Published in final edited form as:

J Pediatr. 2015 October ; 167(4): 795–796. doi:10.1016/j.jpeds.2015.07.039.

Beyond Blame: Parents as Partners

Kelly J. Kelleher, M.D., M.P.H. and

Professor of Pediatrics and Public Health, Colleges of Medicine and Public Health, The Ohio State University

Kimberly Hoagwood, Ph.D.

Vice Chair for Research in the Department of Child and Adolescent Psychiatry at the New York University School of Medicine

In this issue of *The Journal*, Radovic et al present the results of qualitative interviews with slightly more than a dozen primary care clinicians about barriers to adolescent depression care.¹ The topic is worthy of discussion. There has been little progress in alleviating the epidemic of untreated adolescent depression and its consequences, such as suicide, especially in primary care settings. Moreover, few persons familiar within the culture of primary care will be surprised by the principal findings reported by the authors: physicians see parental ‘fault’ as one if not the primary reason that adolescents with depression do not get treatment. This is particularly apparent in systems with co-located specialty services.

Pathways to care for adolescents with depression are known to be fraught with obstacles—60 to 80% of adolescents with depression do not receive appropriate treatment.^{2–4} For most adolescents, access depends greatly upon parental motivation and support. Because the study occurred in an integrated behavioral health system, many of the system barriers were removed, thus allowing more intensive examination of attitudinal barriers interfering with optimal care.

In this study, the authors employed qualitative interviews of physicians in private practice to inquire about barriers to adolescent depression care. Physicians reported mainly attitudinal barriers, such as parental resistance to treatment recommendations, denial, lack of motivation, passivity, and lack of education. The physicians perceived that the treatment goals were largely unattainable without parental commitment. Although this was a small sample from a single site, anyone studying physician attitudes knows that the sentiments shared are reflective of many clinicians in dealing with families of children with chronic illnesses generally and mental disorders specifically. Unfortunately, these physician opinions continue the antiquated separation of family and clinical team in pediatrics that may be a core part of the access problem for adolescents.

Proof/Correspondence to: Kelly J. Kelleher, M.D., M.P.H., Center for Innovation in Pediatric Practice, The Research Institute at Nationwide Children’s Hospital, 700 Children’s Drive, JW4985, Columbus, OH 43205 (Kelly.Kelleher@nationwidechildrens.org).

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

The authors declare no conflicts of interest.

Families see the world differently than clinicians. They identify stigma, negative perceptions of providers towards families, and prior negative experiences with the health care system as barriers to doctor-family communication. Studies have shown that families also note cultural appropriateness of mental healthcare, cultural values attached to outcomes, and suspicion of the medical establishment as barriers. Family contextual factors (e.g., parent stress and social supports) influence whether families stay in treatment and the extent to which they benefit from treatment over time.⁵⁻⁷

We are left with a classic blame game. Physicians decry family commitment and families complain about lack of understanding on the part of physicians. Meanwhile adolescents go without mental healthcare. Perhaps, a better alternative is to invite and motivate families to join the therapeutic team, as some behavioral specialty sites are beginning to do. Called by various names, such as parental empowerment or activation or engagement, this dynamic process tends to include four key components: (1) understanding and acceptance of a child's diagnosis; (2) critical reflection of themselves and their situation by taking stock of their strengths, capabilities and resources; (3) taking charge of their child's care through advocacy, learning how to deal with the health care system, persistence, partnerships, and communication; and (4) persevering in their efforts over time.⁸

The family support movement has employed parents as agents of change based on these components on a limited scale for more than 20 years. Training, credentialing, and employment of family peer advocates (or family support specialists or parent partners) to join the mental health team is a part of the movement. Family peer advocates are often hired in service agencies that are challenged in helping disenfranchised and economically-disadvantaged families from highly diverse backgrounds. The goal of the family peer advocates typically is to develop knowledge and competencies among parents necessary to ensure that their needs are met. Consistent with the literature on barriers to mental health care, especially among families with complex social situations, family peer advocates often are unable to effectively empower families without addressing the perceptual obstacles that families face. These include, the stigma of mental illness, beliefs about child social and behavior problems (e.g., child needs discipline; problems will go away), and attitudes about mental health services (lack of trust, negative experiences with providers). Even when such perceptual barriers are addressed, many of these families are stressed by living situations and personal challenges, and often lack the requisite knowledge, skills and support to effectively advocate on behalf of their children's needs. Thus, a significant component of the parent empowerment training program integrates specific and pragmatic strategies for increasing parent engagement⁹ and links such strategies to lessons from theories of behavior change, with the ultimate goal of activating parents of children with mental health needs as agents of change.¹⁰⁻¹²

The identification of physician reported non-constructive parental attitudes merely begs the question as to why those attitudes exist, what circumstances families face, and how providers may need to think differently about overcoming these barriers. It will take time and new models of reimbursement to implement peer models of support and other solutions in primary care, but it will be worth it to move from blaming to collaboration. True progress in achieving a family-focused, patient-centered medical home in primary care settings for

youths with depression will require that families not be viewed as adversaries, but instead be viewed as partners, and in many cases, as part of the treatment team.

References

1. Radovic A, Reynolds K, McCauley H, Sucato G, Stein B, Miller E. Parents' role in adolescent depression care: primary care provider perspectives. *The Journal of Pediatrics*. 2015
2. Kataoka SH, Zhang L, Wells KB. Unmet need for mental health care among U.S. children: variation by ethnicity and insurance status. *The American journal of psychiatry*. 2002; 159:1548–55. [PubMed: 12202276]
3. Lewandowski RE, Acri MC, Hoagwood KE, Olfson M, Clarke G, Gardner W, et al. Evidence for the management of adolescent depression. *Pediatrics*. 2013; 132:e996–e1009. [PubMed: 24043282]
4. Merikangas KR, He JP, Burstein M, Swendsen J, Avenevoli S, Case B, et al. Service utilization for lifetime mental disorders in U.S. adolescents: results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child and Adolescent Psychiatry*. 2011; 50:32–45. [PubMed: 21156268]
5. Dadds MR, McHugh TA. Social support and treatment outcome in behavioral family therapy for child conduct problems. *Journal of consulting and clinical psychology*. 1992; 60:252–9. [PubMed: 1592955]
6. Kazdin AE, Wassell G. Predictors of barriers to treatment and therapeutic change in outpatient therapy for antisocial children and their families. *Mental health services research*. 2000; 2:27–40. [PubMed: 11254067]
7. McKay MM, Pennington J, Lynn CJ, McCadam K. Understanding urban child mental health I service use: two studies of child, family, and environmental correlates. *The journal of behavioral health services & research*. 2001; 28:475–83. [PubMed: 11732249]
8. Gibson CH. The process of empowerment in mothers of chronically ill children. *Journal of advanced nursing*. 1995; 21:1201–10. [PubMed: 7665789]
9. McKay MM, Stoewe J, McCadam K, Gonzales J. Increasing access to child mental health services for urban children and their caregivers. *Health & social work*. 1998; 23:9–15. [PubMed: 9522199]
10. Fishbein M. A theory of reasoned action: some applications and implications. *Nebraska Symposium on Motivation Nebraska Symposium on Motivation*. 1980; 27:65–116. [PubMed: 7242751]
11. Jaccard, J., Litardo, HA., Wan, CK. Subjective culture and social behavior. Adamopoulos, J., Kashima, Y., editors. 1999. p. 95-106.
12. Jaccard J, Dodge T, Dittus P. Parent-adolescent communication about sex and birth control: a conceptual framework. *New directions for child and adolescent development*. 2002:9–41. [PubMed: 14964942]