Commentary: Involving Families in Psychological Interventions in Pediatric Psychology: Critical Needs and Dilemmas

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Addressing Salient Gaps in Family Participation in Psychological Interventions

In this special issue of the Journal of Pediatric Psychology, Barbara Fiese, the editor, has done our field of pediatric psychology a noteworthy service by bringing together outstanding contributions that emphasize the importance and potential power of family-centered interventions to promote children’s health and psychological well-being. These contributions build upon an emerging body of family-based research in child development and pediatric psychology (Fiese & Wamboldt, 2003; Fiese, Wilder, & Bickham, 2000; Sharpe & Rossiter, 2002; Wysocki & Gavin, 2004).

In the lead off contribution to the special issue, Phares, Lopez, Fields, Kamboulis, and Dubig (this issue) call attention to the continuing gaps in research concerning the limited inclusion of fathers in research, including studies of family-based interventions and the failure to analyze the effects of psychological interventions on mothers and fathers separately. Attention to these important methodological issues is critical for several reasons: Given the very different roles and burdens that can be assumed by mothers versus fathers in caring for children who have a chronic illness as well as in primary care, family-based interventions may be expected to have different effects on different family caretakers. In many families of children with chronic illness, mothers assume the greatest burden of the child’s caretaking throughout the course of the child’s treatment. Although many fathers sustain their role as economic providers, they may become progressively less involved in the child’s medical and day-to-day chronic illness care over the course of the child’s illness. Consequently, the physical and emotional burdens of caretaking, relevant targets of intervention, and hence, the most sensitive psychological outcomes may differ substantially for mothers, fathers, or other family members. Because mothers’, fathers’, and/or siblings’ experience of and beliefs about the stressors and burdens associated with a chronic illness such as cancer may differ (Kazak et al., in press), these individual outcomes may not be equally sensitive to the effects of family-centered interventions, as was shown by Kazak (this issue). Moreover, the potential differences in the roles of family members and their experience of chronic illness suggest that a “one size fits all” family-centered intervention approach will be neither realistic nor effective. In fact, the contributions to this special issue illustrated a range of family-based intervention approaches that took various forms depending on the nature of the child’s condition, associated stressors and morbidity, and family resources.

It may be useful to appreciate that the inconsistent involvement of family members other than mothers in previous descriptive and intervention research in pediatric psychology may relate as much or more to pragmatic barriers (e.g., the time, energy, logistical difficulties needed to engage other family members in interventions) as any other factor. The contributors to this special issue are to be congratulated for their persistence and ingenuity in engaging family members such as fathers and siblings in research on family interventions. By doing so, the work described in this issue has extended the paradigm of family participation in psychological intervention.

The research exemplified in the contributions to this special issue underscores the wide range of critical psychological and health outcomes that can be affected by family influences. Nevertheless, the inconsistent consideration of broader family influences in pediatric psychological assessment and interventions is not necessarily surprising in light of the power of the medical model and prevailing psychological treatment models that tend to target problems in the child. Moreover, the culture of pediatric primary and chronic illness care case, which tend to emphasize the importance of mothers and/or
mother-child dyads. However family-centered clinical perspectives are clearly part of the informed practice of pediatrics (Stein, Coleman, & Epstein, 1997). To broaden the typical mother-child centered paradigm in pediatric practice and referral, our pediatric colleagues need to be informed about the heuristic value and clinical relevance of family-based approaches to assessment and intervention, which are thoughtfully exemplified in this issue.

It might also be noted that an undue emphasis on the role of mothers in clinical assessment and intervention practice is sometimes misleading in light of the extraordinary clinical variations in such clinically relevant family processes such as patterns of family caretaking and sharing of responsibilities for the child’s care, which may be important potential targets for psychological interventions. This issue was brought home to me in our family-centered intervention research in infants and young children who were hospitalized for failure to thrive (FTT). In almost all of these families, the mothers represented the family in clinical encounters with pediatricians by providing the medical history and describing the child’s condition and medical treatment as relevant. Moreover, these providers generally assumed that these mothers, many of whom were not married and from economically disadvantaged families, were the sole caretakers of their children. However, when our research team visited the children’s home to conduct interventions and outcome assessments, we learned that these assumptions did not reflect the reality of their caretaking. In fact, these infants were cared for by a network of family members including grandmothers, aunts, fathers and at times, siblings (Drotar et al., 1985). The critical factors that differentiated FTT from healthy infants in families of comparable socioeconomic circumstances were the level of family organization concerning the infant’s caretaking (Drotar, Eckerle, Satola, Pallotta, & Wyatt, 1990) and the chronicity of family dysfunction (Drotar, Pallotta, & Eckerle, 1994), which provided a focal point for family-centered intervention (Drotar et al., 1985).

Some Unanswered Questions and Future Directions Concerning Family-Based Interventions

Feasibility and Necessity

Any number of relevant questions for future research are raised by the contributions to this issue. One set of relevant questions for family-based psychological interventions with pediatric populations are: what are the best possible and/or in the case of very difficult families, the most feasible ways of engaging family members in psychological interventions that are critical to the child’s health and mental health? The family-based interventions reported in this issue are far removed from standard managed care mental health interventions. For example, the home-based, family-focused approaches tested by Harris, Harris, and Mertlich (this issue) and Ellis et al. (this issue), both of which focused on adolescents with poorly controlled diabetes clearly test the limits of engagement of families. In contrast to traditional mental health approaches in which much of the initiative and responsibility for engagement in psychological treatment intervention is assumed by the family, these investigators invested extraordinary efforts at considerable costs to engage and sustain family members in psychological interventions conducted in the family homes. However, such efforts are not only justified but may be necessary given the population (e.g., these adolescents’ clinically significant diabetes control problems threatened their health and resulted in significant health care costs). Moreover, it can be argued that such problems could not be managed effectively in the context of traditional psychological services because families could or would not have participated. The positive effects of a family-centered multisystems intervention approach in reducing hospitalizations for diabetes control (Ellis et al., this issue) are important given the potential for long-term health benefits of better diabetes control (DCCT Research Group, 1994). These data would suggest that the added time and cost of this time intensive and expressive model of family-centered intervention for this population may be cost effective over the long term. However, as noted by the authors, replication of the findings with a more detailed costs benefits analysis in other settings is necessary before far reaching policy implications can be claimed.

At the same time, as described by Kazak et al. (this issue) that even when delivered by highly experienced research teams, it may be difficult for some families to participate in family-centered psychological interventions. For this reason, alternative methods such as concerted outreach may be necessary to achieve and sustain family participation in interventions. The identification of the critical level of staff resources required to sustain the level of family engagement necessary to modify such troubling outcomes as severe and chronic problems in adherence to medical treatment remains an important one for the field (Drotar, 2000).

Moreover, as reported by Harris et al. (this issue), family-based psychological interventions do not always demonstrate the intended effects and challenge investigators...
to develop alternative methods to increase the power of such interventions. This is where the innovation and creativity of the clinical investigator plays an important role. The complexity of the logistics and intense commitment required to implement and evaluate some of the family-based psychological interventions described in this issue reflected programmatic efforts by research teams. Such efforts were characterized by a sustained commitment to a progressive series of studies in which initial research findings (based on feasibility studies and case series, etc.) were followed by controlled studies.

**Role of Theory in Testing Interventions**

Another set of unanswered questions that need to be addressed pertains to the development and testing of specific theoretical models that guide family-based interventions. Some candidate models described by the contributors to this issue included behavioral family systems theory (Robin & Foster, 1989) and social ecology and family systems theories (Bronfenbrenner, 1979; Kazak, 2001). To develop optimal tests of family-based interventions, it will be important to develop and refine the most critical family intervention-related questions based on theory and informed by research findings. In particular, clear a priori specification of theoretical predictions as they relate to specific strategies and operations for family-based intervention will be particularly important for the development of rigorous tests of more precise questions. For example, what do family-based theories postulate about the importance of and necessity for the involvement of specific family members and subgroups in interventions? How do family processes relate to critical processes of self-management of a chronic illness (Creer, 2000)? Under what conditions is it more effective to target subgroups of the family unit such as mothers and siblings done by Lobato & Kao (this issue) or parents and infants as Browne and Talmi (2005) report? What specific changes in health and psychological outcomes in individual family members as well as for the family system are predicted by relevant theories for family-based intervention models? What specific family processes will be changed by the intervention and how will these mediate clinically relevant outcomes?

To develop generalizable knowledge concerning interventions (Drotar, 1997; Drotar & Lemanek, 2001), the theoretical models that guide the family-centered psychological interventions of the future will need to specify and test the hypothesized mediators of intervention change (e.g., processes that affect and sustain change on key outcomes when they occur). For example, in Ellis et al.’s research (this issue) it was not clear what specific changes in family relationships, communication, problem solving, or management of general or illness-related stressors affected the frequency of hospitalizations among adolescents with diabetes. Future descriptive research, including research on the natural history of the impact of chronic illness on family systems, will be needed to articulate the key targets of interventions and potential processes and change agents that currently comprise the “black box” of family-based interventions.

**Integration of Family-Based Intervention Research and Practice**

Yet another critical future research and clinical care direction relates to the integration of family-centered perspectives into comprehensive care and research with children and adolescents with chronic illness. Innovative efforts have been made in developing, implementing, and testing family-centered models of chronic illness care in some settings (Anderson, Loughlin, Goldberg, & Laffel, 2001; Kazak, 2001). On the other hand, it is not clear to what extent prevailing models of the comprehensive pediatric chronic illness care, including psychosocial care are effective, especially for management of the wide range of clinical, structural, and relationship problems that are presented by families (Drotar & Lemanek, 2001). Parent-child centered models of comprehensive pediatric chronic illness care or psychological interventions may not provide the best match for families who demonstrate a range of ethnicities and family structures. For example, one would anticipate that parent-centered models of pediatric care and psychological intervention would be less applicable to culturally diverse, extended families who share the child’s caretaking owing to the complex patterns of responsibility taking and decision-making in such families (Walders & Drotar, 1999; Walders, Drotar, & Kercsmar, 2000).

Finally, closer integration of research and practice that results in greater inclusion of family-centered psychological intervention models and comprehensive care across settings will require additional data to support potential changes in policy and practice. Comprehensive descriptions of family members’ involvement in different modalities of care (e.g., primary care, care of children with chronic illness) and family-health care provider communication concerning critical decisions involving health care and psychological intervention would help to identify potential gaps in service delivery (Krauss, Wells, Gulley, & Anderson, 2001; Xu, Borders, & Arif, 2004). Significant discrepancies in family members versus providers’ perceptions of needs and clinical care
agendas that relate to meaningful clinical care outcomes such as attendance at clinic visits, adherence to the treatment recommendations, and satisfaction with care could be logical targets for intervention.

Documentation of the applicability, effectiveness, and level of implementation of research-based family-centered models in clinical care is a related and important long-range agenda item. Glasgow et al. (2004) have proposed a model that is applicable to determining the degree to which interventions, including family-centered psychological interventions, are implemented in practice settings. Relevant parameters of the Reach, Efficacy, Adoption, Implementation and Maintenance model include: (a) reach, or the percentage and representativeness of eligible families who participate in a program; (b) efficacy or effectiveness of a program, in this case a family-centered intervention in clinically relevant outcomes; (c) adoption defined as the percentage and representativeness of settings that adopt family intervention model; (d) implementation, to what extent were the interventions implemented as intended in the research, especially when conducted by clinical staff in applied settings, and (e) maintenance, long-term effects, the extent to which intervention components were continued, modified, or abandoned. Among the interventions described in this issue, Browne and Talmi’s intervention with parents and infants, which was conducted in a pediatric neonatal intensive clinical care setting, would appear to have potential to be integrated with the ongoing medical care of neonates. But to accomplish this intervention, relevant and as yet unanswered questions related to costs of the intervention, the expertise, training, and ongoing supervision of interventionists, and value-added contribution to comprehensive care would need to be addressed.

The editor of this issue of JPP, together with an outstanding group of contributors have advanced the science of family intervention research with pediatric populations. Although a great deal of work still lies ahead, I hope and trust that the work of these innovative investigators will inspire such efforts.

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References


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