

## **A Contextual Family/Systems Approach to Pediatric Psychology: Introduction to the Special Issue**

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*Introduced the special issue on "Family Systems in Pediatric Psychology" by organizing the papers around a series of themes relevant to understanding families in pediatric psychology. Themes reflect the relationships between parent and child adjustment, family subsystems, legacies and traditions, social support systems, family interventions, the constancy of change in families, the challenges of conducting longitudinal research, the inclusion of fathers, and the importance of a competency framework in pediatric family psychology. The paper concludes with recommendations for pediatric family psychology, including suggestions for increasing diversity, expanding methodological approaches, and enhancing family competence.*

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**KEY WORDS:** families; pediatric illness; adjustment; research.

Families are unquestionably accepted in pediatric medicine and psychology. This is particularly clear in daily practice, where children are generally unable to even consent to psychological or medical care without the involvement of responsible adults. The development of pediatric family research has appeared to lag behind clinical practice, or has often not been directed towards clinically applicable findings. Yet, research on families in pediatrics continues to be of broad interest and the topic of increasing numbers of studies, including a previous special issue of the *Journal of Pediatric Psychology*. As with many areas of psychology, the integration of clinical practice and research (in the scientist-practitioner model)

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in the area of families whose children have medical problems is a goal worthy of pursuit.

The papers in this special issue of JPP on "Family Systems in Pediatric Psychology" represent many crucial lines of ongoing work in the field. Most important, they reflect the perseverance and creativity of pediatric psychologists conducting research that is often difficult, complex, and without clear precedents or consensus with regard to methods. It is hoped that these papers will stimulate readers to apply the knowledge gained to their clinical practice and will inspire ideas and methods in research to promote ongoing growth in the field.

In this editorial, a series of "facts" about families are used to organize themes about families which are reflected in the papers. Comments on the current state of development of the field of families and other systems in pediatric psychology are intertwined, including recommendations for future work.

## SOME FACTS ABOUT FAMILIES AND THEIR ILLUSTRATION

### *Child and Parent Adjustment Are Interrelated*

Pediatricians and pediatric psychologists have long appreciated the importance of families and have realized that child and family functioning are interrelated in complex ways. Drotar (1997) provides a review of the relationship of parent and family functioning to psychological adjustment of children with chronic illnesses. The studies reviewed speak strongly to the associations between child and parent adjustment; they also reveal the often repeated conceptual and methodological obstacles in this work (e.g., using one-parent report as a measure of family, lack of conceptual family-based models to guide empirical work). In his paper, Drotar utilizes his own experiences and provides integrative recommendations for ways in which future research questions and methodologies can better tease out these complex patterns. The conclusions are important and show that there is much work to be done in this area. Indeed, it appears that the time is ripe for researchers to begin implementing the suggestions of Drotar and others in pursuing these important interrelationships.

### *Families Are Composed of Subsystems*

Families are whole units, yet importantly comprise many interrelated subsystems. That is, dyadic (e.g., parents, parent-child, sibling-patient) and larger (e.g., mother-father-child, father-patient-sibling, child-mother-grandmother) subsystems exist in all families and overlap in their daily functioning and in the establishment of patterns over time. It is appealing to be able to assess the whole family. However, family measurement strategies to date have been disappointing

in terms of capturing the gestalt of family functioning. Use of measurement strategies for subsystems is a helpful alternative. This more specialized approach also allows for careful selection of measures appropriate to the child's and family's developmental level, critical aspects in the study of families in pediatrics.

In this issue, Holmbeck and colleagues (1997) examine individual, parental, and marital functioning in families of 8- to 9-year-old children with spina bifida and their mothers and fathers, and in a matched comparison group. Their findings, showing group (spina bifida, comparison) differences primarily with respect to parenting stress and coping strategies (and not in marital satisfaction), highlight the information gained from examining subsystems. The restriction of the sample to 8- to 9-year-olds is an important advancement in the literature over studies with broad age ranges. Pending replication at other developmental levels, these lines of research should begin to clarify the role of child and family development in adjustment to pediatric illness.

#### *Families Have Strong Legacies and Traditions That Affect Current Behavior*

When a child develops an illness, whether acute or chronic, serious or relative time-limited, family members' experiences with illness and beliefs about health and illness are important components of the child's and family's coping. This fabric, or narrative, of family experiences has often been lacking in pediatric family psychological research. In this issue, Fiese (1997) provides a model showing how family stories and rituals illustrate and impact families. The examples are compelling reminders of how pediatric family psychologists can "listen" to the "stories" of families and use this information in framing interventions, or services. They also challenge us to develop ways of including methodologies in our research which capture the meaning of events for specific families, being careful not to assume that "one size fits all" in the pediatric setting.

#### *External Support Is Important*

In examining families, the lens may be focused at many different planes within the social ecology. The papers in this issue overwhelmingly focus at the level of the immediate family. Yet, evidence for the powerful and positive impact of social support (Basic Behavioral Science Task Force of the National Advisory Mental Health Council, 1996) indicates that linkages between individuals, families, and social support systems should be regularly included in research and practice. Sheeran, Marvin, and Pianta (1997) provide an in-depth analysis of mothers' resolution of their child's diagnosis (with cerebral palsy or a seizure disorder) by probing for mental representations of relationships. They found that those with resolved feelings about the diagnosis perceived their social support

systems to be more helpful than the unresolved mothers, suggesting the complexity of relationships both internal and external to the family.

### *Family Interventions in Pediatrics Are Important*

There is a small but important body of research on the efficacy of family interventions in pediatric illness (Campbell & Patterson, 1995). However, this is clearly an area of need. In this issue, Kaslow and her colleagues (1997) write about the process of designing and using a manualized intervention with urban, African American, low SES families with children who have sickle cell disease. The authors share the process of research and, in particular, how they resolve the challenges of adhering to methodological rigor in a busy medical center with families who often present with multiple difficulties. The project speaks to the importance of identifying and describing the key components of the intervention while also remaining flexible to the needs of the families and the treatment setting.

### *Families Change Constantly*

One of the biggest challenges facing pediatric family psychologists is capturing the fluid nature of families and other systems. The vast majority of research provides a "snapshot" of one point in time, highlighting the need for prospective investigations. Chaney and his colleagues (1997) use a transactional model and provide prospective data (over 1 year) on child, maternal, and paternal adjustment in families of children with diabetes. The data support the overall adaptive levels of functioning seen in families of children with diabetes. However, the prospective design allows for closer examination of family patterns. For example, the ways in which fluctuations in fathers' level of distress may impact child and spouse are intriguing with respect to identification of more discrete research questions and also with respect to clinical intervention. That is, what are the normative fluctuations in family functioning over the course of an illness and treatment? And, are there points at which different types of interventions may be most effective?

### *Longitudinal Family Research, Although Crucial, Is Difficult*

As researchers conclude articles with calls to conduct longitudinal research, it sometimes seems as if we repeat this mantra, while knowing that few will successfully be able to accomplish it. Indeed, sometimes the obstacles seem overwhelming. Janus and Goldberg (1997) present data on factors related to attrition in longitudinal pediatric research which provide helpful ideas for conducting longitudinal studies. In a 4-year study of infants with cystic fibrosis,

congenital heart disease, and never-ill infants, the families of CF children were most likely to stay in the study, a finding attributed to their ongoing relationship with the treatment center. In the pediatric samples, parental well-being was the strongest predictor of stable participation, although level of illness severity also proved important. Data such as these should be helpful as researchers become more able to identify and address some of the predictors of attrition.

### *Fathers Have Often Been Neglected in Pediatric Family Psychology*

One of the persistent beliefs, dangerously translated into pediatric family research and practice, is that “you won’t get the fathers” (for therapy, for research). Several papers in this volume include data from fathers (Chaney et al., 1997; Holmbeck et al., 1997; Janus & Goldberg, 1997; Sheeran et al., 1997). The findings offer strong support for the incorporation of fathers (or another person in the family system) in family assessment and research. For example, Holmbeck et al. (1997) find that fathers may have unique vulnerabilities but also have coping patterns that differ from mothers. Weiss, Marvin, and Pianta (1997) show that their ethnographic interview approach, including both mothers and fathers, identified patterns of family functioning in families of children with cerebral palsy, which are richer than those that would have been derived from mothers alone. Using a transactional model, Chaney et al. (1997) show how fathers’ adjustment over time is a strong predictor of child and mother adjustment in families of children with diabetes. Finally, in their study of factors influencing participation in a longitudinal study, Janus and Goldberg (1997) discuss the differential level of involvement of mothers and fathers in longitudinal research.

### *Families Are Competent*

All the papers in this issue convey a strong respect for families and a view of basically healthy families coping with illness and treatment-related stressor. Indeed, the literature has moved markedly from early studies whose goals were to identify pathology. The notion that families of children with serious illness and physically handicapping conditions are different but not deviant is reasonably well accepted and replicated across a variety of pediatric conditions (Cadman, Rosenbaum, Boyle, & Offord, 1991; Kazak & Marvin, 1984; Kazak, Segal-Andrews, & Johnson, 1995). In this issue, Weiss et al. (1997) utilize a structured interview and ethnographic methods to derive four patterns of child care utilized by families of children with cerebral palsy. This line of research is promising, as it specifies how families cope adaptively with pediatric illness. At the same time, it can help to identify those patterns that are less adaptive, with implications for intervention.

## SUMMARY AND RECOMMENDATIONS

From the topics reviewed, several recommendations for pediatric family psychology can be extracted. These are not exhaustive. Indeed, the breadth of multidisciplinary literature that is applicable to pediatric family psychology is extensive and beyond the scope of this commentary. They are, rather, basic recommendations, with the understanding that amplification and flexibility are needed in utilizing them.

*Frame Questions from a Family/Systems Orientation.* Any pediatric question can be framed in systems terms. The information gained from a family/systems framework enhances the understanding of the pediatric patient in context. For example, questions about the efficacy of interventions for procedural pain can be conceptualized in terms of the ways in which families intervene with their child, or how parents are able to maintain or generalize the benefits of psychological interventions. Similarly, neuropsychological evaluations can include parents as partners in the process of assessment, thereby increasing understanding of the child's functioning in context.

*Include Data from More Than One Member of the System.* The complexity of systems cannot be captured with data from only one respondent. Although there are many challenges inherent in reducing and analyzing data from more than one person, the value gained exceeds the cost, as a more complete view of the system is obtained. This strategy allows for further examination of interrelationships among family members and clarifies subsystems with the family, including fathers and siblings. It also allows for inclusion of data from persons outside the immediate family, such as health-care team members, school, or other important community members.

*Aim to Capture Diversity.* Families are extremely diverse in their composition and functioning. In pediatric family psychology, the need to increase research on families of varied ethnic and socioeconomic backgrounds is of paramount importance. Diversity also applies to medical conditions. Although we still have much to learn about pediatric conditions such as diabetes, cancer, and spina bifida, there are other areas in which little pediatric family research has been conducted (e.g., HIV/AIDS, transplantation, adoption of children with special health care needs, families of terminally ill children). To attain this knowledge, creative, flexible, and specific research strategies are necessary.

*Broaden the Boundaries of Systems.* Using a social ecological or other systems framework (cf. Kazak, 1989), the interrelatedness of the family with other systems is clear. Thus, for example, peers, social support networks, hospital systems, and schools are all areas in which pediatric family psychology should contribute. The benefits in terms of a contextual understanding of children, families, and hospitals appear increasingly important in a time of changing health-care strategies.

*Maintain a Developmental, Normative, Competency Framework.* Families facing serious pediatric illnesses are essentially normal families confronting an abnormal stressor. The most productive approaches are those that integrate our large existing database on development, family function, and coping with stressors with pediatric illness (Kazak & Simms, 1996). In all cases, the goals of research, as in clinical practice, should be to enhance competency, while identifying vulnerabilities.

*Orient Towards Pediatric Practice.* Family-centered care is well established in pediatrics and is a natural fit with a family/system framework. The ways in which research findings can be translated into interventions (at the level of individual families as well as in designing programs of pediatric psychology service) are areas warranting further development. An integrated clinical research perspective in which programs are designed and evaluated which build on family competencies, include multiple members of the family (and other) system(s), explore the wide heterogeneity of families, illnesses, and treatments, with a developmental framework is encouraged and supported by existing data.

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