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Parents of Children With Mental Illness: Exploring the Caregiver Experience and Caregiver-Focused Interventions

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Serious mental illness in children can significantly impact the parents who care for these children in both positive and negative ways. Caregiver strain and enrichment manifests in all areas of parents' lives, including work, mental and physical health, and social and family relationships. Research has identified numerous predictors of caregiver strain such as severity of child's illness and impairment, race, and social support. These parents need strengths-based, parent-focused interventions to help them care for themselves and their family in a healthy, effective manner. A brief summary describes 4 types of interventions for parents of children with mental illness and the supporting research. Education, support, and skill building are all important components in parent interventions. A parent focus for interventions and research will decrease caregiver strain and create a healthier environment for the entire family.

IMPLICATIONS FOR PRACTICE

- Mental illness in children has significant impact on parents, so clinical intakes should include assessment of parental strain to determine the needs of the entire family in the treatment process.

Mental illness in children affects more than just the children—it impacts the entire family. Parents become both caregivers, managing the fluctuating moods and behaviors of their children, and case managers, coordinating the services needed by their children. Parent caregivers of children with mental illness struggle to meet the needs of their entire family by balancing the needs of their child, other family members, and themselves. They may face challenges such as financial burden, sibling rivalry, stigma, self-doubt and blame, marital stress, and difficulty accessing services, in addition to dealing with the symptoms their child is experiencing (Commonwealth Institute, 1999). Family caregivers have been described as stressed, with the potential of having more problems than the persons for whom they care (Lefley, 1997).

Family involvement in mental health treatment and service can empower parents to more successfully manage their children's illness and to be educated advocates for their own children and for others, leading to more positive outcomes for the entire family. Children of caregivers who perceived themselves as competent and knowledgeable in one study functioned better than children of caregivers who felt less empowered (Resendez, Quist, & Matshazi, 2000). Despite the impact mental illness can have on the entire family, many therapeutic approaches do not recognize or address the strengths and needs of the parents or whole family. Families not only struggle with the symptoms and impairment of their child's mental illness but also struggle to get appropriate services from treatment providers (Mackinaw-Koons & Fristad, 2004). A review of intervention studies for children and adolescents suffering with depression found that only 3 of 14 of the interventions studied included a family component (Kaslow & Thompson, 1998). The focus has been primarily on the impact mental illness can have on children's functioning in areas such as home, school, and peers, and less literature focuses on how mental illness in children impacts the functioning of those closest to them such as their parents and siblings.

This article reviews the literature on the biopsychosocial impact of mental illness in children on their parents who are acting as caregivers. The review describes the impact of the caregiver experience on various spheres of life, including mental and physical health, work, and social and family relationships, and summarizes the predictors of the presence and nature of caregiver strain as found in previous research. To conclude, the authors describe some of the available parent-focused interventions and supporting research for use with families of children with mental illness.

The Caregiver Experience

Caring for a loved one who needs additional support because of illness can be a challenging experience fraught with unfamiliar roles, increased responsibilities, and heightened stress. The difficulty associated with these experiences has been referred to as caregiver burden or strain. *Caregiver burden* has been described as the "presence of problems, difficulties or adverse events which affect the life [lives] of the psychiatric patient's significant other[s]" (Platt, 1985, p. 383). Similarly, *caregiver strain* has been used to refer to negative consequences, both physical and emotional, that impact caregivers as a result of the additional responsibilities of caring for a loved one who is ill (Heflinger & Brannan, 2006). The research on caregiver strain and burden focuses mainly on caring for adult children with mental illness, children with chronic illness, or the elderly. Less research focuses on caring for children suffering from mental illness, even though in the general population, approximately 10.7% of parents feel burdened as a result of the psychiatric symptoms experienced by their children (Angold et al., 1998). Raising a child can be a difficult process, and adding the symptomatology and impairment of mental illness can magnify the stress and strain parents experience. Despite the challenges, some caregivers report positive aspects of caring for their loved ones, referred to as *caregiver enrichment,* which may enhance the quality of experiences in a family's daily life (Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998). However, caregiver enrichment has been the focus of very little research.

Families in Society: The Journal of Contemporary Social Services | www.FamiliesinSociety.org
DOI: 10.1606/1044-3894.4097 | ©2011 Alliance for Children and Families

Volume 92, Issue 2
Pages: 183–190
URL: http://www.familiesinsociety.org/ShowAbstract.asp?docid=4097

183

graphics and quizzes are incorporated into the sessions. Results indicate reductions in anxiety symptoms, and reports from a case review indicate that parents and children were satisfied with this intervention because they were able to complete the sessions at their own pace and at times that were convenient for them (Spence et al.). The Incredible Years training program (Taylor et al., 2008) teaches parents methods for coping with difficult behavior in children with a unique combination of phone calls, e-mails, and home visits, so parents have the convenience of online methods in addition to the advantage of in-person training (Taylor et al.). Parents using this intervention have reported high achievement of the goals outlined by the program.

Interventions Summary

Despite varying formats, all of these interventions focus on the needs of caregivers of children with mental illness in an effort to enhance caregiver strengths and resources and decrease caregiver strain, therefore improving the health and functioning of the entire family. PEP stresses the importance of education about illness, treatment, and symptom management for caregivers. The various models of psychotherapy use therapeutic techniques to address mental health symptoms and family dynamics. PMT also provides education for caregivers, but it is specifically focused on techniques to manage difficult behavior in children. Technology-based interventions incorporate the growing area of technology into mental health by providing caregivers with alternative options that may be more adaptive to caregivers' busy lives. The common elements across these interventions are education, support, and skill building. Additionally, most of these parent-focused interventions provide flexibility in format and topics addressed with the recognition that parents have varying strengths and needs and may prefer nontraditional options for education and support.

Conclusion

Raising a healthy child can be challenging but adding the additional roles, worries, and struggles of caring for a child suffering from mental illness can significantly impact numerous areas of a parent's life, including mental and physical health, work, and social and family relationships. If parents are not healthy and supported, they may not be able to provide themselves, their child, and the rest of their family with the best possible care. Also in the midst of these difficulties, parents may simply overlook the enriching aspects of the caregiving experience and the strengths or resources they bring to the experience. As such, initial clinical intakes of children with mental illness should include assessment of caregiver and family strain and enrichment in various areas of life to determine the families' strengths and needs relevant to the treatment process. Social workers are particularly suited to conducting these types of assessments and for working with these families because of the profession's ecological, strengths-based orientation.

Despite the potentially large impact of the caregiver experience, treatment of children with mental illness often focuses on treating the child's symptoms and helping the child cope with his or her illness rather than encouraging strengths and empowering families with the education and resources they need to be effective and healthy caregivers. The interventions described in this article acknowledge that the parents are an integral part of their child's care, and social workers may find these interventions to be an effective addition in working with this population. To successfully incorporate these interventions into their work with families, social workers need to stay up-to-date on the cur-

rent evidence-based research, and in order for social workers to do this, additional research and resources for practitioner education and training in the various caregiver-focused interventions are needed. Only a few of the available models for each of the types of interventions are highlighted in this article, and so practitioners should do further research before determining which model may be most appropriate for their clients. When implementation of these full interventions is not possible in clinical settings, social workers may need to deconstruct the intervention to determine which of the caregiver-focused treatment components (e.g., education, support, and skill building) can be successfully incorporated into their treatment planning.

In the physically and emotionally close environment of a family, mental health symptoms and impairment in children can negatively impact everyone around them, and consequently, the negative impact on the family can cycle back to further complicate the child's difficulties. To alleviate family strain, increase caregiver enrichment, and improve chances of child recovery, practitioners working with children with mental illness should incorporate not only caregivers but also siblings and extended family into a family-focused, strengths-based treatment when appropriate. However, social workers should also use their clinical judgment to determine when family members need more help than they can provide as a part of the child's treatment, and in those cases, it is important to have information on hand for caregiver referrals.

Though the primary focus of this article has been on the micro level, there are important implications for social work practice at a macro level as well. Many of the challenges that cause strain in families of children with mental illness are consequences of the shortcomings of the macro environment (e.g., unsympathetic nature of workplace, lack of appropriate child care, failure of the health care system, and widespread stigma against mental illness). By providing educational, strengths-building interventions to families, social workers empower parents to advocate for their own family in their local schools and neighborhood, which in turn may positively affect others in their area who are being impacted by the presence of mental illness in their families. Additionally, social workers can introduce parents to recovery and consumer-based organizations that provide opportunities for support, education, and advocacy, such as the National Alliance on Mental Illness (NAMI; http://www.nami.org).

As professionals, social workers also have the tools and opportunities to advocate for change for families of children with mental illness. In their agencies, social workers can encourage other coworkers to adopt a family-focused, strengths-based framework when working with families, and they can advocate for agency-wide training on evidence-based interventions that align with these values. On the state and national level, social workers can be involved with organizations such as NAMI and the National Association of Social Workers to stay up-to-date on legislative actions that provide opportunities for advocating for change. The stressful nature of parenting a child with a mental illness may be inevitable, but social workers can help by providing parents with the best services and treatment, by empowering parents to identify their strengths and the enrichment in their experiences, and by working side by side with parents and other professionals to advocate for change at a macro level to provide better conditions for families of children with mental illness.

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