Perceived Barriers and Facilitators to Mental and Behavioral Health Screening and Treatment in Primary Care for Women in Northeast Tennessee

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Perceived Barriers and Facilitators to Mental and Behavioral Health Screening and Treatment in Primary Care for Women in Northeast Tennessee

A thesis
presented to
the faculty of the Department of Psychology
East Tennessee State University

In partial fulfillment
of the requirements for the
Master of Arts in Psychology

by
Sarah K. Hill
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Keywords: Mental Health, Behavioral Health, Screening, Treatment, Primary Care, Qualitative Analysis
ABSTRACT

by

Sarah Hill

Between one quarter and one third of all primary care patients meet criteria for at least one mental disorder. However, many women are not screened for mental disorders as recommended by the literature. Some studies suggest even lower rates of screening and treatment in rural areas. This researcher sought to identify barriers and facilitators to mental and behavioral health screening and treatment for women in primary care and solicit feedback on how to ameliorate perceived barriers. Given the limited extant data describing rural Appalachian women’s perceptions of barriers and facilitators to receiving mental health services an exploratory qualitative analysis was conducted. Eighteen individual interviews with female primary care patients were conducted. Results identified stigma, lack of support, and lack of patient education around mental health as major barriers; facilitators included integrated care and positive experiences with providers. Directions for future research and implications for behavioral health practice in rural primary care are discussed.
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CHAPTER 1
INTRODUCTION

Despite mental health parity laws and other policy efforts aimed at increasing access to mental and behavioral health care, there are still significant barriers to screening and treatment for many Americans. Consequently, many people suffering from mental disorders do not receive the help they need (Substance Abuse and Mental Health Services Administration [SAMHSA], 2011). For rural Americans this problem is exacerbated by disparities in socioeconomic status (United States Department of Agriculture [USDA], 2012), access to health care services (Health Resources and Services Administration [HRSA], 2012), insurance status (Department of Health and Human Services [DHHS], 2012; Ziller, Coburn, & Yousefian, 2006), and higher perceived stigma or lack of privacy (Brown et al., 2010; Hoyt, Conger, Valde, & Weihs, 1997; Rost, Smith, & Taylor, 1993). In rural Appalachia the same barriers exist, although there is little research focusing specifically on rural Appalachian residents’ experiences of seeking help for mental or behavioral health concerns in primary care or otherwise (Hendryx, 2008). Appalachian health researchers also debate whether cultural values of self-determinism and “fatalism” may impact Appalachian residents’ willingness to address psychological issues (Fox, Merwin, & Blank, 1995; Hoyt et al., 1997).

Unfortunately, even less is known about the experience of rural women, Appalachian or otherwise, seeking mental or behavioral health care. Some research has suggested that rural women experience depression at significantly higher rates than nonrural women (Simmons, Braun, Charnigo, Havens, & Wright, 2008). However, none of the studies reviewed by Simmons
and colleagues speak to Appalachian communities, and nothing is known of Appalachian women’s experiences with mental and behavioral health treatment within a primary care setting.

**Statement of the Problem**

The problem to be addressed by this study is the lack of understanding of rural Appalachian women’s experiences of mental and behavioral health screening and treatment in primary care. Specifically, this study is an examination of women’s perceptions of barriers and facilitators to discussing mental and behavioral health concerns with their primary care providers, and to seeking and receiving treatment for a mental disorder. Given the nature of qualitative methods to be used in this study (e.g., individual interviews) and the paucity of research literature from which to draw, there are no explicit hypotheses proposed. However, based on the limited existing research and the study’s theoretical underpinnings, I expect that certain thematic trends will emerge from the interview data. Specifically, I anticipate participants will endorse economic, logistical, sociological, and cultural barriers to seeking help for mental and behavioral health concerns.

**Background**

Historically viewed as distinct, mental (psychological and behavioral) and physical health are now widely known to be related (deGruy, 1997). Kroenke et al. (1994) found that a steep linear relationship exists between the number of physical symptoms patients have and the number of psychological symptoms they experience. Mental health has been shown to be a moderator of physical disease (Prince et al., 2007) as well as a causal factor in the development of physical disease (Boscarino, 2004; Everson-Rose & Lewis, 2005). Because so many behavioral issues arise in primary care and often complicate the treatment of physiological health problems (deGruy & Etz, 2010), behavioral health problems are of growing concern within
medicine and the public health arena (CDC, 2011). Yet, in addition to being viewed as separate from health care, behavioral health services have long been seen as supplementary or secondary to health care (Byrd, O’Donohue, & Cummings, 2005).

Though traditionally viewed as specialty services, now behavioral health is categorized alongside other essential health services (e.g., medicine and nursing) and considered less of a specialty, making the way for collaborative care systems (deGruy, 1997; Glied & Frank, 2008). A collaborative care system is one in which a primary care physician or nurse coordinates patient care with a mental health provider (deGruy, 1997). This change is fairly recent, and it was strengthened by the Mental Health Parity and Addiction Equity Act, which was passed in 2008. In passing that law Congress required mental health and substance abuse treatment to be provided “in a way that is no more restrictive than all other medical and surgical procedures” (SAMHSA, 2011). In part, the law prevents insurance companies from applying separate copays or deductibles to mental health and substance abuse treatment, which had previously been the case (SAMHSA, 2011). The lifting of barriers in the infrastructure of mental health and health care administration has led to easier collaboration between providers (deGruy & Etz, 2010). This paradigm shift is a welcome one, given the prevalence of behavioral health needs evidenced in primary care (deGruy & Etz, 2010).

**Prevalence and Description of Selected Mental and Behavioral Health Concerns**

According to a CDC report released in 2011, roughly 25% of all American adults have a diagnosable mental disorder (Reeves et al., 2011). Kessler, Chiu, Demler, and Walters (2005) also found a similar annual prevalence rate of 26% for mental disorders classified in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) and a troubling lifetime prevalence of 46% for anxiety, mood, impulse-control, and substance use disorders combined.
(Kessler, Berglund, et al., 2005; Kessler, Chiu, et al., 2005). These epidemiological studies reflect earlier estimates of mental health diagnoses in the U.S. primary care population (26%; Spitzer et al., 1994).

Some of the most significant behavioral health concerns among U.S. adults are depression, anxiety, substance abuse, and intimate partner violence (IPV; Hunter, Goodie, Oordt, & Dobmeyer, 2009; Kramer, Lorenzon, & Mueller, 2004). These psychological health concerns appear frequently in primary care and often complicate treatment of physical health issues (Gunn & Blount, 2009). In a study examining the prevalence of the most commonly diagnosed mental disorders, Kessler, Chiu, et al. (2005) found that 9.5% of U.S. adults suffered from a mood disorder during one 12-month period, with 45% of those with a mood disorder being classified as “severe” (Kessler, Chiu, et al., 2005). According to results from the 2010 National Survey on Drug Use and Health, 6.8% of U.S. adults had experienced at least one major depressive episode (MDE) in the previous year (SAMHSA, 2012). SAMHSA’s 2012 findings are consistent with decades of data showing women have significantly higher rates of past year depression than men (8.4%, and 5.1%, respectively; Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993; Parker & Brotchie, 2010; Rosenfield, 1980; SAMHSA, 2012).

While mood disorders, including major depressive disorder, have a lifetime prevalence rate among U.S. adults of 21%, anxiety disorders are experienced more frequently, at 29% lifetime prevalence (Kessler, Berglund, et al., 2005). Anxiety disorders have been associated with persistent high use of health care (Ford, Trestman, Tennen, & Allen, 2005) and represent a particular challenge for primary care providers because of the high number of somatic complaints associated with anxiety (Ford et al., 2005; Wittchen, 2002). In one study both anxiety and depressive disorders were associated with future specialty outpatient services, which
may suggest the need for additional services from behavioral health specialists (Ford et al., 2005).

Substance use disorders in the U.S. adult population have a lifetime prevalence of 15% (Kessler, Berglund, et al., 2005), with alcohol and marijuana being the most frequently abused substances (American Psychiatric Association [APA], 2000). As with mood and anxiety disorders, substance use disorders can lead to and exacerbate physical health conditions and complicate treatment (Lydecker et al., 2010). Given the frequent overlap of somatic complaints with substance use disorders (Hassan & Ali, 2011), primary care providers may be the first health care providers to observe a patient’s substance problem. Additionally, many physicians report feeling unprepared to treat substance use disorders in primary care (Miller, Sheppard, Colenda, & Magen, 2001).

Estimating the prevalence of intimate partner violence (IPV) is more of a challenge, because there is no consensus among researchers about what IPV entails. Operational definitions incorporate some or all of the following: sexual, physical, and psychological abuse (Kramer et al., 2004). Due to disagreements in defining IPV, prevalence rates vary widely; studies estimate between 20%-66% of all women have experienced IPV at some point in their lives (Bailey & Daugherty, 2007; Kramer et al., 2004; Schafer, Caetano, & Clark, 1998; Thompson et al., 2006). Annual prevalence rates are lower; one study found 28% of women had experienced emotional abuse, 12% physical abuse (50% of which was classified as severe), and 4% sexual abuse within the past year (Kramer et al., 2004). Because many types of abuse involve a physical injury, victims often present at health care clinics for treatment (D’Avolio et al., 2001; Hathaway et al., 2000). However, despite its prevalence, many primary care providers do not routinely screen

Unfortunately, many of the behavioral health issues discussed here are comorbid with each other. Some evidence suggests a diagnosable mental disorder may be a risk factor for developing a substance use disorder (Swendsen et al., 2010). Comorbidities increase the challenge for health care providers, many of whom may be unprepared to deal with comorbid psychiatric diagnoses, and make it more difficult for patients to receive the care they need (Kuehn, 2010).

**Problems in Diagnosis and Treatment of Mental Disorders in Primary Care**

Patients who present with a mental or behavioral health concern represent an ever-growing portion of the primary care population. Between one quarter and one third of all primary care patients meet criteria for at least one mental disorder (Carbone et al., 2000; Ford et al., 2005). In fact, around 90% of all presenting problems in primary care have no known physiological etiology (Kroenke & Mangelsdorff, 1989), and at least some of those patients are expressing somatic symptoms of a mental disorder or psychological distress (Byrd et al., 2005). Yet, of those patients with a diagnosable mental disorder seen in primary care, less than half will have their disorder detected by a general practitioner (Carbone et al., 2000; Ford et al., 2005; Wittchen, 2002). This issue is complicated by the fact that many Americans treated for mental disorders never see a behavioral health specialist but rely on primary care providers to manage their disorders (Wang et al., 2000). Training in mental health varies both between and within primary care disciplines, presumably leading to differences in the care provided to patients (American Academy of Family Physicians, 2013; American Association of Nurse Practitioners, 2013).
Even knowing the need for improvements in behavioral health care, it is startling that so many Americans with mental disorders do not receive treatment. The 2010 National Survey on Drug Use and Health (NSDUH) data show that of those adults who suffered from any mental disorder, only 39% sought treatment (SAMHSA, 2012). Among those diagnosed with a serious mental illness, 60.8% sought treatment (SAMHSA, 2012), which is consistent with findings suggesting primary care patients who seek treatment for mental disorders are among the highest users of care (Carbone et al., 2000; Ford et al., 2005).

Another study found that of those with major depressive disorder, 57.3% received some kind of treatment within the year prior to their interview, yet only 41.3% of those seen by a primary care provider received minimally adequate treatment (Kessler et al., 2003). Minimally adequate treatment was defined by the researchers as receiving either “at least 4 outpatient visits with any type of physician for pharmacotherapy…or at least 8 outpatient visits with any professional in the specialty mental health sector for psychotherapy lasting a mean of at least 30 minutes” (Kessler et al., 2003, p. 3098). Thus, while the demand for mental and behavioral health services has certainly extended into primary care, there is evidence to suggest that patients who are treated there may not be receiving the help they need.

Looking at rates of treatment, there is evidence that between 50%-60% of those with depression do not have their disorder detected by a primary care provider (Sherbourne et al., 2001). Furthermore, a study by Drapalski, Milford, Goldberg, Brown, and Dixon (2008) suggests that among individuals with serious mental illness, personal characteristics like race and financial resources, and situational factors including life stressors and personal crises are likely to be barriers to seeking services. The study also identified interpersonal characteristics like stigma, previous experiences with health care providers, and distrust as barriers. Consistent with
the figures cited above, the authors concluded that psychiatric illness itself may be a barrier to seeking and receiving services among their study population of veterans with serious mental illness (2008).

**Barriers to Mental and Behavioral Health Screening and Treatment in Rural America**

While barriers to screening and treatment of mental and behavioral health issues certainly exist everywhere, these problems are even more acutely felt in rural areas. The likelihood that a mental disorder will be treated exclusively by a primary care provider increases in rural areas, where providers are required to be generalists and where access to behavioral health care is limited and/or viewed as stigmatizing (Gamm, Stone, & Pittman, 2003). Rural areas are often designated as “medically underserved” or as health professional shortage areas, based on the Health Resources and Services Administration (HRSA; HRSA, 2012). Within the Tennessee First Congressional District, 7 of 12 counties are designated as having mental health professional shortages, and six qualify as medically underserved (HRSA, 2012). When too few mental health professionals exist in an area, the treatment of mental disorders falls to primary care providers who may not be adequately trained to deliver quality care (Gamm et al., 2003; Wang et al., 2000).

Compared with their urban counterparts, rural Americans are faced with more disparities in general. Rural residents are more likely to “lag behind” urban residents in educational attainment according to a White House Council of Economic Advisers blog report (Romer & Wolverton, 2010). Additionally, more rural Americans live in poverty than those from urban areas. Based on the United States Department of Agriculture (USDA)’s rural-urban continuum codes, approximately 7.9 million nonmetropolitan Americans (16.5% of the nonmetropolitan population) were living in poverty, compared with 14.9% of those in metropolitan areas (USDA,
In the South, the gap between metropolitan and non-metropolitan poverty rates is higher than in any other area of the country, with 16.2% of metropolitan Southerners living in poverty, while 19.6% of nonmetropolitan Southern residents were poor (USDA, 2012).

Specifically related to health care inequalities, researchers have found that rural residents experience more disparities in access to primary care than their nonrural counterparts (Arcury, Gesler, et al., 2005; Ricketts, Johnson-Webb, & Randolph, 1999). Arcury, Gesler and colleagues (2005) found that while rural America represents 20% of the nation’s population, fewer than 11% of American physicians work in rural areas. Additionally, rural residents typically experience longer travel times to reach health care providers (Arcury, Preisser, Gesler, & Powers, 2005; Ricketts et al., 1999), and they may have to travel on poorer roads (Dewees, 2000), which can be especially problematic in inclement weather.

In addition to the lack of access to health care providers and problems surrounding transportation, rural Americans experience disparities surrounding health insurance coverage as well. The lack of health insurance coverage among rural Americans may be due to unemployment as well as underemployment and self-employment (CDC, 2011). Underemployment, which refers to part-time or seasonal work, often limits a person’s ability to purchase health insurance through his or her employer (CDC, 2011). In 2009, 57% of unemployed Americans were also uninsured, and 68% of those adults stated they lost their health insurance because they lost their job or were no longer able to afford coverage (Schwartz & Streeter, 2011). According to a brief report issued by the Rural Policy Research Institute (RUPRI) in 2009, rural economies lost jobs more rapidly during the recent economic recession than urban economies, which may be more diverse (Drabenstott & Moore, 2009).
Additionally, many rural underinsured Americans may be underinsured because they are unable to afford the out-of-pocket costs of insurance premiums, which are substantially higher than those for urban Americans (38.8% of health care costs for rural, nonadjacent-to-urban-area residents, vs. 32.3% for urban Americans; Ziller et al., 2006). Ziller and colleagues (2006) were unable to explain why this disparity exists. The lack of satisfactory explanation for why more rural Americans are under- or uninsured may indicate that psychological and social factors contribute as well.

A 2011 report prepared for the Appalachian Regional Commission (ARC) shows that a substantial portion of northeast Tennessee residents under age 65 do not have any health insurance (Lane et al., 2011). Within the Tennessee First Congressional District, rates of uninsured are high. For 4 of the 12 First District counties, this means uninsured nonelderly residents make up between 21%-40% of the population (Lane et al., 2011). For four other counties in the First District, rates of nonelderly uninsured residents reach between 41%-60% (Lane et al., 2011). This represents another major disparity in accessing health care. These uninsured rates are significantly higher than the statewide uninsured rate of 19% among nonelderly adults in 2010-2011 (Schwartz & Streeter, 2011). Additionally, although the national uninsured rate of 21% for 2010-2011 matches the lowest uninsured rate for the eight Tennessee counties mentioned previously, local uninsured rates in this area nearly triple 21% in some instances (Lane et al., 2011; Schwartz & Streeter, 2011).

In addition to disparities in socioeconomic and health insurance statuses, rural Americans are more likely to endorse certain sociocultural factors that may contribute to limited access to or use of health care. For example, rural residents may experience higher levels of stigma related to specific mental health issues (Brown et al., 2010; Rost et al., 1993), or they may feel less
comfortable seeking treatment for mental health concerns in a small town where anonymity is more difficult (Hoyt et al., 1997). Furthermore, rural residents often seek help for mental health concerns from informal sources (e.g., family, religious organizations, friends, and self-help), and this phenomenon may be more common among minority or insulated cultures (Blank, Mahmood, Fox, & Guterbock, 2002). Some researchers suggest this may be related to stereotypically rural values of self-reliance, individualism, and fatalism (Coward et al., 1983; Fox et al., 1995; Hoyt et al., 1997).

Finally, despite claims that rural areas experience prevalence rates for mental health diagnoses similar to their urban counterparts, some evidence shows that rural women may be at increased risk for depressive disorders (Simmons et al., 2008). In one 1993 study, 41.4% of participants reported clinically significant depressive symptoms within the last 2 weeks (compared with a national lifetime prevalence rate of 16.2% and an annual prevalence rate of 6.8% in 2001-2; Hauenstein & Boyd, 1994; Kessler et al., 2003). Sears et al. (1999) found 35.5% of women in a primary care sample were diagnosed with major depression. Additionally, Carruth and Logan (2002) observed a 24% prevalence rate for depression among a sample of female farmworkers in Louisiana. Each of these studies was conducted using rural women as participants, suggesting rurality may negatively impact women’s mental and behavioral health.

**Barriers to Mental and Behavioral Health Screening and Treatment Among Women**

Much of the literature on mental and behavioral health screenings in primary care does not focus on gender differences. Thus, there is little research describing mental health screening in women generally, although much attention has been given to specific subsets of women who may experience higher rates of mental and behavioral health problems than the general population. Since 2000 there have been dozens of studies published on screening pregnant and
postpartum women, largely for depression. Several of these studies address the prevalence of mental disorders during and after pregnancy (Gaynes et al., 2005; Lindahl, Pearson, & Colpe, 2005; Vesga-Lopez et al., 2008), while others describe the process of detecting diagnosable mental disorders and the utility of specific screeners (Chaudron, Szilagyi, Kitzman, Wadkins, & Conwell, 2004; Hanna, Jarman, & Savage, 2004; Horowitz & Goodman, 2006).

One possible reason for low rates of treatment of depression among rural women may be the lack of a formal screening process (Tudiver, Edwards, & Pfortmiller, 2010). In their study the authors conducted a chart audit of 615 female patients to identify formal and informal depression screening processes across 19 rural health clinics in the U.S. They found that only 2.4% of charts documented a formal depression screening (i.e., documenting specific depression-related questions asked), while 33.2% were screened informally. The authors also found a higher prevalence of depression among their rural sample compared with the national average (19% versus 8%; 2010). They suggested that because national rates of depression reflect detection using formal screening processes, many instances of depression in rural clinics may be undiagnosed and untreated due to a lack of adequate screening (2010).

Another study, conducted in rural eastern North Carolina, used focus groups with low-income pregnant women to identify perceived barriers to seeking help for depressive symptoms during pregnancy (Jesse, Dolbier, & Blanchard, 2008). The participants identified lack of trust, stigma, dissatisfaction with the health care system, and not wanting help as the major barriers to seeking help for depressive symptoms. Lack of trust referred to fears that the provider would break confidentiality (including speaking with another health care provider) or violate the patient’s privacy, as well as a lack of trust in relationships with providers. In particular, the study revealed a significant racial disparity in barriers identified, with African American women
reporting more difficulty trusting providers, more experience with stigma or judgment, and higher dissatisfaction with length of wait and discontinuity of care (Jesse et al., 2008). In addition to pregnant and postpartum women, the literature addresses other special populations, including incarcerated women (Green, Miranda, Daroowalla, & Siddique, 2005) and women with cancer (Ell et al., 2002).

In a study examining barriers to receiving mental and behavioral health services among American women, Sherbourne et al. (2001) identified multiple “predisposing” and “enabling” factors that contribute to unmet need, including minority status, lower education attainment, lack of health insurance, lack of social support, and lack of a usual source of health care. Additionally, they found that 35% of women chose not to receive services but preferred to “handle their problems themselves,” which may speak to perceived stigma or poor mental health care experiences (Sherbourne et al., 2001, p. 240). The authors note that this sense of self-determination may also be a function of cultural differences.

Finally, in a study examining the relationship between rurality, gender, and mental health treatment, Hauenstein et al. (2006) found that rural women experienced lower rates of treatment for mental disorders than their urban counterparts, although higher rates of treatment than rural males. Interestingly, Hauenstein and colleagues found that mental health deteriorated slightly but significantly for both men and women as their level of rurality increased (2006). Moreover, the authors also found that women (compared with men) were more likely “to perceive a need for mental health treatment, to desire specific mental health treatments, and to receive their care in primary care settings” (2006, p. 180). These findings shed light on the potential impact of incorporating psychology into primary care in rural areas.
Theory

As the above literature review suggests, recent research supports looking at different factors across multiple domains (psychological, interpersonal, social, biological) to understand what may contribute to help-seeking behavior. This section explores three theoretical models of human development and behavior, each of which addresses the interconnectedness of the biological, psychological, and sociological realms of behavior.

Ecological Systems Theory

Urie Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner, 1979) defines human development as the product of interaction between an individual and his or her environment. Bronfenbrenner’s theory suggested that each person develops within a unique environmental context, based on his or her relationships with others, as well as other social and nonsocial aspects of the environment (1979, p. 18). Although previous theories (reinforcement, behavior theory) acknowledged an individual’s environmental setting as relevant to learning and behavior, Bronfenbrenner was among the first to emphasize the interaction between a person and the environment.

The Ecological Systems Theory can be viewed as a series of four concentric circles or systems surrounding an individual. The four systems—micro-, meso-, exo-, and macro—each interact with the individual in a bidirectional fashion, and all influence development (Bronfenbrenner, 1979).

The microsystem is the circle closest to the individual, and it includes “face-to-face influences…such as interactions within one’s immediate family, informal social networks, or work groups” (McElroy, Bibeau, Steckler, & Glanz, 1988, p. 354). The microsystem also encompasses activities and roles the individual experiences within the immediate surroundings
(Bronfenbrenner, 1979), such as providing food and shelter for a child, in the role of parent. The
microsystem exerts the most influence on the individual, of the four systems.

The mesosystem involves the interaction of two or more settings in which the individual
is involved (Bronfenbrenner, 1979). For example, this may include the interrelations of one’s
spouse and coworkers. Bronfenbrenner referred to the mesosystem as “a system of
microsystems” (1979, p. 25).

The exosystem refers to settings that do not directly include the individual but that
influence or are influenced by his or her development nonetheless (Bronfenbrenner, 1979).
Examples of this might include a spouse’s work setting, neighbors, a friend’s elderly parents, or
even the current economic climate. Even though these settings and events are only impacting the
individual indirectly, the effect can still be profound.

The final level of the Ecological Systems Theory is the macrosystem, which includes
laws, customs, and cultural values, practices, and beliefs that influence the individual as well as
the other lower-order systems (micro-, meso-, and exo-; Bronfenbrenner, 1979). The
macrosystem includes things like cultural beliefs about gender and the value a community places
on its religious practices.

Each of these systems influences the individual’s development, as seen in the examples
provided. However, the individual also impacts the various systems surrounding them. This
bidirectional relationship between individual and environment is constantly changing as the
person takes on or lets go of roles or surroundings. The inclusion of a fifth system—the
chronosystem—underscores time’s influence on the other four systems and on the individual
(Bronfenbrenner, 1979).
Bronfenbrenner’s theory of Ecological Systems suggests that when change occurs within one system, it is filtered through the lower-order systems, impacting them and eventually reaching the individual (Bronfenbrenner, 1979). Bronfenbrenner’s theory does not focus specifically on behavior but more broadly on development. However, Bronfenbrenner’s theory provides support for the notion that an individual’s behavior and attitudes should be examined contextually and should be viewed as dynamic and complex. Therefore, while the Ecological Systems Theory suggests that a model for understanding certain behaviors—in the case of this research, health-promoting behaviors—might incorporate different factors across multiple domains, it is not helpful in identifying those factors specifically.

Social Learning Theory

Albert Bandura’s Social Learning Theory (1977, 1986) does address individual factors, and as a theory of behavior rather than development, it may provide better insight into individuals’ health care decision-making and behaviors. Bandura’s theory defines behavior as “the continuous, reciprocal interaction between cognitive, behavioral and environmental determinants” (1977, p. vii). Bandura sometimes described his model of behavior as “reciprocal determinism,” meaning that the individual’s behavior changes and is changed by his or her personal factors and the environment (1977). Visually, Bandura’s model is often represented as a triangle, with three bidirectional arrows between personal factors and behavior, personal factors and environmental factors, and behavior and environmental factors. Social learning theory states that the relative influence of each of these components of behavior differs based on the setting and the behavior in question.

Bandura’s theory evolved in part because he saw behaviorism’s explanation of learning as overly simplistic (Bandura, 1977). For example, one major aspect of Bandura’s theory is the
importance placed on vicarious learning. In opposition to behaviorism, which posits that learning happens only through direct experience, Social Learning Theory states that most learning happens via observation of others’ actions and their consequences (1977). Bandura noted that learning would be extremely slow and tedious if every person had to go through his or her own trial-and-error process.

One way that observational learning happens is through modeling. Modeling refers to the process of observing others to form an idea of how new behaviors are formed and using that information as a guide for action (Bandura, 1977). Much modeling occurs by conveying symbolic information verbally, which allows for nearly any behavior to be communicated quickly and efficiently without the need for demonstration. For example, in giving directions to a strange place, one might provide information about left- and right-turns rather than driving a new route with a friend; this saves time and is an example of modeling behavior. At other times modeling may occur by conveying the behavior through pictures or live actions (1977).

Another of Bandura’s constructs that may be of significance to this study (based on its presence in health care literature) is self-efficacy (Bandura, 1990; Maibach & Murphy, 1995; Sarkar, Fisher, & Schillinger, 2006; Schwarzer, 1992; Torres & Solberg, 2001). Self-efficacy refers to people’s capability “to exert control over events that affect their lives” (Bandura, 1989, p. 1175). Individuals’ perceived self-efficacy, or their beliefs regarding their capabilities, appears to influence strongly whether difficult tasks are viewed as something to be mastered (high perceived self-efficacy) or to be avoided (low perceived self-efficacy; Bandura, 1977). For this study, self-efficacy may explain some women’s avoidance of or engagement in health behaviors like regular check-ups and preventive screenings. Additionally, using Bandura’s model to explain how behavior, personal, and environmental factors interact and influence one
another may illuminate other important factors that contribute to health care decision-making and behavior.

**Roy Adaptation Model**

Finally, a third theoretical model developed by nursing scholar Sister Callista Roy may also provide direction for identifying specific factors related to health care decision-making and behavior and describing their relationship to one another. The Roy Adaptation Model (RAM; Roy & Andrews, 1999) was formally developed by Roy in 1970 as a way of conceptualizing and facilitating how nurses aid their patients in the process of adaptation (e.g., adaptation to an illness or to a specific set of behaviors; 1999). The bases of the model are key scientific and philosophic assumptions. The scientific assumptions state that human beings and groups “are… holistic, adaptive systems that constantly change and interact with their environment” (Rogers & Keller, 2009, p. 2). The philosophic assumptions state, in part, that human behavior is purposeful rather than driven by cause-and-effect; that humans have a need for relationships; and that there is value and a common purposefulness in human existence (Roy & Andrews, 1999).

From the RAM perspective, health is viewed as a process, and the individual is striving towards “becoming integrated and whole,” through adaptation in four modes: physiologic-physical, self-concept/group identity, role function, and interdependence (Rogers & Keller, 2009, p. 2). The physiologic-physical mode refers to humans’ basic physical needs, including, for example, oxygenation and nutrition. When humans in groups are considered, adequacy and abundance of resources must be assessed. The self-concept mode refers to an individual’s beliefs and feelings about him- or herself, including body sensation and body image (physical self), and “self-consistency, self-ideal, and moral-ethical-spiritual self” (personal self; Roy & Andrews, 1999, p. 49). In considering groups the group identity mode refers to interpersonal
relationships, group self-image, and culture. The role function mode describes expectations about how one group or individual should behave toward people in other roles. Role clarity is essential for individuals or groups to achieve goals (1999). The final mode, interdependence, refers to “interactions related to the giving and receiving of love, respect, and value” (1999, p. 50). In the interdependence mode Roy specifically focuses on relationships with significant others and with support systems and how these relationships can improve an individual’s or a group’s adaptiveness.

These four modes overlap and intersect such that behavior in one mode affects or stimulates the other modes as well. Thus, coping skills developed to address deficiencies in the physiologic-physical mode necessarily impact the individual’s beliefs about his or her body and may also alter role expectations and relationships with close others. However, while the modes may interact, the RAM describes adaptation as a whole in linear terms, whereby environmental stimuli result in coping processes, which in turn lead to the four modes of adaptation (Roy & Andrews, 1999). Although Roy viewed humans as influenced by their environment, she described the process of adaptation more along the lines of an input-output system rather than an interactive process with a feedback loop. In fact, because the RAM is a theoretical nursing model, it views nurses as the mechanism by which behavior is evaluated as being either adaptive or ineffective. Thus, in this model nurses are responsible for guiding patients in healthy adjustments to their coping behaviors, which results in healthy adaptation (1999).

The RAM has been applied to a variety of populations in the past 40 years, including patients with multiple sclerosis, cancer, and heart disease; women preparing for Cesarean childbirth; pediatric cancer patients; spouses and caregivers of critically ill patients; and as a means of addressing the nutritional health and physical activity needs of the elderly (Chen,
In one study Weinert developed her own conceptual model of adaptation to chronic illness among rural women, closely based on Roy’s Adaptation Model (Weinert, 2008). She identified three major categories of constructs: environmental stimuli, psychosocial responses, and illness management. Weinert predicted that the environmental stimuli (chronic illness, rurality, demographics, hardiness, optimism, and spirituality) would produce psychosocial responses (as measured by social support, self-esteem, acceptance, stress, depression, and loneliness scales) that would impact illness management (including self-efficacy, resource use, formation of partnerships, quality of life and happiness measures) either positively or negatively (2008).

Like the RAM and unlike Bronfenbrenner or Bandura, this model does not recognize the potentially bidirectional nature of relationships between environmental stimuli, psychosocial responses, and behavior (in this case, illness management). Nevertheless, Weinert’s recognition of specific variables that may impact an individual’s health reflects the health psychology literature where such variables were previously studied. This study’s literature review identified several of the same variables as Weinert—including access to and use of resources, rurality, socioeconomic status, religious beliefs, social support, and self-reliance—indicating these factors may be relevant for the present study population. However, because this model examined behavior from a theoretical perspective, it may be useful and illuminating to integrate the bidirectional interactions found in the Ecological Systems Theory and Social Learning Theory with elements of the Roy Adaptation Model, as it was revised by Weinert.
The present study incorporates elements of each of these three theoretical models to provide a framework for understanding rural women’s health care decisions and behaviors. An emphasis on environmental contexts, including the importance of interpersonal relationships, comes from Bronfenbrenner’s Ecological Systems Theory. From Bandura’s Social Learning Theory, an individual’s capacity for vicarious learning and intrapersonal factors such as self-efficacy add to the theoretical framework. In addition, this study emphasizes the interaction between an individual and his or her environment, as found in both of these psychological theories. From Weinert’s adaptation of the Roy Adaptation Model comes the proposed relationship between environmental factors, psychosocial responses, and health-care decision making.
CHAPTER 2

METHODS

Purpose of Research

The purpose of the current study is to explore rural women’s experiences with mental and behavioral health screening and treatment in primary care settings to identify barriers and facilitators to treatment-seeking. A qualitative approach was chosen given the limited extant data describing rural Appalachian women’s perceptions of barriers and facilitators to receiving mental and behavioral health services. The qualitative paradigm fits well with this type of study because qualitative research provides substantial contextual data that are important for understanding complex behaviors and attitudes.

The present study is situated within a larger research project that examines not only the barriers and facilitators to mental and behavioral health screening and treatment for women in primary care but also identifies what factors impact women’s health screening behaviors, specifically pap smears and mammograms. This study represents one phase of that project, which also involves a chart audit to understand the mental health and women’s health screening behaviors of providers and compliance of patients at two nurse-managed primary care clinics in northeast Tennessee.

Qualitative Methods

Qualitative methodology is increasingly used in psychological and other social science studies as a way of accessing “depth rather than breadth” (Ambert, Adler, Adler, & Detzner, 1995, p. 880). For example, community psychology increasingly relies on qualitative methods to address complex issues (Stein & Mankowski, 2004). Community psychologists often conduct research from an ecological perspective, incorporating geographic, sociocultural, and historical
aspects of behavior. Their research methods are an especially appropriate framework for this study because community psychology emphasizes diversity, the ecological framework of behavior, and the empowerment of research participants (Banyard & Miller, 1998). Another important implication of this perspective is that participants are viewed as the experts on their own experiences and community.

Participants

This study recruited 18 adult women aged 21 or older attending a nurse-managed primary care clinic in northeast Tennessee. The mean age of participants was 47 (SD=13.9) and 94.4% self-identified as Caucasian. Nearly all the women (N = 16) had at least earned a General Educational Development (GED) or high school diploma, and 55.6% (N =10) had attended some college. A large percentage (83.3%, N = 15) of the sample live below federal poverty guidelines, although 72.2% (N = 13) had some kind of health insurance. In addition, 88.9% (N = 16) reported having a family member with a mental health diagnosis. Detailed demographic information for the participants can be found in Table 1.
### Table 1

**Sample Characteristics**

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>n(%)</th>
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<tbody>
<tr>
<td>21-30</td>
<td>3(16.7%)</td>
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<tr>
<td>31-40</td>
<td>4(22.2%)</td>
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<tr>
<td>41-50</td>
<td>3(16.7%)</td>
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<td>4(22.2%)</td>
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<td>61-70</td>
<td>4(22.2%)</td>
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<table>
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<tr>
<th>Place of Residence</th>
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<tr>
<td>Rural Western North Carolina</td>
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<tr>
<td>Rural Northeast Tennessee</td>
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<tr>
<th>Race</th>
<th>n(%)</th>
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<tr>
<td>White</td>
<td>17(94.4%)</td>
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<tr>
<td>White/American Indian</td>
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<th>Ethnicity</th>
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<tr>
<td>Living with Partner</td>
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<tr>
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<tr>
<td>Divorced/Separated</td>
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<tr>
<td>High School Diploma/GED</td>
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<tr>
<td>Some College/2-Year Degree</td>
<td>10(55.6%)</td>
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<tr>
<td>4+ Years College</td>
<td>1(5.6%)</td>
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<table>
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<th>Family Income</th>
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<tr>
<td>&lt;=$10,000</td>
<td>7(38.9%)</td>
</tr>
<tr>
<td>$10,001-20,000</td>
<td>7(38.9%)</td>
</tr>
<tr>
<td>$20,001-30,000</td>
<td>2(11.1%)</td>
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<tr>
<td>&gt;=$50,000</td>
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<th>Living Below Poverty Guidelines</th>
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<td>Yes</td>
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<td>3(16.7%)</td>
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<table>
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<tr>
<th>Insurance</th>
<th>n(%)</th>
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</thead>
<tbody>
<tr>
<td>Uninsured</td>
<td>5(27.8%)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>4(22.2%)</td>
</tr>
<tr>
<td>Medicare</td>
<td>4(22.2%)</td>
</tr>
<tr>
<td>Medicaid &amp; Medicare</td>
<td>3(16.7%)</td>
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<tr>
<td>Commercial/Private</td>
<td>2(11.1%)</td>
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</table>

<table>
<thead>
<tr>
<th>Family Member with Mental Illness</th>
<th>n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>16(88.9%)</td>
</tr>
<tr>
<td>No</td>
<td>2(11.1%)</td>
</tr>
</tbody>
</table>
Interview Construction and Data Collection

Interview questions reflected the literature on barriers and facilitators to mental and behavioral health screening and treatment cited above and were refined prior to data collection based on discussion with local primary care providers and community members, and again during the data collection process based on participant responses. Questions were designed to elicit information about participants’ relationships with their primary care providers and their willingness and comfort level discussing certain physical, psychological, and social health issues with their providers.

In addition to questions focusing on psychological health and well-being, there were specific questions related to physical health screenings. The decision was made to include questions about routine physical health screenings for cholesterol and blood pressure as well as pap smears and mammograms because these preventive screenings are the main reasons that physically healthy women visit their primary care providers. These screenings present opportunities for patients and providers to screen for psychological health concerns at the same time. See Appendix A for the complete list of interview questions.

Qualitative research design is an adaptable and emergent process. Therefore, the interview process was an iterative one, and participants’ feedback about and their responses to the questions led to changes in the language used and/or addition or removal of questions as deemed appropriate by the research team.

In addition to the interview questions, participants completed a brief, one-page demographics questionnaire with the interviewer. No personal identifying information was collected. Each participant’s demographic information was tied to her interview responses; however, no identifying information was collected or stored for the participants. The brief
questionnaire collected the following information: age, zip code, race, ethnicity, education level, marital status, number of people in household, health insurance status, family income, and whether she has a family member with a mental health diagnosis. These data were used to describe the participant sample.

Potential participants were identified by staff at the clinic and asked if they were willing to speak with a graduate student in clinical psychology during their visit. If a potential participant agreed to speak with me, I introduced myself and the study and asked her if she would be willing to participate in a discussion about her experiences in primary care. The informed consent document was reviewed with each participant orally and each participant was given the opportunity to ask questions prior to beginning the interview.

Interviews were held in a private examination room at the clinic, and participants were assured that their conversation would not be overheard by or discussed with people outside the room. Interviews ranged in length of time from 7 to 23 minutes, with the average interview lasting approximately 14 minutes. Each interview was audio-recorded using a digital recorder. In addition, I took notes describing participants’ nonverbal cues and behavior.

While data collection was conducted by me, I required assistance with the process of data analysis. A clinical psychology undergraduate student affiliated with the larger research project and registered as study personnel with the ETSU Institutional Review Board served as the primary research support. Other research team members included two members of this thesis committee.

Interviews were conducted until a saturation point was reached. Saturation refers to the point at which “major trends begin to recur, and outlying or secondary themes have already emerged” (Ambert et al., 1995, p. 886). The first three stages of thematic analysis, detailed
below, were conducted concurrent with data collection. The undergraduate team member and I determined that no new themes emerged during the last three interviews, and together we decided that saturation had been reached.

**Data Analysis**

Inductive thematic analysis refers to a specific method of qualitative data analysis that identifies, analyzes, and reports patterns (themes) within data (Braun & Clarke, 2006). The process of thematic analysis yields descriptions of data that are in-depth and detailed, and it is a “particularly useful method when you are investigating an under-researched area” (p. 11). For this study an inductive, or “bottom-up,” thematic analysis was conducted such that any patterns or themes identified were explicitly tied to the data and not heavily based on inference or the researchers’ theoretical perspectives. While it is impossible to completely eliminate researchers’ biases or expectations of outcomes, every effort was made to remain aware of and reduce the influence of such biases and expectations when analyzing the data. At least two members of the research team conducted each step of the thematic analysis, further reducing bias and the possibility that important themes were overlooked.

Braun and Clarke (2006) describe six phases of thematic analysis, which were explicitly followed in this study. In the first phase the audiotape recordings of interview sessions were transcribed verbatim, and a research team member verified each transcription. Any notes or observations made during interviews were incorporated into an audit trail for the study. Audio recordings of the interviews will be destroyed after the study concludes. During phase one, the undergraduate team member and I familiarized ourselves with the data by reading each transcript multiple times and taking notes.
During phase two preliminary coding occurred, whereby words or phrases repeated by one or more participants were noted and given a descriptive identifier, or code. Each code was connected to one or more data extracts, or specific pieces of dialogue from the transcripts. I completed this process independently and reviewed and verified each code with another team member. The third phase involved sorting the codes into potential themes, identifying potential relationships “between codes, between themes and between different levels of themes (e.g., main overarching themes and sub-themes within them)” (Braun & Clarke, 2006; p. 20). Again, this process was completed independently and reviewed with another team member.

In the fourth phase the potential themes were reviewed and refined until the data within themes fit together meaningfully and there was a clear distinction between themes. Additionally, the themes were evaluated for their ability to accurately reflect the data set as a whole. This process involved rereading the transcripts to determine whether the existing themes were adequate to describe the whole data set; further, the transcripts were reread to identify any additional data within themes that were missed in earlier stages. This phase was completed with help from two other team members through multiple discussions about how to arrange themes meaningfully so that they captured the whole data set.

Phase five involved defining and naming each theme. This involved discussions with research team members to determine how each theme fits into the “broader overall ‘story’ that you are telling about your data” (Braun & Clarke, 2006; p. 22). Finally, phase six entailed writing the thematic analysis in a clear, logical comprehensive report. That report incorporates a frequency ranking of thematic responses, detailed operational definitions of each theme, and selected dialogue from the interviews. The report was written independently and reviewed by two other team members for accuracy and thoroughness.
CHAPTER 3

RESULTS

Saturation was reached after interviewing 18 primary care patient participants. The dominant themes from the interviews can be conceptually separated into two distinct categories related to barriers and facilitators to mental and behavioral health screening and treatment. Three main themes within barriers were identified: stigma, lack of support, and lack of education. Within facilitators, two themes were identified: integrated care and positive experiences with providers.

Barriers

Stigma

Stigma appeared in 61% (N = 11) of the interviews. It was described by participants in three distinct ways that are classified as distinct subthemes: internalized stigma, immediate interpersonal stigma, and public stigma.

Internalized Stigma. First, some participants characterized stigma as a personal, private sense of shame and embarrassment. Within the context of mental and behavioral health care, this internalized stigma was described as being unable to admit to or talk about a mental disorder:

I didn’t want to face it. I just wanted to forget it. (P10)

I think a lot of mental issues are just embarrassing. Some of them are maybe avoided. (P14)

But a lot of people are scared. They don’t wanna believe that there’s something wrong. Because I didn’t want to believe. And it took me years. (P18)
Here, participants referred specifically to their internal struggles to admit they had unmet mental or behavioral health care needs. Many described mental disorders as taboo or something shameful to be hidden:

Being out in that waiting room you’re thinking, “Oh that person knows why I’m here.” (P3)

Some people think, “Ok, they’re sending me to see a mental person, there must be something wrong with me. Um, why are they sending me to this person?” (P10)

I think they think of it as a weakness if you have to go see a mental health professional. (P11)

You don’t brag about that stuff. How often do you see me brag? “Oh, I’m sick, I’ve got depression.” I said, you don’t want nobody to know. I said, you hide that thing. (P18)

**Immediate Interpersonal Stigma.** Another type of stigma identified by the participants was immediate interpersonal stigma. This type of stigma reflects a sense of judgment and shame generated by a close other. When participants described this stigma, they spoke about husbands, parents, and even health care providers as being the stigmatizers of mental illness:

Your average medical person doesn’t have enough understanding or education or…so they don’t want to talk about it, because they don’t know what to do about it…They’ll write the prescription for the medicine but they don’t want to talk about it. (P5)

There’s still a stigmatism with mental health and they may never speak to you again if you tell them you think that they need to go see mental health. (P17)

[Some people are scared of] what people will think… I didn’t want my family to know, and some people in this county, they don’t believe in medicine. My parents was one of them. (P18)
Public Stigma. The most common type of stigma mentioned by participants was a broad, public stigma. This public stigma refers to being recognized publicly for something shameful or to be exposed as inferior and suffer a public loss of respect. Several women referred specifically to the public stigma associated with being treated for mental disorders:

Well, you know, just nobody likes to go to the crazy doctor. Because that’s what everybody says, you know, they go to the crazy doctor…If they put the doctors and mental health people in together, then, you know, nobody wouldn’t think nothing about you going. (P2)

Nobody wants to talk about mental health. (P5)

And we don’t in our society value that. You know, we look down our noses at people that have those kinds of weaknesses. (P11)

They’re afraid people will see them come in, know that they’re here. You know, that big ol’ thing about being seen. (P12)

Many of the data extracts related to public stigma centered on seeing or knowing someone receives mental or behavioral health services. One woman spoke to the lack of confidentiality and privacy in the community where the clinic is located:

This is a small town. You talk to one person about something, and the next thing you know the whole county knows. (P10)

Another woman also described public stigma and lack of privacy surrounding mental and behavioral health care, while noting the difference between a traditional mental health provider’s office and the primary care clinic:
When you’re out in the waiting room, you know, it’s like you don’t know if somebody’s here for physical or mental issues and it doesn’t single you out, like, “Ha-ha, you’re a mental patient.” (P3)

**Lack of Support**

Lack of support appeared in 66.67% (N = 12) of the interviews. Just as with stigma, participants identified different types of support, the lack of which represented barriers to mental and behavioral health screening and treatment. The women identified *financial support, social support*, and *provider support* as inadequate or completely absent, which limited their ability to seek and/or receive services.

**Financial Support.** Financial support includes the monetary resources needed to afford and attend health care visits. Participants identified transportation obstacles as well as a lack of adequate insurance as barriers to care. When asked how transportation might impact their decision to seek services, participants responded:

- If I don’t have the gas to get there. (laughs) (P1)
- Well, gas prices is one thing. (P2)
- Ourself, for example, we don’t have a running vehicle right now…We have to depend on someone else. (P16)

Another participant saw her spouse’s lack of insurance as a barrier to receiving needed services:

- They cut therapy out of his insurance so…he’s not seeing anybody now. (P6)

One woman explained that she could not afford behavioral health care:

- It only costs $75! Well, my son didn’t have a dime of insurance and now I’m going to have to pay for his funeral. I can’t take $75 and go to grief counseling. It ain’t happening. (P17)
**Social Support.** A second type of support addressed by participants was social support. The lack of support from others to bring concerns to a provider was identified twice, in both cases referencing close friends or family:

When I had my kids, I had depression really bad. And I’d try to talk to family members and I even tried to talk to my OB about it. And they were all pretty much, “Oh, it’s normal.” You know? And then the family members—“Suck it up, you chose this.” So there wasn’t a whole lot of encouragement to go talk to somebody. (P12)

I didn’t have that help. I dealt with it by myself. (P18)

**Provider Support.** A third type of support highlighted by the participants was support from their providers. Several women noted that the absence of provider support to seek mental or behavioral health services played a part in their ability to receive care.

I dread coming down here because of the way that she [primary care provider] looks at things. I mean, I am just not happy with that at all. (P4)

I tried, you know, to talk to them and tell them what’s wrong but it seems like they just didn’t, didn’t care or something. They didn’t want to help me. (P8)

They [mental health providers] don’t really help…I came to them for advice, and they look at me like I’m supposed to give my own advice. (P13)

One woman described a unique relationship with her provider, which came about because she is close friends with him and because she is a nurse:

You know, it’s kind of a different talk than a regular person walking in to see a doctor and a nurse walking in to see a doctor…They kinda know, “Well, she knows what she needs or what’s going on or what her concerns are.” (P17)

In two interviews participants described their providers’ unwillingness to discuss mental health:
I just know that if I have a problem or an issue, the first response will be, “Oh, you need to get in touch with your psychiatrist.” (P5)

So many doctors tend to tell you that it’s all in your head when you know it’s there but they don’t mean it the way you do. (P16)

In each of these instances, participants clearly perceived a difference between the care they expected from their providers and the care they received.

**Lack of Education**

In addition to the barriers of stigma and lack of support, 61% of participants (N = 11) acknowledged a third barrier, a lack of education. As with the previous two themes, lack of education is divided into subthemes: *poor mental health literacy, maladaptive coping styles, resistance, and limited information*. Each of these represents a gap in education that serves as an obstacle to screening and treatment.

**Poor Mental Health Literacy.** Poor mental health literacy refers to a lack of understanding of what mental and behavioral health services areas well as misinformation about mental and behavioral health. One participant struggled to explain what a mental health provider does:

I guess like a psychiatrist, I don’t know… I really don’t. (P4)

Other women described attitudes about mental health in the community as “backwards” or ill-informed:

Johnson County, I don’t know, they’re backwards. Um, you’re raised that you’re supposed to control your mind instead of letting your mind control you. So it’s a hard thing for people to change what they’ve always believed. (P16)
When people think of mental illness, they don’t think depression. They don’t think anxiety. They think crazy…Mental illness is a broad spectrum and so, I just don’t think people—I don’t think women know enough about it to realize that there’s some help out there. (P17)

Another aspect of mental health care where participants were misinformed related to psychotropic medications:

I’m afraid to ever go off of them. Because it makes you crazy. (P1)

Some people are afraid that they’ll get addicted to the pills. Which I can’t—I can go two, three days. Won’t need them, but I still take them. I wished I didn’t have to take them, but I do…Which they’ve stopped working…So I just did quit taking them. (P18)

Another common instance of misinformation related to the referral process. Half of all participants referenced the referral process, and several believed a referral was necessary to see a mental or behavioral health provider.

Maladaptive Coping Styles. One woman referred to others’ tendencies to self-medicate rather than see a mental health provider:

There’s so many people that would rather just go to the pill bottle and the bottle than to go in and talk to people, and I can’t understand that. (P7)

She was the only participant to draw a direct connection between substance abuse and mental health, although several other interviewees referenced the prevalence of substance abuse problems in the region. Because of that, this subtheme is included as a significant finding.

Resistance. Resistance refers to an unwillingness to seek or use mental or behavioral health services. Some participants described opposition to seeing a mental health provider, even if there was a mental health diagnosis:
I don’t want to go to mental health people. I don’t think I need to do that. I mean, I’ve dealt with this. (P4)

I haven’t really talked to my doctor about mental. I do have depression and I’ve tried a couple of, you know, anti-depressants and stuff and it just seemed to make it worse…So I’d just kind of give up. (P12)

One woman suggested that resistance is common throughout the community:

They’re so stubborn they don’t realize they need it. That’s usually the way it is. (P17)

**Limited Information.** The final subtheme under lack of education is limited information. This refers to a lack of awareness of mental and behavioral health services available, particularly integrated behavioral health services at the clinic where the women are all patients. A sizeable minority of participants (44%, N = 8) had no prior knowledge of the behavioral health services available at the clinic:

Oh, y’all have that? (P2)

I had no idea. (P5)

No, I didn’t know they had it here. (P12)

That I was unaware of. (P15)

I think it’s a good idea, but I wasn’t aware of it. (P17)

**Facilitators**

**Integrated Care**

For the purposes of this study integrated care refers to the delivery of behavioral health services in a primary care setting. A large majority of participants (77.8%, N = 14) suggested features of integrated care would be likely to increase behavioral health service use. Some
women acknowledged aspects of integration that are already working to increase services, while others offered suggestions for how a more integrated model would bring more women to the clinic. The theme of integrated care can be divided into two subthemes: *convenience* and *procedural facilitators*.

**Convenience.** Convenience as related to integrated care refers to aspects of integration, already in place, which make service use more likely. Several participants described the benefit of having a mental health provider in the same location who could provide immediate service:

Well you know, I guess, you know, to be here… In case, you know, you was to need one of you’uns…You know, if you started crying or something like that. (P8)

That would make it more convenient…I think that’s great because that way between the two of them, they can really help someone. (P10)

For me, scheduling appointments is always a drag and that’s one of the reasons why I put things off…My mental health provider was my physician, at one point, in Boone… It was the perfect solution for me. (P11)

If they were in the same office, it’d probably be a lot easier. I know a lot of people won’t go because it’s way in Johnson City instead of right here underfoot where they could easily get here to it. (P12)

It’s better…You don’t have to go here, there, and everywhere. (P13)

Less doctors’ appointments, not having to make more than one trip, especially in this area. (P16)

That would be a case whereas they’re there, they’re seeing me, they’re talking to me, I’m crying, I’m having issues because I’m scared and this, that, and the other—that would be
the perfect opportunity to say, “Somebody here, you know, if you don’t care—have a word with for a few minutes.” (P17)

**Procedural Facilitators.** The second subtheme under integrated care is procedural facilitators. These facilitators are suggestions offered by participants to increase behavioral health service use at the clinic. The facilitators are contained within the integrated care theme because they also represent features of integrated care, such as increased screening for mental and behavior concerns in primary care:

I would ask if you want to see a counselor and set up an appointment. (P9)

I mean, to an extent the provider should know the patient well enough to where they can spot things…And it just takes continued asking, “Are you certain you’re all right this way?” (P16)

Other women discussed the need for better advertisement of services:

I think availability is the biggest issue. And people knowing you’re offering the care. (P5).

It could be more advertisement. Maybe geared towards more, more towards women. (P15).

One participant emphasized the need for providers to collect more history related to mental and behavioral health:

You have to fill [forms] out if you go to CSU or you go into rehab or something, they ask all those kinds of questions… I think maybe if um, a little attention was maybe paid to more, when those questions are asked—which they do do here, I’ve noticed. Oh I don’t know if they do it with everybody—but they kind of ask other questions when they see that somebody’s got those kind of issues. (P14)
Positive Experiences with Providers

Having positive experiences interacting with providers was another reason participants cited that increased their comfort with seeking screening or treatment in the future. Two thirds (N = 12) of participants referenced positive experiences with a provider. The positive experiences theme is divided into two subthemes: comfortable talking with providers and confidentiality/lack of judgment.

Comfortable Talking with Providers. Many participants expressed a greater willingness to seek out or use behavioral health services based on their relationship with a trusted provider, often a primary care provider:

- I just saw her from the time that I was a teenager on up, you know, I saw her for years straight. And she just took time to set down and listen to me. (P4)
- She seems like a really easy person to talk to, and I tend to overly talk to her. (P7)
- She’s kind of not a doctor. She’s kinda like a friend that I can talk to. (P9)
- I think the world of my care provider, I really do…She’s really helped me get through a very, very emotional time right now…I talked to a counselor here, and he’s helped a lot. So now it’s got to the point that I can be around people, I can laugh, joke. I can do things. (P10)
- I can come in here and talk to them about anything…plus I’ve been coming here for a long time now. Like 12 years, 13 years, so it’s like family. (P15)
- She was a lifesaver. She was the only person that he would see. And if it wasn’t for her, he probably would not be here. (P16)
- They do their job here. They see that you’re having problems, they’ll take their time to figure out what’s going on with you. (P18).
Another participant described feeling more comfortable discussing behavioral health concerns with a female provider:

Oh, another thing, when I was with the mental health over here, Linda, you know, having a female doctor. And the doctors here…made it comfortable. (P17)

Confidentiality and Lack of Judgment. Confidentiality refers to the assurance that information provided by a patient to her provider will not be disclosed to a third party. Lack of judgment refers to the patient’s sense that her provider is not speaking or behaving critically towards her. Some women expressed feeling more likely to discuss mental or behavioral health issues with their provider because of the confidential nature of the conversation:

Where you can open up to them more than can sometimes the family members. (P6)

The communication between the two would be good for most anyone with problems, or you know, things that they can’t talk about to other people. (P7)

But it would be enough to have someone that you could talk to that you knew that it would not go no further than where you’re at…You feel more secure, more apt to talk about what things is going on, you know. (P10)

Other participants referenced their providers’ lack of judgment as a facilitator to discussing mental and behavioral health concerns:

I never felt pressured or uncomfortable or embarrassed or anything. (P14)

And the one thing about it was, with them, with the mental health provider, was they mainly listened. And they don’t judge you…That, talking to Jeff in here, that really gave me a lot of peace of mind…A mental health person can just say, “I’m here to listen…Whatever you need to say.” (P10)
CHAPTER 4
DISCUSSION

I sought to identify perceived barriers and facilitators to mental and behavioral health screening and treatment in primary care among rural women attending a nurse-managed primary care clinic in northeast Tennessee, where behavioral health is integrated into the primary care site. This is the first study of which I am aware that has attempted to identify barriers and facilitators to screening and treatment among female patients in a primary care setting. The main findings were that women were reluctant to seek out and/or use mental and behavioral health services because of perceived stigma surrounding mental health, a lack of support, and a lack of patient education around mental and behavioral health. Additionally, participants identified facilitators, including an integrated model of care and positive experiences receiving care in the past. The present discussion addresses the barriers to screening and treatment first, followed by the facilitators.

Stigma was a major theme and represented a powerful obstacle to screening and treatment seeking for the study sample. Participants identified three separate types of stigma: internalized, immediate interpersonal, and public stigma. This reflects the literature on stigma to an extent; much stigma research differentiates between two types of stigma: self-stigma, also called internalized stigma, and public stigma (Brown et al., 2010; Corrigan & Watson, 2002). Both of these types were identified by participants. Another important distinction within the literature is the difference between enacted stigma and felt, or perceived, stigma (Scambler & Hopkins, 1986). Enacted stigma refers to discrimination based on perceived unacceptability but does not include legitimate discrimination (e.g., persons with epilepsy being banned from operating heavy machinery). Felt stigma refers to the fear of enacted stigma but also to the
shame associated with being “other,” or outside the norm (1986). Both of these types of stigma were identified by participants as well.

However, participants in this study also made a distinction between the stigmatizing actions and attitudes of close others—including nuclear family members, spouses, and providers—and more distal members of the community. Providers are grouped with family members because patients share also personal, private information with them. The distinction between these two types of stigma suggests an increased influence of close others relative to community members, which has not been well-examined in the literature. This finding is consistent with some of the theoretical framework of this study, specifically Bronfenbrenner’s Ecological Systems Theory. Bronfenbrenner noted that the largest environmental influence on an individual comes from his or her relationships with close others (1979). To that end, immediate interpersonal relationships where stigma exists may create a more significant barrier to screening and treatment, relative to more distal relationships. The closest parallel to public stigma as described by these participants would involve the Ecological Systems layers of exosystem (including community members) and macrosystem (including an individual’s culture and social customs; 1979). The outer layers of the ecosystem influence the inner layers. Thus, Bronfenbrenner’s theory may provide an explanation for the development and interaction of different levels of stigma between an individual and his or her environment.

Like public stigma, immediate interpersonal stigma may reflect a cultural understanding of mental illness passed down from one generation to the next rather than any personal experience with mental or behavioral health. Unlike public stigma, I propose that immediate interpersonal stigma may be more susceptible to change. In several interviews participants described how family members’ and spouses’ opinions and biases changed following an
experience with mental health services. These anecdotes offered by participants are consistent with some retrospective and prospective design studies that found people who had direct, face-to-face contact with individuals with mental disorders displayed more positive and less negative attitudes towards those individuals (Couture & Penn, 2003). Corrigan and Watson (2002) also describe a reduction in negative attitudes following interpersonal contact with individuals with a mental disorder. Nonetheless, the literature on “contact theory” is not entirely conclusive, and some prospective studies reviewed by Couture and Penn (2003) found no significant results. Additionally, there is a lack of true experimental research measuring the impact of contact on mental illness stigma. Further study is needed to determine whether the immediate interpersonal stigma identified by this study’s participants is truly distinguishable from public stigma.

Many of the women who identified stigma as a barrier described more than one type, suggesting that those who have experienced one kind of stigma are more likely to recognize and have experienced another kind. In fact, some research has shown that individuals with a mental disorder who live in a community where mental illness is stigmatized are more likely to endorse self-stigma (Brown et al., 2010). I submit that the relationship between the three types of stigma identified by participants can be described this way: public stigma creates an atmosphere around mental illness that perpetuates negative stereotypes and unequal treatment; internalized stigma is the internal reflection of public stigma, such that individuals with mental disorders believe the negative stereotypes about themselves; and immediate interpersonal stigma exists because individuals with mental disorders are hesitant to expose themselves to others for fear of judgment. This cycle of stigma continues unless educational interventions take place.

Another major barrier to screening and treatment identified by the participants was a lack of support. This included a lack of monetary resources, social support, and provider support. It
was expected that participants would identify financial barriers, given the economic climate of northeast Tennessee and the evidence that the financial burden of mental and behavioral health is often viewed as an obstacle to receiving services (Drapalski et al., 2008; Sherbourne et al., 2001). Nor was it surprising that the women identified a lack of social support as a barrier to seeking and receiving care. Social support has been identified as a facilitator to seeking and receiving treatment for serious mental illness (Borba et al., 2012), engaging in preventive health practices (Hurdle, 2001), coping with mental disorders (Letvak, 2002), and managing chronic illness (Weinert, 2008). Given that social support can help individuals deal with challenging circumstances, it would follow that its absence could serve as an obstacle to healthy behaviors.

Another finding within the lack of support theme was some participants’ perception of a lack of provider support; interestingly, this has not been reported in the literature. Three women described feeling shut down by their provider or feeling like their provider was not helpful related to their mental and behavioral health needs. In just one instance, the participant was referencing her primary care provider. Evidence exists in the literature to suggest that primary care providers may feel overwhelmed by the volume of mental and behavioral health concerns in primary care (Gamm et al., 2003) or by a lack of training in psychological and psychiatric care (Gamm et al., 2003; Lambert & Agger, 1995). This may be due to problems in the primary care infrastructure and in provider training that create obstacles for patients seeking mental and behavioral health services. However, the problems described by study participants seem to reveal interpersonal difficulties, not only between patients and primary care providers, but also between patients and mental health providers. This highlights the significance of the patient-provider relationship, especially when a patient may already engage in self-stigmatizing behaviors or perceive her provider’s attitude as judgmental.
The third barrier identified by participants was lack of education. This referred to poor mental health literacy, maladaptive coping styles, resistance to seeking or receiving services, and limited information about available services. Poor mental health literacy is defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm et al., 1997, p. 182); this is a serious barrier to screening and treatment because people without good understanding of mental and behavioral health services are unlikely to seek help. Even though a majority (61.1%, N = 11) of participants attended at least some college, representing a higher educational attainment than the average for northeast Tennessee (U.S. Census Bureau, 2013), several women provided incorrect information about some aspect of mental disorders or treatment. Some participants drew a link between misinformation about mental and behavioral health and a “backwards” culture. This suggests that education level may not be the best predictor of mental health literacy.

Participants also identified two other ways in which culture and a lack of education were connected—through maladaptive coping styles and a resistance to mental and behavioral health care. In each instance participants described an unwillingness to seek out care, and some denied needing services in spite of a mental health diagnosis. This may reflect a sense of fatalism surrounding health that has been described as characteristic of Appalachians (Drew & Schoenberg, 2011; Hutson, Dorgan, Phillips, & Behringer, 2007; Royse & Dignan, 2011; Shell & Tudiver, 2004). In their study examining cancer prevention and treatment decision-making, Drew and Schoenberg suggest that fatalism is an oversimplified explanation of resistance to or avoidance of healthy behaviors. They posit that a complex relationship of multiple factors including “a legacy of self-reliance” and “a culturally acceptable idiom of fatalism” may prevent women from making the desired choices about their health (Drew & Schoenberg, 2011, p. 164).
If fatalistic or self-reliant attitudes towards mental illness are partial barriers to screening and treatment, it will be challenging to design interventions that can alter that mindset. Previous health education interventions in Appalachia have successfully targeted women’s central role in the health of their families, so that may be a useful approach (Denham, Meyer, Toborg, & Mande, 2004).

The fourth subtheme within lack of education was limited information. Many participants were unaware of the behavioral health services offered at their primary care clinic. This underscores the need for change in clinic operations to increase service use. This could take many forms including flyers and brochures placed in exam rooms and more introduction of the behavioral health consultant to patients by the providers.

In addition to these barriers, participants also identified two facilitators of mental and behavioral health screening and treatment. These facilitators were integrated care and positive experiences with providers. Integrated care was identified by participants as a possible way of addressing low service use. The women talked about how an integrated model would address some of the logistical problems of receiving services, potentially bringing more patients in for care. Participants recognized its convenience, and many saw it as “one-stop shopping” or “two services for the price of one.” This is consistent with the literature on collaborative care that has shown that most patients prefer when mental health and primary care providers communicate about their care (Mauksch et al., 2001).

Participants also offered suggestions for the improvement of mental and behavioral health service delivery that were consistent with an integrated model of care. These included more frequent screening for mental and behavioral concerns, better advertisement of services, and collecting more thorough history about mental and behavioral health. The literature on
integrated care includes these as components of a well-integrated system (Collins, Hewson, Munger, & Wade, 2010; Gatchel & Oordt, 2003; Haley et al., 1998). The recommendation of these changes to their care suggests that participants are interested in integration and comfortable with changes in service delivery they see as beneficial.

The second facilitator named by participants was positive experiences with providers. Participants mentioned feeling comfortable talking about mental illness with a provider and having a good working relationship. Many of the women described their providers as compassionate and approachable about anything, which helped patients present their concerns. These aspects of interpersonal communication have been shown repeatedly to be important in a successful patient-provider relationship (Battaglia, Finley, & Liebschutz, 2003; Lein & Wills, 2007; Meredith, Orlando, Humphrey, Camp, & Sherbourne, 2001). Additionally, several participants noted that the length of their relationships with providers over time made them more likely to discuss mental and behavioral health. This is a major strength of primary care practices, where providers sometimes follow patients across decades and are able to develop strong relationships (Kringos, Boerma, Hutchinson, van der Zee, & Groenewegen, 2010). The time span of patient-provider relationships may be especially important in small communities.

The other aspect of positive experiences with providers related to the confidential nature of the patient-provider relationship, and not feeling judged by providers when discussing mental or behavioral health concerns. Trust in providers has been identified as an important predictor in patient disclosure and satisfaction with care (Bova et al., 2012). Participants described confiding in trustworthy providers concerns they were unable to discuss with anyone else. They also noted that good providers never cause a patient to feel embarrassed or criticized for any concern she presents. The importance of the interpersonal, not just the professional aspects of the patient-
provider relationship cannot be understated. Research has shown that patients of providers who practice patient-centered communication are more likely to self-disclose and work collaboratively with providers to address issues (Helitzer et al., 2011). In a situation where patients may already feel stigmatized by their mental health status, the ability to talk to a provider without feeling judged is vital.

In summary, three major barriers were identified by participants: stigma, lack of support, and lack of education. I propose that these barriers interact with one another such that low levels of education leads to increased stigma, which leads to low levels of support. It may be that interventions targeted at increasing understanding of mental illness and treatment options lead to a reduction in stigmatizing attitudes and behaviors and increased levels of support. Two major facilitators were also identified: integrated care and positive experiences with providers. These facilitators should serve as directional guides for providers seeking to improve the mental and behavioral health care of their patients. Innovations in behavioral health service delivery continue at a rapid rate, and some of these are already present at the clinic. Advertisement of the behavioral health provider’s services and the tele-health system should be redoubled to increase awareness of and use of services. Finally, a continued emphasis should be placed on the interpersonal relationship between patient and provider to ensure a safe environment for patients to discuss mental and behavioral health concerns and needs.

There are some limitations to the present study. All data were collected at one nurse-managed primary care clinic where integrated care is being practiced, which likely influenced some participants’ exposure to integrated practices and may have produced a favorable bias among patients who were aware of integration at the clinic. Additionally, the provider at the clinic with the largest patient load is a family nurse practitioner and clinical nurse specialist with
an extensive mental health background. The mental health expertise of this provider was noted by many participants, and she represented the only experience with mental health providers for several participants. This may have limited their ability to identify barriers and facilitators to screening and treatment in primary care because of a lack of exposure to traditional mental health services. All participants were patients of one clinic; thus, results may not be representative of all women in the rural northeast Tennessee region. Participants may have been limited in their ability to identify all the barriers to screening and treatment in primary care because selection for participation in the study involved visiting a primary care clinic. A large majority of participants (72%, N = 13) had some form of insurance, which may have resulted in an underestimation of the impact of financial resources on service use. Finally, all participants were sampled from a rural, Southern Appalachian region; it is possible that the experiences of women in Southern Appalachia are different from women in other areas.

Threats to internal validity were minimized by having a second research team member review and code transcriptions. Coders were within 90% agreement with one another, minimizing variability in thematic interpretation.

Results of this study may have important implications for the provision of mental and behavioral health services in primary care settings and for future research. As previously discussed, this study is situated within a larger project examining the experiences of women in primary care clinics in northeast Tennessee. The findings from this study will be presented to study collaborators within the community, including the clinic and its community advisory board, to assist in the improvement of service delivery in that clinic. Additionally, each participant will be invited to attend a presentation of findings. At the presentation feedback will be solicited from stakeholders and participants. Ideally, the specific barriers identified by study
participants will be targeted with tailored interventions aimed at increasing and improving behavioral health services. After combining the thematic analysis findings with that feedback and the data collected from chart audits, the next phase of the larger research project will begin. In that phase, the research team will compile and pilot a set of survey measures related to the themes that emerged from the interviews. Based on participant feedback on those measures, a model for explaining mental health care decision-making among rural northeast Tennessee women will be developed and tested.

One major benefit to following up this study with quantitative research is that it will allow more women to be engaged in the overall research project and provide a better understanding of the experience of seeking and receiving mental and behavioral health services. Future studies should examine the experiences of rural women in primary care clinics where integrated care is not currently practiced. An attempt to describe the experiences of diverse populations, including women who do not regularly attend primary care clinics, should be made. Future research should also continue to explore the experience of mental illness stigma for rural women and determine whether the category of immediate interpersonal stigma is a useful one.
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APPENDICES
Appendix A
Individual Interview Questions

1. How often do you visit your provider when you’re not sick (like for wellness exams, lab work, or a behavioral health need)?

2. For the next series of questions, I am NOT asking you disclose personal information. Rather, I am interested in how often your provider has talked with you about:
   a. Depression?
   b. Anxiety or nerves?
   c. Cholesterol?
   d. Blood pressure?
   e. Mammogram and pap smears?
   f. Violence in your home?
   g. Substance use problems?

3. Have you ever asked or wanted to ask your provider about these things? (Depression, anxiety or nerves, cholesterol, blood pressure, mammogram and pap smears, violence in your home, substance use problems)
   a. If yes, what about your provider makes you feel comfortable doing so?
   b. If no, what prevented you?

4. What about your provider makes you more or less comfortable having an annual wellness exam, including pap and mammogram?
   i. Do any of these other things impact your decision-- provider’s facility?

5. Imagine that you or your family member needed to see a mental/behavioral health provider. What kinds of things do you think they could help you with?
   a. If you had [use provided answer] issues, would you feel more comfortable talking with a mental health specialist or with your provider?

6. If provider: Would it make a difference if the mental health specialist were in the same office as your provider?
7. There is a new model of care that puts mental health specialists in the same office as providers. In this new model, providers and mental health specialists talk to one another often about how to provide patient care, and providers often ask mental health specialists to meet with their patients during office visits to work on behavioral health issues.
   a. Does this model appeal to you?
   b. What are some of the possible advantages?
   c. What are some of the possible disadvantages?
8. What suggestions do you have to help women be more likely to get regular annual wellness exams, including pap and mammogram?
9. What suggestions do you have to help women be more likely to use behavioral health services?
10. Do you feel like you are getting all the care that you need—mental, physical, and women’s health?
11. Do you have any questions for me?
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