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Evolution of Child Mental Health Services in Primary Care

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Abstract

Objective—While the importance of mental health assessment and treatment in primary care is increasingly recognized, the research that underlies current practices largely stems from a considerable body of non-mental health primary care studies. Our purpose was to describe trends in research over the past two decades and suggest further key items for the research agenda.

Methods—We reviewed the literature broadly on health services research in pediatrics, especially studies of changes in primary care practice, and examined recent articles in primary care mental health services.

Results—The evolution of primary care mental health services for children has been slow, but the focus of research has changed with the development of clinical improvements. Proposals to deliver more effective services have evolved over the past forty years in a series of approaches that paralleled initiatives in the broader fields of medicine and pediatrics. Current trends in electronic technology, practice consolidation and coordination, and personalized medicine are likely to increase the pace of change in mental health services for primary care.

Conclusion—The evolution of pediatric mental health services in primary care suggests a continuing expansion from a focus initially on provider behavior and quality to a growing attention to patient and systems' behavior over time and within communities.

Keywords

Mental health services; primary care; quality improvement

All primary care clinicians now know the basic facts. Mental disorders, as a group, are the most common chronic conditions among pediatric patients. ¹⁻³ They cause extensive morbidity and mortality both during childhood and extending into adulthood. ⁴⁻⁵ Mental disorders are associated with high rates of health service use and costs of care, especially when they are comorbid with substance abuse or other chronic medical disorders. ⁶⁻⁸

In the face of this epidemic, the mental health treatment system boasts significant improvements. Many new evidence-based treatments and assessment tools are available. In

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addition, new parity legislation across many states and most recently the federal government supports a broader range of mental health benefits for commercially – insured children that are almost as expansive as those traditionally provided to Medicaid insured children in the U.S. ⁹ Even with these changes, primary care settings (and other child-focused human service agencies such as schools, juvenile justice programs and child welfare systems) are the principal mental health systems for children and their families in our society. ¹⁰ This is in part due to the high patient costs required for specialty mental health care, the stigma associated with these conditions, and the inadequacy of specialty care workforce to manage the large number of youths with mental disorders. ¹¹⁻¹³ Moreover, current financing systems such as behavioral health carveouts and utilization management of specialty care push mental health care into the primary care system in spite of the frequent concerns expressed by primary care clinicians about their capacity and training for this type of care. ¹⁴⁻¹⁵

Because primary care is now so important in mental health care, many researchers have studied primary care clinicians' roles in identifying, assessing, treating, and coordinating care for children and adolescents with mental disorders. Unfortunately, there is little evidence that such understanding has yet improved outcomes for children and adolescents with mental disorders. Identification studies suggest that primary care clinicians are diagnosing more psychosocial problems than in the past, but that inadequate recognition is still the norm in most practices. 16 Long term studies of treatment and outcomes in primary care are almost non-existent. The few studies that have followed routine community care suggest modest benefit at best for those treated in typical primary care settings. ¹⁷ In fact, children and adolescents treated with psychotropic drugs in primary care settings often do not remain on their drugs for sufficient time to obtain therapeutic benefit. ¹⁸ Few children referred from primary care attend specialty evaluations, making the availability of effective interventions in primary care all the more relevant. 19-20 Among those who eventually connect with specialty care, most do not complete the prescribed treatment course. Non-adherence with psychotropic drug prescribing is extremely high and the number of visits for most youth who receive psychotherapy in community settings does not approach that found to be necessary in randomized efficacy trials. Adherence issues for mental health treatment are particularly concerning. In contrast to many other chronic conditions where adherence is a problem in a minority of patients ²¹⁻²², long term adherence for pediatric patients with psychiatric drug treatment is very low. New studies underscore parent concerns about the potential for the development of drug dependence, and uncertainty about long term changes to brain function and stigma are all sufficient to instill powerful ambivalence among parents about psychiatric drugs for their children. 23-24

Hoagwood has summed up the state of affairs in child mental health services by noting, "We know what to do, just not how to deliver it." ²⁵ Proposals to deliver more effective services have evolved over the past forty years in a series of approaches that paralleled initiatives in the broader fields of medicine and pediatrics.

Phase 1: Patient-Doctor Communication: Identification of Mental Disorders

The earliest attempts to improve mental health care delivery for primary care patients were part of efforts to improve doctor-patient communication in primary care more generally. Medical training initiatives on medical interviewing and patient assertiveness training achieved prominence in the 1970s and 1980s in pediatrics, family medicine, and internal medicine training programs. ²⁶⁻²⁷ These programs asserted that the doctor-patient relationship was essential in garnering patient trust, improving communication and identification of problems, engaging the patient in treatment planning, and encouraging adherence. Doctor-patient relationship studies were prominent in care for children, women and the elderly patients. ²⁸⁻³⁰

The initial foray into primary care as a site for delivery of mental health services was launched shortly after the seminal paper by Regier in 1978 that noted the limited access of patients with mental disorders to specialty care and the extensive use of primary care services by persons with mental disorders. In work that was focused primarily on internal medicine and family practice sites during the 1970s and 1980s, investigators focused on primary care clinician awareness of mental disorders and communication strategies to elicit patient symptoms and engagement. Early studies in pediatrics resembled those in other primary care disciplines with a focus on improving physician awareness of emotional and behavioral symptoms and identification of mental disorders. Such efforts were associated with rapid increases in diagnoses and treatment of mental disorders in pediatric settings in the last quarter of the $20^{\rm th}$ century, although the relationship between changes in training and changes in practice is not clear. 36

Pediatric studies on improving communication and interviewing techniques for eliciting symptoms and engaging patients continue to this day. Research on training pediatric primary care clinicians in communication techniques demonstrates that patients seeing such clinicians are more likely to report family violence, emotional and behavioral symptoms, and other family concerns. Where the provided interacting with clinicians trained in such techniques may have improved outcomes in subsequent assessments. While new methods of training from research studies appear to be effective in enhancing communication between primary care clinicians and families around child mental health issues, it is less clear that routine pediatric training provides clinicians the skills they need. Although pediatricians trained in the last decade of the 20th century all received at least one month of child behavioral developmental experience, these clinicians report high levels of concern about their preparedness to diagnose and manage pediatric mental disorders except for ADHD. 14-15 Unfortunately, no consensus exists on how additional training would benefit primary care clinicians in the absence of changes to specialty mental health financing and access.

Phase 2: Emergence of screening and guidelines: Outlining evidence for assessment and treatment

While patient-doctor communication remains a central tenet of primary care science, an explosion of interest in evidence-based medicine rapidly changed the focus of many investigators studying primary care quality generally and mental disorders specifically from identification to management. Researchers found significant deficits in the quality of primary care preventive and chronic care services with low rates of physician adherence to recommendations and poor patient compliance with treatment for many conditions. ⁴⁵⁻⁴⁶ The largest of these studies by the RAND group coincided with one of the first systematic reviews of quality studies in pediatric journals in the early 1990s. ⁴⁷⁻⁴⁸

During this same period, the quality of mental health services for children and adolescents in primary care was also found to be suspect. Although diagnoses increased, many studies documented flaws in assessment and treatment provided to youths in primary care. Continued under-recognition of psychosocial issues was noted along with low rates of adherence to specialty referrals and psychotropic drug prescriptions. $^{49-50}$

In response, an avalanche of guidelines, practice parameters and recommendations for improving the quality of care has descended upon primary care clinicians from specialty and guild organizations, including guidelines for pediatric mental health services. ⁵¹⁻⁵² A comprehensive set of recommendations on an overall office approach to child and adolescent mental disorders is currently being developed by the American Academy of Pediatrics Task Force on Mental Health and partner organizations from a variety of disciplines. These recommendations will be forthcoming in 2009. Many of the preventive components of these

recommendations have already been released as part of the Bright Futures (www.brightfutures.org) initiative.

One contentious aspect of these recommendations is the requirement that primary care providers use standardized screening and assessment tools for early identification in primary care. The longstanding literature from both adult studies and child studies suggests that standardized tools do increase the identification of under-recognized mental disorders. 53-55 Nevertheless, few practices routinely use standardized tools for universal screening. Reasons for the lack of use include significant staff costs for administration of such tools, the frequent absence of treatment and specialty resources if problems are identified, and high rates of false positive generated by current short standardized screening tools. 56-57 These practical problems require urgent solution because of new court decisions in states like Massachusetts and Texas requiring formal screening tools, new payments in several states for clinicians that implement screening, and growing agreement about management of children who screen positive; these initiatives have all increased the pressure for universal screening for all pediatric patients. 58-60

Phase 3: Quality Improvement: Changing Practice

While guidelines and practice parameters outline the core elements of ideal care, few studies in primary care have demonstrated any significant improvements in quality with recommendations alone. Instead, primary care researchers turned to quality improvement/ assurance interventions to implement the many guidelines and practice parameters with the aim of improving care, especially the delivery of preventive services. Most of these studies have occurred in the past decade and were carefully reviewed recently. ⁶¹ These interventions generally included training, reminders, extra reimbursement and feedback for volunteer practices participating in this research. For pediatrics, these quality improvement studies have been most successful in improving the receipt of immunizations and in enhancing the rate of screening tests such as Chlamydia labs. ⁶²⁻⁶³ For other chronic health conditions, traditional quality improvement studies targeted at changing clinician behavior have met with more limited success.

There have been few controlled quality improvement studies for mental health services in primary care. The largest of these demonstrated improvement in depression outcomes for adults in multiple managed care organizations with the greatest improvements for persons from low socioeconomic neighborhoods. ⁶⁴ As with general medical quality improvement studies, these mental health services QI efforts achieved modest clinical improvements across the board. Both symptoms and functioning improved among intervention group patients as compared to those not receiving quality improvement interventions. In addition, care processes were noted to be improved at intervention sites. These modest gains were achieved at significant cost for the intervention sites. Similarly, one large study has examined adolescent depression in multiple primary care sites. As with the aforementioned studies of adults, adolescents in the quality improvement arm demonstrated lower levels of symptoms and enhanced functioning as compared to those in the control practices. However, less than a third of patients in either arm received the targeted specialty mental health services prescribed, and symptoms were only modestly improved. ⁶⁵ An ADHD guideline implementation study found similar results in part because of the complexity of patients.

In sum, quality improvement studies for mental health services targeted at changing primary care clinicians and their behavior consistently show significant but modest improvements in rates of identification of new mental disorders, increased treatments and some improvements in symptoms. These modest gains have come at a significant cost, and all required research level interventions. It is not clear if routine quality improvement efforts in healthcare systems

will show benefit for patients, although large scale screening studies have increased identification rates. ⁶⁷⁻⁶⁸ Moreover, it is unlikely that pediatric mental health services will be the target of significant quality improvement attention in large managed care organizations because children make up such a small portion of the healthcare dollar. It is difficult to implement quality improvement in primary care because quality improvement QI methods are too data-intensive and dependent on financial data. Most measurement systems such as the National Committee on Quality Assurance Health Employer Data Information System and other like systems are based on the use of financial claims and calculating clinician achievement of goals based on paid claims. ⁶⁹ Primary care mental health quality is poorly reflected in paid claims since primary care billing often does not include mental disorder diagnoses or counseling codes. Until detailed electronic health records are widely available and easily analyzed, typical quality improvement efforts in primary care and pay for performance are unlikely to include much work on mental health services by primary care clinicians because of the heavy emphasis on use of claims to determine quality incentives.

Phase 4: Next Steps--Implementing The Medical Home

The evolution of mental health services in primary care for children and adolescents is frustratingly slow for families and clinicians anxious for solutions that work. However, each phase of research has yielded important tools for improving care. The early phase on doctorpatient communication and identification continues to provide important screening tools, training for clinicians and an emphasis on the scope of the problem. The continual refinement in treatment guidelines and practice parameters offer families and clinicians roadmaps for the process of care and decision support in making choices. ⁷⁰ Quality improvement interventions aimed at clinicians alter the flow of patients and processes in medical settings to more easily embed high quality care. Still, significant deficits in care coordination, financing and patient communication remain to more fully engage patients, families, communities and the primary care system effectively. 71-72 In response, investigators have articulated more comprehensive models that include system-level quality initiatives added to strong patient engagement strategies embedded in more organized primary care systems and tied to specialty and community services. The clearest articulation of such comprehensive models is the Chronic Care model outlined by Von Korff and Wagner. 73 They include many of the aspects of the "Medical Home" endorsed by the American Academy of Pediatrics which may be a more acceptable term for many organizations. 74 These components include systems that engage patients efficiently, provide decision support for both patients and clinicians, monitor progress and outcomes, exchange information across time and place, and link with community resources. Tests in controlled environments suggest that such comprehensive and coordinated primary care systems may be able to more effectively deliver chronic care services like those necessary for pediatric patients with mental disorders or homeless children. 75-77

Future research on primary care mental health services for children and adolescents, like previous research on communication, guidelines and quality improvement, will be driven in large part by marked changes in practice occurring in primary care more globally. At least three important trends will shape these efforts. First, dramatic changes in digital technology beyond the electronic health record will change the focus of primary care practice for chronic disorders from in-office visits to out of office-management and coordination. Secondly, alignment of value purchasing incentives and restructuring of healthcare systems for increased regional accountability will change the responsibilities and information available to primary care clinicians confronted by pediatric mental health symptoms. Thirdly, personalized medicine will increasingly allow for specific dosing and monitoring of treatment for individuals when genetic, behavioral, environmental and historical data are combined.

Digital Health Technology

Most discussions of digital technology in medical care have focused upon the electronic health record. Such records have been slow to migrate to the primary care office because of high startup costs, an inpatient focus and workflow concerns. However, changes in reimbursement systems such as incentives for use of electronic health records and the cost of conducting quality audits without EHRs are increasing their uptake. More importantly than basic EHRs, the uses of other types of digital technology have larger implications for improving primary care mental health services and enhancing research on the same. These other types of technology can be grossly divided into those technologies that provide patient and family engagement with their care and the medical systems to those that provide decision support for the clinician and practice, although some technologies do both.

For example, computerized psychosocial screening and assessment in pediatric waiting rooms may facilitate physician recognition and correct diagnosis of these patients. Logistical challenges frequently prevent such psychosocial screening from occurring. Front office staff members often lack the time to distribute and score paper questionnaires, and primary care providers have competing clinical responsibilities during brief visits with patients. 81 Touchpad computers in the waiting room or at-home screening prior to office visits with secure wireless connections can help overcome these logistical challenges. Because patients and/or their caregivers directly answer psychosocial questions in waiting rooms or in their homes via this technology, neither clinic staff nor primary care providers must take time to administer, score and transcribe screening tools and more detailed assessments for these concerns. Instead, primary care providers can utilize their limited time to offer assessments, counseling, and referral assistance to those pediatric patients who endorse a particular concern through this technology. The development of primary care adaptive testing tools through the NIH Roadmap Initiative known as "PROMIS" will allow highly efficient assessments across multiple domains in real time. Adaptive testing regressions employ known patterns of response from large sample to selectively administer questions to respondents based on last previous response.⁸² Simulation studies suggest that most patients can complete assessment tools in one-quarter to one-half the time that usual paper based assessments take.⁸³

Even more important than assessment tools for primary care clinicians will be digital technologies that engage patients and their families to take more active roles in their own care. Some of these support learning, symptom management and self care for parents or adolescent patients.⁸⁴ These include online therapeutic workbooks and cognitive therapy supports for depression to self-management training tools for adolescents with ADHD. Even more interesting are tools that help primary care clinicians manage their patients on psychotropic medications. New tools for assessing symptoms and side effects in real-time using interactive voice response telephone systems and text messaging systems are currently under study for patients with mental disorders in primary care. 85 These types of tools will help primary care clinicians manage the increasingly demanding nature of recommendations from the Food and Drug Administration and others for careful follow-up and monitoring of youth with psychiatric illness, especially those on medications. As another example, telephone support services (TSS) represent one potential tool as part of a more comprehensive medical home initiative for improving access, adherence, and outcomes in primary care mental health services especially for hard to reach populations on medication. ⁸⁶ TSS involve a health care provider (e.g., nurse), who is either a member of a clinical practice or is associated with groups of practices for efficiency, making several follow-up phone calls to families after a clinic visit. These calls can feature symptom and side effect monitoring as well as discussing ways of overcoming challenges to implementing treatment plans among others.⁸⁷

TSS has improved antidepressant adherence and outcomes for adults from primary care. 88-89 However, future research is needed to determine if TSS has efficacy for pediatric mental

health care. In addition, reaching families whose contact information frequently changes and securing reimbursement for these telephone services may prove challenging. However, given the recent increase in insurance coverage for telehealth services and the potential of billing case management services for those with public health insurance, these barriers may be overcome soon in many communities. ⁹⁰

Structural changes in primary care

While digital technology through computers or cell phones will speed communications and monitoring of patients with mental disorders, marked changes in the structure of primary care organizations will likely have an even greater impact. Primary care organizations are growing in size and reach across the country with fewer and fewer primary care clinicians practicing in small groups. ⁹¹ This is a natural market response to the increasing demands for accountability, the delivery of more comprehensive services, the cost of implementing new medical technologies and the negotiating ability for contracting. Regardless of the origin, the alignment of incentives in contracting with larger practices means that purchasers will increasingly use pay for performance contracting, outcomes purchasing and an increasing number of quality of life measures to incentivize care. 92-93 Structures and processes that allow primary care clinicians to manage patients with mental disorders with fewer no-shows, greater referral success and more careful monitoring will have natural advantages. Thus, primary care practices will be seeking more deliberate and effective partnerships with mental health providers. These may take the form of co-location of services or even preferred sub-contracts with mental health specialists. Co-location of behavioral health providers within primary care practices offers several advantages for improving mental health treatment. 94-95 Co-location may increase families' mental health care utilization because services are offered in a non-stigmatized setting unassociated with behavioral concerns. ⁹⁶ In addition, co-location may increase care coordination and educational exchanges between pediatricians and mental health providers. Williams, Palmes, Klinepeter, Pulley, and Foy's survey of private practice pediatricians suggested that these primary care clinicians were typically amenable to such co-location. 97 Among adults in primary care settings, co-location is much more likely to yield effective interaction with mental health specialists than usual care or even facilitated referrals in trials of various structures. 96-97

While these changes are occurring in primary care, mental health services in the community will also be consolidated and re-organized over time. The push for changes comes from different sources in various locales, but some of the results are similar. States are changing payment and policy to support a greater role for primary care physicians in early screening of children for mental disorders, greater assessment and management fees for primary care, and long distance consultation support from mental health specialists. ^{90, 98-99} By necessity, most of these services will be organized at a regional or community level and will require pediatricians to help coordinate regional mapping of specialty resources such as developing airline resource guides for pediatric psychotherapy and standardized referral processes. Unfortunately, research has not kept pace with policy and practice initiatives re-organizing mental health specialty support for primary care at the state level such as in North Carolina or Massachusetts, and many questions remain unanswered. ^{96, 100}

Personalized medicine

Digital communications technology and primary care infrastructure will support greatly improved processes of care. However, personalized medicine will markedly alter the approach to diagnosis and treatment of particular mental disorders. Personalized medicine is defined variously as the use of individual genetic and behavioral information to tailor specific treatments for individual patients. ¹⁰¹ Although much of the excitement of personalized medicine focuses on the controversial issues around identifying individuals at risk of specific

conditions early through genetic testing, the real-world applications for children in primary care already under study are those associated with pharmacogenomics. It is clear that pharmacokinetics of psychotropic drugs among children are highly variable. In the past, primary care clinicians managed this patient variability with trial and error approaches. However, a significant part of this variability for some medications is related to metabolism that is in large part determined by genetics. Two important examples are differential response and dosing to risperadone and sertraline. \$\frac{102-103}{103}\$ The ability to tailor dosing of specific drugs to genetic profile when combined with standardized diagnostic assessments and some evaluation of patient adherence history should greatly enhance primary care treatment specificity and effectiveness. While pharmacogenetic profiling is already available for some drugs, formal trials in primary care settings await tools with applicability to a greater number of children and adolescents and the lowering of costs through mass production and competition.

Conclusion

Primary care mental health services and related research have evolved significantly over the past three decades. No longer concerned only with identification of children and adolescents with mental disorders, current proposals call for quality improvement initiatives in the context of a structurally and financially integrated medical home that includes digital records and tracking systems, moving towards the use of personalized medicine. Such systems offer real hope that reliable and continuous chronic care for pediatric patients with mental disorders can be supported across episodes and sites.

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