behaviors and processes, (c) studies that isolate different health trajectories as well as predictors of such differential outcomes, (d) tests of prospective mediational or causal predictor models based on longitudinal data, and (e) prevention, health promotion, and intervention studies with multiple data collection points that identify intervening mechanisms of change in health outcome. In response to the Call for Papers, 15 manuscripts were submitted. This issue includes eight of these articles; the first focuses on statistical strategies that can be used with longitudinal data and the other seven papers are empirical studies.

Longitudinal studies permit examination of changes in health-related behaviors and processes over time. Such designs can be retrospective or prospective, with the latter having clear advantages over the former (Loeber & Farrington, 1994). As will be argued in more detail below, prospective longitudinal investigations of children with chronic physical conditions may be particularly informative when change is examined during critical developmental periods or transition points (e.g., early childhood, the transition to school, the early adolescent transition, the

transition to adulthood). Indeed, a chronic condition is “chronic”; the impact of the condition is likely to unfold over time. At the most complex level of analysis, the task for the researcher is to understand a chronic condition that is changing over time in an individual that is also changing, developing, and maturing over time.

Despite the advantages of longitudinal designs in addressing such issues, most studies in the fields of clinical child psychology and pediatric psychology are not longitudinal. In an earlier special issue of the *Journal of Consulting and Clinical Psychology* (JCCP) on “The Role of Longitudinal Data with Child Psychopathology and Treatment,” Wierson and Forehand (1994) conducted a review of articles published on children and adolescents between 1983 and 1992 and found that only 4% were longitudinal (with 13% of those in JCCP being longitudinal). Of course, not all research questions require longitudinal designs, but Wierson and Forehand’s (1994) review suggests that such designs are more the exception than the rule. Within the field of pediatric psychology (and in JPP, in particular), most scholars suggest in their “future directions” sections that longitudinal data would be beneficial. Indeed, Wallander and Varni (1998) argued that developmentally oriented longitudinal studies in the field of pediatric psychology would be informative: “General developmental processes should become more salient features of the conceptualizations of adjustment in this special group. Longitudinal designs need to become the norm” (p. 42).

In this introductory article, we first discuss advantages of longitudinal research in the study of children and adolescents with chronic conditions. Next, we provide an overview of several factors one may wish to consider when designing longitudinal studies with pediatric populations. Finally, we provide a brief overview of the articles included in this special issue.

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Advantages of Longitudinal Research in the Study of Children with Chronic Physical Conditions

Loeber and Farrington (1994) detailed several advantages of longitudinal designs in clinical child research (also see Rutter, 1994). These advantages include the following: (a) maladaptation can be studied prospectively, including the onset, duration, termination, and outcomes of maladaptive trajectories (e.g., Are factors associated with the onset of problem behavior different than factors that are related to the maintenance of problem behavior?), (b) the provision of knowledge on the continuity, discontinuity, and escalation of problem behavior (e.g., What adolescent problem behaviors are continuations of those that began in childhood?), (c) the prediction of future outcomes from earlier factors (e.g., What factors in childhood predict the onset of problem behavior in adolescence?), (d) the ability to establish a typology of developmental sequences and trajectories (e.g., Are there different subtypes of problem behavior trajectories?), (e) the study of how at-risk populations negotiate and are affected by critical developmental periods [e.g., How does mastery (or lack of mastery) of certain adolescent developmental tasks influence adolescents' ability to manage future adversities?], and (f) the study of prevention interventions and the maintenance of change (e.g., What factors predict which individuals will maintain treatment gains?; Loeber & Farrington, 1994).

With respect to pediatric populations in particular, recent advances in medical care have dramatically enhanced survival rates for children suffering from chronic conditions (Rowland, 2005). These changes have prompted researchers to examine long-term effects of illness and illness-related variables on development. Longitudinal research is generally agreed to be the most appropriate methodological approach for studying developmental change over time and long-term effects of significant events on development (Loeber & Farrington, 1994; Rappaport, Randall, Shore, & Chung, 2003; Wierson & Forehand, 1994). Therefore, longitudinal methodology and a developmental psychopathology perspective can be integral to the advancement of knowledge in the field of pediatric psychology.

Developmental psychopathology provides several key concepts applicable to longitudinal research in pediatric psychology (e.g., developmental trajectories, resilience, risk and protective processes, continuity-discontinuity, multifinality, equifinality; Cicchetti & Rogosch, 2002). For example, research on developmental trajectories has elucidated developmental processes

leading to eventual maladaptation. It is assumed that some developmental trajectories are indicative of developmental failure that probabilistically increase the chances that a negative outcome will occur. In adolescents with type 1 diabetes, for example, children who are granted excessive levels of self-care autonomy during the early adolescent period are on a developmental trajectory that is more likely to result in less favorable treatment adherence and higher hospitalization rates (Wysocki et al., 1996). Alternatively, certain behavioral trajectories in children with chronic illness may indicate normative adjustment. For example, symptoms of psychological distress following diagnosis may be normative, with such symptoms being expected to decrease over time (La Greca & Schuman, 1999).

Several longitudinal studies have focused on long-term adjustment and developmental outcomes in pediatric populations, including cancer, spina bifida, traumatic brain injury (TBI), and juvenile rheumatoid arthritis (e.g., Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004; Kupst et al., 1995; Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003; Wade et al., 2004; Wade, Drotar, Taylor, & Stancin, 1995). These studies have revealed that some illness groups seem to adjust relatively well over the long term (e.g., survivors of pediatric cancer; Kupst et al., 1995), whereas others may be at risk for psychosocial deficits (e.g., children with juvenile rheumatoid arthritis; Reiter-Purtill et al., 2003). With respect to the latter study, Reiter-Purtill et al. (2003) found more significant effects for their analyses of longitudinal data than for their analyses of cross-sectional data, again highlighting the importance of examining overtime processes.

Relatedly, in our own work, children with spina bifida exhibited more child-reported depressive symptoms than able-bodied children when they were 8–9 years old (Holmbeck et al., 2003). Over four waves of data (from ages 8–15), however, trajectories of depressive symptoms tended to be flat for the spina bifida sample, whereas the slope increased significantly for the able-bodied sample, with the two trajectories crossing at age 12 (Holmbeck, 2005). In other words, if we relied exclusively on cross-sectional data during preadolescence, we would have concluded that children with spina bifida exhibit more depressive symptoms than able-bodied children. With longitudinal data, the picture becomes more complex. Able-bodied children follow a typical early adolescent trajectory of depression, with symptoms increasing with age. Children with spina bifida do not show this trajectory and report lower levels of depressive symptoms than their able-bodied counterparts at older ages.

Longitudinal methodology also enables pediatric psychologists to understand the complex interplay between development and illness status. For example, we know that decreased family cohesion and increased family conflict in response to pubertal development during adolescence are considered normative developmental processes in typically developing youth (Holmbeck, 1996). Families of adolescents with spina bifida, however, do not appear to experience these changes in family relations during adolescence, possibly representing a lack of familial responsiveness to physical developmental changes in this population (Coakley, Holmbeck, Friedman, Greenley, & Thill, 2002). Simply put, longitudinal research with pediatric populations sheds light on similarities and differences between the “normative” development of typically developing children and the development of children affected by chronic illness.

As developmental expectations change over time (on the part of children, parents, and health professionals), new medical and psychosocial challenges may emerge or become more salient. For instance, autonomy development and medical adherence issues are important constructs in individuals with chronic conditions and particularly during adolescence and young adulthood (Wysocki et al., 1996). In children with a pediatric TBI, effects of condition on academic functioning may only become apparent over time as school-related cognitive requirements increase with the introduction of more abstract material (Wade et al., 1995). In addition, not only do developmental expectations change over time, but the impact of the illness, in terms of symptoms, course, and treatment also changes over time (La Greca & Schuman, 1999). Moreover, the impact of chronic illness on development may vary depending upon timing of disease onset, such as congenital versus childhood onset (e.g., Anderson, Anderson, Grimwood, & Nolan, 2004).

Using longitudinal studies, several risk and protective factors for positive and negative outcomes in children with chronic illness have been established (e.g., Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004). Some risk factors for poor developmental outcomes are disease specific, such as illness severity and functional ability (Reiter-Purtill et al., 2003; Schwartz et al., 2003). Measures of family functioning, such as poor parental coping and poor family support, are general risk factors that have been shown to impact long-term coping of families of children in many different illness groups (e.g., Friedman et al., 2004; Kupst et al., 1995; Thompson et al., 2003; Wade et al., 1995). Finally, longitudinal data are required to understand the directionality and causality of relationships between risk factors and long-term

adjustment. For example, poor family functioning is both a risk factor for the incidence of TBI in children, as well as a risk factor for poor long-term adjustment to TBI (Wade et al., 1995).

Given this overview of some of the advantages of longitudinal research strategies, we now discuss some considerations that may prove useful in designing longitudinal studies for pediatric populations.

Considerations in Designing Longitudinal Research with Pediatric Populations

Although there are a number of general design-related issues and challenges to consider when developing longitudinal research protocols (e.g., financial cost, participant attrition, the degree to which the same measures can be used across different age groups), we focus here on issues that are particularly relevant to the study of children with chronic physical conditions. In this section, we discuss cohort effects, the number of data collection points, measurement issues, and attrition and sample size issues in studies of pediatric populations.

With respect to cohort effects, treatments that are applied to children with chronic conditions are continually being upgraded (e.g., in children with type 1 diabetes). Thus, different cohorts of research participants may have developed differentially because of the type of “standard care” that was in place for each cohort. To manage this particular barrier to longitudinal research, cohort-sequential research designs are useful (Loeber & Farrington, 1994; Willett, Singer, & Martin, 1998). With such designs, multiple cohorts are followed over time, thus permitting examination of cohort effects and whether longitudinal findings vary as a function of the type of care available for particular cohorts at given times. At a more complex level, if a particular cohort-sequential study includes longitudinal data on multiple age groups simultaneously (e.g., if one follows 9-year olds until age 11, 11-year olds until age 13, and 13-year olds until age 15), one is able to “link up” multiple short-term cohort-specific longitudinal studies that cover a fairly wide developmental period (e.g., the hypothetical study just noted would cover ages 9–15 in just 3 years of data collection). Such a design is referred to as an accelerated cohort-sequential longitudinal design (Anderson, 1993).

Although two data points may provide information about increases or decreases over time, the basic rule of thumb is that more data collections are preferred (Willett et al., 1998). Moreover, because developmental change is continuous, two points provide little information regarding

the "patterns of change" (pp. 407, Willett et al., 1998; also see Gottman & Rushe, 1993). For statistical reasons, growth models that include linear effects are best estimated with at least three data points, and models that include quadratic effects are best estimated with at least four data points (Willett et al., 1998). Also, if one seeks to test a mediational model (Holmbeck, 1997, 2002), longitudinal designs can provide the data necessary to test such models (Cole & Maxwell, 2003). Although one can test such models with two waves of data, mediational effects are best tested with three waves of data (e.g., T1 predictor → T2 mediator → T3 outcome; Cole & Maxwell, 2003).

With respect to multiple waves of data collection, an important measurement issue involves determining which respondents are the most qualified reporters of constructs of interest and whether such respondents should vary with age of child. Although this issue is relevant to all longitudinal research, the issue becomes more complex for some variables in pediatric psychology. With respect to medical adherence, for example, parents may be the most appropriate reporters for preadolescents. But, with age, children may be able to contribute to the assessment of adherence. As such, parents and children can be interviewed as a dyad (see Harris et al., 2000). Having said this, it is also important to note that growth analyses require that there be no change in the measures over time (Willett et al., 1998). Thus, if one seeks to conduct such analyses, the researcher needs to determine whether the chosen measures can be administered repeatedly over the time span of the study.

Attrition is also a factor in longitudinal research that takes on added salience in studies of pediatric populations. The changing course of a particular child's condition may necessitate attrition from a longitudinal study. For example, some children may become too ill to participate or, at the other end of the severity continuum, some children with mild forms of a condition may no longer view themselves as having a chronic illness and may prefer to withdraw from the study (Patenaude & Kupst, 2005). Statistically speaking, attrition in studies of pediatric populations is probably more likely to be nonrandom than in studies of typically developing children. Relatedly, attrition is also a particularly critical issue in the field of pediatric psychology because initial sample sizes are not likely to be large, due to low base rates in the population. Again, from a statistical perspective, longitudinal studies in pediatric psychology are almost always underpowered. To address this issue, many have suggested the utility of multisite studies (Patenaude & Kupst, 2005). However, potential problems can arise

from pooling data across a heterogeneous set of institutions. With multisite studies, participants are nested within sites; thus, "site" would need to be included as a variable of interest. Moreover, quality of care and population characteristics may differ across sites. Finally, some have found that severity of illness is related to retention in longitudinal studies (e.g., higher retention rates with higher severity; Janus & Goldberg, 1997). Such differential attrition may lead to higher estimates of maladjustment in some populations (Janus & Goldberg, 1997). In our own work with children with spina bifida, we have managed to retain children with mild and moderate forms of this condition by repeatedly stressing to our participants our intent to study the full range of severity. We also conduct our assessments during home visits, thus making no travel demands on the families.

The Studies in This Special Issue of JPP

The first article included in this special issue is a very readable overview of individual growth curve modeling as applied to several examples relevant to the field of pediatric psychology (DeLucia & Pitts, in press). Not only are the procedures carefully explained, but these procedures are compared to methods that may be more familiar to the readership. Moreover, computer syntax is provided. The remaining seven papers are empirical in nature and cover a variety of chronic conditions (i.e., very low birth weight, spina bifida, sickle cell disease, juvenile idiopathic arthritis, pediatric hematopoietic stem-cell transplants, TBI, and type 1 diabetes). Six of the seven papers examine overtime changes in outcomes of interest (Greenley, Holmbeck, & Rose, in press; Hoff, Palermo, Schluchter, Zebracki, & Drotar, in press; Moore, Taylor, Klein, Minich, & Hack, in press; Parsons et al., in press; Wade et al., in press; Wysocki et al., in press). More specifically, these articles examined moderators of associations between time (or other predictors) and outcomes. For example, Hoff et al. (in press) examined whether disease type (sickle cell disease, juvenile idiopathic arthritis) and early levels of pain moderated associations between depressive symptoms and later levels of pain. Moore et al. (in press) examined whether overtime changes in family burden and parental distress were moderated by other measures of family environment across three groups varying on birth weight status (e.g., age × group × family resources). More generally, when examining predictors of growth in an outcome over time (i.e., change), one is essentially testing an interaction effect with time (predictor × time → outcome).

One of the articles (Coakley, Holmbeck, & Bryant, in press) is a study of resilience and multifinality that focuses on why participants who begin with the same condition (i.e., spina bifida) move toward different end points (positive adaptation vs. nonadaptation). Two articles focus specifically on issues related to missing data and attrition, two critical areas of concern for researchers who conduct longitudinal studies (Parsons et al., in press; Wade et al., in press). Three studies focus on developmentally relevant variables (e.g., autonomy, family conflict, puberty; Coakley et al., in press; Greenley et al., in press; Wysocki et al., in press), and one of the longitudinal studies is conducted within the context of a randomized intervention trial (Wysocki et al., in press). Finally, there was also considerable variability in the statistics employed: Individual growth curves modeling using SAS Proc Mixed (DeLucia & Pitts, in press; Hoff et al., in press; Moore et al., in press; Parsons et al., in press; Wade et al., in press), growth modeling using HLM (Greenley et al., in press), Optimal Data Analysis (ODA; Coakley et al., in press), and repeated measures analyses (Wysocki et al., in press).

In closing, we are delighted that there are enough longitudinal programs of research in pediatric psychology to fill a special issue of this journal. On the other hand, there were some areas that were not well represented. Very few studies examined developmental variables or the manner in which the management of a chronic illness is modified as a function of individual developmental changes. Moreover, while most of the studies examined variables that moderated associations between time and outcome, none of the articles tested mediational causal models to answer important "why?" questions (Cole & Maxwell, 2003). Indeed, if we find, for example, that two groups differ with respect to trajectories of change over time, we still do not know why such differences emerged. Mediational models can begin to explain these group differences. With advances in research on pediatric populations, we will understand better the impact of chronic conditions, as these conditions unfold over time in children who are themselves developing over time. With such understanding, we will be able to design developmentally relevant intervention strategies for such youth and their families.

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