

A QUALITATIVE ANALYSIS OF THE MENTAL HEALTH EXPERIENCES OF BLACK  
APPALACHIAN RESIDENTS

A Thesis  
by  
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# A QUALITATIVE ANALYSIS OF THE MENTAL HEALTH EXPERIENCES OF BLACK APPALACHIAN RESIDENTS

## **Abstract**

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There is a dearth of research on the mental health of Black residents of rural Appalachia despite a significant historical and cultural presence within the region and a currently growing population. Research on ethnic minorities living in rural areas indicates greater risk of severe mental health issues and less access to quality of care, leaving rural Black Appalachian residents in a precarious position and with limited research to guide appropriate care. Five Black women who were raised in Central and Southern rural Appalachian counties were identified through purposive sampling and subsequently interviewed about their experiences with mental health and mental health treatment. Grounded theory guided the interpretations of the interviews and triangulation was utilized during analysis. Analysis revealed themes of personal responsibility, self-reliance, and shame in interviewee's experiences and understandings of mental health. Furthermore, religion was identified as a major source of support for interviewees and their families through both prayer and engaging in Church services and community. Instrumental and emotional support were differentially provided to the interviewees and their loved ones struggling with mental illness. Suggested areas for community intervention include workshops and implementing integrated health care.

*Keywords:* Black American, Appalachian, mental health, attitudes, behaviors, community

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## **A Qualitative Analysis of the Mental Health Experiences of Black Appalachian Residents**

Poor mental health is a global phenomenon that is responsible for over 122 billion years lived with disability (GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, 2018). Mental health and substance use disorders are the leading causes of disease burden in the United States, accounting for 34% of disability adjusted life years (Cox & Sawyer, 2017). The burden of mental illness is even higher in the Appalachian region with rural areas in particular claiming higher rates of depression and suicide than the rest of the United States. (PDA Inc. et al., 2017). It is evident that the rural areas of Appalachia need mental health services to address the high prevalence of poor mental health.

The high need for mental health care is exacerbated by a lack of access to consistent and quality care. Among adults in the U.S. with mental health concerns, 57% receive no treatment even if they have health insurance, indicating that access to treatment goes beyond financial concerns (Mental Health America, 2020). Among children experiencing Major Depressive Episodes, only 27.3% receive consistent treatment with almost 60% of these children receiving no treatment (Mental Health America, 2020). Despite comparable or greater need of mental health services, minoritized individuals, Appalachian residents, and rural residents are significantly less likely to receive any mental health care than the general population due to barriers such as cost, transportation, availability, and personal or community stigma towards mental health (Alegría et al., 2008; Douthit et al., 2015; James et al., 2018; Meyer et al., 2015; PDA Inc. et al., 2017; Peterson et al., 2009; Smalley et al., 2010). Considering that minorities living in rural areas have been shown to have even less access to mental health care than other populations, it is crucial for us to address mental health in rural Appalachia, where the ethnic/racial minority population is rapidly growing (Bolin et al., 2015; Cherry et al., 2018; Cohen et al., 2017; James et al., 2018;

Kozhimannil & Henning-Smith, 2018; Peterson et al., 2009; Pollard & Jacobsen, 2020; Smalley et al., 2010). Minorities living in rural Appalachia may have compounding risk factors and barriers to mental health care which must be explored and addressed.

Non-Hispanic Black residents are the largest ethnic-racial minority group in the region, making up 9.8% of the total Appalachian population and 7.7% of rural Appalachian counties (Pollard & Jacobsen, 2020). Only a small portion of Black Appalachian residents are recent migrants into the area, as most were born and raised in Appalachia, and many can claim generations of family living in the area (Pollard, 2004). While Black Appalachian residents have a historical presence in the area, public perception and research on Appalachia overlooks their presence (Pollard, 2004; Simpson, 2020; Webb, n.d.). This lack of attention has resulted in uncertainty about Black Appalachian culture and its influence on their views about and experience with mental health. Given the paucity of research on Black Appalachian residents, we should draw from the literature on mental health in Black Americans and Appalachian residents to help guide our research into Black Appalachian residents specifically.

### **Black Mental Health**

Over 17% of Non-Hispanic Black Americans had a diagnosable mental illness in 2019, and 4% were diagnosed with a serious mental illness which have high levels of impairment across multiple life domains (National Institute of Mental Health [NIMH], 2021). While the rate of Black Americans with a mental illness is below the national average (17.3% vs 20.6%), there is a disparity in care provided. Less than one third of Black Americans with a mental illness received any mental health services and were 50% less likely to receive those services than White Americans with a mental illness (NIMH, 2021). In addition to the disparate access to care, presenting to the emergency department (ED) with mental health concerns is less likely to result

in a transfer to inpatient care for Black patients despite higher rates of mental health related ED presentations (Moniz, 2019; Ting et al., 2012). This indicates that Black Americans are not receiving equitable mental health treatment when they seek help for mental health crises.

The experience of racism is salient to the development and progression of mental health issues for Black individuals. Black Americans who report racial discrimination have been noted to endorse negative mental health outcomes such as anxiety, depression, and poor self-esteem more often than those who report no racial discrimination (Priest et al., 2013). Both high stakes incidents of racism such as police brutality, and the cumulation of daily racial microaggressions and institutional racism contribute to suicidality in Black individuals (Borum, 2014; Oh et al., 2020). Given that discrimination is something done to an individual and they do not have control over it, the coping strategies employed by a Black individual facing this experience are essential to protect against the negative effects of discrimination. Consequently, social support, religiousness, and certain forms of racial socialization may promote resilience in the face of incidental and cumulative racism.

Social support may be a particularly salient factor in mental health outcomes for Black Americans due to their endorsement of collectivism which normalizes and promotes strong social networks (Utsey et al., 2007). Consequently, Black individuals who do not have the strong familial and social support systems that are expected and typical of their culture seem to be more likely to display poor mental health outcomes (Joe & Niedermeier, 2008; Lincoln et al., 2012; Taylor et al., 2020). For example, negative interactions with and perceived low emotional support from family was identified as a risk factor for suicidal ideation in Black individuals (Lincoln et al., 2012). Low contact with family members and low emotional attachment with family and friends is also associated with greater levels of depressive symptoms (Taylor et al., 2020). As

such, social support needs to be positive, frequent, and emotionally fulfilling to be protective against poor mental health outcomes.

Religiousness is a major influence on Black culture and can serve as both a protective and risk factor for poor mental health. Depressed members of Black churches who did not receive emotional and tangible support displayed more rapidly increasing depressive symptoms over time compared to depressed Black church members who did receive such support (Holt et al., 2018). It is possible that the community that is fostered by Black churches is what is protective for this population. This is supported by the research showing that individuals with an Afrocentric worldview and closer connection to their African heritage often engage in social religious behaviors and cooperative religious coping styles that are protective against suicidal ideation (Walker et al., 2018). However, negative interactions with one's church community is known to increase depressive symptoms, demonstrating that a breakdown in the social aspect of religious practices confers risk (Holt et al., 2018). It is also important to note that religious communities may stigmatize help-seeking outside of the church, limiting options for those with mental health concerns (Planey et al., 2019).

Racial socialization, or the process of learning one's heritage and its implications for how you interact with and experience the world, is noted to increase positive psychological adjustment in Black adolescents (Neblett et al., 2008; Priest et al., 2013). It could potentially serve as a preventative measure for poor mental health in the face of racism by promoting adaptive cognitions around those experiences from a young age. Relatedly, acculturative stress and higher acculturation into mainstream White society is related to increased depressive symptoms and suicidal ideation in Black college students (Borum, 2014; Joe & Niedermeier, 2008; Walker et al., 2008). Thus, confidence in one's identity as a Black individual in the United States and comfort

with navigating their and mainstream culture is protective against many negative mental health outcomes. Racial socialization may be more salient to the mental health of Black Appalachian residents since they are a small portion of the Appalachian population and possibly do not have access to cultural spaces unique to them.

Unfortunately, community attitudes toward mental health can prevent individuals from seeking out care when they need it. Several qualitative studies have noted that a barrier to seeking care for Black individuals is the shame and stigma promoted by their communities. In some Black communities, mental illness is seen as a personal weakness/failing, it is dangerous, and if you endorse symptoms then you are exaggerating and treatment is not warranted (Harris et al., 2020; Planey et al., 2019). These messages are both internalized and communicated in social circles from a young age, so that when a Black individual is facing depression, anxiety, or suicidal thoughts, they may feel as if formal mental health treatment is not a viable option for them. This is exacerbated when they or someone they know has had a bad experience with mental health providers due to cultural insensitivity or disregard (Planey et al., 2019). The cultural mistrust of mental health care providers is warranted given the profession's history of simultaneously over-pathologizing and downplaying the concerns of Black individuals and may be protective in its own way, but it is also preventing those in need from searching for a Black provider or one that is multiculturally trained. Consequently, community seems to be a double-edged sword for Black Americans, providing both protective social support and a detrimental avoidance of formal mental health treatment.

While the research about Black communities and individuals' experiences of mental health provides a wealth of information, it is not clear how it applies to Black residents of Appalachia, especially those whose family has been residents for generations. Thus, reviewing the

literature on the culture of the Appalachian region, specifically mental health outcomes and attitudes of its residents, is warranted. Integrating the information from the mental health literature on Black Americans and Appalachian residents should provide valuable information on potential cultural influences on the mental health experience of Black Appalachian residents that may inform treatment practices.

### **Appalachian Mental Health**

Similar to Black Americans, Appalachian residents display poor mental health outcomes and a high need for mental health care but do not receive adequate mental health services. Appalachia has higher rates of depression and suicide deaths than the United States as a whole, but also claims a shortage of both primary care providers and specialty mental health care providers (PDA Inc. et al., 2017). We can also infer from research on rural resident service use that Appalachian residents have low rates of inpatient mental health service utilization (Douthit et al., 2015; Moniz, 2019; Spoons et al., 2011). The lack of services provided despite high need may be indicative of cultural beliefs about mental health or a consequence of Appalachian counties to be below or near the poverty line.

Studies on Appalachian culture have gone through several shifts in how the culture is conceptualized, from focusing on deficits, to primarily values and strengths, to a more integrated view. Several researchers have suggested and advocated for the literature to acknowledge Appalachian culture, and culture in general, as constantly shifting and highly contextual rather than a static and generalizable phenomenon (Erikson, 1977; Keefe, 2005; Obermiller & Maloney, 2016). As such, there may not be an easily recognizable overall Appalachian culture but rather one that varies greatly across the counties and states included in Appalachia based on their specific histories and contexts. There are some broad concepts that seem to be present in many

Appalachian communities which allows us to tentatively describe an Appalachian culture. Research indicates that Appalachian communities tend to uphold and value strong communal ties, which have been shown to be protective against poor mental health and suicidality (Joe & Niedermeier, 2008; Keefe, 1988; Lincoln et al., 2012; Nguyen-Feng et al., 2015). For Appalachian residents, family seems to serve as the primary source of social support with members providing for the emotional, physical, and material needs of others in the family (Keefe, 1988). Unfortunately, this strong reliance on family, which may be protective against poor mental health also prevents individuals from seeking out care due to mistrust of outsiders (Keefe, 1988; Keefe & Curtin, 2012). Furthermore, Erikson (1977) described Appalachian natives as caught between individualism and collectivism which makes maintaining those kinship bonds difficult, and the breakdown of social connections is a known risk factor for psychological distress (Holt et al., 2018; Joe & Niedermeier, 2008; Lincoln et al., 2012; Taylor et al., 2020). Avoidance of mental health care early on in symptom presentation due to stigma and mistrust likely results in increasing severity of distress which could account for the high rate of depression and suicide in this population (PDA Inc. et al., 2017).

Religion, which is noted to be protective against suicidality in most cases, has a strong presence in Appalachian culture with native Appalachian residents more likely to endorse religious beliefs (91%) than non-native Appalachian residents in the same area (77%) though there is great variability in religious denominations (Gearing & Alonzo, 2018; Gearing & Lizardi, 2009; Humphrey, 1988; Keefe & Curtin, 2012; Keefe & Parsons, 2005). The available research suggests that while Appalachians historically had to rely on individual forms of religion such as prayer and reading the Bible, the church became a vital piece of the social community in Appalachian towns (Humphrey, 1988; Keefe & Curtin, 2012). As noted before, the church

community can provide protection from poor mental health through strong social bonds, but negative interactions within the community can be detrimental to mental health (Holt et al., 2018). While we know that many Black Americans engage in the protective cooperative religious coping styles, there is no research on Appalachian residents in general to determine whether their religious coping styles are protective against or exacerbate mental health concerns (Walker et al., 2018). Furthermore, mental illness is often seen as a punishment from God for not following one's religious duties. Appalachian residents who endorse the idea of mental illness as a religious punishment are likely to believe that only God can cure them and do not see professional mental health services as a viable option (Humphrey, 1988; Keefe & Curtin, 2012). Consequently, Appalachian religious practices may not be as much of a protective factor against poor mental health as it is for other groups, as it often denounces service help-seeking outside of the religion which further impacts mental health.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5 - TR; American Psychiatric Association, 2022) recognizes various international cultural concepts of distress as important for a culturally informed understanding of clients and patients. These concepts of distress often do not equate to a single DSM-5 disorder but provide valuable information about cognitive and physical symptoms that often present together during times of psychological distress for an individual with a particular cultural background. *Nerves* is a culture bound syndrome present in Appalachia that is equated with depression and anxiety in DSM nomenclature, often involves somatic symptoms and is frequently described as a physiological ailment by those who are afflicted (Erikson, 1977; Keefe & Curtin, 2012). It is characterized as the accumulated stress of dysfunctions in the family system, poverty, and high work demands (Keefe & Curtin, 2012). Unresolved nerves in Appalachian natives have been nominally linked to



poor mental health outcomes including suicidality (Halperin & Reiter-Purtill, 2005; Keefe & Curtin, 2012). Appalachian residents are entrenched in the shifting identities of ability and disability which takes the form of persevering through a hardship like “nerves” because it is simply a part of life and a natural response to hardship so treatment is not warranted, or accepting and internalizing the illness identity and often seeking treatment for somatic complaints (Erikson, 1977; Keefe & Curtin, 2012; Snell-Rood et al., 2019). This cultural belief that poor mental health is a natural part of life combined with the religious belief that poor mental health is a religious matter means that formal mental health treatment is not easily accepted and those with severe mental illness often do not receive the care they need to function.

### **Black Appalachian Mental Health**

While there is a paucity of research on Black Appalachian residents, experts suggest that research on Appalachian mental health can be tentatively applied to Black Appalachian residents (W. Turner, personal communication, October 8, 2020; S. E. Keefe, personal communication, December 30, 2020). Considering this, we can assume that Black residents of Appalachia engage in communal and solitary religious practices, but it is unclear what the typical religious coping style may be and how it impacts their mental health (Humphrey, 1988; Keefe & Curtin, 2012; Keefe & Parsons, 2005; Walker et al., 2018). There is likely a strong mistrust of outsiders as a result of strong community ties, which may prevent help-seeking from formal mental health services (Keefe, 1988; Keefe & Curtin, 2012). Interestingly, the high religiousness and strong community bonds noted in Appalachian culture is also noted in Black American culture. This may reinforce the likelihood that Black residents of Appalachia engage in these cultural practices which impact mental health beliefs and behaviors.

We do know that Black Appalachian youth, and Black rural youth more broadly, are noted to have similar rates of mental health disorders and higher suicidality, but lower rates of service utilization than White Appalachian youth (Angold et al., 2002; Costello et al., 1996; Kodjo & Auinger, 2004; Matthew & West, 2012). It should be noted that Black youth participants were severely underrepresented in these studies and these results may not reflect Appalachian areas with a larger Black population. Ethnic minorities living in rural areas display low rates of service utilization, partially as a result of rural minorities being highly likely to live at or below the poverty line and having low rates of health insurance coverage (Bolin et al., 2015; Peterson et al., 2009; Smalley et al., 2010). While this is valuable information and is likely to hold true for Black Appalachian residents living in rural areas, there is no known research on structural and cognitive barriers to mental health service utilization unique to Black Appalachian residents.

Racism is a salient issue in Appalachia, with many Black Appalachian residents holding vigils, protests, and anti-racism workshops in their communities. However, these do not appear to be large-scale efforts with many unwilling to get involved because of the lack of support and fear of repercussions in mostly White areas (Cabbell, 1980; Simpson, 2020; Whang, 2020). Black Appalachian residents experience racism and discrimination in their communities, but it appears the fear of repercussions prevents the Black Appalachian residents from forming a strong social network amongst themselves to provide validation of their feelings and experiences with racism. Racial socialization in childhood for Black Appalachian residents may not take on the protective form that was previously discussed, thus negatively impacting their ability to navigate the consequences of racism individually cognitively and emotionally and as a group (Neblett et al., 2008; Priest et al., 2013). With racism and lack of social support being known risk factors for depression, anxiety, low self-esteem, and suicidality, this may contribute to the increased

suicidality observed in Black Appalachian youths (Borum, 2014; Matthew & West, 2012; Oh et al., 2020; WHO, 2014).

The experience of Black individuals living in rural Appalachia needs to be examined through an intersectional framework. Intersectionality posits that a group or individual must be considered within the context of all of their socially constructed identities and how those identities impact each other to inform their unique experience of social and power structures inherent to the culture they live in (Hill-Collins & Bilge, 2016). These unique experiences are likely to impact mental health and experiences with mental health treatment and would be lost when researching a single identity. For example, a Black straight woman and a White gay man would both likely experience discrimination, but that discrimination would present in different situations and in different formats that would differentially impact their mental health and potentially their experience with mental health treatment. Consequently, examining the mental health experiences of Black rural Appalachian residents through the singular lens of rural, Appalachian, or Black American residents would not provide an accurate representation. Furthermore, we cannot simply find the commonalities between the three and claim it is true for Black rural Appalachian residents, since their experience may reflect parts that are common between two but not all three of the frameworks, or it may be largely unique. As such, we must explore the cultural beliefs and attitudes about mental health and mental health treatment of Black residents of rural Appalachia.

To understand the nature of rural Black Appalachian's experience of mental health in a way that will inform future efforts to provide culturally sensitive and acceptable care, we must first determine their conceptualization of and attitudes towards mental health and mental health care. This study aims to address the following questions through interviews with Black residents

of rural Appalachia: (a) What kinds of experiences have they had with mental illness? (b) How is mental illness conceptualized by Black residents of rural Appalachia? (c) What strengths and resources do members of Black Appalachian communities use to protect its members against mental illness? (d) How do the attitudes of community members impact the individual with a mental illness? (e) What kind of experiences have they had with formal mental health treatment? (f) Do the community's attitudes towards mental health and mental health care impact the acceptability of treatment?

## **Method**

### **Design**

This is a qualitative study utilizing semi-structured individual interviews informed and guided by grounded theory. A single social construct and/or process, such as how mental illness is characterized and handled by a community, is chosen in order to gain new or deeper understanding of what and why the construct or process is occurring as it is (Starks & Trinidad, 2007). In this study, the goal is to create an explanatory model of how Black Appalachian residents perceive, experience, and handle mental illness within their community in order to inform future community resources and interventions. Additionally, Charmaz (2005) argues that grounded theory is well-suited for social-justice oriented research because it offers theoretical explanations for personal and institutional injustices and provides direction for intervention.

### **Participants**

Purposive and snowball sampling was utilized to recruit participants for the individual interviews. The initial participants were identified through the author's connections within the local community who knew adults (18-years old and older) who identify as Black and were born and raised in rural Appalachia (two participants were identified in this manner). Additional

participants were located by contacting churches, community groups, and historical centers in rural Appalachian communities that cater to Black residents (two participants were identified in this manner). One participant was recommended and contacted through a previous participant. In total, around 29 community centers, churches, and museums, and six private individuals identified through snowball sampling were contacted by phone or email. Three individuals or representatives responded to a request for an interview but did not respond during the scheduling process. For this study, a community was considered to be rural if the county was designated as “rural” or “non-metro” by the Appalachian Regional Commission (Pollard & Jacobsen, 2020). There were no restrictions placed on how long an individual lived in Appalachia, if they moved away and came back, or if they lived in the same area as they were born as this is an exploratory study seeking to gain a basic information on mental health in Black Appalachian residents. Researchers have also indicated that there appears to be a pattern of leaving and returning to Appalachia among those born in the area, thus this pattern may be integral in their conceptualization of and experience with mental health (L. Curtin, personal communication, March 31, 2021). This study did not place restrictions on the sampled interviewee’s type of experience with mental illness (e.g., personally diagnosed with mental illness, been in a close relationship with someone with a mental illness, or no experience with mental illness in any form) because grounded theory seeks to develop a multi-faceted explanatory model using a wide range of experiences and participants (Starks & Trinidad, 2007). Each participant was given an alias to help ensure confidentiality, which is necessary given the sensitive topic being discussed and the small communities being sampled. A monetary incentive in the form of a \$25 gift-card was given to all interviewees for their participation in this study.

Thematic saturation was used to guide the recruitment of an adequate sample. Green and Thorogood (2004) described thematic saturation as the point at which no new themes are developed from new observations or analyses. There has been debate about whether saturation can be accurately determined a priori to data collection, with most who support a priori determinations of the point of saturation requiring a predetermined set of themes and codes that will be applied to the data (Lowe et al., 2018; Sebele-Mpofu, 2020). Other researchers support that saturation cannot be definitively decided a priori, that it must be revisited and reconsidered throughout the data collection process (Malterud et al., 2016; Sim et al., 2018). Thematic saturation was deemed to be reached after the fifth interview.

All five interviewees identified as female, with four being over the age of 60 and one in her late twenties. Three of the interviewees were from Central Appalachia (2 from South Central) and the other two were from Southern Appalachian counties (Pollard & Jacobson, 2021). One interviewee, R4, was raised in Southern Appalachia and now resides outside of Appalachia. Two, both from Central Appalachian counties, briefly moved away from Appalachia (R1 for 15 years, R3 for 2 years). The last two participants have continuously lived in rural Appalachia (R2 Central Appalachia, 75 years and R5 Southern Appalachia, 74 years). All participants stated that they are Christian, though they practice within different denominations. Refer to Table. 1 for a complete breakdown of interviewee demographics.

### **Interview Procedure**

This study was reviewed and approved by Appalachian State University's Institutional Research Board (IRB; 21-0254). Participants engaged in interviews with the author over Zoom (R1 and R2) or phone (R3, R4 & R5). Informed consent was shown electronically and/or described verbally to each participant, and verbal consent was obtained from each participant to

both avoid the risk of breaking their anonymity and to avoid potential technology restraints with requiring electronic or physical signatures. Audio was recorded for the four of the five interviews to aid in transcription and analysis. The fifth interview (R3) was unable to be recorded due to a technological error, though extensive notes and verbatim phrases were transcribed by the author during the interview. Interviews ranged from 38 minutes to 84 minutes in length, depending upon the verbosity of the interviewee and whether follow-up questions were required.

The semi-structured interview schedule was partially informed by the Cultural Formulation Interview in the DSM-5 and was created to address the aims previously laid out (American Psychiatric Association, 2013). It is in a stem-and-leaf format to allow for questions to be answered and asked naturally given the flow of conversation between the interviewer and interviewee. Interviewees were asked to discuss their experience with and beliefs about mental illness and mental health treatment; see Appendix for the interview schedule. Due to the interview being semi-structured, questions were asked and ordered based on the natural progression of the conversation and the researcher was able to ask follow-up questions outside of the set interview schedule as needed for clarification or exploration.

### **Data Analysis**

After transcription of an individual interview, the author and research assistants utilized grounded theory and constant comparative analysis to guide the analysis process. Each interview transcript underwent initial line-by-line coding to ensure a descriptive and detailed analysis by multiple members of the research team. Investigator triangulation, which is a qualitative research technique using multiple researchers to analyze the same data, was utilized to help reduce potential bias in coding (Carter et al., 2014). The initial codes were then tentatively grouped into thematic clusters. Subsequent transcripts were then analyzed using the above method and then

compared to themes and codes from previous interviews to identify where themes could subsume each other or be separated into new ones. This process occurred with every interview conducted and once saturation was reached, themes and codes were reevaluated for a final overview.

ATLAS.ti, an electronic qualitative research tool, was utilized to track and manage codes and themes across the interviews.

## **Interpretations**

### **The Community**

Interviewees were asked to describe their communities, to explain who they consider to be “their people” in order to provide context for this study. Most described historically Black neighborhoods, while one claimed her entire town as her community. Several participants noted that the demographics of their community does not always match their own demographic descriptors. For example, R1 noted that her town in Central Appalachia is ethnically and racially diverse while R4 and R5 noted that their Southern Appalachian communities are predominantly White, isolated, and conservative. Interestingly, population statistics indicate that Southern Appalachian counties have a higher percentage of racial and ethnic minorities than Central Appalachian counties (most Southern counties are made up of over 10% racial-ethnic minorities and over 5% Black while Central counties are less than 10% are racial ethnic minorities and less than 5% are Black; Pollard & Jacobsen, 2020). This may be a result of participants comparing their communities to urban areas within their region of Appalachia. Urban or metro areas in Southern Appalachia do have greater percentages of Black residents than their rural counterparts (less than 12.4% in rural vs greater than 25% in urban areas) while less than 5% of Central Appalachia residents are Black across both rural and urban areas (Pollard & Jacobsen, 2020). Given this information, it is likely that R1 was comparing her community to others around her



and found it to be similarly diverse as her neighboring communities, while R4 and R5 found their communities to be significantly less diverse than their neighboring communities in Southern Appalachia.

The communities of interviewees were “female driven... maybe not always on paper” with women frequently taking on formal and social leadership roles. Additionally, respondents noted that their communities are aging and are increasingly “dried up” with local businesses and community centers/activities such as the YMCA closing. Rural and Appalachian communities are becoming older with the out-migration of young residents, and local businesses are closing as a result of changing economic structures (i.e., Black economic structures were a casualty of racial integration and the influx of chain stores and restaurants in rural areas; Pollard & Jacobson, 2021; Keefe & Junaluska Heritage Association, 2020; Woodson, 1989).

## **Mental Health and Mental Illness**

### *Awareness*

Mental health awareness was frequently discussed by participants regarding how they overcame their negative perceptions of people with mental health concerns and mental health treatment. The source of their mental health literacy varied widely, with some learning about it at university, outreach groups and books, friends or family sharing their experiences, and through their jobs. Several interviewees advocated for increased awareness of resources within their community as well as open discussions on ways to manage distress before treatment is warranted. Specifically, R1 and R2 noted that it would be useful if their churches, the hub of the communities, held a workshop to promote mental health literacy, treatment options in the community, and teach basic coping skills to attendees. Research suggests that programs to increase mental health knowledge are successful at decreasing and potentially eliminating public

stigma (Corrigan et al., 2012; Larson et al., 2012). Furthermore, there is evidence supporting the use of workshops to teach coping skills and provide local resources in enabling mental wellness among community members through resilience and greater access to resources (Codjoe et al., 2021; Gaiha et al., 2021; Woods et al., 2020;).

### *Personal Responsibility & Self-Reliance*

When speaking about those in their lives who have struggled with mental health concerns or describing what they consider to be mentally healthy, many participants described the ideas of personal responsibility and self-reliance. Interviewees discussed how it is important to be independent and take care of the self to not impinge on the family and community. R4 was succinct in her explanation of what she views as being mentally healthy: “[someone] who is, um, able to take care of their own self and operate in what we call a normal lifestyle.” She implies here that self-reliance and the ability to “take care of their own self” is the expectation for a mentally healthy person, and anything else may not be highly regarded. While help-seeking is not explicitly discouraged, it appears that self-reliance and “learning how to cope” is expected to be learned without any help because it may be an imposition on others. R3, who struggles with anxiety, made this statement about help-seeking- “That’s the people pleaser piece of me. I’m afraid to ask for help for myself because I don’t want to seem selfish, I’d rather help people.” While the community may expect its members to have strategies to face life’s challenges and provide for others in the community, it appears the communities do not promote seeking help with developing those strategies and instead promotes self-reliance and the necessity of “pulling yourself up by the bootstraps” (R2).

In the literature this expectation of self-reliance has been coined the “Superwoman Schema” in Black American women, has been noted in Appalachian communities, and has

negative implications for mental health care (Woods-Giscombe et al., 2016; Snell-Rood et al., 2019). Woods-Giscombe et al. (2016) noted in a qualitative study that the Superwoman Schema involves a perceived obligation by Black women to project strength towards others, suppress and avoid emotions relating to vulnerability and dependence, succeed regardless of limitations and focus on caregiving rather than self-care. Appalachian women also reported feeling a need to hide their symptoms and distress until it became overwhelming so that others would not notice or interfere (Snell-Rood et al., 2017). Both Appalachian and Black women did not seek mental health treatment until they felt they could no longer address their symptoms on their own, which has been noted to result in increased severity of symptoms and higher rates of suicide-related emergency department visits (Woods-Giscombe et al., 2016; Snell-Rood et al., 2017; Ting et al., 2012). Alternatively, self-reliance has been described as a consequence of limited access to care and related to resiliency in rural communities (Boilen, 2021). Self-reliance may be a beneficial strategy when faced with limited access to quality mental health care, or it can result in increased severity of symptoms and risk for suicide.

Several women commented on it being a person's responsibility to seek help when needed and to follow through with interventions. The distressed individual was seemingly expected to deal with their mental health on their own until it impacted the community, at which point help-seeking was acceptable and necessary for those with mental health concerns. Respondents spoke of their, and the community's, willingness to provide other needs such as housing and food, and to facilitate treatment if the person with mental health concerns was willing to ask for help.

In addition to having personal responsibility and being self-reliant, most interviewees discussed how being active in the community is important in deciding who is mentally healthy. Community members are expected to function within and possibly better the community through

social roles and jobs. R4 and R5 both spoke to the idea of productivity in the community as an indicator of mental health, which spoke to the value of having a job and physical resources. While unemployment, homelessness and mental health concerns are not mutually exclusive, those who are unemployed and/or housing insecure are significantly more likely to demonstrate mental health concerns (Boardman, 2011; Goldsmith & Diette, 2012; Wilson & Finch, 2021). R5 expanded on this by stating that someone who is “not trying to be a part of what is happening to the family, outside of their family, the nation or the world” is not mentally healthy. This explanation indicates that social involvement with family and wider social groups is more of an indicator of mental health. The issue with social involvement was discussed by R3, who struggles with anxiety. At one point she noted that her history of avoiding social situations and obligations such as church services and family gatherings negatively impacted her long-term relationships. Her experience of social withdrawal and social exclusion highlights the role of social support in mediating mental health concerns (Joe & Niedermeier, 2008; Lincoln et al., 2012; Taylor et al., 2020). The role of social support in the mental health of rural-residing Black Appalachian individuals will be explored later in this paper.

### *Shame*

Rural Black Appalachian communities’ mental health stigma resulted in feelings of personal and familial shame and attempts to manage symptoms to avoid any impact on the community. Historically, community members appear to achieve this through hiding their symptoms due to a lack of available community resources and stigma around mental health. Several respondents noted that mental health concerns were not spoken about outside of the immediate family due to the shame of having to handle mental illness in your family and the pervasive idea of mental illness being equated to violence. R3, who reported dealing with anxiety

throughout her life discussed feeling ashamed of her symptoms and having family members tell her that she was being selfish by showing her symptoms and that she was “vying for attention.” R3’s experience has been noted in literature on stigma in Black American communities, specifically around the idea that endorsement of mental health symptoms is equivalent to exaggerating for attention and does not require treatment (Harris et al., 2020; Planey et al., 2019). Help-seeking is often prevented as a result of stigma within a community, and this results in symptoms increasing in severity over time, which may increase its visibility and impact in the community, thereby increasing stigma over mental health (Bismar & Wang, 2021; Malik & Mann, 2022; Sheehan, 2021).

### **Illness Perceptions**

Respondents frequently attributed the cause of mental health concerns to situational factors in their environment. Some noted traumas from childhood sexual abuse, military service, and seeing the death of family members as reasons for their loved ones’ mental health concerns. Respondents also discussed the loss of resources like a stable job, education, money, and housing, and “being unable to cope with it” as a cause of declining mental health. Looking outward for causes of mental health concerns is consistent with research on Appalachian residents, specifically the concept of “nerves” (Keefe & Curtin, 2012). “Nerves” are a cultural concept of distress which involves primarily somatic symptoms and poor mood as a result of often chronic external stressors such as poverty, demanding jobs, and family conflict. Culture, education, and the nosology (system of classifying disease i.e., DSM-5) heavily influence our beliefs and knowledge surrounding the causes, symptoms, consequences, and our control over an illness or a disorder. This collection of beliefs around illness and disease is known as illness perceptions and it has implications for help-seeking behaviors and the acceptability of therapeutic interventions

(Fernández de la Cruz et al., 2016). Related to illness perceptions and attributions, research suggests that Black Americans are significantly more likely to have an external locus of control, which is when outside influences are considered to have more influence over our behavior; whereas White Americans are more likely to endorse an internal locus of control, which is when individuals are considered to have more influence over their own behaviors (Furnham, 2009; Shaw & Krause, 2001; Zahodne et al., 2015). Western psychotherapy tends to focus on what clients can do to change the way they think and behave, which requires acceptance of an internal locus of control. Black Americans who are presenting to treatment may be seeking help with dealing with distress related to racism and discrimination, situations which would be completely invalidated if a clinician were to suggest cognitive reframing or altering behavior to avoid such confrontations as treatment options. Furthermore, Black Americans have institutional and societal forces impacting the decisions they can make in domains such as career, healthcare, safety, and housing; thus an external locus of control is not a consequence of “faulty” or “disordered” thinking. Additionally, an external locus of control has been shown to be protective against the internalization of negative thoughts and beliefs arising from negative situations such as death of a loved one or interpersonal conflict and bullying (Reknes et al., 2019; Specht et al., 2010). Consequently, having an external locus of control may be well suited for those with identities that have been minoritized and discriminated against, such as Black Americans.

Additionally, racism was noted as having a potentially large impact on the mental health of the two Southern Appalachian respondents (R4 & R5) and R1, but the lasting effects being offset by a strong sense of racial-ethnic identification. Interviewees from Central Appalachia did not perceive racism to be particularly salient in their everyday lives nor their mental health. This difference in the experience of racism between Southern and Central Appalachia may be related

to the different roles each region played in the Civil Rights movement, which 4 out of 5 interviewees experienced in their early lives.

### **Importance of Religion**

Religion played a significant role in each interviewee's life and thoughts around mental health, which is consistent with previous research on Black Americans and Appalachian residents (Holt et al., 2018; Keefe & Curtin, 2012; Keefe & Parsons, 2005). Each participant identified as Christian, though all belonged to different denominations of Christianity. Two themes came out of our discussions that have impact on mental health interventions in Black Appalachian communities: religious coping and the religious community.

Several interviewees spoke to using religion and their relationship with God as a way to cope with the stressors in their lives. In relation to coping with racism, R1 stated:

“Knowing who I am, knowing who I am in the Lord, knowing where I come from, it helps me with those kinds of issues. If I didn't have my faith in God, then I could easily have uh been buried in depression or going into drinking or something like that but my faith in God has kept me from slipping down that slope.”

Other interviewees spoke to the role of prayer in handling the stress of taking care of someone else with mental health concerns. R5 frequently stated that she “knows God put [her] here for a reason” when discussing how she persevered through the violence and disruption she faced with her ex-husband.

Religious leaders served as counsel and provided intervention for stress and mental health concerns according to several of the interviewees. R1, who is a religious leader herself, spoke about providing individual counseling to her congregation, and noted using God as initial guidance on whether to seek treatment, and then continuing to pray and “seek direction from

Him” while seeking formal treatment. Other interviewees discussed how their church community regularly provide social support and are supportive during stressful times, which has been shown to be a protective factor against poor mental health outcomes (Holt et al., 2018; Walker et al., 2018). R1 and R3 also noted how the church community can be detrimental to those with mental health concerns by blaming their symptoms on a “lack of faith” or by further stigmatizing seeking treatment. While the interviewees discussed these religious views that have been seen in Appalachian communities as possibilities, none of the interviewees endorsed believing in them (Humphrey, 1988; Keefe & Curtin, 2012). R1 explicitly noted that her congregation is encouraged to seek out formal treatment if it is desired and/or warranted. Historically, reliance on prayer, or spirituality, was more common than involvement with religious institutions in Appalachia (Humphrey, 1988). Previous research and the interviews indicate that currently both spirituality and religiousness (involvement with religious institutions) are highly valued and play a significant role in maintaining mental health for Appalachian and Black American communities (Keefe & Curtin, 2012; Keefe & Parsons, 2005; Walker et al., 2018).

### **Social Support**

Interviewees spoke extensively on the role of immediate family in addressing mental health concerns. It was notable that unless someone struggled with severe mental illness (R5’s ex-husband), immediate family were the only ones to know the details of and engaged in caretaking for the person with mental health concerns. R1 noted that she did not share her ex-husband’s mental health and her struggle with taking care of him with her family, and R3 explained that she did not share her struggle with anxiety outside of her mother and grandmother. Furthermore, when speaking of her cousin, R4 shared that she knew her cousin was likely struggling with alcohol use but did not know for certain and never spoke with him or other family members about



it. Keeping mental health concerns within the immediate family may be a result of stigma and the desire to avoid judgement from others. Emotional and instrumental support were differentially provided to those with mental health concerns and their caretakers.

Emotional support was provided by caregivers to those with mental health concerns, and to the caregivers by the community in response. R5 and R1 discussed their own roles as caregivers for their ex-husbands with mental health concerns and highlighted the significant impact being a caregiver had on their relationships and general functioning. R5 stated “I am flat sick of him, and I know he can’t control it. He’s mentally ill you know; you just get to the point where you are tired of it,” while R1 noted that “sometimes it’s like you don’t know what to expect, you know, from day to day, you’re walking on eggshells.” Neither involved their families in providing care or support for themselves due to the stigma and shame around their experience. Caregiver burnout, which both women appeared to be experiencing with their ex-husbands, is most often spoken of in relation to those taking care of those with physical illnesses and needs, but it is also seen in those living with and caring for those with mental illness. (Gérain & Zech, 2020; Leung et al., 2022). Family members who take on the role of supporting another with mental health concerns have demonstrated significant impacts on their own mental wellbeing, and it appears that this is where the community tends to intervene. The community (friends, Church, etc.) provided emotional support to the women in response to their burnout, potentially serving as a protective factor against a decline in their mental health, which can be a consequence of caregiver burnout. Emotional support has been shown to improve wellbeing, prevent distress, improve satisfaction with family and work, and improve quality of life (Carney-Crompton & Tan, 2002; Cohen et al., 2013; Morelli et al., 2015; Semmer et al., 2008; Wayne et al., 2006).

Instrumental support, or the provision of practical resources and solutions, was frequently provided to those with mental health concerns. Family members spoke about being the sole source of income for the family, providing housing and paying off the struggling person's debts. The community was often noted to help provide food, clothing, and occasionally a time-limited place to sleep. Instrumental support can be seen as fulfilling basic needs such as housing and food in order to facilitate the opportunity for mental health support and treatment. Research suggests that instrumental support, while it aids recovery from physical illness and medical procedures and prevents postpartum depression, appears to improve mental health and general wellbeing as a function of emotional support (Morelli et al., 2015; Negron et al., 2013; Schultz et al., 2022; Semmer et al., 2008). Instrumental support reduces distress and improves wellbeing if it is given an emotional meaning (i.e., being provided a place to stay means this person cares for me) or if it is partnered with emotional support (i.e., supportive conversation in addition to resources). Consequently, we can infer that while the instrumental support offered to those with mental health concerns was helpful, the emotional support was more effective at maintaining mental wellbeing in the caregivers and it may have reduced distress in those with mental health concerns.

### **Recommended Next Steps**

Cultural mistrust of healthcare providers is evident in both Black American and Appalachian communities. For Black Americans Burkett (2017) suggested the use of the term "obstructed use" to describe the historical influences, such as generational impoverishment as a result of institutional racism and generational trauma regarding unconsented medical trials and experiments on Black Americans on current service utilization. Black Americans have spoken about mistrust for healthcare providers due to a long history of medical trials without consent, misdiagnosis, and negative side-effects to medication, which may influence their underutilization

of mental health services (Burkett, 2017; NIMH, 2021; Rueter et al., 2007). Research on Appalachian communities suggests a heavy mistrust of outsiders, which tends to include healthcare professionals, which prevents help seeking until symptoms severity is high and emergency services are warranted (Keefe, 1988; Keefe & Curtin, 2012; Douthit et al., 2015; Spont et al., 2011; Haynes et al., 2017). Interviewees spoke to the desire to avoid mental health treatment until symptoms are too much to handle on their own and avoiding the use of medication. R1 and R5 cited negative past experiences with their loved ones struggling with side effects such as tardive dyskinesia, drowsiness or “making you like a zombie,” and struggling with medication noncompliance as their reasons for finding medication-based treatments unacceptable. Beyond negative past experiences, other respondents noted that medication would be a last resort for themselves, which highlights the community expectation of “pulling yourself up by your bootstraps.” The interviewees found therapy to be an acceptable option should it be warranted, while medication will be avoided until their distress is too severe. This is consistent with research indicating that Black Americans and rural or Appalachian residents have low service utilization as a result of a sense of self-reliance, stigma and cultural mistrust (Burkett, 2017; Haynes et al., 2017; Keller & Owens, 2022; Lindsey et al., 2006).

Relatedly, interviewees discussed the types of interventions and treatments they find to be most acceptable. Every interviewee noted that therapy is generally an acceptable option, with a few specifying a certain type of therapeutic intervention being preferable. R1 explained that she has known people who’ve become “dependent on their therapist” and that instead of long-term therapy the therapist should facilitate change and coping skills with the goal of ending therapy. R3 also made note of the importance of skills-based treatment in addressing her anxiety. While research indicates that psychotherapy, regardless of the specific type, is generally effective at

addressing symptoms and reducing distress, it is important to take in consideration the preferences of clients so that therapeutic buy-in is increased and clients return for more sessions if warranted (Howard et al., 1996). Short-term, goal-directed therapy is also more cost effective for clients, a concern which was shared by the interviewees and is best highlighted with this statement by R3: “Many can’t really justify spending that money to talk to a professional when you could use it to spend it on bills or whatever else.” The cost of services has also been presented as a barrier for Black Americans, rural residents, and Appalachian residents, all of whom are more likely to be uninsured or underinsured (Pollard & Jacobsen, 2020; Terlizzi & Cohen, 2022; Tolbert et al., 2020).

Limited options for quality mental health care, the resulting long-waitlists and the obviousness of the clinics were noted as large barriers to accessing care. R5 noted that the community mental health clinic was “mostly a joke” because the staff is too overwhelmed to provide quality services. Furthermore, she noted that everyone in the community will know if you are there seeking services, due to it being the only mental health clinic in the area and thus being well-known, which is a common concern in rural communities (Boilen, 2021). This speaks to the need to increase the number of providers to rural areas, which thus far has been an unsuccessful goal of federal, state, and local governments because of limited resources, infrastructure, support, and pay for licensed professionals in rural communities (Jameson & Blank, 2007). Integrated health has been proposed as a solution to the barriers associated with acceptability and accessibility in rural areas and has been found accessible by rural Appalachian women (Boilen, 2021; Hill et al., 2016). In 2017, Black Americans had similar rates of access to a primary care provider (73.4%) but were more likely to have untimely access to care (18.2%) than White Americans (76.8% & 11.1% respectively; Agency for Healthcare Research and Quality, 2020).

Thus, implementing integrated care may theoretically provide mental health care to rural Black Appalachian residents at the same rate as their counterparts, but the timeliness of the care may still be disparate. Researchers and integrated health facilities should collaborate on a review of their referral and warm-handoff rates to determine whether their Black and other minoritized patients are receiving the same quality of services as their counterparts.

Community-based participatory research may help determine the perceived and actual causes of disparate access and/or quality of care and provide direction for community action on improving access and acceptability to all community members. Leaders in local faith communities and community health workers are considered ideal candidates for initiating participatory research due to their connections and established trusted relationship with the local and sometimes hard to reach communities (Agency for Health Care Research and Quality, 2004; NC Department of Health and Human Services, 2018). Additionally, religious leaders and community health workers would be well suited to providing solutions and interventions that will utilize their organization's strengths and fill in the gaps they have worked around. Researchers and community stakeholders should seriously consider utilizing participatory research to address the needs of Black Appalachian residents.

### **Limitations**

This study was the first foray into exploring the mental health experiences of Black rural residents of Appalachia, and as such has limitations regarding its scope. The sampling method used for this study resulted in interviewees who were women and primarily over the age of 60. The women were well established leaders in their community, which led to them being contacted by the author for their participation, and since snowball sampling was not successful for recruitment, this study primarily sampled female community leaders. Due to this, we cannot

generalize their experiences and thoughts about mental health and mental health treatment to Black Appalachian residents who are male, younger, and less active in the community. Another limitation of this study is that we sought participants from a wide geographic area, the entire Appalachian region, in an attempt to establish whether there may be a common experience among Black Appalachian residents. While this goal was marginally achieved, this study is not useful for determining the exact needs of any one Black Appalachian community. Considering this, it is recommended that local communities, researchers, mental health practitioners, and governments conduct their own needs assessment using participatory research methods.

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**Table 1***Interviewee Demographics*

Interviewee	Age	Region	Time in Appalachia	Denomination
R1	64 years	Central	59 years	Non-denominational
R2	75 years	South Central	75 years	Mennonite Brethren
R3	28 years	South Central	26 years	Mennonite Brethren
R4	69 years	Southern	29 years	United Methodist
R5	74 years	Southern	74 years	Baptist

## Appendix A: Informed Consent

### Information to Consider about this Research

**TITLE OF STUDY:** An interpretive phenomenological analysis of the mental health experiences of Black Appalachian Residents

**PRINCIPAL INVESTIGATOR**

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**PURPOSE OF STUDY**

You are being asked to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information.

The purpose of this study is to gain insight into Black Appalachian residents' attitudes towards and experiences with mental health and mental health services. Information gained from this study will be used to help strengthen services in place or develop new mental health services that are acceptable and beneficial to Black residents of Appalachia if they are in need of them.

**STUDY PROCEDURES**

You will be invited to participate in an interview with the principal investigator over a video platform or in person at a location of your choosing, depending on COVID-19 restrictions. Audio will be recorded to provide a transcription to the investigator for analysis purposes.

The interview questions are pre-determined, and you may refuse to answer any with no explanation or penalty. The investigator may decide to ask follow-up questions that are new to explore a topic further, and you reserve the right to refuse to answer those questions as well. The entire interview is expected to last around 1 hour, at which point your participation may end. The transcript of the interview will be reviewed and analyzed by the investigator. You will have the option to review the investigator's analysis for accuracy, but this is optional and will have no impact on receiving compensation.

**RISKS**

Mental health is a potentially sensitive topic and as such, several steps will be taken. Your identity will be kept anonymous to keep others from finding out about your participation and the potentially sensitive information you may share. Information for local mental health resources will be provided to you should you wish it.

You may decline to answer any or all questions and you may terminate your involvement at any time if you choose.



**BENEFITS**

There will be no direct benefit to you for your participation in this study. However, we hope that the information obtained from this study may inform future mental health services available to and potentially tailored to Black residents of Appalachia.

**CONFIDENTIALITY**

Your responses to this interview will be anonymous. When answering questions please do not use any information that could be used to identify yourself or others. Every effort will be made by the researcher to preserve your confidentiality including the following:

- You will be given an alias used in all records, notes, and publications of this research. Only the principal investigator will know your identifying information.
- Audio recordings of the interview will be deleted after your interview has been transcribed and all identifying information that accidentally is included in the interview recording will be removed from the transcript.
- All transcripts and notes will be kept on a secure, password protected computer drive accessible only to authorized researchers.

Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

**COMPENSATION**

A \$25 Visa gift card is offered for your participation in this study. Compensation will be offered after completion of the approximately 1-hour interview. Refusal to answer certain questions or declining to review the investigator's analysis will not affect your compensation. Due to limited funds, you will not receive compensation if you decide to completely withdraw from the study and terminate the interview.

**VOLUNTARY PARTICIPATION**

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. After you sign the consent form, you are still free to withdraw at any time and without giving a reason. Withdrawing from this study will not affect the relationship you have, if any, with the researcher. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed.

**CONSENT**

I have read, and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

The Appalachian State University Institutional Review Board (IRB) has determined that this study is exempt from IRB oversight.

**To maintain your anonymity, you are asked to provide verbal consent to participate in this study instead of signing.**

## **Appendix B: Interview Schedule**

Thank you for agreeing to speak with me today. I'd like to have a conversation with you about your experiences with mental health as a Black resident of rural Appalachia and how your community has played a role in that experience. This interview, as well as my interviews with others, will hopefully help inform the development of mental health resources that are appropriate and acceptable to Black residents of and communities in rural Appalachia. What questions do you have for me before we begin?

### **Demographic Information Questions**

- 1) How do you describe your race?
- 2) How do you describe your ethnicity?
- 3) How old are you?
- 4) How do you describe your gender?
- 5) How long have you lived in Appalachia?
- 6) What is your religious affiliation?
  - a) Denomination?

### **Semi-structured Interview Questions**

- 1) How would you describe your community?
  - a) Who or what is included in your community?
- 2) What do you consider to be mentally healthy in a person?
  - a) How does someone stay or become mentally healthy? What behaviors or types of thinking do they engage in (use interviewee's conceptualization of mental health)?
    - i) What kinds of support do family, friends, and community provide to promote or maintain mental health?
    - ii) Does your religion play a role in maintaining mental health?
- 3) How would you describe someone who is not mentally healthy, or is mentally ill?
  - a) What do you think causes someone to become mentally ill?
  - b) What kinds of stressful situations do you think make the mental illness worse?

Now I am going to ask you some questions about you, your family, friends, and others in your community. To protect their privacy, I ask that you do not use their names or any other information that can be used to identify them. If you do end up slipping and using their name, the audio of our discussion today will be deleted after it has been transcribed and their information will not be included in the transcript.

- 4) Have you or a close family member or friend been impacted by personal experiences with a mental illness as you previously described it?
  - a) How did it affect your personal life?
  - b) How did it affect (your/their) engagement in your community?
  - c) How did those around (you/them react) to the mental illness?
  - d) How did (you/they) cope with the mental illness?
  - e) What kinds of treatment, help, advice, or healing was sought out for the mental illness?
    - i) Which kinds of help were the most useful? The least useful?
    - ii) What kind of support did you receive from people in your community?
    - iii) Did anything keep you/them from seeking out or obtaining help for the mental illness?
  - f) Did you provide any support to your friend/family member?
    - i) If so, what kind of support and how did they react to it?
    - ii) If not, what kept you from providing support?

- g) Were there any community resources that were notably helpful or harmful to you/them?
  - h) Has your experience with racism or discrimination played a role in your mental health?
  - i) Did you think anything different about mental health after experiencing or witnessing mental illness?
- 5) What do you think of formal mental health services like therapy and medication?
- a) How did you come to this?
    - i) Do you have personal history with therapy or medication?
      - (1) If so, how was your experience with (therapy/medication)?
      - (2) Did people in your community know about your usage of (therapy/medication)?
        - (a) How did they react to use of (therapy/medication)?
    - ii) Have people in your community spoken about therapy and medication?
      - (1) What is the consensus on therapy and medication among those in your community?
  - b) Would you ever seek out therapy or medication (again)? Why or why not?
    - i) How did your previous experience with (medication/therapy) influence your decision?
    - ii) How has your community influenced your decision?
  - c) What kinds of help do you think would be most helpful for others in your community who might struggle with a mental illness?
- 6) Thank you for sharing your experiences with me, I appreciate having been given this opportunity to have this discussion with you. Is there anything we did not touch on that you feel would be important for me to know?
- 7) Do you know of any other adults who identify as Black and was born and raised in rural Appalachia?
  - a) Are you willing to provide me with their information so that I may contact them about potentially interviewing with me?
    - i) If not willing to provide other's contact information:
      - (1) Will you provide them with this flyer so that they can contact me if they are interested in speaking with me?

## Appendix C: IRB Letter

**To:** Shayla Moniz  
Psychology  
CAMPUS EMAIL

**From:** IRB Administration  
**Date:** 8/30/2021  
**RE:** Notice of Exempt Research Determination  
**Agrants #:**  
**Grant Title:**

**STUDY #:** 21-0254

**STUDY TITLE:** An Interpretive Phenomenological Analysis of the Mental Health Experiences of Black Appalachian Residents

**Exemption Category:** 2.Survey, interview, public observation

**NOTE:** This project, like all exempt and non-exempt research with human subjects at Appalachian State University, is subject to other requirements, laws, regulations, policies, and guidelines of Appalachian State University and the state of North Carolina. As of August 24, 2020 and until further notice, this includes the requirement by the Office of Research to pause in-person research projects until it receives an additional review to ensure the existence of an adequate COVID-19 mitigation protocol. Please see the full requirement on the [Research Protections website](#).

This study involves no more than minimal risks and meets the exemption category or categories cited above. In accordance with the 2018 federal regulations regarding research with human subjects [45 CFR 46] and University policy and procedures, the research activities described in the study materials are exempt from IRB review.

What an exempt determination means for your project:

1. The Office of Research Protections staff have determined that your project constitutes research with human subjects, but that your research is exempt from the federal regulations governing human subjects research, per [45 CFR 46.104](#).
2. Because this research is exempt from federal regulations, the recruitment and consent processes are also exempt from Intuition Review Board (IRB) review. This means that the procedures you described and the materials you provided were not reviewed by the IRB, further review of these materials are not necessary, and that you can change the consent procedures and materials without submitting a modification.
3. **You still need to get consent from adult subjects and, if your study involves children, you need to get assent and parental permission.** At the very least, your consent, assent, and parental permission processes should explain to research subjects: (a) the purpose, procedures, risks, and benefits of the research; (b) if compensation is available; (c) that the research is voluntary and there is no penalty or loss of benefits for not participating or discontinuing participation; and (d) how to contact the Principal Investigator (and the Faculty Advisor if the PI is a student). You can also use exempt research consent template, which accounts for all of these suggested elements of consent: <https://researchprotections.appstate.edu/human-subjects-irb/irb-forms>. **Please note that if your consent form states that the study was “approved by the IRB” this should be removed. You can replace it with a sentence that says that the study was determined to be exempt from review by IRB Administration. In addition, be sure that the number you have listed for the IRB is 828-262-2692**
4. **Special procedures and populations for which specific consent language is suggested.** Research involving children, research that uses the SONA database for recruitment, research with students at Appalachian State University, or research that uses MTurk for recruitment should use the specific language outlined by The Office of Research Protections on our [website](#).

5. **Study changes that require you to submit a modification request:** most changes to your research will not require review by the Office of Research Protections. However, the following changes require further review by our office:

- the addition of an external funding source;
- the addition of a potential for a conflict of interest;
- a change in location of the research (i.e., country, school system, off site location);
- change in contact information for the Principal Investigator,
- the addition of non-Appalachian State University faculty, staff, or students to the research team, or
- **Changes to study procedures.** If you change your study procedures, you may need to submit a modification for further review. Changes to procedures that may require a modification are outlined in our SOP on exempt research, a link to which you can find below. Before submitting a modification to change procedures, we suggest contacting our office at [irb@appstate.edu](mailto:irb@appstate.edu) or (828) 262-2692 to confirm whether a modification is required.

**Investigator Responsibilities:** All individuals engaged in research with human participants are responsible for compliance with University policies and procedures, and IRB determinations. The Principal Investigator (PI), or Faculty Advisor if the PI is a student, is ultimately responsible for ensuring the protection of research participants; conducting sound ethical research that complies with federal regulations, University policy and procedures; and maintaining study records. The PI should review the IRB's list of PI responsibilities.

**To Close the Study:** When research procedures with human participants are completed, please send the Request for Closure of IRB Review form to [irb@appstate.edu](mailto:irb@appstate.edu).

If you have any questions, please email [IRB@appstate.edu](mailto:IRB@appstate.edu) or contact the Director of Research Protections at (828) 262-2692.

Best wishes with your research.

#### **Important Links for Exempt Research:**

Note: If the link does not work, please copy and paste into your browser, or visit <https://researchprotections.appstate.edu/human-subjects>.

1. Standard Operating Procedure for exempt research (#9): [https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/sop\\_9\\_approved\\_1.21.2019.pdf](https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/sop_9_approved_1.21.2019.pdf)

2. PI responsibilities: <https://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/PI%20Responsibilities.pdf>

3. IRB forms: <http://researchprotections.appstate.edu/human-subjects/irb-forms>

### **Vita**

Shayla Rene Moniz was born in Jacksonville, Florida, to Katrina Neil née Johnson. She was raised in a blended family by Katrina and Kelly Neil with an older brother, twin sister and a younger stepbrother. Shayla graduated high school and received her A.A. degree in 2016 from Riverside High School and Florida State College at Jacksonville. She then earned her B.S. in Psychology in 2019 at Appalachian State University where she studied abroad for a semester and completed an honors thesis. Following graduation, Shayla returned to Florida to work in an inpatient behavioral health facility with children and teens. She returned to Appalachian State University in the Fall of 2020 to enter the Clinical Psychology Psy. D. program under the mentorship of Dr. John Paul Jameson. Shayla's career goals include working with underserved populations in a community mental health facility.