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STAKEHOLDER VIEWS ON BEHAVIORAL HEALTH CARE IN THE PEDIATRIC
PRIMARY CARE SETTING: A QUALITATIVE APPROACH TOWARDS INTEGRATION
OF CARE

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy in Psychology at Virginia Commonwealth University.

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Abstract

STAKEHOLDER VIEWS ON BEHAVIORAL HEALTH CARE IN THE PEDIATRIC PRIMARY CARE SETTING: A QUALITATIVE APPROACH TOWARDS INTEGRATION OF CARE

By: Alexis Michelle Quinoy, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Psychology at Virginia Commonwealth University.

Virginia Commonwealth University, 2015

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The pediatric primary care setting has been discussed as playing a central role for the identification and treatment of behavioral and mental health disorders in youth. Although this setting is in a unique position to provide these services, there are many barriers to the integration of mental health care and pediatric primary care. The aim of this study is to examine perspectives of multiple stakeholders (i.e., patient, parent, nurse, resident, faculty, clinic director) in a pediatric primary care setting to explore barriers, behavioral and mental health needs, and facilitators to the integration and provision of mental health care for children and families in pediatric primary care. The study involved both focus group and individual interviews with a total of 36 stakeholders (patient $n = 2$; parent $n = 7$; nurse $n = 4$; resident $n = 16$; faculty $n = 5$; clinic director $n = 2$). A grounded theory approach was used to analyze the focus group and

interview data. Barriers to integration and consequences of these barriers are presented, as well as facilitators identified by stakeholders to overcome these obstacles. Identified behavioral and mental health needs will also be presented. Limitations of the study and future directions are discussed.

Stakeholder Views on Behavioral Health Care in the Pediatric Primary Care Setting: A Qualitative Approach Towards Integration of Care

Prevalence rates of mental health problems in youth have been reported to be as high as 27% (Horwitz, Leaf, Leventhal, Forsyth, & Speechley, 1992; U. S. Public Health Service, 2000), with well over 7 million children in the United States displaying diagnosable psychiatric impairment (Holden & Schuman, 1995). Further, epidemiological data suggest that 11% to 20% of youth seen in a pediatric primary care setting are affected by one or more Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (*DSM-IV-TR*; APA, 2000) diagnoses and up to 42% of youth might demonstrate at least a sub-threshold mental health problem (Brown, Riley, & Wissow, 2007; Chavira, Stein, Bailey, & Stein 2004; Polaha, Dalton, & Allen, 2011). Estimates demonstrate that up to one-half of children seen in a pediatric primary care setting with a clinical or sub-threshold mental health issue display significantly impaired functioning (Costello, Burns, Angold, & Leaf, 1993). Unfortunately, only about half of these children are identified, and only approximately 5% receive any type of mental health treatment (Holden & Schuman, 1995; Richardson, Keller, Selby-Harrington, & Parrish, 1996; Simonian, 2006). Recently the American Academy of Pediatrics Task Force on Mental Health (TFOMH) reported that despite a lifetime prevalence of 46.4% for mental health problems, fewer than 50% of children and adolescents are identified. Importantly, about 33% of children with a mental health problem are identified in primary care settings (TFOMH, 2010). These data suggest that there is a serious need for improved identification of children suffering from a mental health problem as well as a need for increased access to mental health services.

The under-identification and subsequent failure to treat mental health problems in youth can lead to numerous, and potentially serious long-term sequelae such as increased use of health

care services, prolonged distress for children and their families, poorer adherence to treatment for medical problems, and the persistence of mental health issues into adulthood (Riley & Wissow, 1994). This “public crisis in mental healthcare,” as concluded in a report by the Office of the U.S. Surgeon General (U.S. Public Health Service, 2000, p. 11), has led many in the field to suggest various solutions for increasing access to mental healthcare such as increasing public awareness, policy changes, and alternative locations for mental health care. For example, Child Mind Institute’s “*Speak Up for Kids*” campaign was launched in 2010 to provide the public with information about children’s mental health through talks in communities. In addition, policy changes such as the Patient Protection and Affordable Care Act of 2010 help to increase access to mental health services through insurance provisions, as well as increasing funding for community mental health centers. These findings have also led many in the field to investigate alternative locations for identification and treatment of youth, including schools (Anglin, Naylor, & Kaplan, 1996; Han & Weiss, 2005; Hoagwood & Erwin, 1997) and primary care settings (American Academy of Pediatrics, 2009; Asarnow et al., 2005; Borowsky, Mozayeny, & Ireland, 2003; Brugman, Reijneveld, Verhulst, & Verloove-Vanhorick, 2001; Gardner, Kelleher, Pajer, & Campo, 2003; Simonian, 2006; Wren, Scholle, Heo, & Comer, 2003).

The pediatric primary care setting has been proposed as an ideal setting for identification and treatment of youth with psychosocial issues for many reasons (Black, 2002; Schor, 2004). As stated previously, recent research has indicated that mental health problems are present in as many as 20% of pediatric primary care cases (Polaha et al., 2011; Wren et al., 2003). Other evidence has shown that mental health disorders, as a whole, are the most common conditions among youth seen in pediatric settings (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003). PPCPs (PPCPs) have become increasingly involved in the management of children’s mental

health due to this increased recognition of high prevalence rates of mental health problems in pediatric primary care. For example, in 1999 the American Academy of Pediatrics (AAP) formally recognized the subspecialty of developmental-behavioral pediatrics, indicating the increased recognition of the importance of integrating behavioral health into pediatric primary care (McMenamy & Perrin, 2002). The AAP also concluded that PPCPs were in a unique position to play an important role in children's mental health due to the opportunity for a trusting therapeutic relationship throughout the child's lifetime and the ability to implement preventative efforts by promoting both physical and mental well-being, as well as timely interventions for common psychosocial issues encountered in the course of development (AAP, 2009).

Moreover, children with mental health problems have a higher probability of seeking help in the medical setting versus children without mental health problems (Costello, 1986; Simonian, 2006), and generally speaking, pediatric primary care might be the only setting where many children and families seek and or receive medical care due to greater access to pediatric primary care than traditional mental health services (Tarnowski, 1991). In some communities, there is a lack of community mental health resources, thus PPCPs are the only provider with whom a child might come into contact (Schor, 2004). Essentially, many children only have their PPCP as a resource for any type of health care. As a result, pediatric primary care has been indicated as the "de facto" mental health system because PPCPs are most likely to come into contact with children and families, as well as evaluate children more regularly than other providers (Norquist & Regier, 1996; Simonian, 2006).

In addition, unlike school-based mental health care, where access to care might not always be available (e.g., summers, when school is closed), primary care settings have the ability to provide care year-round, which is important for continuity of care (AAP, 1995). Another

reason pediatric primary care has been suggested as an optimal location as compared with school-based care, is the increased availability of records (Etherage, 2005). Health information transfers regulated by the Health Insurance Portability and Accountability Act (HIPAA; 1996) can be challenging between service sectors due to concerns about confidentiality and privacy. A shared system of record keeping between primary care providers and mental health providers could make the transfer of pertinent information, such as a patient's diagnosis and treatment, more efficient. Overall, this could allow for a more comprehensive approach to patient care. Additionally, PPCPs prescribe the majority of psychoactive medications to youth in the U.S. providing further evidence for the importance of including mental health providers in their patient's overall care (Ringelsen, Oliver, & Menvielle, 2002). Care provided in pediatric primary care might also be covered by insurance policies that do not include traditional mental health coverage (National Alliance on Mental Illness (NAMI), 2011).

Seeking help in a primary care setting is also associated with less stigma than a traditional mental health setting, thus it may be more acceptable to some families and is often the first place parents will seek advice about their children's behavioral problems (Schor, 2004; Simonian, 2006; Williams, Klinepeter, Palmes, Pulley, & Foy, 2004). Indeed, 50 to 60% of all visits to PPCPs involved behavioral and emotional concerns (Cassidy & Jellinek, 1998) and 50% of parents reported psychosocial concerns about their children at regular well-child visits (Cooper, Valleley, Polaha, Begeny, & Evans, 2006; Sharp, Pantell, Murphy, & Lewis, 1992). In addition, research has shown that many parents consult PPCPs regarding behavioral issues prior to seeking services from behavioral health providers and that patients are more likely to use mental health services if their primary care providers suggest these services (Schor, 2004). In

sum, providers in pediatric primary care settings act as gatekeepers in the identification and management of children's mental health issues.

Over 30 years ago the phrase "new morbidity" was coined to label the impact of psychosocial problems on pediatric primary care (Haggerty, Roghmann, & Pless, 1975). Specifically, it described how emotional and behavioral problems are of major concern to parents of youth seen in this setting and how PPCPs will inevitably become more involved in treating mental health problems. Despite a three decades long debate over identification and treatment of mental health problems in pediatric primary care (Costello, 1986; Goldberg, Reiger, McNerny, Pless, & Roghmann, 1979; Horwitz et al., 1992), as well as recommendations and support for better coordination and integration of behavioral health into pediatric primary care, the care system remains fragmented and falls short of providing adequate assessment and treatment of children's mental health problems (Costello et al., 1988; Horwitz et al., 1992; Simonian, 2006). This study represented an effort to identify barriers and facilitators of integrated mental health care in pediatric primary care. The current study examined the views, through the use of focus groups, of relevant stakeholders in a pediatric primary care clinic with regard to integrating behavioral health care in order to assist in the development of a program to address these needs. Although there has been discussion in the literature of general barriers and facilitators of integration of behavioral health in pediatric primary care (Cohen, Calderon, Salinas, SenGupta, & Reiter, 2012; Bitar, Springer, Gee, Graff, & Schydlower, 2009), few studies address these issues from the perspective of multiple stakeholders.

Before describing the study, several literatures will be reviewed. First, the focus on integration of mental health into the pediatric primary care setting will be discussed. Next, I will review the current literature addressing barriers and facilitators of behavioral health integration

in the pediatric primary care setting. Third, I will present the rationale for using stakeholder input to design a behavioral health program in this setting. Relatedly, I will discuss the reasoning for using qualitative methods for this initial needs assessment, as well as the decision to explore the data using a grounded theory approach. Finally, I will describe the Qualitative Interview of Child/Family Behavioral Health Stakeholders in Pediatric Primary Care (PEDS Qual) study, which is the second phase to a program of research in this setting. The first phase, the Pediatric Anxiety and Depression Screening (PEDS) study, sought to identify the level of a variety of behavioral health problems in a large pediatric primary care setting. The current study extends the work of the first phase through the use of qualitative methods.

Integration into Pediatric Primary Care

As described earlier, many reasons have been cited to support the pediatric primary care setting as an ideal location for increased access to mental health care for children and families. Most children and families have ongoing relationships with PPCPs and trust these providers to make decisions in the best interest of their child (Schor, 2004; Simonian, 2006). In addition, assessment and treatment in a pediatric primary care setting might carry fewer stigmas than receiving care in specialty mental health clinics (Williams et al., 2004). Due to the prevalence of mental health disorders in pediatric primary care, there is a clear need to address these issues by integrating mental health care into the pediatric primary care setting. Furthermore, integration of behavioral health in pediatric primary care can lead to improved health outcomes as well as cost savings (Maruish, 2000). In this section I will present a brief history of the evolution of mental health care in pediatric primary care. Then, I will discuss different approaches that have been discussed in the literature of how best to integrate behavioral health into the pediatric primary care setting.

Mental health care and primary care have a shared history that has evolved over the past 40 years (Kelleher & Stevens, 2009). The literature demonstrates formal collaboration between psychologists and pediatric populations since the 1960s. For instance, an early example from this era described a private pediatric practice that invited a psychologist to work in their clinic a half day a week (Smith, Rome, & Freedheim, 1967). In addition, the term *pediatric psychologist* was making its appearance in the literature around this time (Wright, 1967). Early on there was reluctance in the mental health community about seeing patients in medical settings, but due to the many advantages (e.g., less perceived stigma, collaborative relationship with pediatrician) mental health care's presence in pediatric settings began to increase (Smith et al., 1967). Also at this time the term "new morbidity," as stated earlier, was coined (Haggerty et al., 1975), as scientists and providers began to understand how often mental health problems presented in pediatric primary care.

The next two decades brought about efforts to improve general doctor-patient communication in primary care through the assistance of training initiatives with psychologists (Wasserman, Inui, Barriatua, Carter, & Lipincott, 1984). An influential paper in the 1970's noted the lack of access patients with mental illness had to traditional specialty care and how primary care was used extensively as an alternative location by these patients for services (Regier, Goldberg, & Taube, 1978). This seminal paper launched the first attempts at a more structured look into primary care settings as an ideal location for the integration of behavioral health, first with studies in adult primary care (e.g., Jones, Badger, Ficken, Leeper, & Anderson, 1988; Katon et al., 1996; Klinkman & Okkes, 1998) and then in pediatric primary care (e.g., Brown et al., 2007; Erickson, Gerstle, & Feldstein, 2005; Kelleher, McInerney, Gardner, Childs, & Wasserman, 2000).

Due to the growing recognition of mental health disorders in pediatric primary care, many major policy reports began describing the importance of mental health treatment in pediatric primary care and began disseminating recommendations for the prevention, identification, and management of mental health disorders for pediatricians (e.g., AAP, 1993; Ford, Steinberg, Pidano, Honigfeld, & Meyers, 2006). To implement these recommendations, many ways of integrating mental health care into pediatric primary care settings have been suggested (Etherage, 2005; Ford et al., 2006; Kolko, Campo, Kilbourne, & Kelleher, 2012; Williams et al., 2004). In this next section, I will give a brief summary of how investigators have attempted to integrate behavioral health into the pediatric primary care setting, before discussing the many barriers they have faced along the way.

Methods and Models of Mental Health Integration in Pediatric Primary Care

Collaboration between behavioral health and PPCPs is important for identification and treatment of youth with mental health issues (Black & Nabors, 2004). Integrated care is the practice of integrating behavioral health care into pediatric primary care settings and vice versa in order to improve the quality of care for children and families (NAMI, 2011). Methods of integration have been suggested ranging from distributing information about mental health care to families to fully integrated collaborative care (Etherage, 2005; Kolko, Campo, Kilbourne, & Kelleher, 2012; Williams et al., 2004).

One of the least integrated approaches discussed in the literature is distributing information, supports, and resources to families about mental health care through the use of posters, brochures, and fact sheets displayed in pediatric primary care offices (NAMI, 2011). Although this method might raise awareness about mental health and connects children and

families to important resources, it remains unclear whether the method ultimately leads to direct care for a child with mental health issues.

Mental health screening is another method proposed to increase identification and referral in pediatric primary care settings (Brown and Wissow, 2010; Simonian, 2006). Researchers have recommended that PPCPs use checklists or questionnaires to ask children and families about their symptoms and functioning in order to identify any psychosocial issues (Simonian, 2006). Mental health screening has proven useful in the early detection and identification of mental health issues as well as increased referrals to mental health services and supports (Riekert, Stancin, Palermo, & Drotar, 1999). Despite evidence of the utility of mental health screening, up to 71% of PPCPs report not routinely using a formal screening instrument in their practice (Gardner et al., 2003; Sand et al., 2005). Primary care providers have reported other limitations to this method including, screening without appropriate follow up due to a lack of community mental health services, and concerns about confidentiality (Brown & Wissow, 2010).

Although mental health screening might help link youth to services in the community, the low rate of referral of children identified with mental health problems to mental health specialists for therapy services, emphasizes the need for psychologists and other mental health providers to become more actively involved in the primary care setting (Holden & Schuman, 1995). There is a fairly extensive literature on various models of collaboration between primary care providers and psychologists or other mental health specialists (e.g., Cannata, Ward- Zimmerman, & Hodder, 2006; James & Folen, 2005; Rosman, Perry, & Hepburn, 2005; Williams, Shore, & Foy, 2006). Models of collaboration between providers in pediatric primary care and psychology have been proposed to guide implementation of integrated care practices in this setting, and in turn increase identification of youth with mental health problems and increase rates of referral

(Black & Nabors, 2004; Riekert et al., 1999). Five models of integrated care have been discussed in the pediatric psychology literature: (a) Independent functions model; (b) Indirect consultation model; (c) Co-location model; (d) Collaborative/Integrated services model; (e) Systems approach. Each is described in greater detail below.

Independent functions model. One of the more traditional approaches to coordinated care is referral of a patient with a possible mental health issue by a primary care provider to a community mental health provider (Stancin, Perrin, & Ramirez, 2009). Ideally, the referrals might consider the family's treatment preferences and potential barriers to access. Furthermore, follow-up and coordination between providers would ideally be encouraged (Stancin et al., 2009). Benefits of this model of care include the limited time required, due to only brief communication between the two providers. This model is similar to medical consultation and therefore is most familiar to the PPCP, hence easily implemented into the primary care setting (Roberts & Wright, 1982). The model is also efficient, cost effective, and useful in most circumstances.

Alternatively, a disadvantage of this model is the limited communication and relationship between providers, which can decrease the opportunity for important dialogue and might limit discussion of treatment alternatives (Drotar, 1995). Additionally, parents may not take their children to mental health providers even though referred due to many barriers, discussed later in the paper. Collaboration is limited and communication might only happen before and after the referral. Furthermore, as stated previously, a shortage of child mental health providers has led to limited referral options and/or long waiting times for children and families in many communities (Rushton, Bruckman, & Kelleher, 2002). For example, one study found that up to 66% of families referred for on-site consultation and counseling followed through with mental health

referrals and follow-up, compared to only 2.6% of families referred for offsite counseling (Lieberman, Adalist-Estrin, Erinle, & Sloan, 2006).

Indirect consultation model. In this model, the PPCP manages a patient's assessment and treatment with a mental health provider acting as a teacher or informed colleague who provides advice and/or education for patient management (Roberts & Wright, 1982; Strosahl, 1998). Depending on the patient issue, nature of relationship between providers, and/or setting, this model might look different. Thus, instead of referring children and families to a mental health provider in the community, primary care providers deliver supportive counseling, education, and treatment within the primary care setting for mild to moderate issues. If needed for consultation on cases, mental health providers can be available in-person, by phone or by video conference (Strosahl, 1998).

Improving the primary care provider's ability to treat a child directly in this setting has been cited as an advantage to this model (Drotar, 1995). The model also allows the provider to draw upon the expertise of a mental health provider when needed. However, the primary care provider might not be able to provide long-term therapy or evidence-based treatment. In addition, many primary care providers are uncomfortable or unwilling to provide these services in their offices due to barriers such as lack of training and lack of time for providing necessary care (Pidano, Kimmelblatt, & Neace, 2011).

Co-location model. In the co-location model, primary care and mental health clinicians are physically located in the same clinical setting. Mental health providers function as independent practitioners, co-located in the primary care setting, but employed by mental health, schools or other systems (Dobmeyer, Rowan, Etherage, & Wilson, 2003; Williams et al., 2006).

This model has the potential to facilitate communication and collaborative care between primary care providers and mental health providers. One major advantage is that a possible shorter wait time for mental health services, as well as only having to go to one location, may increase child and family adherence to treatment recommendations (William et al., 2006). Despite this advantage, co-location does not guarantee collaboration or coordinate care with PPCPs, and might even encourage handing over responsibility for a patient from one provider to the other.

Collaborative/Integrated services model. Recently, a more integrated approach has been recommended that focuses attention on the physical, developmental, and emotional aspects of mental health treatment for optimal patient care (Stancin, Perrin, & Ramirez, 2009). Shared responsibility and joint decision making among providers differentiates this model from those previously discussed (Roberts, 1986; Stabler, 1979). In the *collaborative/integrated services model*, mental health providers are an integral part of a comprehensive, team-based approach to care, and share office space and medical records with the primary care providers, as well as attend regular team meetings, trainings, and collaborate about patient care (Drotar, 1995; Stancin et al., 2009;). Mental health providers work, as a team with primary care providers on an ongoing basis to address both the mental and physical health needs of youth. A mental health provider also consults in well- and sick-child visits with the primary care provider, allowing for more direct communication about child and family issues. Integrated care at this level recognizes the connection between physical and mental health in every primary care encounter (NIHCM Foundation, 2009).

A major benefit to this model is the potential to bypass the need for youth and families to go outside of the primary care setting for treatment with the ability to see patients at the same time

and even same exam room as their PPCP (Lieberman et al., 2006). In effect, allowing children and their families access to both mental and physical health services in one setting might increase satisfaction with services and treatment.

Despite the benefits, sustainability issues can arise. For example, one of the biggest barriers is the time needed to establish an effective collaborative team, as well as the cost it takes for a hospital or practice to maintain enough specialty providers for a multidisciplinary team (Drotar, 1995). Billing and reimbursement issues arise due to multiple visits in the same day and/or insurance not recognizing consultation as billable (NIHCM Foundation, 2009).

Systems approach. The models described above focus on the interactions and relationships between the mental health providers, primary care providers, and other professionals. In contrast, the systems-oriented perspective describes the impact of the broader context in which these collaborative relationships occur (Drotar, 1995; Mullins, Gillman, & Harbeck, 1992).

In this model, importance is placed on planning interventions at several different levels, while involving multiple stakeholders (Mullins et al., 1992). The systems perspective can be used to develop new and more efficient settings of care delivery and professional roles (McMenamy & Perrin, 2002). For example, this model could assist in developing a pediatric behavioral screening service in a pediatric primary care setting that addresses the relations between clinic-based and community needs. A major advantage is the involvement of multiple professionals in multiple settings, allowing for comprehensive care of patients. Drotar (1995) stated, “the systems approach to consultation has conceptual elegance and intuitive appeal and opens up opportunities for creating the type of change that can make traditional patient-centered consultation pale by comparison” (p. 22). In contrast, a major disadvantage of the systems-

oriented approach is the difficulty of implementation and coordination of system-related variables (Drotar, 1995).

In summary, many different methods and models of integrated care have been suggested and are currently being implemented ranging from distributing information to families about mental health care in primary care settings to fully integrated collaborative care between primary care providers and mental health providers (Etherage, 2005; Kolko et al., 2012; Williams et al., 2006). Depending on numerous factors (e.g., time, funding, availability of providers), different models might be preferable in different settings. There are a number of integrated care models that exist in the United States (Reynolds-Grant & Weems, 2012; Sarvet et al., 2010), two of which are described below.

Examples of integrated care programs. The *Massachusetts Child Psychiatry Access Project* (MCPAP; Sarvet et al., 2010) is a statewide program, funded by the state of Massachusetts, which utilizes six regional consultation teams to assist PPCPs in addressing the needs of children with mental health issues. The regional consultation teams consist of several child psychiatrists, one psychologist/social worker and one care coordinator. Child psychiatrists and/or psychologist provide telephone consultations with the primary care provider, as well as in-person assessments and evaluations with children and their families. The care coordinator works with children and families to find services and supports in their communities and also keeps primary care providers informed of the child's mental health care to further improve coordination of care (Sarvet et al., 2010).

The MCPAP also provides training for PPCPs on how to address mental health issues. With the training, primary care providers can address the needs of children with mild to moderate mental health issues and only need to consult the teams when an issue arises. The children with

more complicated or serious mental health issues can then be referred to mental health providers in the community (Sarvet et al., 2010). In this program, the PPCP is directly a part of the mental health system and has multiple resources at his/her disposal to ensure that children with a mental health condition receive appropriate care. Although state-funded, the developers are working on obtaining contributions from private insurers for the services provided to those families with private insurance (Sarvet et al., 2010). A complete description of this program is beyond the scope of the paper please visit the MCPAP's website (www.mcpap.com) for further information.

A similar program, *North Carolina Center of Excellence for Integrated Care*, is a statewide resource for medical and mental health providers (Dickens, 2010; Reynolds-Grant & Weems, 2012). The program is funded through a contract with the State of North Carolina, Office of Rural Health and Community Care and the Governor's Institute on Alcohol and Substance Abuse and aims to integrate medical and mental health services to provide better care and improve psychosocial outcomes. The program focuses on increasing the capacity of primary care providers to provide appropriate, evidence-based behavioral health services, and allowing mental health providers to screen and refer their patients for physical illness.

The program offers training, education, and technical assistance to primary care providers in order to assist them in integrating mental health services into their settings and also assists mental health providers with integration into the medical setting by preparing them for medical screenings and referrals to medical services (Dickens, 2010). The program also focuses on local model development as well as process and policy changes to increase integration (Reynolds-Grant & Weems, 2012). Essentially, the center acts as an intermediary to ensure strong, effective coordination and collaboration between mental health and medical providers in order to better serve children and families with mental health issues. The program has helped to reduce

wait times for referrals and appointments in primary care settings by increasing the number of mental health providers integrated into medical practice (Reynolds-Grant & Weems, 2012). For a complete description of the program, please see their website (www.icarenc.org).

The two examples described above portray models on the more integrated end of the spectrum and focus on many system-level factors that allow for coordination and collaboration throughout multiple settings throughout a state. These models of collaboration between providers in pediatric primary care and mental health care have been proposed as one way to implement integrated care practices in the primary care setting (Black & Nabors, 2004; Reikert, Stancin, Palermo, & Drotar, 1999). Unfortunately, due to many barriers and challenges with integration, many of these models are not implemented thoroughly or even at all. Barriers to integrated care are reviewed to illustrate the many challenges faced at the patient, provider, and system level.

Barriers to Integrated Care

Over the past three decades, many in the field have suggested the need for integration of mental health services and pediatric primary care to improve the accessibility and acceptability of mental health care for children and families. Despite research showing that integrated care is a good solution, as well as evidence on ways to best integrate the two fields; many barriers and challenges exist.

Similar barriers to implementation have been identified in the mental health treatment literature (e.g., Aarons, Hurlburt, & Horwitz, 2011; Proctor et al., 2009; Southam-Gerow, Rodriguez, Chorpita, & Daleiden, 2012). For example, the Mental Health Systems Ecological (MHSE) model suggests consideration of factors (e.g., child and family, therapist, organization, and service system factors) that might lead to more successful outcomes when disseminating a

treatment into a new setting (Southam-Gerow et al., 2012). In addition, in order to capture the complex nature of service settings, Schoenwald & Hoagwood's model also provides similar levels of variables to consider when developing and adapting treatments including: (1) client level factors, (2) provider level factors, (3) clinic/agency level factors, and (4) service system level factors (2001). Using a similar framework, the relevant literature on these barriers is examined focusing on: (a) patient level barriers; (b) provider level barriers; and (c) system level barriers. Consideration of these barriers to integrated care will allow for identification of potential solutions or modifications at each level in order to improve collaboration between mental health and pediatric primary care.

Patient level barriers to integration. Most children and families who seek care from a mental health specialist do so because they have recognized mental health symptoms, impairment in their daily life, or because some crisis has compelled them. In contrast, children and families seeking care from their primary care provider may not think that their visit would involve mental health issues (AAP, 2009). For example, they might be at the clinic for a well-child visit, acute care for a physical ailment, or help with a challenging behavior. It has been recommended that PPCPs discuss emotional and behavioral concerns from children and families in their visits, regardless of the reason for the appointment (AAP, 2009). However, this might not always happen due to various obstacles including lack of communication, barriers related to parent's perceptions about the nature of mental health issues, and barriers related to parent's perception about mental health services.

Burklow and colleagues (2001) surveyed parents from urban ($n = 67$) and suburban ($n = 67$) primary care settings on the impact of nine common psychosocial concerns in their children (66% Caucasian, 22% African-American) and their expectations of their PPCPs to discuss these

concerns during their medical visit. They found that overall, 87% of the parents surveyed thought their primary care providers should ask about psychosocial issues during the visit (Burklow, Vaughn, Valerius, & Schultz, 2001). However, research has also demonstrated that parents are hesitant to ask about children's emotional and behavioral issues without being prompted by the pediatric primary care provider (Sayal & Taylor, 2004; Dulcan et al., 1990) therefore creating a lack of communication between parents and provider. This barrier of parental expression of concerns and hence lack of recognition by primary care provider may contribute to psychosocial problems in children being under-diagnosed.

Another barrier described in the literature is lack of education for parents on mental health issues and services. In a qualitative study using focus groups and interviews, parents ($N = 24$; 66% Hispanic) enrolled in California's Healthy Families Program (HFP), which provides HMO-style benefits through 21 private and public health plans, stated that they needed more assistance on how to navigate the mental health system during the initial stages of contact with their health plan or provider (Cohen et al., 2012).

Furthermore, evidence has indicated that only about half of children and families referred for mental health services actually attend their first visit; with even fewer actually participating in treatment (Perrin, 1998). Reasons for this challenge, include parental perception of need for mental health services, as well as the stigma associated with receiving treatment outside of the pediatric primary care setting (Simonian, 2006; Sayal et al., 2010); these two factors are shown to affect parental decision-making when it comes to treatment for their children. Importantly, the stigma of seeking care in a pediatric primary care setting is low compared to an outside provider, therefore indicating the need for integrated care. If mental health services were co-located or integrated with pediatric primary care, it may allow for more convenient access for children and

families and increase treatment attendance. In addition, Sayal and colleagues (2010) found that parents' ability to cope with their children's issues and their awareness and knowledge about mental health problems and services are important factors in seeking help.

In addition, research with adult minority populations has shown mixed results with some studies indicating that patients are more satisfied with physicians of their same race or ethnicity, while other studies have suggested that patients who perceive personal similarity with a physician, despite race or ethnicity, is associated with higher satisfaction (Somnath, Komaromy, Koepsell, & Bindman, 1999; Street, O'Malley, Cooper, & Haidet, 2008). Furthermore, language differences have been identified as an obstacle towards integrated care by both patients and providers (Bitar et al., 2009). PPCPs and behavioral health specialists should thus be aware of potential cultural differences in their approach to engaging families in discussion about mental health problems.

Importantly, factors associated with socioeconomic status (SES) are another barrier that directly impact access to and use of mental health and primary care services (Bitar et al., 2009). Such barriers include lack of insurance coverage, high cost of treatment, and inconsistent transportation (Pidano et al., 2011).

In sum, many patient-level barriers contribute to and help explain the slow development of integrated care models that increase collaboration and communication between mental health care and pediatric primary care. These challenges include communication of parental concerns; parental perceptions of services and needs, stigma, and potentially racial/ethnic match between the patient and provider. Provider perceptions of barriers have also been identified in the literature. These obstacles might hinder the integration of mental health and pediatric primary

care, and include but are not limited to issues with time, training, level of comfort in diagnosing children with mental health issues, and lack of resources, as described below.

Provider level barriers to integration. Despite the potential for increased access of mental health services in pediatric primary care, evidence shows that youth are not often being identified in this setting, and among those who are identified, many do not receive treatment (Hartung & Lefler, 2010). Estimates indicate that PPCPs identify only about 20% of children with mental health issues and only a fraction of these children are referred for services (Simonian, 2006). For example, Rushton and colleagues (2002) conducted a large, multisite study to determine what actions primary care providers took when a new psychiatric problem was identified. Out of 4,000 patients identified, 39% received no treatment, 33% received consultation with the primary care provider, 10% were prescribed medication, and only 16% were referred to an outside mental health provider (Rushton et al., 2002). In addition, evidence indicates that parents report psychosocial concerns to PPCPs, but only 40% of the providers respond to their concerns (Sharp et al., 1992). Barriers associated with provider perceptions' of responsibility, lack of time, lack of appropriate education/training, and level of comfort with assessing and diagnosing mental health issues in children, have all been shown to contribute to the lack of identification and referral.

A primary obstacle to integration is lack of provider education and/or training that may impede proper assessment and diagnosis of mental health issues in children. Primary care providers often report inadequate training on mental health issues (Bitar et al., 2009) negatively impacting their ability to identify and diagnose psychological disorders, and also limiting their use of formal screening instruments (Gardner et al., 2003; Sand et al., 2005; Simonian, 2006). Many of these screening instruments, along with their psychometric properties are discussed in

research journals that PPCPs may not regularly review (Simonian, 2006). In addition, research has shown that even when PPCPs do screen, they tend to use the screening data to make decisions for medication treatment, rather than for mental health treatment (Simonian, 2006).

Level of comfort with assessing and diagnosing emotional and behavioral issues is another obstacle related to lack of provider education/ and or training (Pidano et al., 2011). Lack of advanced training on child development and behavior has been shown to contribute to a lack of confidence in assessing and managing these issues in children (Bitar et al., 2009; Horwitz et al., 2007; Pidano et al., 2011). For example, Pidano and colleagues (2011) conducted a survey of 48 PPCPs focusing on their comfort levels in diagnosing and treating patients with mental health disorders, the actions they would take based on assessment outcome, as well as perceptions of barriers to services, awareness of mental health resources in their communities, and interest in collaborating with mental health providers. Results suggested that providers were significantly more comfortable with assessment than treatment for all disorders except Attention Deficit Hyperactivity Disorder (ADHD) and learning disorders. The highest levels of comfort were found for ADHD, and the lowest levels for bipolar disorder, psychosis, and Posttraumatic Stress Disorder (PTSD) (Pidano et al., 2011).

Lack of education and/or training has also been found to be a barrier for mental health providers. Psychologists' unfamiliarity with the primary care practice model, especially in the private practice setting, has been shown to impede integration into primary care settings (Evers-Szostak, 1997). Mental health providers must take the time to learn about and adapt their practice to the primary care setting in which they may work in order to effectively at build collaborative relationships and ultimately be seen as part of an integrated team (Schroeder, 1996).

Furthermore, primary care provider perceptions' of responsibility might also be related to lack of training and/or education. For example, a survey study found that more than 80% of providers viewed themselves as responsible for identifying such issues as ADHD, eating disorders, depression, substance abuse, behavior problems, and hostile parenting (Stein et al., 2008). However, except in the case of ADHD, the providers tended to view their role as making referrals for treatment rather than treating and managing patients themselves (Stein et al., 2008). In summary, providers will do what they are comfortable with or conduct services as they see appropriate for their role. Increased education about mental health screening and treatment may help providers feel more comfortable in this position.

Another finding from Pidano and colleagues (2011) was that although 85% of primary care providers agreed that they would like to collaborate with a mental health provider, only 60% stated they would like to have a mental health provider onsite. Interestingly, providers also reported that their most significant barrier to services was access to mental health providers in the community, with almost 40% of providers indicating at least a two-month wait for services, and another 40% reporting a 3 to 6 month wait (Pidano et al., 2011).

Another barrier that has been identified in the literature is that many PPCPs do not ask their patients about mental health issues (Brown et al., 2007). As stated earlier, most parents of children feel that their pediatrician should ask about these issues and might not bring them up unless a provider asks. Ethical reasons have been provided as a rationale for why physicians do not initiate these conversations. Research has demonstrated that pediatricians' reluctance to identify children's behavior problems may be due to concerns about labeling children, and therefore creating a self-fulfilling prophecy (Gyllenberg et al., 2010). Providers also might not screen or ask about psychosocial issues because of the belief of limited access to appropriate

mental health resources. For example, pediatricians have indicated that once children have been screened, there might not be anyone in the community they could refer a family to for services and therefore they have identified a problem but have no solution (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). Another ethical issue relates to concerns over the appropriate course of action if providers identify a patient with a sub-clinical mental health problem. Specifically, there are few guidelines to help predict which of these patients will progress to the development of a diagnosable clinical disorder or to determine what type of intervention to administer (Brown & Wissow, 2010). The identification of children with moderate levels of symptoms could further burden PPCPs and may discourage screening practices overall.

Other barriers that providers report as obstacles to integration of care are lack of time and space. PPCPs have concerns about how screening will affect their practice due to feeling already at capacity and adding more providers would not help the situation (Simonian, 2006). Mental health services could increase the length of pediatric visits and be a source of burden for providers (Cooper et al., 2006). Pediatric primary care visits, on average, take about 10 to 15 minutes, leaving limited time for discussion and identification of psychosocial issues with a provider (Sices et al., 2003; Stancin & Palermo, 1997). Time constraints limit the opportunity for PPCPs to systematically address psychosocial concerns. For example, a recent study examined pediatricians' responses to behavioral health concerns raised in the context of rural primary care visits with a particular focus on time spent (Cooper et al., 2006). Patient visits in two rural pediatrician offices were observed. Length of visit, raised concerns, and provider responses were recorded. Results indicated that either the parent or provider raised behavioral and emotional issues in approximately 27% of all observed primary care visits. About 9% of all visits were identified as a mental health visit prior to the appointment, and these previously

identified visits lasted about 7 minutes longer than visits for non-mental health issues.

Additionally, mental health concerns were raised during approximately 18% of visits that were not originally identified as a mental health visit. In these situations, visit length significantly increased by about 5 minutes on average. This evidence demonstrates the impact of mental health concerns on provider's time.

In addition, research has found that pediatricians who reported increased burden in treating psychosocial problems were less likely to identify children who demonstrated mental health symptoms on a screening measure, even after accounting for what was discussed during the visit (Brown et al., 2007). This evidence suggests that even a slight increase in burden negatively impacts the primary care provider's ability to identify problems.

Overall, many provider-level barriers negatively impact the integration of mental health care and pediatric primary care. System-level barriers have also been identified, which hinder the integration of mental health and pediatric primary care on a broader level, and include issues with provider education and/or training, reimbursement of services and policy issues.

System level barriers to integration. System level variables that influence practice patterns related to identification and management of mental health disorders have also been cited as barriers to increased identification and integration. For example, although PPCPs report positive attitudes toward mental illness prevention for their patients, they perceive significant financial and educational barriers to implementing such activities (Stancin & Palermo, 1997). There is also a shortage of mental health providers and management and organizational issues as significant barriers to collaborated care. The NIHCM Foundation (2009) stated “the significant undersupply of mental health professionals trained to serve children; policy, training and other barriers that limit primary care providers' abilities to provide these services; and the inadequate

financing of mental health services” all serve as barriers to the integration of mental health in primary care.

A critical barrier identified is a shortage of pediatric mental health providers, especially in rural areas (Bitar et al., 2009; Pidano et al., 2011). A shortage of providers means that demand for mental health services quickly overwhelms the ability for the providers to accept referrals and/or consult with PPCPs. As described earlier, this shortage also affects assessment and diagnostic practices of PPCPs and might limit their treatment and referral options. As a result, providers and families face longer wait times for services for their children or may not have an option for these services at all (Bitar et al., 2009).

As noted, many PPCPs report feeling inadequately prepared to handle mental health issues and evidence suggests that providers who feel they do not have the training to handle these issues might avoid addressing them altogether (Cheng, DeWitt, Savageau, & O'Connor, 2003). Stein and colleagues (2008) found that only 28.3% of primary care providers, who responded to a survey about medical education, had completed a fellowship in a child mental health-associated area. Further, over 70% of physicians surveyed indicated not having enough knowledge and support to detect and manage mental health problems in children (Cawthorpe, 2005). In addition, many providers are unfamiliar with the wide range of services (e.g., diagnostic, evaluative, educational, assessment, and therapeutic) that mental health providers can provide to their pediatric patients and their families (Brown & Wissow, 2010), hence underutilizing important resources. Increasing provider training and education can help to improve provider confidence and competence in treating mental health issues in children.

Management and organization issues have also been cited as potential barriers towards integration of care. In a focus group study, providers expressed concern related to planning and

implementing mental health into their primary care offices particularly as it related to communicating how changes are to be implemented (Bitar et al., 2009). Providers also felt that at times decisions were made without everyone's approval and that important mandates that affected their practice were often made using a "top down" approach.

The level of insurance coverage and affordability of children's mental health services is a major barrier to the identification of mental health issues. Drotar (2012) stated, "one of the most critical influences on the growth of behavioral screening in primary care involves reimbursement for clinical services" (p.479). Inadequate reimbursement for mental health treatment and the lack of funding for integrated care initiatives make it extremely difficult for pediatric primary care and mental health providers to provide these services for children and families (Pidano et al., 2011; Williams, Shore, Foy, 2006). Indeed, statutes exist that make it illegal in some states for psychologists to partner with physicians, almost making it impossible for integration to happen at all (Drotar, 2012). Many insurers, both private and public, do not provide reimbursement for collaborative or integrative care and mental health benefits are often "carved out," meaning that primary care providers are excluded from the network of providers who can provide and bill for mental health services (Mauch, Kautz, & Smith, 2008). This creates a disincentive for mental health screening and assessments as part of the primary care visit. Organizational rules in managed care systems also may limit the ability of pediatricians to successfully refer patients for specialty mental health care (Cartland & Yudkowsky, 1992).

One way that insurance companies have tried to improve reimbursement issues and acknowledge the importance of integration is by bringing behavioral health management into their own provider networks (NIHCM Foundation, 2009). Despite this change, many individual programs or states choose to not participate. For example, while Medicaid Early Periodic

Screening, Diagnostic, and Treatment (EPSDT) provisions require that all children are regularly screened and tested to identify any conditions requiring treatment, including mental, emotional and cognitive developmental delays, state Medicaid programs vary widely and only 60% of Medicaid programs reimburse for screening and assessment (NIHCM Foundation, 2009).

Reimbursement of mental health services by mental health professionals within the primary care setting is also a challenge. Third party payers often will not reimburse for these services within primary care settings (Clay & Stern, 2005). In some cases pediatricians are reimbursed for providing mental health services, whereas licensed psychologists are not reimbursed. Similarly, time spent communicating with providers in the primary care setting and other necessary professionals is nearly always exempt from reimbursement yet it is essential for optimal service provision (NIHCM Foundation, 2009). In addition, even when integrated care initiatives are initially funded by a state or grant funds and are successful, the end of the external funding period usually brings about the termination of the integrated care practice (Williams et al., 2006). In summary, these system-level barriers contribute to segmentation of services. Segmentation in the system and the subsequent failure in communication mean successful integration initiatives are not implemented leading to no standardization of care across collaborative models.

Overall, there are a number of factors complicating the move toward integration of mental health care into pediatric primary care settings and solutions to these challenges need to be identified. Collaborative care models are one solution that has been proposed, but they also bring with them certain challenges. Identification of barriers is the first step in this process and allows researchers and providers to identify levels for change that will enhance communication and collaboration between mental health and pediatric primary care and in turn, increase access

to these services for children and families. Each primary care setting will have its own unique barriers toward integration. Collaborating with relevant stakeholders in these individual settings may help facilitate integration of care by identifying specific barriers and facilitators to including mental health services in pediatric primary care. The current study was designed to identify needs for mental health care in a pediatric primary care clinic, as well as identify barriers and facilitators to providing this care.

Stakeholder Involvement in Integrated Care Development

One way of identifying the needs for mental health care in a pediatric primary care setting, as well as the barriers and facilitators to providing this care, is through the involvement of stakeholders in the collaboration process. Models emphasizing collaborative relationships between researchers and community stakeholders have been in use for many years in fields such as education (e.g., Adelman & Taylor, 2004) and public health (e.g., Sullivan & Kelly, 2001); more recently, mental health researchers have begun to use partnership models to disseminate evidence-based treatments (Gotham, 2004; Hoagwood, Burns, & Weisz, 2002).

The guiding models underlying the current study are derived from dissemination and implementation science (e.g., Aarons, Hurlburt, & Horwitz, 2011; Proctor et al., 2009; Schoenwald & Hoagwood, 2001; Southam-Gerow, et al., 2012). In order to capture the complex nature of these settings, the framework in Figure 1 provides levels of variables (adapted from the MHSE and Schoenwald & Hoagwood models) to consider when developing and adapting treatments; these levels include: (1) patient and family factors, (2) provider level factors, (3) clinic/agency level factors, and (4) service system level factors. The variables highlighted in the framework might potentially impact dissemination of any innovation in a service system.

Due to the importance of these patient, provider, agency, and service system factors, research endeavors that hope to create lasting change within a care system are wise to include stakeholders such as patients, families, and providers early in the process (Hoagwood, Burns, & Weisz, 2002; Weisz, Southam-Gerow, Gordis, & Connor-Smith, 2003). It is possible that by increasing the level of involvement of the relevant stakeholders in all aspects of the collaboration process, commitment to the resulting “innovation” or in this case integration of services between primary care and mental health will be enhanced; further strengthening the possibility that changes will endure beyond the term of the initial research project. Community stakeholder involvement is a key element in this framework, and our study aims to make this an important focus in the identification of mental health needs in a pediatric primary care setting. This framework will help identify barriers and facilitators to providing mental health care in this setting and will assist in future development of programs to address these needs.

Stakeholders in the pediatric primary care setting include families; providers (e.g., pediatric residents, nurses); training faculty; clinic directors; other employees of the clinic (support staff); hospital administrators; local, state, and federal policymakers; and payer organizations, including insurance companies and government programs (e.g., Medicare). The literature on involving these multiple stakeholders in studying mental health in pediatric primary care is sparse.

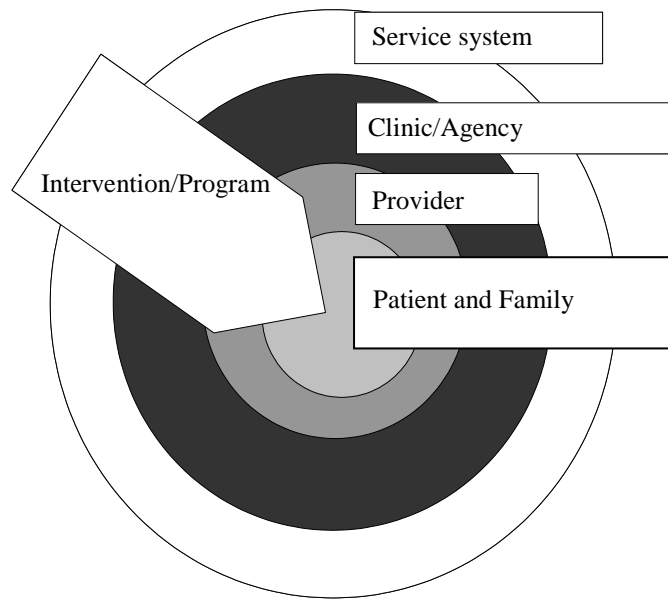


Figure 1. Ecological Framework for Program Implementation.

Such gaps can be addressed in part by engaging in qualitative methods, for reasons described below. The present study represents a second phase of a project designed to examine mental health problems among children and adolescents in a pediatric primary care clinic. The first phase of the study identified the level of a variety of behavioral health problems in children in this pediatric primary care setting. This second phase, through qualitative methods, sought to (a) identify needs for behavioral health care in this pediatric primary care setting, and (b) identify barriers and facilitators to providing that care.

Qualitative Methodological Approach

Through the use of qualitative methods, the study provides data on the perceptions of a wide range of stakeholders in the pediatric primary care setting concerning behavioral and mental health needs and care. Qualitative methods can be useful in a research area where the literature is limited or stagnated (Creswell, 2013) and/or in community-based research projects when involvement and engagement of multiple stakeholders is a goal (Creswell, 2013). Benefits of using qualitative research are that it allows the researcher to understand various factors

involved in both a pediatric primary care and mental health care system by integrating the perspectives of these stakeholders in a cohesive way (Schoenwald & Hoagwood, 2001). Focus groups and interviews lend themselves to the accumulation and integration of perspectives of the various stakeholders in a pediatric primary care setting. Understanding stakeholder perceptions about mental health services may provide a meaningful picture of what is working, what is not, what is confusing, and what is important (Richter, Bottenberg, & Roberto, 1999).

A second benefit of using qualitative research for this study is the paucity of research related to the involvement of stakeholders in studying mental health in pediatric primary care (Bitar et al., 2009; Sayal et al., 2010). Although there is some research on stakeholder attitudes, primarily of providers (e.g., Bitar et al., 2009; Pidano et al., 2011), toward mental health care in pediatric primary care settings, we have yet to understand how best to incorporate these perspectives and attitudes to best address integration of services. Qualitative methods, given their emphasis on understanding and integrating multiple perspectives, represent a strong choice for an under-researched area.

Qualitative research includes a variety of methods such as interviews, observation, and reviews of written documents (for review, see Patton, 2002). In the current study, the qualitative research method chosen was interviews/focus groups. Interviews are a method for collecting in-depth information directly from participants about their perceptions, experiences, concerns, or knowledge (Patton, 2002). Interviews can occur in person or from afar by telephone or other technology (e.g., Skype). In addition, interviews can be conducted individually or in focus groups.

The focus group is a research technique in which guided interactional discussion is employed as a means of generating rich experiential information (Krueger & Casey, 2000). This

method can either identify potential areas of inquiry or help clarify others. The *focus* component of the interaction can be anything that engages the group in collective activity (e.g., discussing a particular issue) (Powell, Single, & Lloyd, 1996). Krueger and Casey (2000) recommend maintaining homogeneity of stakeholder types in one focus group. For example, if the purpose of a study is to obtain information on how doctors' and nurses' opinions differ or are similar on a particular issue, it is best to keep nurses and doctors in separate focus groups. They recommend the separation for two reasons. First, it is easier to compare and contrast across groups if there data were collected independently. And second, the homogeneity of the groups might create a more comfortable environment for participants, as stakeholder types differ in terms of expertise, power, and roles. Focus groups explicitly emphasize the expertise of the stakeholders and downplay that of the researchers. The non-directive nature of the focus group allows participants the opportunity to discuss concerns, disagreements, or to explain their perspectives, enabling the researchers to investigate topics in depth by moderating the discussion as participants explore the issues.

Individual interviews are more private in nature than focus groups and therefore might encourage an individual stakeholder to share more openly (Creswell, 2013; Charmaz, 2006). According to guidelines by Krueger and Casey (2000), if there is reason to believe that an individual's inclusion in a focus group would have negative effects, it is best to give that individual a separate interview. Both methods allow for the use of similar topics/questions with stakeholders and are valuable in obtaining in-depth information.

In the present study, three broad categories of questions were addressed. First, stakeholders offered their perceptions about the types of problems that are typically seen in pediatric primary care and how those problems are currently managed. Second, the stakeholders

discussed their perceptions about how they would ideally like to see those mental health problems handled. Third, stakeholder perceptions about barriers and facilitators of improving how mental health problems are managed in the primary care setting were addressed. The findings serve as a preliminary needs assessment to guide an investigation that will involve augmentation of usual care to address behavioral and mental health problems in the pediatric primary care setting.

A needs assessment is part of a systematic process for determining and addressing needs or "gaps" between current conditions and desired conditions (Kaufman, 1992, 1994; Watkins, Leigh, Platt, & Kaufman, 1998). In this case, integrating behavioral and mental health care into a pediatric primary care setting. A needs assessment is used as part of a planning process in order to improve education/training, organizations, and/or communities and can be an effective tool to clarify problems and identify appropriate interventions or solutions. By clearly identifying the potential barriers and facilitators, resources can be directed towards developing and implementing a feasible and applicable solution, and gathering appropriate and sufficient data informs the process of developing an effective solution that will address the needs and wants of relevant stakeholders (Watkins et al., 1998).

Grounded theory approach. In the current study, instead of using *a priori* themes to code the data as suggested in the original study proposal (e.g., Charmaz, 2006; Creswell, 2013), a grounded theory methodological approach was used (Charmaz, 2006; Glaser & Strauss, 1967). Grounded theory was chosen for this study because of the lack of knowledge regarding the specific behavioral and mental health needs of the relevant stakeholders in this pediatric primary care setting.

Grounded theory is a qualitative research method that enables a “researcher to generate systematically” a theory or framework grounded in empirical data (Walker & Myrick, 2006). This method, with its roots in sociological research, combines the depth and richness of qualitative research, with the rigor and systematic analysis of quantitative survey research (Charmaz, 2006; Glaser & Strauss, 1967). As opposed to developing a theory and then systematically seeking out evidence to verify it, another common approach in quantitative research methods, researchers using grounded theory methods set out to gather data and then systematically develop a theory or framework directly from the data (Walter & Myrick, 2006). In other words, the framework is “grounded” in the data produced in the study.

To achieve theoretical sensitivity using this method, the researcher must begin with as few predetermined ideas, particularly hypotheses, as possible so he or she can be sensitive to the data (Glaser, 1978). This does not mean, however, that the researcher must start as a “tabula rasa.” Instead, s/he must use prior knowledge in a specific way (Dey, 1999). An initial literature review is used to inform a researcher’s analysis rather than direct it; the literature is used as “data” that is constantly compared with the emerging categories from the data. The literature can also be used to justify the study and a subsequent literature review is usually done *after* categories have emerged in the data (Glaser, 1992).

Glaser (1978) discusses three criteria for rigor in a grounded theory approach. The first is *fit and relevance*, which is how well the categories relate to the data and how they are derived from constant comparison and conceptualization of data. The second criterion is *workability*, or the ability to integrate the categories into core categories that emerge. Finally, Glaser highlights the importance of *modifiability*, or ensuring that all the concepts important to the theory are incorporated into it by the constant comparison method. For example, a modifiable framework

can be altered when new, relevant data is compared to existing data. Methodological rigor can also be obtained in more traditional ways, such using a second coder and/or use of coding memos (described later; see Charmaz, 1995).

Qualitative coding, the process of defining what the data are about, is the first analytic step (Charmaz, 2006). Coding is when a researcher names segments of data with a label that simultaneously categorizes each piece of data (Bowker & Star, 1999), and “is the first step in moving beyond concrete statements in the data to making analytic interpretations” (Charmaz, 2006). In other words, the researcher raises the conceptual level of the analysis from description to a more abstract, theoretical level. The researcher then tries to define the properties of the category (e.g., conditions under which it operates and/or changes, relation to other categories), and the most significant theoretical categories are then made into the concepts of their theory or framework (Charmaz, 2006).

Glaser (1978) and Charmaz (1995) identify a two-step coding process in data analysis: 1) substantive coding and 2) selective coding. Substantive coding is the initial, line-by-line, process of generating initial concepts from the data. Selective coding conceptualizes how the substantive codes may relate to each other as hypothesis to be integrated into a theory or framework (Glaser, 1972, 1978). According to Charmaz (2006):

During initial coding [i.e., substantive], the goal is to remain open to all possible theoretical directions indicated by your readings of the data. Later, you use focused [i.e., selective] coding to pinpoint and develop the most salient categories in large batches of data. Theoretical integration begins with focused coding and proceeds through all your subsequent analytic steps (p.46).

When using a grounded theory approach, an important process used throughout coding is called the *constant comparative method* (Glaser, 1978). *Constant comparative methods* are used for coding and involve the researcher continually asking her/himself: a) “What is happening in the

data?” (b) “Under what conditions is it happening?” (c) “What is this data a study of? and (d) “What category does this incident indicate?” (Glaser, 1978). Through the use of *constant comparative methods*, a researcher makes analytic distinctions by making comparisons at each level of analysis (Charmaz, 2006). Essentially, the researcher begins analysis with the initial data collected and “constantly compares” concepts and categories as the framework emerges.

Memo writing is the intermediate step between coding and the first draft of the completed study (Charmaz, 1995). In a memo, hypotheses and ideas are recorded during analysis.

Charmaz states, “When you write memos, you stop and analyze your ideas about the codes in any—and every—way that occurs to you during the moment” (p.72). These ideas are not treated as complete and fixed, as they are initial analytic thoughts and can be altered as thinking changes (Charmaz, 1995). Memo writing records the development of the codes into categories (collections of codes of similar content), categories into core categories (broad groups of similar categories that are used to generate theory), and the emerging theoretical framework (Glaser, 1978). According to Glaser (1978), “the generation of theory occurs around a *core* category. Without a core category an effort of grounded theory will drift in relevancy and workability” (p.93). The core category accounts for most of the variation in the data and therefore other categories relate to it in some way. Memo writing also permits peer review of the study, often used as an added step of rigor (and sometimes called auditing, see Bowen, 2009). In quantitative research, the results of analyses come in the form of test statistics and beta weights, for example. In a qualitative study using a grounded theory approach, the results of the analytic work are a set of probability statements about the relationship between concepts, or an integrated set of conceptual hypotheses developed from the empirical data (Glaser, 1998).

Method

Overview

Data for this study were drawn from a larger research project, the Pediatric Anxiety and Depression Screening (PEDS) study. PEDS was a research partnership involving researchers in the psychology department and several stakeholders associated with the pediatric primary care and adolescent medicine resident training clinics at an urban academic medical center in a large metropolitan area in the Mid-Atlantic region of the United States. The clinics serve a population of largely African-American families on Medicaid. In this research, stakeholders were defined as people who play a role in the pediatric primary care clinic either as patient or provider, are interested in the results of the project, and/or have a stake in what will be done with the results of the project. Representing their needs and interests throughout the process is fundamental to good program evaluation. The first phase of the project consisted of a screening study designed to examine the frequency of anxiety, depression, and disruptive behavior disorder symptoms in this clinic (Hourigan, Southam-Gerow, & Quinoy, 2013). The present study involved both focus group and individual interviews conducted between 2008 and 2009 with various stakeholder groups: (a) patients of the primary care clinic, (b) parents of child patients, (c) pediatric medical residents, (d) pediatric nurses, (e) pediatric training faculty, and (f) pediatric clinic directors. All participants received a \$25 gift card for their participation, and snacks and beverages were provided at the focus group/interviews. Recruitment procedures and questioning route used in the focus groups and individual interviews differed slightly across stakeholder groups and are described in detail below. This study received Institutional Review Board approval by Virginia Commonwealth University.

Participants

Participants were from several different stakeholder categories: patients, parents, pediatric residents, pediatric nurses, pediatric training faculty, and clinic directors. Of note, a nonprobability, convenience sample was used in order to allow for anyone directly involved in the pediatric primary care clinic to participate. The sample is also broad rather than deep, representing many different types of stakeholders.

Patients. Patient participants were English-speaking adolescents, ages 14 to 17, who were currently receiving care at the primary care clinic. A total of two adolescents (one female, one male) participated. Although the original plan was to hold a focus group with patients, due to the small sample size, individual interviews were conducted instead. Both adolescents were 14 years old and identified as African-American. The female patient was in the 8th grade and the male patient was in the 9th grade. Patient participants were children of two of the parent participants and were interviewed at the same time, but in different rooms as the parents. One patient family indicated annual income of \$0 and the other patient family indicated annual income of \$25,000.

Parents. Parent participants were English-speaking and caregivers of children ages 6 to 17 who were currently receiving health services at the pediatric or adolescent medicine clinics at the primary care clinic. A total of seven female parents, mean age 41.57 years ($SD = 9.98$) participated. The average age of the parent participants' children was 12.86 years ($SD = 2.56$). In total, two focus groups consisting of two parents each and three individual interviews were conducted. Although not an ideal number of participants for focus groups, this was limited to when parents could attend meetings. Instead of using an interview format for these participants, a focus group was used in order to gain multiple perspectives in an interactive group setting (Basch, 1987). One of the main benefits of this form of information gathering is the dynamic that

is created when one participant's comment feeds of another comment and so on creating brainstorming and allowing for a more in depth discussion on issues (Basch, 1987). All parent participants identified as African-American and four reported being single/never married, one separated, one divorced, and one as married. Additionally, most caregivers reported having received a high school diploma and/or Associates degree with annual income ranging from no income to \$25,000 ($M = 4,805.14$, $SD = 9,278.50$).

Pediatric nurses. All pediatric nurses in both the pediatric and adolescent medicine clinics were eligible for participation. A total of four out of a possible six nurses participated, including the nurse manager. To minimize the potential concern for a participating nurse feeling constrained because her/his supervisor was in the same group, no focus group or interview included a participant who was directly supervised by another participant. Thus, the nurse manager was interviewed individually. Two nurses identified as Caucasian (including the nurse manager) and the remaining two nurses identified as African-American ($n = 1$) or other ($n = 1$). Three of the nurses (including the nurse manager) had their Bachelor's degree in nursing and one had an Associate's degree in nursing. All of the pediatric nurses were female (age $M = 46.25$ years, $SD = 13.05$) and years of experience ranged from 5 to 29 years.

Pediatric residents. All pediatric residents were eligible for the study and a total of 16 (out of 64) pediatric medical residents participated. The two chief residents were asked to participate, but were not able to due to their schedules. In total, three focus groups and two individual interviews were conducted. Half of the residents identified as Caucasian, with one resident self-identifying as Asian, two as Middle Eastern, one as African/American, and two as Hispanic/Latino. Additionally, most residents were female (62.5%). Average age of the pediatric residents was 30 ($SD = 2.94$) with an average of 2.57 ($SD = 1.51$) years of experience.

Pediatric training faculty. Seven faculty members, the two clinic directors, and the two chief residents comprise the training faculty. A total of five faculty members participated in individual interviews¹. Although the original plan was to hold a focus group with the training faculty, due to scheduling conflicts, individual interviews were conducted. Training faculty participants included three males and two females with the majority Caucasian (75%) and one faculty identifying as Asian Indian. Average age of the pediatric training faculty was 50.20 years ($SD = 15.89$) with average years of experience of 25.40 ($SD = 15.60$).

Clinic directors. Both clinic directors participated in individual interviews. The clinic directors were both Caucasian, male, and averaged 36.50 ($SD = 4.95$) years of experience. Average age of the clinic directors was 61.00 years ($SD = 4.24$).

Procedures

Patient recruitment. Patient participants were recruited from the waiting room of the pediatric primary care clinic through informational flyers that were provided by project staff actively recruiting in waiting room and/or through flyers placed in waiting room tables and check-in station (see Appendix A for patient recruitment flyer). The patients then had the option of either (a) providing contact information for project staff to follow up with them or (b) contacting project staff at a later time to receive further information. These two options were provided due to project staff not always being in waiting room, and allowing patients and parents more time to think about participation before contacting staff. The follow up contact was always with the parent of the patient, as well as with the patient, because of the need for parental consent. At the time of the contact, staff discussed the study with the patient and the parent and

¹ Throughout focus groups, stakeholders discussed a developmental pediatrician as a key member and faculty attending of the pediatric primary care context (e.g., regular consultation, precepted patients) so the research team invited this provider to participate in the study. Inclusion is in agreement with the grounded theory principle of seeing what evolves from the data.

signed interested patients up for one of the focus groups, as well as provided the participant with phone numbers and directions to the focus group/interview location.

Parent recruitment. Parents were recruited in the same manner as the patients (i.e. via informational flyers posted in the pediatric primary care clinic waiting room). See Appendix A for parent recruitment flyer. In addition, parents who had participated in the first screening phase of the study were contacted according to guidelines outlined in the registry protocol of the IRB-approved protocol for the first phase (IRB # 6156). Only participants in the screening study who provided written permission to be contacted for future research purposes were contacted. Staff trained by the principal investigator, Michael A. Southam-Gerow, Ph.D., contacted the former participants about the opportunity.

Pediatric nurse recruitment. The research team attended several staff meetings to provide information about the study to the pediatric nurses (see Appendix B for study information script for staff). Interested nurses were asked to either (a) sign up for a focus group at the meeting or (b) contact the research team at a later date to arrange participation.

Pediatric resident recruitment. Pediatric residents were invited to participate in the focus groups/interviews through the same steps detailed above for the pediatric nurses (see Appendix B for study information script for staff).

Pediatric training faculty recruitment. Training faculty participants were recruited via the same method as the pediatric nurses and residents (see Appendix B for study information script for staff).

Clinic director recruitment. All clinic directors were recruited to participate in interviews directly by the principal investigator, through an invitation mailed to their attention at the pediatric offices and/or sent via email (see Appendix B for invitation letter). Directors

indicated their interest in participation by replying via phone or e-mail to the principal investigator.

Interviews/Focus groups. All participants completed an informed consent process at the time of the focus group/interview. Children also participated in an assent procedure at the same time as the parent consent procedure. Before beginning focus groups and individual interviews, all participants completed demographic information forms.

The principal investigator and three advanced clinical psychology doctoral students conducted the focus groups and individual interviews. The principal investigator conducted the two individual interviews of the clinic directors, and either the principal investigator or an advanced clinical psychology student, depending on schedule, conducted the other groups/interviews. Interviews and groups lasted approximately 45 to 90 minutes.

Questioning route. The study was introduced to all participants as a way of understanding how pediatric primary care clinics may better identify and help treat the behavioral and mental health needs of children and their families. Although the questioning route differed slightly for each stakeholder group due to differing perspective and roles in clinic, the main areas covered for all groups aimed to assess participants' experiences and perceptions on (a) identification and management of behavioral and mental health problems, (b) barriers and limitations to the identification and management of behavioral and mental health problems, (c) mental health services they would like to see in pediatric primary care clinics, (d) training/education on behavioral and mental health problems, (e) facilitators of managing mental health problems in pediatric primary care, and (f) what else the research team should know about behavioral and mental health problems in this setting (see Appendix C for complete description

of stakeholder questioning routes). Interviewers were also encouraged to adapt the approach to follow a line of questioning or gain further insight/clarification from a participant.

Recordings to transcriptions. All interviews were audiotaped using an Olympus OM-3 recorder. An advanced clinical psychology graduate student transcribed the audiotaped sessions, after which a senior undergraduate research assistant transcribed the recordings again. An advanced clinical psychology graduate student then checked the transcripts against the recordings to verify accuracy of content. All interview transcripts were labeled with pseudonyms to ensure confidentiality of participants.

Data Analysis

Overview. As discussed earlier, one way to differentiate approaches to qualitative data analysis would be to clarify whether the investigator plans to (a) rely on knowledge from past work when organizing new data or to (b) allow the themes to emerge from the new data. In this project, the latter approach was used, by using the basic principles of grounded theory data analysis (Charmaz, 2006; Glaser & Strauss, 1967). Overall, data analysis involved data reduction, unitization, and then coding by two coders.

Data handling and coding plan. Coders consisted of an advanced post-baccalaureate research assistant and myself, a clinical psychology doctoral student (A.Q.). Initially, irrelevant noise (e.g., “ums” and “ahs”), participant names, questions from focus group moderators, and the introduction speech by research moderators were removed from transcripts. After data were cleaned, both coders unitized the transcripts. Unitizing is a process of coding data into units that allow the precise description of information-bearing units for identification in further analysis (Rodwell, 1998). The unit of analysis can be as short as a word or as long as several paragraphs, but each must stand alone as one complete idea or thought (Rodwell, 1998). The unitization

phase of data involved both coders dividing the transcripts into many individual units of data, each comprising a single thought or idea. For this study, unitization occurred at the paragraph level of analysis in order to represent complete thought units. Coders unitized one transcript independently and met to reach consensus. Subsequently, the remaining transcripts were independently unitized and both coders then met again to reach consensus. After data were unitized, the team coded the interviews independently using grounded theory methodology, looking for categories and themes arising from the data. Originally, the plan was for coders to meet after each step of coding to compare and refine coding categories and schemes, and for each coder to code each stakeholder group transcript. Due to one coder leaving for her own graduate training, only half of stakeholder transcripts could be coded by both coders. To ensure consistency, the second coder analyzed at least one transcript from each stakeholder group. Additionally, to establish credibility to increase the likelihood that the findings and interpretations accurately reflected the data, the second coder remained available for meetings to discuss emerging themes in the data. Additionally, colleagues knowledgeable about the topic and methodology (i.e., psychologists working in an academic medical center pediatric primary care clinic) reviewed and discussed themes with me throughout the coding process and results writing process.

The coding approach was developed using grounded theory methodology in which the analysis strategy is driven by the data collected (Denzin & Lincoln, 1994). Since no *a priori* hypothesis or categories are being used, each researcher looked for categories and themes that arose from the data. Although the grounded theory approach usually calls for further exploration and clarification of themes in subsequent focus groups in order to reach theoretical saturation, we were not able to administer a second round of interviews because the data are archival. Therefore

theoretical saturation of the data was not achieved. Theoretical saturation is when a researcher reaches the point where no new information is obtained from further data collection and all concepts in the theory are well developed, thus no additional data are needed (Glaser, 1978). Ideally, the process of constant comparison would continue until no new concepts or themes emerged. However, since we were able to collect multiple focus groups and individual interviews from different stakeholders, both coders further explored, compared, and clarified themes between each interview.

Coding followed a two-step process: 1) substantive coding and 2) selective coding. Substantive coding consisted of initial, line-by-line coding where initial concepts were generated from the data. This initial phase of coding produced hundreds of concepts at varying levels of support. Microanalysis (i.e., detailed coding around a concept) was used during coding to ensure that no important ideas or constructs were overlooked. Codes were created for each new idea and theme and codes found to be conceptually similar in nature or related in meaning were grouped together as concepts. Codes were collapsed or removed if they were determined to be conceptually identical or broken into separate codes if distinctions among them became apparent. The themes were developed through constant comparison and memo writing, with the most relevant themes integrated into categories.

All data were initially coded on an Excel spreadsheet by both coders. Once data were ready for analysis, they were uploaded into ATLAS.ti for Mac, a computer software program for qualitative data. ATLAS.ti allows for “tagging” of codes directly from transcript documents. The primary coder (A.Q.) tagged all codes and a predoctoral pediatric psychology intern then assessed codes for accuracy in ATLAS.ti as a secondary data check,. In the final step, the Code Cooccurrence Table in ATLAS.ti was used to explore frequency data and explore relationships

between themes. Frequency data was then uploaded into quantitative data analysis computer software, IBM SPSS Statistics for Macintosh, Version 22 (SPSS; 2013)

Demographic data were also available for each participant. The majority of data were complete, with the exception of four income data points. Demographic data for these participants were entered into SPSS and missing data points were flagged as discrete missing values with a numerical value of 99. These demographic data are presented in the Methods section.

Results

Overview

This focus group interview study involved an analysis of qualitative data related to understanding how pediatric primary care clinics might better identify and help treat the behavioral and mental health needs of children and their families. Results are presented here as follows: (a) frequencies for the qualitative codes, and (b) description of core categories and categories using the voices of the stakeholders.

Theme Frequencies

This section presents the results of frequencies made among stakeholder groups about the barriers (i.e., patient-level, provider-level, system-level), behavioral health needs, facilitators, and consequences to barriers that were found in the stakeholder transcripts through the grounded theory approach. Since a goal of this study is to assess and understand how pediatric primary care clinics may better identify and help treat the behavioral and mental health needs of children and their families, I have retained all relevant themes for analysis and discussion despite low frequency counts for some themes and subthemes (e.g., quick fix). The aim of the following section is to provide the reader with frequencies for each code according to stakeholder group.

Overall frequencies. The identified themes and categories of patient-level barriers, provider-level barriers, system-level barriers, behavioral health needs, facilitators, and consequences of barriers provide the necessary focus for understanding the following sections, which are aimed at describing theme frequencies for each stakeholder group. Average units of data per participant by stakeholder group are presented in Figure 2; percentage of units accounted for by stakeholder group are shown in Figure 3. Broadly, there were 1657 units of total data across the 34 stakeholder participants. The patient group ($n = 2$) accounted for 2.4% of the data (n units = 40), or 20 units per participant whereas the parent group ($n = 7$) accounted for 15.5% of the data (n units = 257), or 36.7 units per participant. The nurse group ($n = 4$) accounted for 9.9% of the data (n units = 164; 41 units per participant) and the resident group ($n = 14$) accounted for 34.1% of the data (n units = 565; 40.3 per participant). In addition, the faculty group ($n = 5$) accounted for 24.6% of the data (n units = 408), or 81.6 units per participant, and the director group ($n = 2$) accounted for 13.5% of the data (n units = 223; 111.5 per participant).

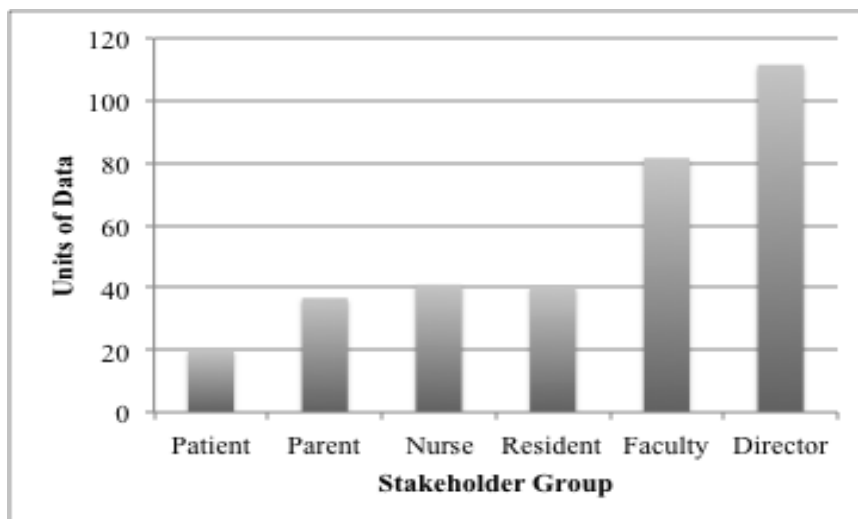


Figure 2. Average Units of Data per Participant by Stakeholder Group.

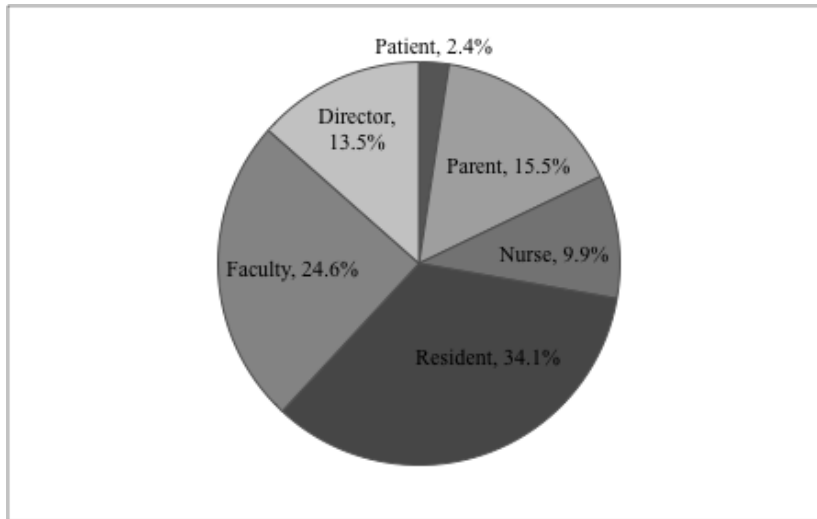


Figure 3. Percentage of Units of Data Accounted for by Stakeholder Group.

Frequency results for patient-level barriers. As shown in Figure 4, parent stakeholders discussed patient-level barriers more often than any other stakeholder group. Parents accounted for 36.4% of the total patient-level barrier units ($n = 319$), whereas directors accounted for 6.0% (see Appendix D for complete frequency and percentage data for categories and core categories). Parents tended to focus their discussion on the themes of *lack of resources*, *patient/parent communication*, and *stigma of mental health*. After parents, resident stakeholders accounted for 27.3% of the patient-level barriers data, focusing on themes of *lack of follow through*, *patient/parent communication*, and *chaotic family/environment*. Of note, for patient interviews, discussion of patient-level barriers accounted for 55.0% of patient stakeholder codes. Themes discussed by patients included *lack of trust*, *patient/parent communication*, *stigma of mental health*, and *chaotic family/environment*.

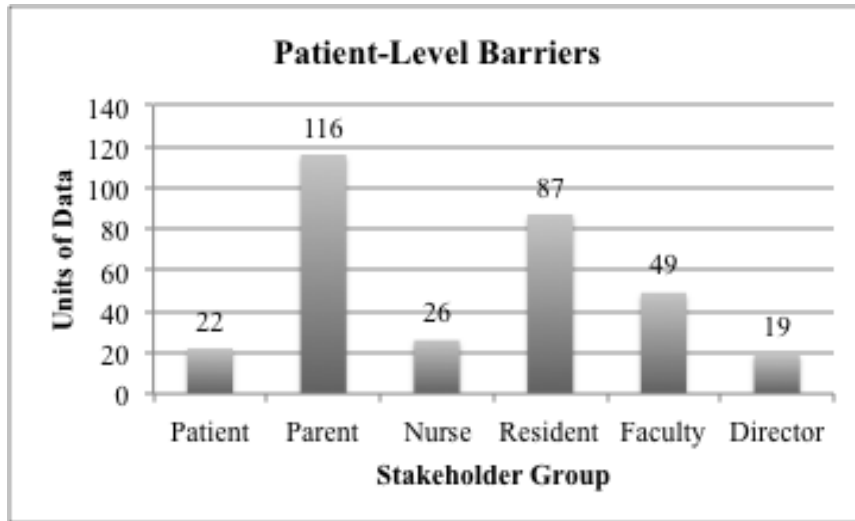


Figure 4. Patient-Level Barriers Units of Data by Stakeholder Group.

Frequency results for provider-level barriers. As shown in Figure 5, resident stakeholders discussed provider-level barriers more often than any other stakeholder group. Residents accounted for 45.9% of the total provider-level barrier units ($n = 242$), whereas patients accounted for 0.0% (see Appendix D for complete frequency and percentage data for categories and core categories). Residents focused their discussion on the themes of *lack of training* and *lack of time*. After residents, faculty stakeholders accounted for 22.0% of the provider-level barriers data, mainly focusing their discussion on themes of *lack of training*. Directors also focused their discussion on *lack of training*, whereas nurses and parents discussed *lack of time*.

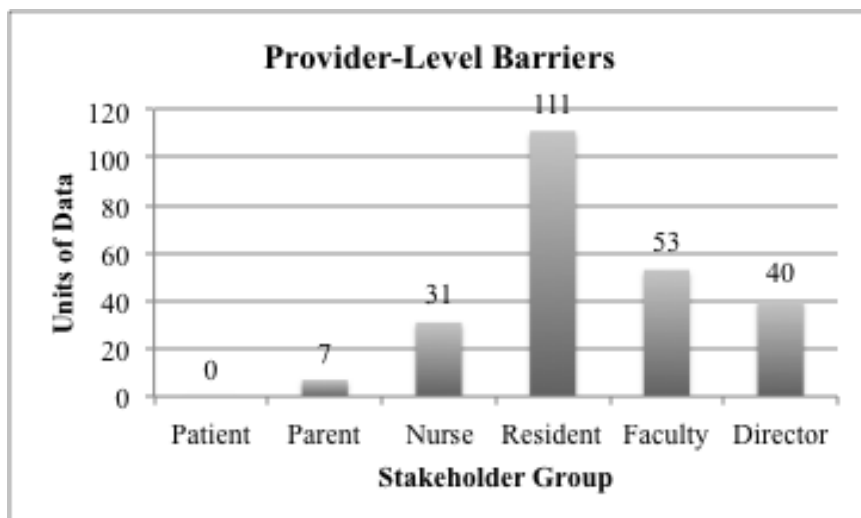


Figure 5. Provider-Level Barriers Units of Data by Stakeholder Group.

Frequency results for system-level barriers. As shown in Figure 6, faculty stakeholders and resident stakeholders discussed system-level barriers more often than other stakeholder groups. Faculty accounted for 35.4% and residents accounted for 33.8% of the total system-level barrier units ($n = 302$). Patient stakeholders, similar to the provider-level barriers category, accounted for 0.0% (see Appendix D for complete frequency and percentage data for themes and core categories). Faculty focused their discussion on themes of *organizational challenge* and *financial*, whereas residents focused their discussion on the themes of *lack of continuity* and *organizational challenge*. Directors focused their discussion on *financial*, whereas nurses focused more on *organizational challenge* and parents on *long wait*.

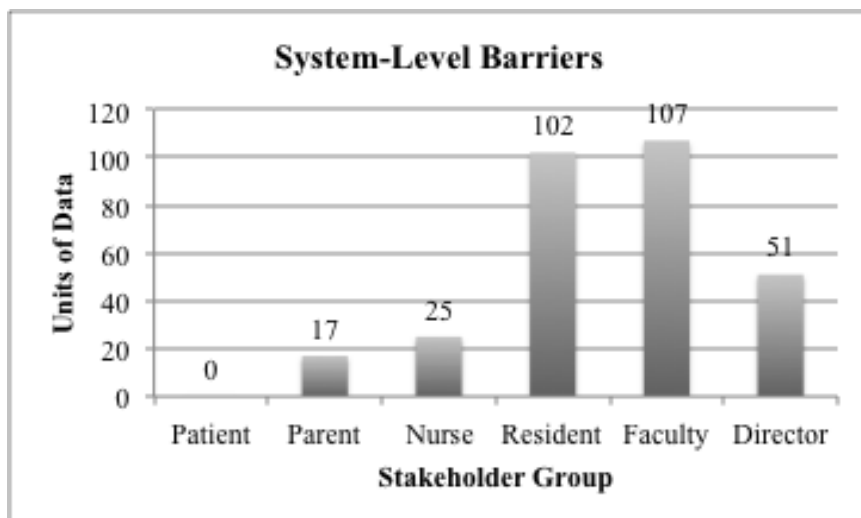


Figure 6. System-Level Barriers Units of Data by Stakeholder Group.

Frequency results for behavioral health needs. As shown in Figure 7, resident stakeholders and faculty stakeholders discussed behavioral health needs more often than other stakeholder groups. Residents accounted for 38.3% and faculty accounted for 33.6% of the total behavioral health needs units ($n = 253$). Patient stakeholders accounted for only 0.4% of the behavioral health need data (see Appendix D for complete frequency and percentage data for categories and core categories). Residents discussed themes of *provider education and training* and *integrated mental health services*, whereas faculty focused their discussion on the themes of *provider education and training*, *continuity of care*, and *specialty mental health care*. Directors also focused their discussion on *provider education and training* and *integrated mental health services*. Parents identified the theme of *specialty mental health care*, whereas nurses equally discussed themes of *continuity of care*, *integrated mental health services*, and *provider education and training*.

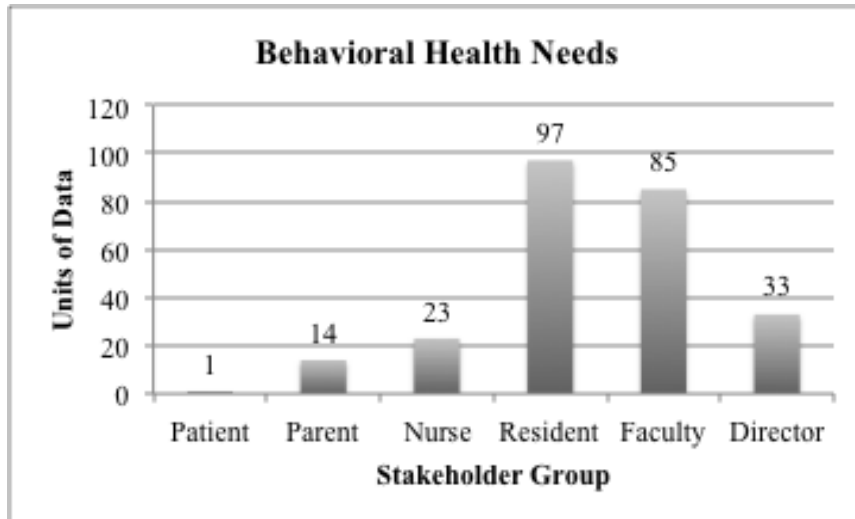


Figure 7. Behavioral Health Needs Units of Data by Stakeholder Group.

Frequency results for facilitators. As shown in Figure 8, resident stakeholders discussed facilitators more often than any other stakeholder group. Residents accounted for 30.1% of the total facilitators units ($n = 469$), whereas patients accounted for 3.6% (see Appendix D for complete frequency and percentage data for categories and core categories). Residents focused their discussion on *provider communication* and *screening*. After residents, faculty stakeholders accounted for 21.5% of the facilitators data, and also focused their discussion on *screening* and *provider communication*. Parents, with 19% of the data, focused their discussion on themes of *communication to families*, *education to families*, and *screening*; and patients focused on *communication to families and trusting relationship*. Directors focused on *provider communication* and *screening*. In addition to *screening*, nurses also discussed *communication to families* as a facilitator.

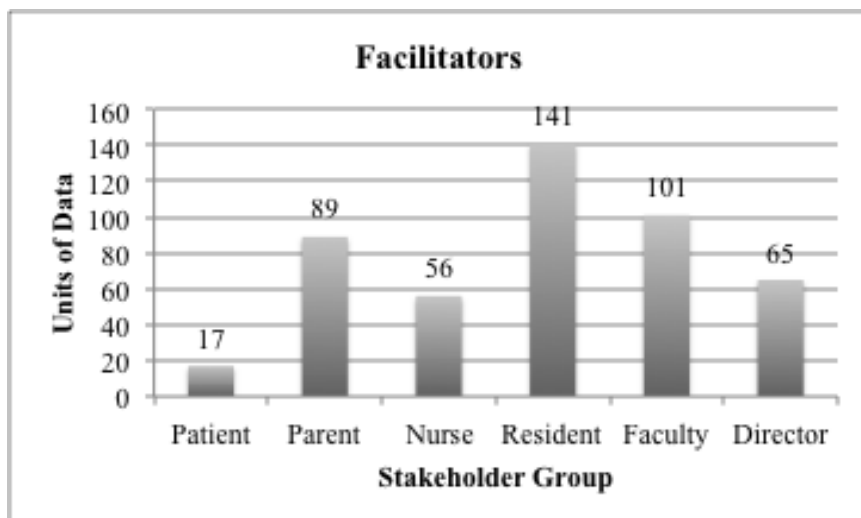


Figure 8. Facilitators Units of Data by Stakeholder Group.

Frequency results for consequences of barriers. As shown in Figure 9, residents also identified consequences of barriers more than other stakeholder groups. Residents accounted for 37.5% of the total consequences of barriers units ($n = 72$), whereas patients accounted for 0.0% (see Appendix D for complete frequency and percentage data for categories and core categories). Directors, faculty, and parents discussed consequences of barriers with similar frequency. Nurses only accounted for 4.2% of the data.

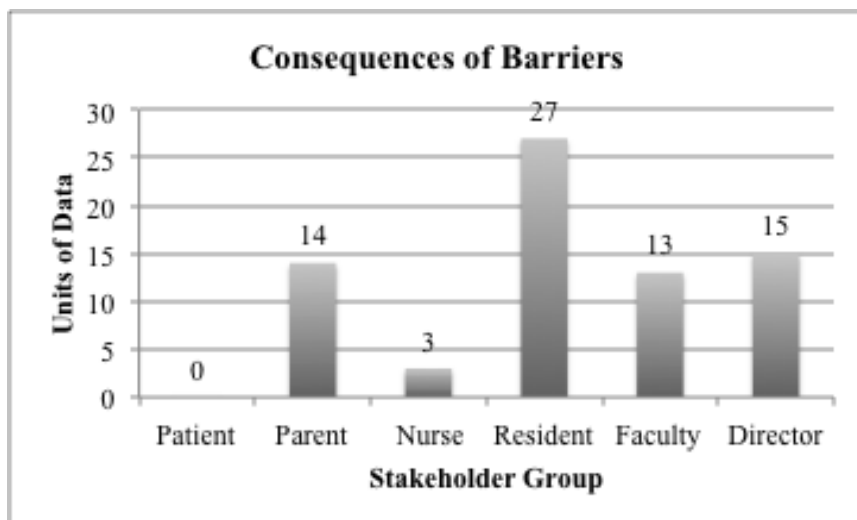


Figure 9. Consequences of Barriers Units of Data by Stakeholder Group.

Description of Themes

This section presents a description of the categories and themes identified during analysis of qualitative data related to understanding how pediatric primary care clinics may better identify and help treat the behavioral and mental health needs of children and their families. Six categories emerged from the analysis: *patient-level barrier*, *provider-level barrier*, *system-level barrier*, *consequences of barriers*, *behavioral health needs*, and *facilitators of care*. Except for *consequences of barriers*, all categories contained themes further describing ideas and concepts that supported the categories. Although categories that emerged were informed by existing literature and prior knowledge and experience of the researcher, data were not forced to fit the literature, and prior knowledge and existing literature were not used to create the categories. The categories emerged through examination and constant comparison of themes, and account for most of the variation of the data and seemed to fit together. Moreover, although the categories are more highly abstracted, they remain grounded in the data. The aim of the following section is to outline the categories and themes together with verbatim extracts of the various stakeholder contributions. Quotations will be used for objectivity and to accurately represent information the participants provided and that interpretations are not based on researcher biases, motivations, and/or perspectives (Elo et al., 2014). The richness and extensiveness of these data belie an easy summary. As a result of the quantity of themes and the corresponding quotes, I have chosen to provide a sample of data from selected themes within categories, rather than presenting data for each theme. For a full review of themes and theme definitions please see Appendix E.

Each stakeholder group was asked to identify and discuss barriers to pediatric mental health integration into primary care. Participants identified issues related to patient and families

themselves (e.g., lack of follow through, lack of resources), providers (e.g., lack of training, lack of time), system (e.g., lack of continuity, lack of screening), and consequences of these barriers.

Patient-level barrier themes. This category accounted for 19.3% of the total units of data amongst all stakeholder groups. The eight themes within this category include *chaotic family/environment, knowledge of mental health care, lack of follow through, lack of resources, lack of trust, patient/parent communication, quick fix, and stigma of mental health*. Here I will discuss the themes of 1) *chaotic family/environment*, 2) *lack of resources*, 3) *lack of follow through*, 4) *lack of trust*, 5) *patient/parent communication*, and 6) *stigma of mental health*.

Chaotic/family environment. Lack of family structure and routine, chaotic environment, lack of guidance, more important priorities (e.g., food, shelter), a cycle of negligence, unavailable parent, and/or a parent's own mental health issues were identified across all stakeholder groups as barriers to patients and families receiving, accessing, and following through on mental health care. One parent summarized the theme succinctly:

I think that right now and the way the world is, there's no real guidance for our children. I mean they feel everything we feel and they deal with things differently. You know we might seem like we're coping but we don't. We run in our room and we act like we've got everything together. We are worried. Secrets separate from them. But it affects them. You know we work too much, we're never home, the schools are messed up and everything is messed up and it's chaotic, and our children are a product of it. The children of this era are a true product of it. I hope and pray that I'm not living anymore to see what's going to happen because it's going to be a real messed up thing if things don't get better.

A patient participant described experiences with an unavailable parent:

The parents should probably just take them out more or show them more kiddie life. Instead of making them do everything on their own. Like cook for themselves, and walk themselves to school, and take their own self out. The parents should do what a parent should do.

A faculty participant stated the following related to this barrier:

We have a spectrum of folks...some loosely developed families with no real structure. Multiple with multiple fathers, living in an environment where there really isn't a single caregiver in charge. Where there's no routine, no get up time, no breakfast time, there's no mealtime in the afternoon or evening, and no bedtime. It's almost a chaotic structure.

Lack of resources. Closely related to the sub-theme above are concerns related to the cost of treatment for mental health issues and the limited financial resources of patients and families. As one parent stated, “Just finances, mainly finances. Most people don't have the type of money that it would take for their children to go into a program and be seen on a one-to-one basis. It's finances mainly.” Furthermore, another parent describes lack of resources as a barrier to care:

See for me I feel as though I'm a single parent, I have 3 children, I'm alone, I don't have the time, those are the things that's going through my mind. I can't afford to take off work, or I can't afford to quit my job. I will have nothing. I don't have nothing now; it's just a lot of things that go through my mind, you know what I'm saying? That makes me feel as though 'OK I'm going to prioritize,' but sometimes you prioritize it wrong, you know, and I'm prioritizing trying to making sure I have money in my pocket so that I can pay bills and put clothes on the kids' backs but then their problem is going off and not being dealt with.

Closely related to financial issues are problems related to transportation and being able to attend appointments. As a nurse described it, “I think my patients have issues with transportation, just even getting here, so that's usually an issue.” Here is a statement by a director that ties in the prior sub-theme of *chaotic/family environment* and begins to discuss *lack of follow through*:

For the patients themselves, I think a lot of the kids that we see who have mental health problems are in part having their problems because they are living in dysfunctional families. Dysfunctional families have a hard time keeping schedules. I am generalizing, but it appears to be that they have trouble keeping appointments, they have trouble setting priorities, and sometimes more pressing priorities have to do with food and shelter or a family member who is physically sick at the same time that somebody is supposed to be going for their counseling appointment. They don't have the transportation.

Lack of follow through. This theme was not identified by patients and/or parents as a barrier to care, but was discussed mostly amongst the provider groups. Participants described

how being late to appointments, not attending appointments, treatment non-adherence, and not following through on a referral presented a barrier to care. As described by a resident, “That is another barrier too, when the scheduler calls them with their appointment time, either she can't get a hold of them or they never show.” Speaking to this point, another resident explained, “A lot of our patients are non-compliant with medications and with coming to their appointments. Being on time to get their vaccination. Most of them can't tell what meds they take everyday. I doubt they can tell you like a diagnosis or whatever. I mean some really highly functional families do, but most of our patients just don't.” Another resident discussed

So in the process you can start them on ADHD medicine and then have them come back in a week, not to talk about the ADHD medicine, but to talk more about the problem. Sometimes you have to defer things, and unfortunately, sometimes that's scary with some of our patients in our practice, because sometimes they don't follow up like they are supposed to. So if you were to start them on something, or you were to say come back and see me in a week, you may not see that kid for another six months.

The following faculty member tied in previous sub-themes to also describe the barrier of a patient and/or caregiver not following through on a mental health referral:

I've had sometimes where parents don't follow through. Sometimes the parents have the same health problems as the child, like ADHD, and they call the number once and can't get in and then they give up. So I think it's very frustrating and a lot of our patients are hesitant to begin with and then when they don't - they have trouble. Again if their insurance doesn't cover it it's also a problem.

Lack of trust. A lack of trust with pediatric primary care and mental health providers was identified as an obstacle to care that impacted a patient and/or parent's willingness to communicate with their providers, follow through with recommendations, or seek help for mental health issues. As one parent explained, “People feel alienated by the culture that is - they are not going to help me anyway. That's their thinking. So they don't want to go to you because they feel like you are not going to help me anyway.” Another parent expressed concern that:

As a parent, you feel like you are alienated from everything that's surrounding you. You don't know who to go for help. Or if I'm going to this person for help, maybe if you don't have money to pay for the light bill and your lights are out and you have your kids in the house without lights. Even though you may not just stay there at night and you automatically are in trouble because that's a danger for your children. And you know most parents know that but you don't have any other choice because you don't have anywhere else to go. I don't know who I can go to or who I can trust to tell them anything in order to make it safe for me and my kids so it's like a trust issue.

This faculty respondent also identified a lack of trust around cultural differences or religious

beliefs:

It's also hard because a number of times people will want the provider to be of their belief system and I find that very hard. They'll say you know I want a Christian provider and you'll be like. "Well I don't know the provider's religion." It isn't something that's on the web that you can find out. I've had people very hesitant to go get help unless that person is going to respect their beliefs. I try really hard to say whatever provider they are, they are going to respect your beliefs but there are people that, at least with mental health issues or behavioral issues, want to be sure that their provider shares the same common values that they have. I don't know how to help with that because I have no idea. I mean I know some providers well enough to know their beliefs but other parents are scared because their child is very dear to them and they don't want them to enter a belief system or be advised things that they don't agree with. It may be good for self-esteem or mental health but be anti their culture. I find that a lot, and then they don't go. So I don't know how to overcome that hurdle.

Patient/Parent communication. Closely tied in to *lack of trust* is a patient or parent's lack of or unwillingness to communicate their questions and concerns. Additionally, language barriers were also identified. For example the nurse manager of the clinic described:

We have a couple of different issues that I think we struggle with in our clinic. First of all, we have a more diverse population coming into our clinic. A higher percentage of Spanish-speaking families coming into the clinics, so assessing what the mental health needs are of that family and that child, and then finding adequate resources for that family. So dealing with those cultural issues as well as the language issues are a challenge.

In relation to a patient's unwillingness to communicate, a faculty respondent stated:

Well if it's a patient they are not going to want their parents to know. Some of them don't feel comfortable that we won't tell their parents so they're not going to - or they feel like they are going to get in trouble saying it so they're not going to - or their school will do something.

Related to *lack of trust* and *chaotic family/environment*, a faculty member added:

Certain families sometimes have other issues going on with the police, so they feel like if they say something to the physician then they are going to automatically call child protective services or somebody. So they don't divulge that information especially if it's a history of drug abuse in the past or something. So that's a barrier.

Patients also identified this barrier, stating, "I might not talk to one of the doctors

because...maybe because I don't feel like I don't need to talk to them about that or they really wouldn't be able to do anything about it," as well as:

They probably wouldn't want the help; they would probably just want to do whatever you got to do on their own. They probably wouldn't want nobody to tell them what to do that will probably make them even madder. Like if someone tells them that they need help or something like they would probably say they don't need help or if someone asks to help them they would probably say no. Because they wouldn't want everybody getting into their business, they probably wouldn't want nobody to know what they were going to do.

Parents particularly feel that the primary care provider should ask about mental health. If

providers do not ask, the parents are not prompted to bring up their concerns. For example:

If it's personal, I have no problem talking to them about it. It's just that over there in the clinic it's not a subject that they ask you about, my children are behavioral problem children so I brought it to their attention; they didn't ask me. Once I did bring it to their attention, the doctor that they have, he took the appropriate steps to lead them to where they needed to go. But it's not something they ask you.

Stigma of mental health. All stakeholder groups identified *stigma of mental health* as one of the primary obstacles to integration of behavioral health into pediatric primary care, as well as a barrier for patient and families to receive specialty mental health care in their communities. One patient described it as, "they just don't want people to know what's going on in their families more or less." The nurse manager stated, "That's one concept or it's 'we don't need these services, it's mental health I don't want to have to deal with it' and society's attitude about mental health issues and paying for services, 'we should be able to do this on our own, pull up by your boot strap, so it'll be okay, Johnny, it'll be better'." A faculty member explained how

mental health services are viewed negatively by patients and families and how a double standard exists between physical health and mental health:

A lot of our clients, whether this is part socioeconomic and even beyond that, it's still the largest part of the population does not view counseling as a good thing as something you should or could do or want to do. It's viewed very negatively. So a lot of times if you look through charts in general PEDS and my charts you'll see patient referred here for counseling. Patient referred there for counseling. When they come back in, have they followed up on that or have they done that? No, I called and they didn't call me back. A very different scenario than if you recommend them for surgery or to the emergency room. Follow through just doesn't take place, so you're just getting people to take the first step. Even if you're careful not to put it in any terms or labels that would make them upset. Most people do not have a positive eagerness towards any kind of counseling. When children's behavior is totally out of control then they are, but until that point it's very hard to get them to do it.

A resident respondent identified the role culture can play towards stigma: "The Hispanics, I think culturally it is not something that they would bring up, and the rest of the population we don't deal with it." In addition, a patient discussed how labels can be placed on those who ask for help: "Because probably they are shy or embarrassed or they probably don't want to tell everybody. Or if they want to, but people probably think they are crazy."

Provider-level barrier themes. This category accounted for 14.6% of the total units of data amongst all stakeholder groups. The four themes within this category include *lack of time*, *lack of training*, *provider communication*, and *unsure where to refer*. Here I will discuss the themes of 1) *lack of training*, 2) *lack of time*, and 3) *provider communication*.

Lack of training. Residents and faculty identified *lack of training* as a significant barrier to mental health care in pediatric primary care. Overall, physicians felt that they had little to no training in psychopharmacology, identification and assessment of mental health disorders, treatment of mental health disorders, variety of experience with mental health disorders, interdisciplinary training, and what to do once they have identified a child with a mental health issue. Due to lack of training, residents and faculty also discussed how they did not feel

comfortable or competent in dealing with mental health issues due to this lack of training. Besides Attention-Deficit Hyperactivity Disorder (ADHD), physicians felt uncomfortable with most other internalizing and externalizing disorders, as well as suicidal, homicidal, or psychotic patients. One resident stated, "I use the V code behavioral disorder because I'm like, 'I don't know which behavioral disorder it is.' It's gotta be something and get away with it." Another resident added, "But depression and anxiety I think are evil little buggers that are just there and we just forget about them. And we don't address them in the appropriate manner, because we are not trained to do that." Another resident reflected on lack of training with psychological screening, "So even if we do the screening tool, I'm still going to refer to psych because I don't know what to do with that. I'm still going to have to refer out." Another idea that was raised was the lack of variety or types of mental health training received:

And part of it is also, when we say we want to do child psych, we get thrown into the acute child psych care, and I'm like well I don't see psychotic children too often in my clinic. I see the misbehaving child who is in our outpatient clinic 20 times more frequently than I see that and I know to refer that on to you, I know to send that kid to the emergency room. It's a little bit harder with a behavioral issue.

One resident simply stated, "I'm making it up." Faculty reflected how the lack of exposure and experience adds to the lack of competence and discomfort in treating mental health issues:

And lack of our training. It's hard because it combines training and frequency of use of that skill. So that though it happens not infrequently that I run into these concerns, it feels like to maintain a level of proficiency at diagnosing and treating these disorders I would want to be doing it almost all the time.

Another faculty member directly expressed, "It's just that when you see that at the top of the chart 'family worried child is depressed,' you're just like 'oh sh*t' because you're not trained, you don't know if I'm asking the right types of questions." A resident also expressed the frustration that can occur, "I mean we are not PhDs in psychology, we're not psychiatrists, we're pediatricians. So, it's kind of understandable in a way, but also sad that we don't know how to

deal with those issues.” Nurses as well felt that their education and experience lacked in mental health training. For example, the nurse manager stated:

Probably nothing. I mean, it’s very slim to none, unless that person strikes out in the general pediatrics field, I would say generally speaking; they’re not getting a whole lot in terms of that. I think by and large, nurses are looking at more immunization information, growth and development types of information, but when it has to do with mental health issues I don’t have somebody that can say she really or he really understands mental health issues and problems...I think in terms of assessment, people have not had formal education per se.

Lack of time. Most stakeholders, with the exception of patients, discussed *lack of time* to adequately identify and treat behavioral and mental health issues as one of the primary obstacles to appropriate care. One resident participant stated:

I mean one of the challenges is doing mental health screening in a 15-minute visit. I mean because of other things we are screening for. We are screening for asthma, we are trying to do anticipatory guidance on a well child check. It’s the problem all health professionals are having in trying to, or primary care professionals are trying to get as much of the different screenings for different areas of illness into that quick interview.

Another resident discussed choosing to spend the extra time needed, but how it may affect the rest of their daily clinic schedule:

That’s the question, what do I do? It is very difficult to, so once you ask those questions and you see some red flags, then you are stuck. Because you still have five patients you need to see, but you don’t want to spend that time. So often I get backed up because I just decide, you know what, I need to get more information, I need to find more resources.

Nurse participants also expressed frustration at the lack of time in the day, “It’s so busy...a lot of times we miss a lot of things. We see like 70-80 patients a day. That’s a normal day. So you might miss a child that was really you know might needed some help there.”

A faculty participant stated the following related to this barrier:

Often in the middle of a busy day I would hope that parents would see I was busy and not say anything, which is a terrible thing. I just, if this happens, it takes about an hour to work with the family and that backs up everything that we’re trying to do even though that’s the most important thing to do that day.

Closely related to the theme of *patient/parent communication*, parent participants indicated how providers appearing rushed might affect their ability to communicate mental health concerns or feel like they have time to listen. For example:

I don't know about the pediatrician...but I'm pretty sure they'd be busy with a whole bunch of things theirself. I don't know how things might get across to them; you know what I'm saying? Unless I make an appointment with them, with the nurse...but like I said they are on their time schedule, they got a lot of things going on with them and I don't know if they have time for really listening to me or my problems.

Additionally, another patient stated, "Yeah, it's like they're rushed, cause they see so many people a day. It's like they're rushed to handle your situation or your child's illness or whatever and move on to the next room." A resident participant also expressed how the short appointment times affect their ability to learn through experience:

Then we are not modeled the advice on the ADD because of how fast clinic goes. You have to wrap up what should have been a 30 minute visit is turning into a 40-45 minute visit because there are issues involved, so you get the attending in there as fast as possible, so you're not exactly watching anticipatory guidance besides the prescription, I mean the prescription is a part of it, but there are behavioral things that need to be taught to the parents and you're not really watching the attending say, well you need to have the child sit in the front of the classroom, and you need to have the homework folder, and you need to...so you don't necessarily, unless you have taken the time and taken the effort to teach yourself what are the right things to be teaching that family, you're not going to hear about it.

Provider communication. Communication between providers was another obstacle discussed in the provision of mental health care for children and families. Director, faculty, nurse, and resident participants expressed frustration with lack of feedback from community and/or within hospital mental health providers on referrals, as well as ability to communicate within the primary care clinic setting. Related to this theme a director stated:

In some areas that works exceedingly well and some areas it just never works well at all. So it's not just the psychiatrists who are bad about it there are many specialists across the board, which just never get around to it. They're too busy and they don't think it's important. It's a mystery and yet they'll want information from the primary care

physician. You know in order for us to see the patient we need a copy of your most recent notes. Okay, we do that, but couldn't you send us a copy of your most recent notes then?

Here a nurse described communicating to providers what she may have picked up on in the room with a patient, and how it depends on how receptive the provider is to information:

If it's something unusual, I mean depending on how receptive the physician is who's seeing them about wanting to know what I heard, I mean it goes either way, I go in there and the doctor doesn't even look at me while I'm trying to talk to him, or they're like 'oh really? Okay thank you, thank you for that' I mean it just depends, it's a personality thing I think.

A faculty participant stated the following related to the barrier:

I don't get very much feedback. I mean the surgeons always tell me the tubes went in well or whatever they did and I get a letter back, but I don't get anything from mental health providers. Except once in a while I get a generic letter, 'Thank you for your referral to...' But I never hear what they did; and I could be part of the team because that kid still comes in to see me with a sprained ankle.

System-level barrier themes. This category accounted for 18.2% of the total units of data amongst all stakeholder groups. The eight themes within this category include *financial, lack of continuity, limited mental health services, long wait, mental health training not required, organizational challenge, shortage of mental health providers, and lack of specialty mental health care*. Here I will discuss the themes of 1) *financial*, 2) *lack of continuity*, 3) *limited mental health services*, and 4) *lack of specialty mental health care*.

Financial. Participants expressed concerns indicating that mental health services are not viewed as profitable or important enough to be worth the financial resources it would take to sustain them. Speaking to this point, a faculty participant stated:

We, as in everybody, we don't pay for it. This problem makes you want to get to the bottom line...It's a capitalistic system and parents don't feel that psychiatric care and counseling is effective or is necessary so it gets ignored and it doesn't get paid for and so then you end up with a lack of resources.

A director participant explained:

Well I think you get to the issue that probably a lot of this stuff is not very profitable. So universities don't hire as many psychiatrists as we would like because there is not huge bucks in psychiatry. I suspect that the same is true of counseling, and I mean we are talking again what will Medicaid pay for these services. No one is going to get rich off of it, and so there is a limit of how many Medicaid patients various services will take... Pediatrics has this issue of balancing... where is the money going to come from to pay for it. I think the finance really drives it. If we were referring to neurosurgeons they would see us the next day because they can open up the kids heads and make 20,000 in the OR.

As discussed in the previous statement, the lack of reimbursement of mental health services is seen as a large financial obstacle to the provision of these services. A faculty participant commented, "There is a big need, but I know there's problems with reimbursement and our poor people that have the most mental health problems have the least resources to help mental health providers earn a living." A director spoke to this issue as well, "One is the limited number of mental health services, especially again for families who are either uninsured, under insured or even on Medicaid. There are a limited number of appointment availabilities; there are a limited number of agencies that will see children." Parent participants also expressed similar frustrations, one parent stating, "God forbid if you don't have the right financial stuff. I mean if you don't have medical coverage that makes it hard as well." Another parent stated, "Mainly finances. Most people don't have the type of money that it would take for their children to go into a program and be seen on a one-to-one basis. It's finances mainly."

Lack of continuity. Residents often discussed the inability to follow a patient in clinic, or *lack of continuity of care*, as a point of frustration and a barrier to appropriately managing patient mental health issues. To this point, a resident stated:

It's just that we don't have true continuity in our continuity clinic. True continuity would be if...say, there is concern of ADHD and I give the initial assessment forms for the family and the teachers...continuity would be for those kids to come back to me and not just one time but multiple times, and unfortunately the way our clinic is set up that often is not the case. They end up seeing whichever physician they get scheduled with and so it's normally a different doctor almost every time.

Additionally, a resident expressed:

I think patient continuity is tough. I think that's an inherent problem within residency programs in general. We fill a need, and I think we do a good job, trying to help as many people with our continuity as we can, but continuity is difficult, and especially when it comes to managing mental health and following up on ADHD, depression, learning disorders, whatever... You need continuity with that, especially as things change, and as symptoms manifest.

Another resident described the impact of *lack of continuity* on patients:

It makes life for the kids that much more difficult too because... I've had a couple of kids that do come back and try to see me each time they come in, and a couple of really tough or sad cases and they like seeing me; we've established rapport, they trust me, and suddenly they're coming back, they think because they're going to their doctors to get their ADD check... to see what wonderful things they've managed to accomplish so we can brag about it... and they're expecting to see me and suddenly [another doctor] walks into the room and they have no bond with him and it's not to say that they don't have good visits... but it's detrimental to the patient as much as it is to us. There's a reward to saying 'Hey, look at me! I did what you told me' and 'Aren't you proud?' You lose that when you get different people each time.

Furthermore, a director participant expressed similar thoughts on the frustration it may cause patients and their caregivers:

I think the frustration we have within the system... because it is a resident clinic there is not a guarantee that there is going to be continuity. Although we try to get them back to see the same resident it's not a done deal until that actually happens and so the parent is frustrated. You come back in and now 'Johnny' has been on Ritalin for a week or two weeks... but now she has to tell the resident all over again, from the beginning, the whole story because the resident wasn't the resident that originally saw the kid. It is true for attendings also, although some of us are up there an awful lot, we are not guaranteed to be the doctor that's going to see them with the resident.

Limited mental health services. Participants discussed issues related to the lack of resources for the identification, assessment, and treatment of mental and behavioral health issues within their pediatric primary care clinic. For example, one resident indicated:

Our clinic is a little bit different because in the real world you may have other people that can help you find resources... but often here we are the social worker. We are the person who is then trying to set up referrals and do all of those things. So it makes it a little bit more difficult... you try to give some anticipatory guidance in the midst of everything

else you are doing... You can't spend all the time trying to address that one problem, the parents can have a list of things they can try in the mean time to make that problem better while they are waiting to be seen by an expert in the field, which we are not.

A nurse participant also expressed, "Lacking in all of my clinics is having access to a social worker and it's a major issue. Social workers... have a good handle on resources and they have a good ability to assess the particular family dynamics and situations and try to match up... the mental health issues and the resource issues." Participants also expressed lack of access to mental health screening tools as a huge gap in resources for their clinic. A resident participant stated, "...for ADHD we use the Vanderbilt forms, but for other mental health problems we don't really have... we don't have any currently." Another resident stated, "So much of what I see in [clinic]... it is hard to do the screening." A faculty participant also expressed, "In terms of screening... I don't know if we have any single screening tool that we recommend for [the residents]. Some ADHD screening tools, but we don't do any routine screening in children for mental health disorders."

Lack of specialty mental health care. Participants also discussed issues related to the lack of accessible and affordable specialty mental health care in the community. Providers expressed their concerns as to whether or not appropriate mental health care would be available once mental health issues were identified in primary care. A faculty participant stated:

One of the most frustrating things we have is identifying a patient who needs a mental health professional. The patients got depression, the patient may be psychotic, the patient may be suicidal and when you try to find a place for them to be seen it's very difficult... it's not unique to our practice. I talk to pediatricians in the community and they have the exact same problem. They can't find a mental health professional who will see the patient on a timely basis and be able to, if necessary, hospitalize that patient during an acute phase until things can be sorted out... none of us feel like we can sit there and say, 'Well I'll use this antipsychotic medication and/or I'll have the family back next week and talk about it more.' You would like to have somebody plugged in with this child immediately.

Along the same lines, another faculty participant added:

When a child presents at a primary care office with major psychiatric symptoms the tendency of the primary care doctor, knowing how hard it is to get the kid in anywhere, will refer him to six places, and he'll be on six waiting lists...so the limited resources again, being overused for backlogging the system because the serious cases just get referred over and over by us. There is a drastic shortage of any and all sorts of mental health support services. If you go through the trouble of identifying a problem early when it's minor it's even harder to get any kind of support.

A parent participant discussed how even when services are provided, they may not be appropriate or adequate for their child:

Here's an example, they got all these in-home services right now with these people driving around who are suppose to be your in-home counselor. They come and they write out this big piece of paper on all these things they expect for a kid to do and how they are going to be coming to do these things. They get paid and they don't even do these jobs. They are supposed to see your kid three days, three times a week and do all these things. They come when they want. Meanwhile, what's going on is they have these meetings once a week at their job and they have them produce this paper saying X, Y and Z about the kid. They never really share that particular paper with the parent to verify whether they got these services. Now all of a sudden Medicaid says after twelve weeks you are done, you can't get your services. But they are now paying for these services that you did not get.

Consequences of barriers themes. This category accounted for 4.3% of the total units of data amongst all stakeholder groups. Throughout discussion of patient-, provider-, and systems-level barriers, participants indicated how these obstacles impacted the integration of mental health care in pediatric primary care. Consequences discussed include a decrease in patient and family motivation, patients "falling through the cracks," misdiagnosis and subsequent lack of or inappropriate treatment, use of emergency department as mental health care, and the risk for mental health problems getting worse and/or tragedy occurring. As one parent explained:

Sometimes by the time you give us the help it's too late...in some instances the parent has hurt the kid or the kid has hurt the parent. Now it's a whole big mess to clean up. Or maybe that day the parent wanted to...reach out for help...but now you took five weeks to call them back. Even though they know you need help, now their pride won't let them say I need help so they say 'ok thank you but that's okay.'

A faculty member stated:

Every time we see somebody who needs services that are not readily available, I think that one of these times something terrible is going to happen. Some real tragedy is going to happen because of not being able to get somebody plugged in, and then we'll all respond to the tragedy. You know the child who does something terrible and injures or kills a number of people, and I'll say, 'Well, you know he was down there at the college the other day and they knew he was sick.'

In reference to this same idea of issues getting worse, a parent commented, "You get the phone number, you make an appointment, then you get to see somebody three months down the road...by that time the problem has greatly increased or something of some detriment could have happened." Residents also indicated the idea of patients "falling through the cracks," for example: "These kids kind of fall through the cracks just because there's nowhere that is willing to take them." Another resident stated, "There's a huge wait, we don't have a lot of direction in where we should be referring...sometimes they get referred to the wrong place or they just fall through the cracks and never get the help they need."

The opportunity for misdiagnosis was another consequence discussed by providers that is tied into their lack of education and training, lack of communication with parents as well as other providers, lack of resources, and lack of time. A resident stated, "A lot of these kids end up being labeled ADHD, but then they end up on medication and it's not helping. So there's this part inside of my brain that's saying, 'Well maybe it's not really ADHD' or 'Maybe there's other components that we're really not addressing,' but again, I don't feel like I really have the resources to truly tease that out." Another resident commented, "Part of the hardest thing is coming up with the accurate diagnosis within that short visit." Nurses also contributed to this idea stating, "I think because clinics are so busy and people are seen very quickly...the opportunity to miss somebody that has some concerns or issues about their child and their mental health are certainly present." Another nurse added, "It's so busy, so it get can get so stressful, a

lot of times we miss a lot of things. We see like 70 to 80 patients a day. That's a normal day. So you might miss a child that was really, you know, might needed some help there."

The use of the emergency department as mental health care was also discussed as a consequence of barriers. A faculty member stated:

Call [inpatient facility], six-month wait. Call [other inpatient facility] and they often have a long wait list. We get responses sometimes from the psychiatry residents, to just send them to the ER and we'll see them there. Well, to me, that's an abuse to this ER system. It's an emergency, but do you want this child with the next car wreck, or the next shooting. In reality, you need to be seen in an office somewhere by someone who knows something about a child's psych, who can, if necessary, admit this patient to inpatient if it's that critical.

A resident expressed a similar sentiment about using the emergency department as mental health care:

What ends up happening, and I've seen it actually down in the ER...but I'll have a kid who is acting out in school, comes to clinic to get evaluated, acting out in clinic, the pediatrician gets concerned, calls their psychiatrist who is on speed dial (if they have one), and say this is what I'm seeing and they're like 'Wow, that sounds bad, take them into the emergency room.' Parents are like, 'but this isn't an emergency, this has been going on all the time.' In order to get them actually seen by anybody, you have to take them to the emergency room and you use up those resources...and you feel bad referring the child to the emergency room when there are kids that actually need the ER and taking up that ER space and when you could have had some valuable feedback and some help, maybe on an outpatient basis and been able to work their way through it. Because there are kids who show up in the ER that get told, 'you don't meet inpatient criteria, I'm sorry it sucks to be you, good luck, bye!' The parents are already frustrated because they spent 5 hours in the ER being told, 'we can't help you.'

Behavioral health need themes. This category accounted for 15.3% of the total units of data amongst all stakeholder groups. The five themes within this category include *clinic resources, continuity of care, integrated mental health services, provider education and training, and specialty mental health care*. Here I will discuss the themes of 1) *continuity of care*, 2) *integrated mental health services*, and 3) *provider education and training*.

Continuity of care. Due to the *lack of continuity* discussed in system-level barriers, participants discussed a need for *continuity of care* in the clinic and among community mental health providers, in order to help improve identification, diagnosis, and treatment of mental and behavioral health disorders in pediatric primary care. Participants also discussed how increased communication and collaboration between providers; particularly feedback from referrals would facilitate *continuity of care*. In relation to this, a faculty participant discussed how having the same provider see the patient multiple times allows for better assessment of symptoms and behaviors:

Looking at this child and thinking every time he comes in he doesn't say anything. You know one time shy and the second time why should you be shy you were here before. The third time this is really strange. You know put it into some perspective...having the same resident have the same patient each time.

A resident described looking forward to the opportunity of *continuity of care* once working in the community: "I'm looking forward to moving to a community practice where if I have a tough behavioral case, I'll say this is my kid, they're coming back and seeing me and if they pop up on somebody else's radar, at least I know they'll come talk to me at the very least." Another faculty participant stated, "Once they get that information...they should never just let it go and I think a close follow up and try to get them good resources...which a lot of times is very difficult."

Additionally, a resident commented on how continuity would help them provider better care for patients:

I think this is probably an internal issue we need to deal with, the lack of continuity. There are certain kids that I am worried about and then if I knew I was going to see them again, I could perhaps check in to see how they were doing, but when you know that you're never going to see them again, it's very difficult to help them.

The idea of the "medical home" also was discussed as a part of continuity. For example:

So I like residents to reinforce with parents that we're the medical home if there are concerns along the way. If there are concerns that come up, we want to be one of the first

people called. We want to be able to help parents at every level through this. If we're dealing with mental health disorders you know there's a lot less that we do in terms of actual treatment and full diagnosis.

Integrated mental health services. All provider participants and parents discussed the need for mental health services to be an integral part of pediatric primary care clinics in order to increase identification and treatment of behavioral health disorders in children. One director summarized this theme succinctly: "To me the easiest thing would be having a mental health person...social worker, licensed professional counselor, clinical psychologist, someone readily available, in the clinic setting, that could meet with families, could act as triage; help us assess and then help refer and also help with follow up. A parent participant stated:

I think if psychological or mental health services are also available where you get your physical or where they see the doctor that would make it easier. Or perhaps if you took your child into the doctor...and the doctor checks him out and realizes it's not physical, this loss of sleep and loss of appetite is caused from a mental situation, that they could say, 'Well just have a seat right here and we'll have so-and-so see you.' Kinda do it like that rather than saying, 'he's depressed, call this number, schedule an appointment.' It'll take a month to get an appointment. If it can be housed in one area I think that would be the ideal.

Another resident discussed how more support in clinic would allow providers to focus more on direct patient care: "So more support, I think, is the biggest thing. Then we can spend a little more time with direct patient care. Whether that means another body to help us to facilitate some of the social and psychological issues." Another director discussed how integrated services would help patient and families:

Because a lot of these families we see, part of the problem is the chaotic-ness of their house, of their social situation, coming back to appointments is as challenging as launching a rocket to the moon for some of them. So if you can do it right then and there it is really nice too...availability of an expert in the system, that we could be using on a regular basis.

Provider education and training. The importance of increased *provider education and training* was also discussed as a need, in order to improve provider confidence and competence

in identification, treatment, and referral of mental health problems, and more clearly define the PPCP's role in mental health care. More training in screening, assessment, diagnosis, psychopharmacology, psychosocial treatments, and referrals were identified; as well as increased exposure to a variety of training populations, settings, and models. In reference to this theme, a resident participant stated, "So it goes back to us getting more training in residency in dealing with mental health issues and understanding...maybe being able to diagnose more effectively these other things and we need more time with the psychiatrists." Another resident added, "We have lectures on mental health issues in kids, but I would like to have more education on how to identify. Once I do identify it, I want to know where to refer them and if it is practical for them to get there and appointments to be made. A resident also discussed the need for training with different populations and settings:

And part of it is...when we say we want to do child psych, we get thrown into the acute child psych care, and I'm like 'well, I don't see psychotic children too often in my clinic. I see the misbehaving child who is in your outpatient clinic 20X more frequently than I see that and I know to refer them on to you. I know to send that kid to the emergency room.' It's a little bit harder with a behavioral issue. So having a rotation where we're allowed to participate or even observe and watch feedback, watch what a counselor does, so if we can't get them into counseling we can at least sit down with them and spew some of the same advice out at them.

A faculty participant suggested:

Right now I think that there's up to a month of mental health training in three years and I think that we might want to go to a full year of mental health training within pediatric residency programs and we will have to eliminate 12 months of other responsibilities. I don't know if I would do it in one exclusive year, but I think that the general pediatrician needs this, if we can't bring those other resources to them.

A director participant added:

Most of the residents learn best by seeing patients, as opposed to sitting by a textbook, or listening to a lecture. So I think really the optimal training is for them to either work in a pediatric psychiatry clinic for part of a rotation, or in some of these counseling services to observe. Or to have those experts in the clinic to help augment what we teach them; because again their level of knowledge in terms of practical stuff that they walk away

from the clinic, is based on the faculty's level of knowledge. The younger faculty in my division, fortunately all of them are people who have gotten more training than I have in this area. There's still a level where each one of them say, I am no longer comfortable with this.

In reference to increased education and training in psychopharmacology, a faculty participant stated:

I would want our pediatricians to get a level of comfort with initial prescription and how to follow closely and if that doesn't seem to work then we would refer. I think that it would be valuable training to get this. But again, I would rather just keep it at a few months. Make sure we're at least proficient and that we don't miss things and make sure that there are plenty of pediatric psychiatrists/psychologists available.

Another faculty participant added to this conversation:

I think that if you had to break it down to the bare minimum, we need psychopharmacology. We need a level of confidence with psychopharmacologic drugs...we would need the training in confidence to use those because I do think it's reasonable. I think that psychological counseling is more available than the full psychiatric evaluation and recommendations for pharmacology. I think that it's reasonable to take a very simplified approach or to go through some simple, basic workflow.

Facilitator of care themes. This category accounted for 28.3% of the total units of data amongst all stakeholder groups. The nine themes within this category include *communication to families, education for families, consult mental health provider, provider collaboration, provider communication, increased accessibility, scheduling, screening, and trusting relationship*. Here I will discuss the themes of 1) *communication to families*, 2) *education for families*, 3) *provider communication*, and 4) *screening*.

Communication to families. All participants described the importance of communication to patients and their families as a way to overcome obstacles and facilitate identification and treatment of mental and behavioral health issues in the pediatric primary care setting. Both patient participants identified the importance of being able to talk with someone as a way of getting help. Related to this, one patient stated, "Kids just need somebody that is ready to be

there for them basically, to be there for them, just feel what they have to say and I guess that's it." The other patient commented:

What would make it easier...probably if people just sat down and listened to really what they had to say instead of jumping to conclusions about them. Because like if somebody says something and, you be like well 'I want to kill myself', people be like 'Oh your crazy.' That would probably drive them to want to kill themselves more.

One patient discussed how the school setting would be another place to reach out to children:

Probably like go to a school and talk to all the kids and get the kids to sign a paper or tell you if they need some kind of help at home. Like the little survey that we did at the hospital. Like questions like what's going on at home and are you being abused and are you using drugs, or are your parents using drugs, and stuff like that.

One parent participant discussed her own experiences with a provider who created a context where patient and parent felt comfortable discussing their issues:

They need to have doctors who not only make sure things are physically well but conversate with them and find out different things about them. So when you walk into the doctor's office it's real nice when you walk in there and you haven't been there in a year and they know, 'Hey Miss' and say your children's names. My kids have a great pediatrician like I said. When we go in he wants to know about how you are doing in school. He conversates with you, you know, the whole works. 'What's up with that hair-do? Why do you wear your pants that way?' We need a lot more personal interaction.

Provider participants also discussed the importance of *communication to families* as a facilitator to identification and treatment. A faculty participant stated:

I like as much communication as possible. I want residents to say as much as you're thinking to the parents. So if we are considering a broad differential then I want them to say that. I want them to talk about the fact that we're worried about...that they're maybe dealing with depression or anxiety. I want them to talk parents through the different options that we have and what we can offer in terms of treatment.

Similarly, a director participant stated:

It is to try and make sure that mom and I and the resident are on the same wavelength on what we think is going on. Make sure they got the story correct, first of all, and then what are the options to deal with it at this point, and what does mom think would be the best thing to do.

A resident participant discussed *communication to families* in relation to *stigma of mental health*:

“So that obviously makes it easier when the parents are noticing, when they are coming to grips with it, where they bring it to your attention. Then you have less of this stigma to address with having mental health issues.”

Education for families. Closely related to *communication to families*, participants discussed the importance of providing education to patient and families as a way of improving communication, increasing knowledge of mental health disorders and treatment, empowering patients and their families, and reducing *stigma of mental health*. One resident participant stated:

I don't think people know they have that right to, or they don't feel empowered enough to because either they don't feel like they are smart enough. So help empowering them to know what is going on. So if you give them things to read, some of that you have to go through with them. And say 'Okay, this is what is going on with your child; these are the steps you need to go through.'

Another resident discussed the potential educating parents in a group setting:

I would like to see a parent education group. Teach them about a particular topic in pediatrics that they would need to learn about, whether it is signs and symptoms of depression, or how to navigate the waters of the school. Those types of things I think would be helpful to help educate, because we not only open them to our kids, but to their parents, and not doing everything for them, but giving them the information. My philosophy is if you teach people, then you empower them to feel like they can do things. In pediatrics you are not just treating the kid, you are treating their family, and their parents. And if you educate the child you need to educate the mom and the dad too.

A nurse participant also reflected the importance of not only educating patients, but their caregivers as well: “I think not only the children need help; I think the parents need help sometimes knowing how to handle their kids that have these issues. They don't know how to deal with it. They need just as much counseling and education on the actual issues.” Parents also discussed wanting more education on mental health issues. One participant noted:

I think the same way y'all teach us how to feed our babies and about colds and all these things. You teach us how to be our own little doctors and nurses and all of that, but nobody is running around teaching us about the characteristics of the child behavior

problems. The same way y'all promote the immunizations, you should be spreading it around these little things so that when we see them as parents we are like, 'oh my kid is doing this or oh my kid is doing that.' So we can check it off. I mean there's so many things I didn't know about mental behavior problems with children. I found out about it only because I had to experience it because I had ten children...I volunteered at school so I got to see certain things. But if I didn't do that and wasn't always around the children, I wouldn't know.

Another parent added how having information on flyers and posters around the hospital would be helpful as well:

Advertising to let kids and their parents know that having a psychological or a mental health issue doesn't mean your crazy, that you're doomed, that the good people at [children's hospital] can help your arms and your legs, but they can also help your mind and your heart, the inside and the outside.

Provider communication. Improved *provider communication* both within clinic and with community mental health providers was discussed as a way to facilitate integration. The ability to make direct referrals to community agencies and providers, shared medical records, and receiving feedback from referrals were all described as ways to develop better communication and improve *continuity of care* for patients. One resident discussed improved communication within consideration of a patient's right to privacy:

Ideally I would like to pick up the phone, schedule an appointment, be able to get feedback from whoever I've referred them to about progress, medications...of course you have to respect their desire for privacy and whatever the patient wants to a certain extent. But just feedback on things I can help with the family too.

Another resident discussed better communication between psychiatry and pediatric primary care:

The best thing is just having better, organized communication between these two departments and then try to have a good phone consultation arranged as soon as you feel like someone needs to be screened. Someone could screen them and give assurance that something is going on or not.

Providers also indicated that shared records or information would allow providers to feel better in support and/or treating certain mental health issues in clinic. One director stated:

Try to obtain some documentation from previous mental health providers as to the diagnosis and their recommendations. I have less of a problem prescribing medication as a bridge if I have access to the information from the psychiatrists who made the diagnosis and prescribed the medicine originally.

Another director discussed the electronic medical record as a way to facilitate sharing protected health information:

Everybody's putting their notes electronically so you can at least have access to them as long as you know your patient actually was seen. And in fact today I got two messages to say that discharge summaries are available on two patients...At the time the notes were finally dictated in the system there is a way to notify the primary care physician that this is now online.

A resident participant discussed the importance of all providers involved, being mindful of communication: "All three people involved need to be more mindful...it would be nice if a PCP has the complete record. Just like a lot of those services, psychiatry and psychology...probably want the patient's medical records too. So it might be helpful if we send that kind of along with the patient.

Screening. Both informal (e.g., asking interview questions related to mental health) and formal (e.g., screening measures) assessment tools were indicated as important in the identification and referral and/or treatment of mental health disorders in pediatric primary care.

A resident participant discussed providing patients and families a screening measure in the waiting room:

I've actually talked with one of our attendings about screenings because, it really sucks walking into a routine ADD room, where every single visit is things are fine, refill script, and walking in and finding that things aren't fine. I can't refill that prescription. I've talked with them about doing actual paper screening tools for the parents to fill out because they are spending 20 minutes anyways waiting in clinic and that'll be something preventative and something that we can look at and have it right there...

Another resident expressed similar sentiment and added how screening would help facilitate communication about mental or behavioral health issues:

A screening tool we can give to parents while they are waiting in the waiting room...give them a clipboard with a developmental assessment or a questionnaire about certain behaviors that would give us red flags to focus on those things. In addition...you are being able to ask a couple of questions about the child's status, you know mental health wise and if some red flags were picked up on those things, you can say, 'You know what I was looking through your paper work and I saw a few things to talk to you about.' Then you can say, 'I need you to come back in a week,' or you could still choose to make that the focus of your visit, provided that it is a well child visit, provided that there are no other glaring health issues, and you can take that time to focus on that mental health issue.

A faculty participant added, "Better screening. Resources that you could really get them into once you screen them instead of saying you have something and there's no help for you." Parent participants also expressed interest in the availability of a screening tool as they wait to be seen by the doctor:

Addressing, yeah, what problems you may have. That's why I was saying as far as, if you have a questionnaire form there while you're waiting, then within that 15 minutes, there should be a 15-minute questionnaire form to give you something to do besides complain about how long the doctor's taking to see you. So if you're doing that, then at that point the doctor should be able to address it, even if not at that time, then they should be able to you know...to address this.

Another faculty participant talked about informal behavioral observations and discussions with the patient and families as a way to begin the screening and identification process:

It's always nice to observe the family interactions because that can be a sign of something going on. If there's a good relationship within the family, you're less likely to feel that they're not going to have support in whatever stress they have. Observing the family interaction and then talking about stressors in their life and kind of going through that pathway.

A resident participant discussed a similar informal interview process as well:

Usually with my adolescents, if I see them the parents will be out of the room, and so we kind of have the sex, drugs conversation...just asking more point blank, how are things going, and those types of things. I think being able to relate to patients and being able to say when I was in that same situation, the patients respond better, so it takes some of that stigma away. So we identify it and I tell them this is what is going on. I give my adolescents an option on whether or not they want me to talk to their parents about things...then I encourage them, if they don't want me to, for them to actually talk to their parents because it is important for the parents to be in the loop. But I also don't want to

take away our therapeutic relationship that we have established by going above them and talking to their parents. Unless, there is a real big suicidal ideation, I am concerned about them in that sense.

Discussion

The current study demonstrates a collaborative effort to identify barriers, behavioral health needs, and facilitators of integrated mental health care in pediatric primary care. This paper presents the results of a qualitative study designed to provide an understanding of relevant stakeholder views in a pediatric primary care clinic with regard to integrating behavioral health care to assist in the development of a program to address these needs. Literature on involving multiple stakeholders in studying mental health's role in pediatric primary care, especially patient and family perspectives, is sparse. The themes and concepts identified here will add to the growing literature of integrated mental health care in pediatric primary care and create an initial step for further exploration of these themes and concepts across various stakeholder groups in the pediatric primary care setting.

Although general barriers and facilitators of integration of behavioral health in pediatric primary care have been discussed in the literature (e.g., Cohen et al., 2012; Bitar et al., 2009), this study is the first to try and examine and address these issues from the perspective of multiple stakeholders. Specifically, six different stakeholder groups were sampled: patients, parents, nurses, residents, faculty, and clinic directors. A grounded theory approach guided analysis of the data in order to allow the themes and categories to develop directly from the stakeholders' ideas and opinions as opposed to a top-down approach.

Overall, stakeholders expressed an awareness of the impact of behavioral health disorders on youth, and generally expressed a high level of motivation and interest to integrate mental health services in the pediatric primary care setting. However, many barriers and consequences

were also discussed that hindered integration. Cutting across all stakeholder groups and taking into consideration all categories and themes that developed from the data, I will discuss several of the main findings.

Stakeholder groups differed in terms of the quantity of their discussion of specific themes. Of note, each stakeholder participant tended to see him or herself as a barrier and focused their discussion on themes closely related to their own challenges. Patients and parents discussed *patient-level barriers* more than other stakeholder groups. Patients focused their discussion largely on barriers related to their family environment and communication. Similarly, parents focused their discussion on lack of resources getting in the way of their ability to follow through, but also issues in communication and their beliefs around mental health as barriers to understanding. On the other hand providers (i.e., nurses, residents, faculty, clinic directors) discussed *provider-level barriers* more often than patients and parents. All provider groups discussed *lack of training* and *lack of time* as significant barriers of their ability to make mental health care an integral part of their daily practice in pediatric primary care. Similarly, *system-level barriers* were discussed most often by residents and faculty with the focus being the lack of true continuity with patient care and *organizational challenges* faced in attempting to integrate mental health care practices in their primary care clinic. In addition, residents and faculty identified behavioral health needs more readily than other participant stakeholders and focused their discussion on the importance of increased *provider education and training* and the need for *integrated mental health services*. Furthermore, patients and parents accounted for the least units of data, whereas clinic directors accounted for the most units of data (see Figure 2).

These findings indicate that each stakeholder focused on what is primarily relevant to his or her role within the pediatric primary care setting. Of note, evidence has shown that provider

perceptions' of responsibility, specifically not seeing themselves as responsible for the provision of mental health care, acts as a barrier toward integration (Stein et al., 2008). In contrast, provider stakeholders within the current study have indicated a sense of responsibility for their own challenges, as well as displayed a need and want for further education and training so they can play a bigger role in the provision of mental health care for their patients. Additionally, the differences in the units of data between patient/parents (2 adolescents, 7 parents) and clinic directors ($n = 2$) demonstrated that the ones who usually make the rules and are dominant in the relationship and their role in the clinic had the most to say.

Next, themes and categories that emerged in the current study, related to integrated pediatric primary care, are demonstrated in the literature as being salient with former study findings, as well as with other stakeholder groups' perceptions of barriers, needs, and facilitators to care. For example, *lack of resources*, is a patient-level barrier that has been found to impact access to and use of mental health and primary care services (Bitar et al., 2009; Pidano et al., 2011). Costs of these services without proper insurance and/or financial means, and problems related to transportation are a challenge for many families. In a focus group study, Bitar and colleagues discovered that physicians identified cost of services and transportation issues as a huge obstacle to accessibility and affordability of behavioral health care (2009).

Additionally, *lack of time* and *lack of training*, as mentioned earlier, have also been found by other investigators to be of concern to provider stakeholder groups (Bitar et al., 2009; Cooper et al., 2006; Simonian, 2006). Evidence demonstrates that lack of provider education and/or training gets in the way of proper assessment and diagnosis of mental health issues and may contribute to low levels of comfort amongst providers in treating these issues (Sand et al., 2005; Bitar et al., 2009; Gardner et al., 2003). Similarly, stakeholders surveyed in other studies have

indicated that time constraints limit the opportunity to systematically address psychosocial concerns, and concerns about additional screening arise due to already feeling at capacity (Simonian, 2006; Cooper et al., 2006; Sices et al., 2003). In contrast, evidence also indicates, as demonstrated in this study, that screening and assessment tools are seen as a facilitator to improve integration of behavioral health care (Bitar et al., 2009). Other needs and facilitators discussed in the literature that emerged as themes in this study include parent and caregiver education, provider training, continuity, and patient-provider relationship (Bitar et al., 2009).

Overall, throughout the integrated care literature, similar themes have emerged indicating that these barriers, needs, and facilitators are not specific to this distinct primary care setting, but a more global, widespread issue. For example, providers in various settings have discussed the challenge of time in integrating pediatric primary care. Unfortunately, in the age of managed care and a medical system currently centered on reimbursable services, mental health screening, assessment, and treatment seem like a burden and potentially unrealistic to providers. It is seen as a daunting task to adequately assess for behavioral and mental health needs in a short amount of time and then, in addition, taking the steps necessary once something is identified. This example highlights the importance of using flexible screening and assessment tools that could be completed and interpreted quickly in the pediatric primary care setting.

From an implementation standpoint that focuses on how to translate evidence-based practices to real-world settings (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005), several of the themes identified in the current study and in the literature are largely related to gaps in stakeholders' understanding of mental health disorders, identification, and treatment and/or the provision of mental health care in pediatric primary. As discussed, providers have identified a dearth in their education and training when it comes to all things mental health. Specifically, providers

indicated a need for more training in order to improve provider confidence and competence in identification, treatment, and referral of mental health problems, and more clearly define the PPCP's role in mental health care. Providers must be given the tools and knowledge to competently identify and treat behavioral health disorders. In training, these barriers can be addressed directly during the course of training by making education in mental health care a requirement for general medical and nursing education. In addition to using lecture and discussion formats to address issues related to screening, assessment, treatment (i.e., psychopharmacology and psychotherapy), and referral, exposure to working with mental health care providers on multidisciplinary teams would allow providers to gain valuable real-world experience. Additionally, opportunity for training with varied mental health populations and in varied settings would support increased competence and comfort in identification and treatment of the breadth of mental and behavioral health issues seen in pediatric primary care.

Additionally, patients and parents identified a lack of knowledge of mental health care, as well as continued stigma of mental health due to a lack of adequate and accurate knowledge related to behavioral and mental health problems. In addition, parents discussed not being aware of the available treatment options and resources and how to access these resources. Both parents and providers highlighted the importance of providing education to patients and families - via increased communication with providers, educational materials, and parent support groups - in order to increase their knowledge of mental health disorders and treatment options. Doing this would help to improve communication, empower patients and families, and reduce stigma of having a mental or behavioral health disorder or knowing someone who does.

Over the past 20 years, PPCPs have become increasingly involved in the management of children's mental and behavioral health disorders due to increased recognition of high prevalence

rates of mental health problems in pediatric primary care. The American Academy of Pediatrics concluded that PPCPs are in a unique position to play an important role in children's mental health due to the opportunity for a trusting relationship throughout a youth's lifetime and the ability to implement preventative efforts by promoting both physical and mental health, as well as timely psychosocial interventions in the course of a youth's development (2009). This sentiment was echoed by all stakeholders, particularly that a trusting relationship and continuity of relationship facilitated the provision of mental health care and increased perceived motivation and treatment adherence. Additionally, W. Douglas Tynan, PhD, a pediatric psychologist who developed a federally funded program that trains pediatric and psychology residents together in primary care settings, importantly stated, "Among low-income, difficult-to-reach populations, this is the most effective way for people to get their mental health services (Novotney, 2014a). Of note, the federally funded program Dr. Tynan helped to develop at Nemours, through hard work to standardize assessments, now boasts 90% screening rates for all children seen in the pediatric primary care clinics (Novotney, 2014a).

Importantly, cooperation at multiple levels of the clinic hierarchy working together is needed in order to create a supportive, proactive culture that works collaboratively in reducing barriers to integrated care. Mentioned by providers in the study was the lack of initiative or knowing who is in control and how this creates issues when attempting to develop or even discuss initiatives in integrated primary care. Workgroups within the clinic system can further facilitate integration of care by (a) identifying key leaders within the organization and establishing strategies to improve provider investment in integrated care; (b) establishing policies and procedures, and (c) helping to build relationships within the clinic and community. Workgroups can also focus on identifying

potential sources of funding for clinic initiatives, as well as working with insurance companies to determine possible routes for reimbursement of services.

Ultimately though, PPCPs will not be able to provide a full range of behavioral health services due to limitations in their professional competence as well as role and time constraints (Power, Blum, Guevara, Jones, & Leslie, 2013). The integration of behavioral health care into pediatric primary care requires a move from the traditional psychotherapy model to consultation and brief intervention. For example, in a recent case study, cognitive behavioral therapy for adolescent depression was adapted into a brief intervention for delivery in pediatric primary care with promising results (Borschuk, Jones, Parker, & Crewe, 2015).

In an integrated behavioral health model, mental health providers are consultants to patients and providers over a longer period of time. Changes in response to the Patient Protection and Affordable Care Act of 2010 highlight the importance of patient-centered medical homes (PCMHs) (Rittenhouse, Shortell, & Fisher, 2009), which emphasizes evidence-based, continuous, and integrated healthcare linked with community services (Institute of Medicine, 2001). PCMHs are best described as a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety (Novotney, 2014b). In recent years, it has become a widely accepted model for how primary care should be organized and delivered throughout the health care system. Importantly, PCMHs provide each patient with an ongoing, active relationship with a primary care provider and a team of professionals, which often includes a behavioral health provider, and delivers proactive, preventive management of physical and mental health issues (Novotney, 2014b).

In summary, the PCMH model is one way to help further integration of behavioral and mental health care in pediatric primary care. One example of this initiative is Project CLIMB

(Consultation and Liaison in Mental Health and Behavior) a collaborative effort between the Pediatric Mental Health Institute and the Child Health Clinic at Children's Hospital Colorado (Bunik, Stafford, Rosenberg, & Talmi, 2008). Project CLIMB provides integrated mental health services in the context of a residency training pediatric primary clinic and seeks to facilitate early identification and treatment of mental health and behavioral issues within a primary pediatric care setting, increase access to mental health services in an underserved population, and train health professionals in meeting the mental and behavioral health needs of children. Project CLIMB has provided mental health consultations to more than 3,200 children at Children's Hospital Colorado has trained hundreds of pediatric primary care professionals in mental health care, behavior and development (Bunik et al., 2008).

Study Limitations & Future Directions

Despite the public health importance of the study and its many methodological strengths (e.g., interviews with multiple stakeholders, consensus coding), the study had some limitations.

One limitation of the sample was the small number of participants in the patient and parent interviews due to time constraints, transportation issues, and difficulty finding childcare for other members of the family in order to attend the interviews. The implication of a small sample size is that the concepts and themes identified with this population may not be generalizable to other pediatric primary care patient populations. Despite this, it was important to present the voices of these patients and parents as they are currently underrepresented in the integrated care literature. The themes and concepts discussed here could be further investigated in other patient and family populations to determine how representative these ideas are to other samples. Future work could implement multiple strategies to recruit patients and parents more effectively. For example,

providing childcare, transportation, as well as providing onsite interviews and focus groups so patients and families would have less of a burden attending meetings (e.g., Ingoldsby, 2010).

Another limitation of the sample was all of the patient participants were adolescents and the parent participants were parents of adolescents. In order to generalize findings and represent a more complete developmental perspective on integration of mental health services in pediatric primary care, future research should seek to include a wider age range of patient participants, as well as include parents of younger children. When including younger children (age 14 or younger) it is important to consider where the child is at his or her developmental, social, and cognitive level in order to approach their participation and level of involvement in a developmentally appropriate manner (see McLaughlin, 2015). A researcher should also be mindful of the power differential present in a focus group or interview with younger children and take precautions to make the child feel as comfortable as possible. Including parents of younger children will also help improve generalizability by determining if similar barriers, consequences of barriers, needs, and facilitators are experienced by parents of younger children and what differences may be present between the two populations.

Similarly, although most stakeholder groups in the clinic were invited to attend focus groups, not all possible stakeholder participants were included (e.g., support staff, administrators). The sample was also one of convenience and represented a broad sample as opposed to a deep sample, which also limits generalizability of the findings. Future studies should conduct focus groups and interviews at multiple pediatric primary care clinics (e.g., academic medical centers, community clinics, private practices) in order to a) increase sample size, b) increase depth of sample, c) increase generalizability of findings by noting similarities and differences in barriers and facilitators in multiple, diverse clinic settings, and d) develop the

ability to seek further clarification from the sample for creation of codes by using member checking. Member checking involves showing the resulting themes and concepts to the same group of stakeholders and participants and asking how much they agree or disagree with the findings (Charmaz, 2006; Glaser 1978). Lastly, although the grounded theory approach calls for further exploration and clarification of themes in subsequent focus groups in order to reach theoretical saturation, we were not able to administer a second round of interviews because the data are archival. Therefore theoretical saturation of the data was not achieved (Glaser, 1978). Ideally, the process of constant comparison would continue until no new concepts or themes emerged.

Although consensus coding was completed for half of the transcripts, rigor was limited because the second coder did not code all of the transcripts. Despite this, rigor, or establishing confidence in the results of the study, also described as *trustworthiness*, was achieved in other ways (Lincoln & Guba, 1985; Thomas & Magilvy, 2011). In their model of *trustworthiness*, Lincoln and Guba discussed four components that are relevant to qualitative research: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. As stated by Krefting (1991, p. 218), “A qualitative study is considered credible when it presents an accurate description or interpretation of human experience that people who also share the same experience would immediately recognize.” *Credibility* is defined as confidence in the truth of findings and *dependability* as showing that the findings are consistent and could be repeated (Lincoln & Guba, 1985). *Credibility* and *dependability* were sought through peer examination where colleagues (i.e. psychologists working in a pediatric primary care clinic at an academic medical center) knowledgeable about the topic and methodology reviewed and discussed themes with me throughout the coding process and results writing process. In addition, after coding was

complete, triangulation with the literature occurred and the emergent themes and categories aligned with what has been found in previous research studies on barriers and facilitators in integrating mental health care into pediatric primary care. Additionally, *confirmability*, the extent to which the findings are shaped by respondents and not researcher bias, motivation, or interest, was established by presenting the results through the use of quotations. (Elo et al., 2014).

Conformability asks that the data accurately represent the information the participants provided, and through the use of quotations, a connection is made between the data and results presented. Lastly, *transferability*, or the ability to transfer research findings or methods from one group to another was established by providing a description of the population studied, as well as providing readers with study materials for future replication of methods (Thomas & Magilvy, 2011).

Further, it is possible that in attempts to reach consensus between two coders, one coder dominated consensus coding give the differential in coder seniority status (graduate-student level and post-baccalaureate research assistant) and familiarity with the literature. One way to safeguard against this would be to identify coders with similar credentials, backgrounds, and/or seniority status.

Moreover, since data were collected in 2008 (seven years ago), relevance of results may be questioned. Certainly, changes in overall health care and mental health care policy and professional education have influenced stakeholder perceptions since these interviews were held; for example, the introduction of the Patient Protection and Affordable Care Act (2010). However, the ideas and opinions collected remain important since they represent a survey of thoughts of a wide array of stakeholders in a pediatric primary care setting. The research-practice gap remains a major public health problem (e.g., McHugh & Barlow, 2012; Southam-Gerow,

Rodriguez, Chorpita, & Daleiden, 2012). Consequently, implementation of integrated care remains a high priority and to the extent that these results can be used in an effort to close the gap and further the initiative of integrating behavioral and mental health care into pediatric primary care, they remain useful and important.

Future research should work to identify mental health competencies required for PPCPs, and find ways to increase educational opportunities for all stakeholders. More research is needed to validate the outcomes associated with increased training and education on providers' knowledge, attitudes, and practice. Research efforts must also focus on exploring the costs and benefits of integrated care models in pediatric primary care, in order to determine best practices. Lastly, much of the research and literature has focused primarily on integrative initiatives for adults, so research that demonstrates the benefits of preventive efforts and promotion of development and well-being within integrated pediatric primary-care settings is important in order to increase federal and state initiatives in funding and help to develop better insurance practices that will allow behavioral health clinicians to see patients in pediatric primary care settings.

Conclusion

Despite these limitations, the study provides an examination and addresses barriers and facilitators of integration of behavioral health in pediatric primary care from the perspective of multiple stakeholders. Although there are many barriers to primary care integration, it is clear that pediatric primary care will continue to be central in improving the accessibility and availability of behavioral health care to children and families. All stakeholder participants in this study demonstrated an awareness of the impact of mental health issues on youth and a willingness to improve integration within their clinic and community, despite the identified barriers. These themes and concepts presented in this paper are hopefully the beginning steps in

identifying important factors in the integration of mental health care and primary care, through the ideas and opinions of important stakeholders in the pediatric primary care setting. This bottom-up approach allows for changes to come from within the clinics, as well as help inform policies that help to make integrated pediatric primary care a possibility for all primary care settings regardless of their locations and/or affiliations.

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Appendix A

PEDS Focus Group Study Parent and Patient Participant Recruitment Flyers

Attention Parents!



Let your voice be heard!

Participate in a group discussion about how to best help your children & families.

To participate in this Focus Group, you should:

- ✓ Have a child between **8-17** who has ever been a patient at VCU pediatric or adolescent medicine clinics
- ✓ Be willing to meet for a single 1 ½ to 2 hour session

Participants will receive a \$25 gift card.



For More Information, Contact Us At:

828-6273 or

PEDSproject@vcu.edu

This study is being conducted by researchers at VCU.

Contact: Michael A. Southam-Gerow, Ph.D.

APPROVED

Michael A. Southam-Gerow, Ph.D.



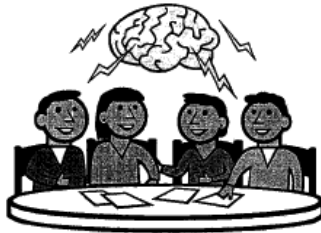
Are You Between The Ages of 14-17?

If so, you may be eligible to participate in a focus group discussion about how to best help children and families at pediatric clinics like this!

To be in the group you should:

- Be between 14 and 17 years old.
- Be a patient at this clinic.
- Be able to get permission from a parent or legal guardian.
- Be willing to meet for 1 $\frac{1}{2}$ to 2 hours.

All Participants will receive a \$25 Gift Card



APPROVED

9/24/07 MKG/DC

*For More Information Please Have
Your Parent or Guardian Contact Us At:
828-6273 or PEDSproject@vcu.edu
This study is being conducted by researchers
at VCU.*

Contact: Michael A. Southam-Gerow, Ph.D.

Appendix B

PEDS Focus Group Study Staff Invitation Letter and Focus Group Study Information Script for Staff



PEDS Focus Group Study
Focus Group Study Invitation

Dear _____:

Greetings! We are contacting you today to invite you to participate in a research project taking place. The Pediatric Anxiety and Depression Study (PEDS) is organized by Dr. Michael Southam-Gerow, a psychologist in VCU's Department of Psychology. Dr. Southam-Gerow and his research team have been collaborating with Drs. Brookman and Friedman on a screening research project in the pediatric and adolescent clinics for two years now. That project has led to another one, the goals of which are to work in conjunction with clinic doctors, nurses, and patients to make behavioral health services at the clinic the best that they can be. To accomplish the goals, focus groups and interviews will be held to identify needs for behavioral health care in pediatric primary care settings as well as to identify barriers and facilitators to providing that care.

We are currently recruiting residents, nurses, faculty members, and clinic directors to participate in one of several focus groups. The purpose of this focus group is to learn about your needs and the needs of your organization and clients in identifying the behavioral health needs of children. Focus groups will be held separately by profession—that is, we will hold focus groups for nurses and clinic doctors separately. We will also hold focus groups separately for residents and separately for training faculty. It is also possible that instead of a focus group, you will be asked to participate in an individual interview. We will ask you to participate in individual interviews if there are fewer than 4 people available to participate in the focus group.

If you choose to participate, you will be asked to complete a few brief forms at the beginning of the group. **The focus group (or individual interview) session will last between 1-2 hours and will take place at a date, time, and location convenient for all members. You will receive a 25 dollar gift certificate.** Your decision to participate or not participate in the study will not in any way affect your employment status. Participation is completely voluntary and you may choose to withdraw from participation in the project at any point.

If you are willing to participate in this study, please let us know via email (PEDSproject@vcu.edu) or telephone (804-828-6273). Please include in your response whether you would prefer to have us contact you via telephone or email to discuss dates and times for the actual focus group meeting. If you prefer to be contacted by telephone, please provide a telephone number and the best days and times to reach you. If you have any questions that you would like answered prior to making a decision about participation, please feel free to contact us via email (PEDSproject@vcu.edu) or telephone (804-828-6273).

Thank you for your time and consideration!

PEDS Project Staff

APPROVED

[Signature]

Version Date 10/9/2007



Focus Group Study Information Script for Staff

Hello. My name is _____, and I am a research staff member with a project at Virginia Commonwealth University, led by Dr. Michael Southam-Gerow. The goals of our study are to work with the staff here to identify needs for behavioral health care at in pediatric clinics. Part of that work is focused on seeing needs exist and the various barriers and facilitators to providing that care to pediatric patients. I would like to speak with you today regarding an opportunity for you to participate in our research study.

I am here today to speak to you to ask for your participation in a focus group study. A focus group is a meeting of 5-8 people to answer questions about a particular topic. The purpose of this focus group is to learn about your needs, the needs of the pediatric clinic and its patients with regard to identifying and treating behavioral health needs of children. You would participate in a focus group with colleagues from your profession and training level. As a result, nurses would all participate in a groups together, residents would do the same, and training faculty would do the same. *Participants will not be asked any personal information during the focus groups.* You will be asked to complete a few brief forms at the beginning of the group. The focus group session will last between 1-2 hours and will take place at a date, time, and location convenient for all members. You will receive a \$25 dollar gift certificate in exchange for you participation. Your decision to participate or not participate in the study will not in any way affect your employment status. Participation is completely voluntary and you may choose to withdraw from participation in the project at any point.

It is also possible that instead of a focus group, you will be asked to participate in an individual interview. We will invite you to be individually interviewed if there are fewer than 4 people available for a focus group.

If you are willing to participate in this study, please let us know via email (pedsproject@vcu.edu) or telephone (804-828-6273). Please include in your response whether you would prefer to have me contact you via telephone or email to discuss dates and times for the actual focus group meeting. If you prefer to be contacted by telephone, please provide a telephone number and the best days and times to reach you. You can also fill out this form and we will contact you soon. If you have any questions that you would like answered prior to making a decision about participation, please feel free to contact me via email (pedsproject@vcu.edu) or telephone (804-828-6273).

Thank you for your time and consideration!

APPROVED

9/24/07 MGO/DC

Version Date 10/9/2007

Appendix C

PEDS Focus Group Study Interview Protocols for Patient, Parent, Nurse, Resident, Faculty, and Director Stakeholder Participants

1. PEDS Focus Group Protocol - Patient

Welcome and thanks for coming today. We appreciate your time and expertise. I am NAME1 and this is my colleague NAME2. We work together on the research project. I will be asking the questions today while NAME2 will be taking care of the logistics and keeping me on track.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions, listen, and make sure everyone has a chance to share. We are interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you.

Remember that your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of the voices that are there to be heard. Second, and relatedly, I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given everyone a random nickname. So, let's start by everyone saying your nickname, where you were born, and the name of your school so the transcriber can have a chance to hear your voices some.

1. What would it take for you to talk with someone about problems you were having with your behavior/emotions?
 - a. Who would you talk to about it?
 - b. Pediatrician/doctor/nurse?
 - i. Why/why not?
 - c. What may make it hard for teens to talk about these kinds of problems?
 - d. What would make it easier?

2. If a teen with an emotional or behavioral problem did talk with someone about it, what do you think would be the best thing to happen?
 - a. What kinds of help do you think kids with problems should receive?
 - i. For themselves?
 - ii. For their families?
 - b. What might make it hard for kids with emotional or behavioral problems to get help?
 - i. What kinds of problems have you heard about?
 - c. Why do you think these problems happen?
3. In your opinion, what are ways to make things easier to get help with behavior and emotional problems that kids have?
4. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other groups as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

2. PEDS Focus Group Protocol - Parent

Welcome and thanks for coming today. We appreciate your time and expertise. I am NAME1 and this is my colleague NAME2. We work together on the research project. I will be asking the questions today while NAME2 will be taking care of the logistics and keeping me on track.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions, listen, and make sure everyone has a chance to share. We are interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you.

Remember that your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of the voices that are there to be heard. Second, and relatedly, I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given everyone a random nickname. So, let's start by everyone saying your nickname,

where you were born, and how many children you have so the transcriber can have a chance to hear your voices some.

1. What would it take for you to talk with someone about problems your child was having with his/her behavior/emotions?
 - a. Who would you talk to about it?
 - b. Pediatrician/doctor/nurse?
 - i. Why/why not?
 - c. What kinds of problems or struggles do you think people would have trying to get help if their child had a behavior or emotional problem?
 - d. What have you heard other talk about?
 - e. Why do you think these problems happen?
2. If a parent with a child with an emotional or behavioral problem did talk with someone about it, what do you think would be the best thing to happen?
 - a. What kinds of help do you think kids with problems should receive?
 - i. For themselves?
 - ii. For their families?
 - b. What are some problems that would make it hard for parents with kids with emotional or behavioral problems to get this kind help?
 - c. What other problems have you heard about?
3. In your opinion, what are ways to make things easier to get help with behavior and emotional problems that kids have?
4. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other groups as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

3. PEDS Focus Group Protocol – Nurse

Welcome and thanks for coming today. We appreciate your time and expertise. I am NAME1 and this is my colleague NAME2. We work together on the research project. I will be asking the questions today while NAME2 will be taking care of the logistics and keeping me on track.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions, listen, and make sure everyone has a chance to share. We are interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you.

Remember that your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of the voices that are there to be heard. Second, and relatedly,

I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given everyone a random nickname. So, let's start by everyone saying your nickname, where you were born, and the name of your nursing school so the transcriber can have a chance to hear your voices some.

1. What are your experiences managing mental health problems?
 - a. Screening?
 - b. If you identify?
 - c. Say to families and/or the patient?
 - d. What problems/struggles getting help for patients with mental health problems have you experienced?
 - e. What problems/struggles have you heard about from others?
 - f. Why do you think these problems happen?
2. What would you like to see happen after you identify a possible mental health problem in one of your patients?
 - a. Who refer to? Why?
 - b. NOT refer to? Why?
 - c. What kinds of services would you like to see happen?
 - i. For the patient?
 - ii. For the patient's parent to help the child?
 - iii. For the patient's parent to help her/himself?
3. What kind of help/guidance/training do you need to help you work more effectively with patients with mental health problems?
4. In your opinion, what are ways to make things easier to help children with mental health problems in primary care?
5. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other groups as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

4. PEDS Focus Group Protocol - Resident

Welcome and thanks for coming today. We appreciate your time and expertise. I am NAME1 and this is my colleague NAME2. We work together on the research project. I will be asking the questions today while NAME2 will be taking care of the logistics and keeping me on track.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions, listen, and make sure everyone has a chance to share. We are interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you.

Remember that your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of the voices that are there to be heard. Second, and relatedly, I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given everyone a random nickname. So, let's start by everyone saying your nickname, where you were born, and the name of your medical school so the transcriber can have a chance to hear your voices some.

1. What are your experiences managing mental health problems?
 - f. Screening?
 - g. If you identify?
 - h. Say to families and/or the patient?
 - i. What problems/struggles getting help for patients with mental health problems have you experienced?
 - j. What problems/struggles have you heard about from others?
 - k. Why do you think these problems happen?
2. What would you like to see happen after you identify a possible mental health problem in one of your patients?
 - a. Who refer to? Why?
 - b. NOT refer to? Why?
 - c. What kinds of services would you like to see happen?
 - i. For the patient?
 - ii. For the patient's parent to help the child?
 - iii. For the patient's parent to help her/himself?
3. What kind of help/guidance/training do you need to help you work more effectively with patients with mental health problems?
4. In your opinion, what are ways to make things easier to help children with mental health problems in primary care?
5. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other groups as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

PEDS Focus Group Protocol - Faculty

Welcome and thanks for coming today. We appreciate your time and expertise. I am NAME1 and this is my colleague NAME2. We work together on the research project. I will be asking the questions today while NAME2 will be taking care of the logistics and keeping me on track.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions, listen, and make sure everyone has a chance to share. We are interested in hearing from each of you. So if you are talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you.

Remember that your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of the voices that are there to be heard. Second, and relatedly, I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given everyone a random nickname. So, let's start by everyone saying your nickname, where you were born, and the name of your medical school so the transcriber can have a chance to hear your voices some.

1. How do you recommend that the residents manage mental health problems?
 - l. Screening?
 - m. If you identify?
 - n. Say to families and/or the patient?
 - o. What problems/struggles getting help for patients with mental health problems have you experienced?
 - p. What problems/struggles have you heard about from others?
 - q. Why do you think these problems happen?
2. What would you like to see happen after you identify a possible mental health problem in one of your patients?
 - a. Who refer to? Why?

- b. NOT refer to? Why?
- c. What kinds of services would you like to see happen?
 - i. For the patient?
 - ii. For the patient's parent to help the child?
 - iii. For the patient's parent to help her/himself?
- 3. When you were at the residents' training level, what training would you have wanted or needed to work more effectively with patients with mental health problems?
 - a. How have times changed since you were trained?
- 4. In your opinion, what are ways to make things easier to help children with mental health problems in primary care?
- 5. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other groups as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

PEDS Focus Group Protocol - Directors

Welcome and thanks for coming today. I appreciate your time and expertise. I am NAME1.

As you know from the Consent Form, we are taping the meeting. This device is the recorder (INDICATE). We are recording the meeting so we don't miss any of your comments.

I am here to ask questions and listen. Remember your comments are confidential. Also, remember that we are interested in any comments you have, negative and positive.

A few ground rules before we get started. First, we have several questions to get to today. Each could take a few minutes or much longer. I ask your help in our getting through each question while also making sure we hear all of your thoughts and relatedly, I want to be sure you understand that I may interrupt you to move things along or that I may ask you to add something. Our goal is that we hear as many different perspectives as there are on these issues.

Last, as I already said, we are recording the session. As a result, someone will be transcribing the tape so we can get your words exactly as you said them. The person doing the transcribing will not see you so will need to know you by your voice alone. To protect your confidentiality, we have given you a random nickname. So, let's start by your saying your nickname, where you were born, and the name of your medical school so the transcriber can have a chance to hear your voice some.

1. How do you recommend that the residents manage mental health problems?
 - r. Screening?
 - s. What to do if you identify a problem?
 - t. What do you say to families and/or the patient?
 - u. What problems/struggles getting help for patients with mental health problems have you experienced?
 - v. What problems/struggles have you heard about from others?
 - w. Why do you think these problems happen?
2. What would you like to see happen after you identify a possible mental health problem in one of your patients?
 - a. Who refer to? Why?
 - b. NOT refer to? Why?
 - c. What kinds of services would you like to see happen?
 - i. For the patient?
 - ii. For the patient's parent to help the child?
 - iii. For the patient's parent to help her/himself?
3. When you were at the residents' training level, what training would you have wanted or needed to work more effectively with patients with mental health problems?
 - a. How have times changed since you were trained?
4. In your opinion, what are ways to make things easier to help children with mental health problems in primary care?
5. What else do you think we should know?

Thank you. Your ideas and thoughts are really helpful as we all work together to figure out the best way to help children and families here at the clinic. We will be thinking about your thoughts and ideas along with the thoughts and ideas of other folks as we move the research forward. Our next step will involve developing a way to do a better job of helping families with children who have mental health issues. Your contribution today will really help that effort.

Appendix D

Frequency and Percentages for Themes by Stakeholder (percentage of theme between and within each stakeholder type)

	Patient	Parent	Nurse	Resident	Faculty	Director
Patient Barrier Total	22 (6.9, 55.0%)	116 (36.4%, 45.1%)	26 (8.2%, 15.9%)	87 (27.3%, 15.4%)	49 (15.4%, 12.0%)	19 (6.0%, 8.5%)
Chaotic family/environment	5	15	7	16	9	4
Knowledge MH care	0	7	3	10	3	2
Lack follow through	0	0	1	22	10	5
Lack of resources	0	29	9	8	6	2
Lack of trust	6	17	0	2	7	1
Pt/Parent comm.	6	24	3	17	6	2
Quick fix	0	0	0	6	2	2
Stigma of MH	5	24	3	6	6	1
Provider Barrier Total	0 (0.0%, 0.0%)	7 (2.9%, 2.7%)	31 (12.8%, 18.9%)	111 (45.9%, 19.6%)	53 (22.0%, 13.0%)	40 (16.5%, 17.9%)
Lack of time	0	5	17	28	7	9
Lack of training	0	2	9	55	33	24
Provider comm.	0	0	4	15	7	7
Unsure where to refer	0	0	1	13	6	0
System Barrier Total	0 (0.0%,	17 (5.6%,	25 (8.3%,	102 (33.8%,	107 (35.4%,	51 (16.9%,

	0.0%)	6.6%)	15.2%)	18.1%)	26.2%)	22.9%)
Financial	0	4	4	10	18	14
Lack of continuity	0	0	2	24	12	3
Limited MH services	0	1	1	14	13	4
Long wait	0	6	3	11	13	8
Training not required	0	0	2	7	3	1
Org. challenge	0	0	10	20	20	9
Shortage MH provider	0	1	1	5	11	7
Lack of specialty MH care	0	5	2	11	17	5
Need Total	1 (0.4%, 2.5%)	14 (5.5%, 5.4%)	23 (9.0%, 14.0%)	97 (38.3%, 17.2%)	85 (33.6%, 20.8%)	33 (13.0%, 14.8%)
Clinic resources	0	0	2	12	7	2
Continuity of care	0	3	6	14	20	1
Integrated MH services	0	4	6	22	17	13
Provider education and training	0	1	6	38	24	13
Specialty MH care	1	6	3	11	17	4
Facilitators Total	17 (3.6%, 42.5%)	89 (19.0%, 34.6%)	56 (11.9%, 34.0%)	141 (30.1%, 25.0%)	101 (21.5%, 24.8%)	65 (13.9%, 29.1%)
Comm. to families	8	27	11	13	11	7
Consult MH provider	0	0	3	13	11	9
Education for families	1	19	7	16	14	7
Increased accessibility	0	6	1	11	8	4
Provider collaboration	0	0	7	18	7	8

Provider comm.	0	2	7	29	18	12
Scheduling	0	6	4	9	2	4
Screening	2	16	13	27	23	12
Trusting relationship	6	13	3	5	7	2
Consequences of Barriers Total	0 (0.0%, 0.0%)	14 (19.4%, 5.4%)	3 (4.2%, 1.8%)	27 (37.5%, 4.8%)	13 (18.0%, 3.2%)	15 (20.8%, 6.7%)

Appendix E

Table of Code Definitions

	Code Definition
Patient-Level Barriers	Patient- and family-level barriers to receiving, accessing, and following through on mental health care
Chaotic family/environment	Lack of family structure and routine, chaotic home environment, lack of guidance, more important priorities (e.g., food, shelter), a cycle of negligence, unavailable parent, and/or a caregiver's own mental health issues.
Knowledge of MH care	Lack of knowledge on what mental health disorders are and the signs and symptoms in children, as well as lack of knowledge and/or understanding of child development. Also, the lack of knowledge of available treatment options/resources and how to access these resources.
Lack of follow through	Patient and their families being late to appointments, not attending appointments, treatment non-adherence, and not following through on referrals.
Lack of resources	Concerns related to cost of treatment for mental health issues and the limited financial resources of patients and their families.
Lack of trust	Lack of trust with providers that impacts patient and/or caregivers willingness to communicate with their providers, follow through with recommendations, and/or seek help for mental health issues.
Patient/Parent communication	Patient and/or caregiver's lack of or unwillingness to communicate their questions and concerns, as well as language barriers.
Quick Fix	Patient and caregivers wanting a quick solution to mental health issues and not treatment options that do not understand or may require time and resources they do not have.
Stigma of MH	Fear of being discriminated against or being viewed negatively for having mental health illness; negative attitudes and beliefs toward people who have a mental health illness. Also, viewing one's own mental health symptoms or issues negatively and feeling like one should be able to get through issues on their own, without help. Double standard between importance and focus on physical health versus mental health.
Provider-Level	Provider-level barriers to identifying and treating behavioral and mental

Barriers	health issues in pediatric primary care.
Lack of time	Not enough time during pediatric primary care appointments to adequately identify and treat behavioral and mental health issues.
Lack of training	Lack of or limited education and training in identification, assessment, and treatment of mental health disorders, as well as in psychopharmacology. Also describes lack of experience with a variety of patient populations and treatment settings, as well as what to do once a mental health issue has been identified.
Provider communication	Lack of communication between providers, specifically lack of feedback from community and/or within hospital mental health providers on referrals, and ability to communicate within the pediatric primary care clinic setting.
Unsure where to refer	Once providers have identified a mental health concern, unsure of what is available in the community, who to call, what is an appropriate referral, as well as concern for identifying but having no place to send child and family.
System-Level Barriers	System-level barriers to the provision of mental health care in pediatric primary care settings.
Financial	Mental health services are not viewed as profitable or important enough to be worth the financial resources it would take to sustain them. Lack of reimbursement for mental health services in pediatric primary care.
Lack of continuity	Inability to follow a patient throughout their care in clinic making management of mental health issues and follow-up difficult. Additionally, how this may affect patient morale and motivation for treatment.
Limited MH services	Lack of resources for the identification, assessment, and treatment of mental and behavioral health issues <i>within</i> their pediatric primary care clinic.
Long wait	Patients and families are unable to get in and see a mental health provider when they need due to long wait list. Concern for ability of patients in acute crisis to be seen in a timely manner.
Training not required	Education and training in psychiatry and/or mental health is not a requirement in medical school, residency, as well as nursing school. Providers must seek training on their own.
Organizational challenge	Concern about organization and management issues within clinic and system related to ability to integrate mental health care into pediatric primary care clinic. Clinic infrastructure not being set up for integrated training, not wanting to step on other disciplines toes, no one taking the initiative or knowing who is in control, lack of space, and scheduling system issues.
Shortage of MH providers	Not enough specialists in mental health care (e.g., social work, psychology, psychiatry) within hospital/clinic system and community to take care of all the issues seen in primary care. Additionally, certain settings have fewer specialists than others due to reimbursement issues and/or certain settings not as profitable.
Lack of specialty MH	Lack of accessible, affordable, and appropriate specialty mental health

care	care in the community.
Behavioral Health Needs	Needs identified by stakeholders for the provision of mental health care in pediatric primary care.
Clinic resources	Need for better tools within the clinic to allow providers to make better decisions for risk assessments, as well as for making decisions on symptom presentations. Also need for a comprehensive list of referrals and resources that providers can use in clinic, due to responsibility of the referral process falling on their shoulders.
Continuity of care	A need for continuity of care in the clinic and among community mental health providers, in order to help improve identification, diagnosis, and treatment of mental and behavioral health disorders in pediatric primary care.
Integrated MH services	Need for mental health services to be an integral part of pediatric primary care clinics in order to increase identification and treatment of mental and behavioral health disorders in children and adolescents.
Provider education and training	The need for increased provider education and training in order to improve provider confidence and competence in identification, treatment, and referral of mental health problems, and more clearly define the PPCP's role in mental health care.
Specialty MH care	The need for identifying and building relationships with specialty mental health care providers in the community. Increased accessibility and availability of special mental health care providers for patients and families. Need for more acute mental health care services for children.
Facilitators of Care	Facilitators identified by stakeholders that would make the provision of mental health care in pediatric primary care easier and allow for behavioral health needs to be met.
Communication to families	Increased communication to patients and families as a way to overcome obstacles and facilitate identification and treatment of mental and behavioral health issues in the pediatric primary care setting.
Consult MH provider	Ability to consult a mental health provider in person or by phone on same day of appointment to help in identification, treatment, and referral of mental health issues.
Education for families	Providing education to patient and families to help improve communication, increase knowledge of mental health disorders and treatment, empower patients and families, and reduce stigma of mental health.
Increased accessibility	Ability to make direct referrals to providers instead of the sole responsibility being placed on caregivers. Faster intake and assessment process to triage patients. Also, free services (e.g., transportation, classes), community programs, and mental health presence in schools.
Provider collaboration	Ability to have a shared medical record (e.g., electronic) for diagnosis and treatment purposes on shared patients. Receiving feedback from within hospital/clinic and community providers. Increased meetings involving all stakeholders/multidisciplinary team.
Provider communication	Improving communication between providers both within clinic and with community mental health providers in order to facilitate

	integration and provision of mental health care in pediatric primary care settings.
Scheduling	Being able to schedule more regular mental health appointments, as well as having longer appointment slots available. Having more control over scheduling of patients and ensuring that same provider sees patient for follow-up appointments.
Screening	Using both informal (e.g., asking interview questions related to mental health) and formal (e.g., screening measures) assessment tools to aid in identification, referral, and treatment of behavioral and mental health disorders in pediatric primary care.
Trusting relationship	Importance of establishing rapport and having a safe, trusting relationship with patients and families to increase buy in of mental health care and motivate patients to communicate and follow-up. Creating a comfortable, safe environment for patients and families to discuss mental health issues.
Consequences of Barriers	How barriers impact integration of mental health care in pediatric primary care, such as a decrease in patient and family motivation, patients “falling through the cracks,” misdiagnosis and subsequent lack of or inappropriate treatment, use of emergency department as mental health care, and the risk for mental health problems getting worse and/or tragedy occurring.

Vita

Alexis Michelle Quinoy was born on July 13, 1983 in Miami, Florida and is an American citizen. She graduated from Chattahoochee High School, Alpharetta, Georgia in 2001. She received her Bachelor of Science in Psychology with a minor in Spanish for Native Speakers and graduated Cum Laude from The University of Florida, Gainesville, Florida in 2005. She is a member of Phi Beta Kappa. Ms. Quinoy earned her Master of Science in Psychology from Virginia Commonwealth University in 2011 and will earn her doctorate in Clinical Psychology at Virginia Commonwealth University in August 2015 after completion of her psychology predoctoral internship. She is currently the Integrated Primary Care Psychology Intern at Children's Hospital Colorado in Aurora, Colorado. After earning her Doctor of Philosophy in Clinical Psychology, Ms. Quinoy will begin her career as a Postdoctoral Associate in Medical Psychology at the University of Florida, Gainesville, Florida.