UACC Generations Health Study

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TABLE OF CONTENTS

ABSTRACT 4
I. INTRODUCTION 5
II. LITERATURE REVIEW 5
III. METHODS 15
IV. RESULTS 18
V. DISCUSSION 38
VI. CONCLUSION AND RECOMMENDATIONS 42
REFERENCES 48
APPENDIX A: Key Informant Interview Questionnaire 51
APPENDIX B: Health Story Circle Agenda 55
APPENDIX C: Key Informant Responses 57

ABSTRACT

Appalachians, both urban and rural, face significant health disparities when compared to the general population in the United States. There has been substantial research conducted on the leading causes of illness and death among first- and second-generation Urban Appalachians; however, the information surrounding third-, fourth-, and fifth-generation Appalachians is sparse. This paper will explore the following question: What is the problem of maintaining health and other demographic data on Urban Appalachians as the third, fourth, and fifth generations come along? How do we solve this problem?

Keywords: Urban Appalachian, 3rd Generation, 4th Generation, 5th Generation, Health, Mental Health

I. INTRODUCTION

This paper is intended to be an internal document for the Urban Appalachian Community Coalition (UACC) to help guide future research into the health issues of third-, fourth-, and fifth-generation Urban Appalachians. This paper serves to explore the perceptions of health issues among third-, fourth-, and fifth-generation Urban Appalachians through key informant interviews and story circles. It will also explore the problem of maintaining health and other demographic data on Urban Appalachians and provide potential solutions to this problem. Health disparities have been well documented for first- and second-generation Urban Appalachians. First-generation Urban Appalachians are defined as the Appalachians who migrated from the Appalachian region to urban areas. Second-generation Urban Appalachians are the children of the first generation, third-generation are the children of the second, etc. In Lower Price Hill, environmental factors were deemed to have been a detriment to the health of the white Urban Appalachian children studied; this included lead poisoning and health conditions related to smoking. Significant disparities were identified for developmental delay and intellectual disability as well as for diabetes and hypertension/high blood pressure. A rate of two out of every ten white Appalachians were found to not get medical care due to the costs associated with care (Maloney, Rodriguez, & Sullivan 2022).

II. LITERATURE REVIEW

Urban Appalachian Health

In Virginia, smoking prevalence was 7.52% points higher in Appalachian counties than non-Appalachian counties, and 6.16% points higher in rural counties than urban. Pilehvari et al.

found that smokers in rural Appalachia were more likely to smoke earlier in life, smoke heavier, and were less likely to successfully quit smoking which results in Appalachian smokers being "disproportionately affected by smoking related illnesses" (Pilehvari et al. 2023: 811). "Smokers" in the study were defined as "adults who reported having smoked more than 100 cigarettes in their lifetime and a current smoking frequency of 'every day' or 'some days'" (Pilehvari et al. 2023: 812). The study used a social vulnerability index (SVI), and the SVI score in the rural Appalachian counties was higher than those in urban Appalachian counties studied (Pilehvari et al. 2023).

In a study on barriers to lactation services in Appalachia, some of the challenges reported included families not supporting breastfeeding, difficulty in providers reaching clients, a small number of lactation professionals and supporters compared to the Appalachian population, and a lack of ethnic/racial diversity among the lactation professionals and supporters. The lactation professionals and supporters also called for more training regarding lactation and substance use, mental health, and birth trauma as well as with interacting with LGBTQ+ families (Seiger et al. 2022). Some more of the barriers identified include troubles with other providers not being aware of lactation services, not supporting breastfeeding, or not referring to LPSs; hospital practices and policies surrounding the labor, delivery, and postpartum stages of childbirth; "non-medically indicated supplementation;" members of a client's social circle (family, partners, etc.) not being supportive of breastfeeding; and clients negative views of breastfeeding. (Seiger et al. 2022: S800).

Negative attitudes toward obesity can impact the level of care adults with obesity may receive due to some healthcare providers seeing obese patients as “lazy, unable to control their eating, and unable to take responsibility for themselves” (Weissman et al. 2019: 404). Some healthcare providers even plainly express disgust of obese adults and make disparaging remarks which serve to reinforce the social isolation obese adults face; this further discourages them from seeking health promoting activities. It has been found that obese adults have a greater prevalence of serious psychological distress than their non-obese counterparts. More than half of older obese adults reported not needing to see a doctor despite having one or more chronic health conditions. It was noted that women with obesity were less likely to have seen a doctor in the past year and reported having greater difficulties receiving care. Additionally, an increase in Body Mass Index (BMI) was positively correlated to an increase in an increase of delay and/or avoidance of healthcare (Weissman et al. 2019).

Barriers to healthcare for women were identified as “lack of access to healthcare; cultural insensitivity; cultural incompetence on the part of some health care providers; and health policies that did not adequately address health care for women living in poverty who lacked education” (Slusher, Withrow-Fletcher, and Hauser-Whitaker 2010: 85). Barriers to healthcare for Appalachians were identified as “lack of available services, ethnocentric providers, cost, and lack of insurance” (Slusher, Withrow-Fletcher, and Hauser-Whitaker 2010: 85). The study found that Appalachian women do, in fact, partake in self-care behaviors to promote their health. (Slusher, Withrow-Fletcher, and Hauser-Whitaker 2010).

In a study exploring how doctors view Appalachian patients, it was found that non-Appalachian professionals judged the behaviors from the perspective of the dominant society and thus viewed the behaviors as negative characteristics of Appalachian clients which may be detrimental to health care delivery to Appalachian clients. Conversely, Appalachian professionals placed behavior in its appropriate cultural context and viewed the behaviors as either positive or neutral. Appalachians tend not to seek healthcare from facilities staffed by professionals who interpreted the Appalachian lifestyle from a negative perspective (Tripp-Reimer 1982).

Ludke, Obermiller, and Horner wrote about the health status and health determinants of Urban Appalachians, but largely focused on first- and second-generation Urban Appalachians. In a study of first-generation white Appalachian adults, it was found that, from 1999-2005, the physical health status of Appalachians was stable but significantly lower than non-Appalachians. Appalachians and non-Appalachians had identical scores for mental health. Additionally, 'Appalachians perceived their health to be poorer than did non-Appalachians" (Ludke & Obermiller 2012: 317). Appalachians faced greater risk for chronic physical health problems than non-Appalachians. There was also some evidence that the risk of hypertension, high cholesterol, and depression was possibly increasing among Appalachians. Appalachians live at a comparatively lower socioeconomic status than non-Appalachians which could be a factor that puts the Appalachians at a higher risk of poor health. A greater number of Appalachians perceived the cost of healthcare to be unreasonable than did non-Appalachians, though the percentage for both groups increased over time. The cost of healthcare is seen as a greater barrier to Appalachians' use of the healthcare system. Appalachians have poorer dental health than non-Appalachians. Despite the fact that cigarette smoking has decreased among Appalachians, more

Appalachians use tobacco (both smoking and smokeless) than non-Appalachians. Compared to non-Appalachians, Appalachians were significantly less likely to partake in physical activity. Appalachians were less likely to view their diets as healthy and were less likely to consume the recommended servings of fruits and vegetables per day than were non-Appalachians. Appalachians were, however, less likely to consume alcohol and much less likely to be binge drinkers than non-Appalachians (Ludke & Obermiller 2012).

Ludke, Obermiller, and Horner also studied first- and second-generation white Appalachian children. They found that the perceived health status of children by primary caregivers was comparable between Appalachians and non-Appalachians. The primary caregivers did perceive, however, that the Appalachian children had a higher risk of behavioral and emotional health problems than non-Appalachians. In 2007, Appalachian and non-Appalachian children between 12 and 17 had comparable levels of behavioral and emotional health; However, between 2000 and 2005, they became increasingly more likely to have behavioral and emotional health issues. The researchers found that 15% of Appalachian children had asthma and 7% of those without asthma had some sort of recurrent respiratory issue. The proportion of Appalachian children with Attention Deficit Disorder (ADD) increased from 5% to 11% between 2000 and 2005. It was found that Appalachian children were more likely than their non-Appalachian counterparts to have hearing problems. It was found that more Appalachian children lived in single-parent households than non-Appalachian children resulting in higher risk for poor health conditions. Additionally, the Appalachian children were more likely to live in low-income households and less likely to live in high income households. Appalachian children

were less likely to have private insurance coverage; however, Appalachian children had more primary care services available to them (Ludke & Obermiller 2012).

Hayes studied perspectives of older Appalachian women who lived alone in terms of informal and formal health care. The study found that keeping active was a key form of self-care for these women, and that the home was central to their ideas of health. The study found that the women were good about caring for themselves when ill and sought care when their methods of care did not work or when their health become more dire, but that the women were doing very little preventative care (Hayes 2006).

Identifying and Tracking Urban Appalachians

Ludke, Obermiller, Rademacher, and Turner performed a study identifying Appalachians and came up with four approaches. The first approach, a place-based approach, uses place of origin by asking a person if they have roots in Appalachia; if a person has roots in the federally defined region of Appalachia, they are considered Appalachian. This can be identified through asking where the person, their parents, their grandparents, etc. are from, and if they or their ancestors are from an Appalachian county, they are Appalachian. Alternatively, instead of asking people directly, the use of public and/or genealogical records could be used for acquiring this information through genealogical records. The major strength of this method is that Appalachians tend to have close kin relationships and generally know where they, their parents, and often their grandparents were born. A weakness to this method comes in the fact that the geographical area designated as Appalachia is not necessarily universally agreed upon. Another weakness comes

from the fact that not everyone born in Appalachia has Appalachian heritage (Ludke et al. 2010; Ludke & Obermiller 2012).

The second approach involved place of residence, so if a person lives in an Appalachian area/neighborhood then they are Appalachian. A weakness of this approach is that not everyone who lives in Appalachia or Appalachian neighborhoods has Appalachian heritage (Ludke et al. 2010).

The third approach was to just ask people if they identify as Appalachian. The strength of this method is that people know if they identify as Appalachian. However, a weakness is that some people might not want to be identified as Appalachian due to negative stereotyping or they might associate with other terms such as “hillbilly” (Ludke et al. 2010: 38; Ludke & Obermiller 2012).

The fourth method was the Attribute-Based Approach which involves using cultural attributes to identify Appalachians. This includes using values that are commonly associated to Appalachians (i.e., familism, love of place, individualism, religion, and neighborliness). A major drawback to this method is that there is not a general agreement as to what the specific attributes of Appalachians are. Additionally, multiple groups outside of Appalachia may have similar attributes (Ludke et al. 2010; Ludke & Obermiller 2012). The authors indicate that not one of these methods is necessarily better than the other, and that each may be best for different situations. Additionally, it is suggested that for studies where the interest lies in subsequent generations of Appalachians, self-identification is possibly the most suitable (Ludke & Obermiller 2012; Ludke et al. 2010).

The researchers identified that there was not concordance across the questions identifying Appalachians. For example, just because a person's place of birth was in Appalachia did not mean that they self-identified as Appalachian. Additionally, some respondents had family roots in Appalachia but did not consider themselves to be Appalachian. Finally, there were respondents who had Appalachian roots but were not born in Appalachia, and some who were born in Appalachia but did not have family roots in Appalachia (Ludke et al., 2010).

One issue in identifying Urban Appalachians comes from the fact that, by the third generation, peoples' ethnic ties will weaken as they acculturate into the mainstream culture. This is especially true as they enter the middle class, and socioeconomic factors become stronger than their ethnicity. Philliber writes:

> These second- and third-generation Appalachians… are unlikely to consider themselves Appalachians or be considered so by others. First, there will be little about these people to identify them as Appalachians. The distinctive accents of their parents will be replaced by speech patterns of Midwestern city dwellers. They will have learned the ways of the city people and know little of the ways people live in Appalachia. In the land of their ancestors they will be known as "city slickers" and "Yankees" … These people have no place to call home in Appalachia. Their families live outside the region. They remain poor, but they do not remain Appalachian" (Obermiller & Philliber 1987: 64-65)

Later generations of Urban Appalachians may become alienated from their Appalachian identity. Thus, it will become more difficult for a researcher to identify them as Appalachian (Obermiller & Philliber 1987).

In studying early school leaving for Appalachian women, Patricia Ziegel Timm conducted interviews and collected data from 50 families. In identifying participants, Timm spoke with “kin-sets of women—mothers, daughters, grandmothers, aunts, cousins, and sisters,” and mentioned one instance where three mothers brought their children, siblings, and parents into what was effectively a story circle where she listened to them talk about their experiences with the education system and leaving school (Obermiller 1996: 108).

M. Kathryn Brown writes about community-based participatory research (CBPR) as a method to study communities underserved by typical health data-collection protocols. CBPR contains the following elements:

> recognition of the community as the unit of identity; building on strengths and resources within the community; facilitation of the collaborative, equitable involvement of all partners in all phases of the research; integration of knowledge and intervention for the mutual benefit of all partners; promotion of a colearning and empowering process that attends to social inequalities; application of a cyclical and iterative process; understanding health from both positive and ecological perspectives; dissemination of findings and knowledge gained to all partners; and a long-term commitment by all partners (Ludke & Obermiller, 2012: 341-342).

The CBPR method has a long history in Appalachia and has been used effectively many times, even in Lower Price Hill (Ludke & Obermiller 2012).

Balcazar, Grineski, and Collins performed a study exploring the relationship between generation, citizenship, and health outcomes for Hispanic persons in the United States. The

researchers discuss how, traditionally, a three-group framework is used where a child's immigrant generational status has been conceptualized with a basis of the child's and parents' nativity and the classical immigrant assimilation model that posits that immigrants will adopt the behaviors of the dominant cultural group gradually over time. The researchers also discuss an expanded three-group framework which includes a 2.5 generation (U.S. born children with one foreign born parent and one parent born in the U.S.) as well as identifying the first generation not just by nativity, but by citizenship as well. The methods of data collection for this study included a cross-sectional, population-based mail survey; the first mailing had a survey packet (with consent letter), a two-dollar incentive, and a return envelope with postage paid; the second mailing, a reminder postcard, was sent a week later; a week after the reminder postcard, the survey packet, two-dollar incentive, and return envelope were sent to non-respondents. The immigrant generational status of the child was operationalized using nativity (born inside or outside of the U.S.) for the child, the child's parents, and the child's four grandparents. Also, the operationalization included the child's US citizenship status. The study utilized an expanded generational cohort framework; this framework allowed the researchers to identify specific thresholds of duration for the immigrant respiratory health advantage (Balcazar, Grineski, and Collins 2015).

In a study trying to identify the hidden demographic data of the transgender population in the United States, researchers used online convenience sampling. The researchers found that the online medium gave respondents anonymity, increased the reach of the researchers, and decreased the burden of survey completion on the respondents due to the fact that respondents could complete the survey at any time, place, and speed of their choosing. The researchers found

that the use of internet-based research was a good supplement to community based and clinical research studies due to the fact that it helped to combat bias that may appear in those types of studies (Rosser et al. 2007). The researchers also found that the online studies made the surveys more accessible to "those who are geographically isolated, homebound, disabled, and members of the military on active duty, as well as others prevented from participation in offline studies by geography, work, time, or mobility issues" (Rosser et al. 2007: 60-61).

III. METHODS

Key Informant Interviews

Interviewees were selected through convenience sampling. Members of the UACC Research Committee were reached out to via email. Out of 16 members of the research committee reached out to, six responded and five were interviewed. Key informants were asked about their own ability and methods in identifying succeeding generations of Urban Appalachians along with illnesses, causes of death, and barriers to care they perceived in the Urban Appalachian community. Additionally, I reached out to one of my professors at the University of Cincinnati (UC) who is unaffiliated with UACC but has conducted research tracking multiple generations of demographic groups in the past.

Key Informant #1

Key Informant #1 is a community resource worker who also works in Appalachian studies. She is a second-generation Urban Appalachian woman in her 70s. She lives in Cincinnati, Ohio. She identified her race as Caucasian with some Native American. The highest level of education she achieved was an associate degree.

Key Informant #2

Key Informant #2 is a community member who also works in Appalachian studies. She is a first-generation Urban Appalachian woman in her 30s. She lives in Hamilton, Ohio. She identified her race as White and Native American. Her family makes more than $50,000 a year.

Key Informant #3

Key Informant #3 is a community member who lives in Dayton, Ohio. He is a third/ fourth generation Urban Appalachian man in his 40s. He identified his race as White and Melungeon. His family makes more than $50,000 a year.

Key Informant #4

Key Informant #4 participates in Appalachian studies. He is an Urban Appalachian man in his 30s. He identified his race as White, and believes he is Appalachian by ethnicity but discussed how he felt that, as an Urban Appalachian, he wasn't sure if he would be considered an Appalachian. His family makes more than $50,000 a year.

Key Informant #5

Key Informant #5 is a professor at the University of Cincinnati who is unaffiliated with the Urban Appalachian Community Coalition.

Key Informant #6

Key informant 6 is involved with Appalachian studies. She is a second-generation Appalachian woman in her 50s who identified her race as white. She lives in Cincinnati, Ohio. Her family makes more than $50,000 per year.

The Key Informant Questionnaire can be found in Appendix A.

Story Circles

The participants for the story circles were once again selected through convenience sampling, and were found and selected by Pauletta Hansel and Maureen Sullivan. The story circles were conducted and facilitated by Pauletta Hansel. Other members of the UACC Research team in addition to myself included Maureen Sullivan and Nikita Dessai. The Story Circles had two rounds, the first round followed the prompt, "Tell a story about a time you were concerned about your or your family member's or a neighbor's health" and the second round followed the prompt, "Tell a story that shows how the health concerns for your neighborhood has changed in the last ten or so years" (Hansel 2023). Each round saw the participants going around the circle and telling their stories with each round followed by a period of cross talk where circle participants could ask questions and make comments about other participants' stories. For more detail, see Appendix B for the full Story Circle Agenda.

Story Circle #1

Story Circle #1 was composed of four Urban Appalachian women of second and third generations and was conducted at the East Price Hill Library Branch.

Story Circle #2

Story Circle #2 was composed of seven Urban Appalachian women of second and third generations and was conducted at the Methodist Church on State Street in Lower Price Hill.

IV. RESULTS

Health Status

Key Informant #1

For leading causes of illness for adults in the community, Key Informant #1 reported COVID-19 and side-effects, asthma, cancer (particularly lung cancer), diabetes (mentioning that it is mostly type two with some type one), and illnesses resulting from pollution and lead paint. Key Informant #1 mentioned that the pollution and lead paint have been causing problems for multiple generations over the last 50 years. For teens, Key Informant #1 mentioned breathing issues (including asthma) and hunger. For children, Key Informant #1 mentioned asthma, hunger, cancer, mesothelioma, cystic fibrosis, and type one diabetes.

For leading causes of death for adults in the community, Key Informant #1 once again referenced cancer and COVID-19. Key Informant #1 did not mention any causes of death for teens. For children, Key Informant #1 mentioned cancer, but specified that it was only a few kids and was mostly hitting adults.

For mental illness/conditions for adults in the community, Key Informant #1 reported depression, anxiety, and panic attacks as well as mentioning domestic violence as an important aspect related to mental health. For both teens and children, Key Informant #1 mentioned trauma (related to bullying, domestic violence, and violence happening outside of the home), depression, anxiety, and panic attacks.

Key Informant #1 spoke to substance abuse within the community, mentioning that there is not a lot of alcohol use among the younger generations but there is a lot of marijuana use by

kids as young as 12. Key Informant #1 mentioned that trauma is extremely prevalent in the younger generations and that there are not many stable families. Additionally, Key Informant #1 mentioned that she perceives electronics (particularly phones) as putting people in a health deficit (both physically and psychologically) as well as being a cause of misinformation. Key Informant #1 did mention that younger people do tend to be healthier as a result of mandatory school programs, such as vaccine requirements, along with the presence of clinics in the schools. As a result of these programs, Key Informant #1 mentioned that young people feel more comfortable seeing doctors. Key Informant #1 also mentioned that care for mothers and infants tends to be pretty good due to community support.

Key Informant #1 does not believe Urban Appalachians in Lower Price Hill are getting good healthcare. She talked about how those with doctors outside of the neighborhood feel better about the healthcare they receive, but that there are no doctors in the neighborhood anymore which is a problem for those who lack transportation. Key Informant #1 went on to talk about how some, but not all, insurance providers provide transportation but the transportation can be untimely and may not allow for more than one child to ride along. Additionally, she mentioned how bus routes do not go far enough for some residents to reach their doctors. Key Informant #1 talked about how schools have clinics, but those clinics are dependent on insurance. Insurance coverage can be a huge barrier due to the fact that getting and maintaining insurance is a major hassle for people, and that even with insurance things are not perfect. She talked about how most people have Medicaid or Buckeye Insurance, but how Buckeye does not serve dental coverage for a lot of dentists. Key Informant #1 talked about some more barriers that cause people in the community to not get good healthcare and mentioned that people do not like going to the

emergency room as a major one. Additionally, she mentioned that there are often a low number of hospital beds/rooms which makes it difficult to receive care. On top of all that, Key Informant #1 talked about how people do not trust doctors and lack good education surrounding healthcare which she believes has only gotten worse since the COVID-19 pandemic.

Key Informant #2

For leading causes of illness for adults in the community, Key Informant #2 reported postindustrial decline which in turn led to joblessness and poverty; additionally, she mentioned that there are capitalist policies and philosophy that maintain the socioeconomic status quo. Key Informant #2 also identified addiction, poor diet, lack of education/knowledge/awareness surrounding health, and lack of access to resources (such as healthcare, transportation, insurance, and wealth) as causes of illness. For teens and children, Key Informant #2 mentioned that lack of education/knowledge/awareness surrounding health and lack of access to healthcare were once again issues; additionally, she mentioned there being a lack of opportunity and healthy outlets for teens and children as well as a lack of parental/family support.

For leading causes of death for adults in the community, Key Informant #2 mentioned cancer, diabetes, heart disease, and addiction. Key Informant #2 also highlighted accidents including car accidents, overdose, and on-the-job accidents. For teens, Key Informant #2 mentioned accidents, suicide, addiction, and abuse/neglect. For children, Key informant #2 mentioned abuse/neglect and accidents (which for children include bad falls and car accidents).

For mental illness/conditions for adults, teens, and children in the community, Key Informant #2 mentioned depression, anxiety, and Post Traumatic Stress Disorder (PTSD). For

adults only, Key Informant #2 mentioned bipolar disorder. For adults and teens, she mentioned addiction. For teens and children, Key Informant #2 mentioned ADD/Attention Deficit Hyperactivity Disorder (ADHD). Key Informant #2 perceives the levels of depression to be higher in Urban Appalachian communities than in other populations. Going into more detail about the causes of PTSD, she talked about Urban Appalachians being veterans; suffering traumatic brain injury; having cancer; and experiencing joblessness and generational socioeconomic insecurity. Key Informant #2 believes that Appalachians more readily join the military than other populations, and thus experience the PTSD that is associated with military service. In talking about the prevalence of autism and down syndrome within the Urban Appalachian community, Key Informant #2 mentioned that she does not believe that autism and down syndrome are any more frequent than in the general population.

Key Informant #2 talked about how she perceives addiction as a rising and ongoing concern within the younger generations of the Urban Appalachian community. Additionally, she talked about how anxiety is more prevalent among the younger generations of Urban Appalachians and how it has been increasing ever since the COVID-19 Pandemic.

Key Informant #2 believes that Urban Appalachians are getting good healthcare sometimes. She talked about barriers that cause people in the community to not get good healthcare and mentioned a lack of trust mixed with fear/anxiety around the medical field. She also talked about how there is fear/anxiety around receiving a possible diagnosis, both in terms of being afraid of needing more interaction with the medical field as well as fear of a disease itself. Key Informant #2 mentioned how she sees this more in the older generations, but it is still

present in the younger generations. She also mentioned that Urban Appalachians will opt to do what is familiar and stick with tradition, meaning that they will use home remedies whenever possible to avoid going to the doctor. She talked about lack of resources, meaning lack of insurance, a work schedule that is inflexible to an employee seeking healthcare, and lack of finances. Finally, she talked about lack of access to healthcare which comes in the form of lack of transportation to appointments, long distances to healthcare, and unaffordability of care.

Key Informant #3

For leading causes of illness for adults in the community, Key Informant #3 listed diabetes, obesity, alcohol related conditions, cancer (particularly lung cancer), cigarette smoking, other lung issues, Chronic Obstructive Pulmonary Disease (COPD), heart issues, addiction, and poor diet. For teens, Key Informant #3 once again believes obesity and diabetes to be leading causes of illness. For children, he mentioned obesity again, as well as congenital defects (which include conditions that result from incomplete development such as having a hole in the heart).

For leading causes of death for adults in the community, Key Informant #3 once again mentioned diabetes, obesity, cancer, and heart issues. For teens, he talked about the leading causes being accidents (such as car or four-wheeler accidents) and suicide. For children, Key Informant #3 once again referenced congenital birth defects, but also mentioned sudden infant death syndrome that occurs from unsafe sleeping habits of the parents sleeping with their children.

For mental illness/conditions for only adults in the community, Key Informant #3 mentioned personality disorders. For mental illness/conditions for both adults and teens in the

community, Key Informant #3 mentioned major depressive disorder, bipolar disorder, and addiction/chemical dependency (alcohol and/or drugs). ADHD was mentioned for adults, teens, and children. Key Informant #3 was otherwise unsure about mental illnesses/conditions among children. He believes that all of these mental conditions have some sort of genetic component that runs in families.

In talking more about illness among the younger generations, Key Informant #3 discussed that he does not believe parents are making healthy choices for their children while they are young (particularly, in their diets). He also talked about how poverty and lack of access to good food is a major problem for the younger generations of Urban Appalachians. Key Informant #3 also talked about how a lot of the health issues the younger generations of Urban Appalachians are faced with likely have a lot to do with their genetics and health issues that are passed down in families.

Key Informant #3 believes that Urban Appalachians are getting good healthcare sometimes. He believes that people with access and good health insurance generally get good care. He talked about barriers that cause people in the community to not get good healthcare and mentioned that many people lack access to healthcare and good (or any) health insurance. He also talked about how the healthcare provided by the government is not necessarily good and does not necessarily equate to good treatment. Key Informant #3 talked about lack of employment / underemployment being a major barrier to accessing healthcare. Additionally, he mentioned that the cost of care is often too high for people to be able to afford. Next, Key Informant #3 discussed how culturally, Appalachians do not like going to the doctor and have a

general distrust/negative view of doctors and the healthcare industry. He talked about how people will go in to get healthcare, and come out with bad outcomes even when getting good healthcare (e.g., dying in the hospital) resulting in a greater distrust in the medical industry. He also mentioned that Urban Appalachians are likely to wait too long to see a doctor. Finally, Key Informant #3 talked about how he does not believe that the good (meaning better skilled) doctors come to Appalachia/Appalachian communities because they will not make as much money as they would elsewhere.

Key Informant #4

Key Informant #4 mentioned industrial pollution (naming heavy metals in the air in particular) as a leading cause of illness for adults, teens, and children in the Urban Appalachian community. For leading causes of illness for adults in the community, Key Informant #4 listed poor diet, cancer, smoking, and heart disease. For teens, he mentioned communicable diseases and lifestyle choices. For children, he mentioned communicable diseases from being exposed to other children, but was otherwise unsure about leading causes of illness for children.

For leading causes of death for adults in the community, Key Informant #4 perceived lifestyle choices (such as smoking), undiagnosed mental illness, suicide, dire economics, heart disease, and poor diet (partially as a result of lack of access to good food, but also due to some laziness in not wanting to choose the healthy option for their family). For teenagers, he once again mentioned lifestyle choices and suicide (although, he believes there to be less suicide among teens compared to adults), as well as obesity and genetic factors. For children, Key Informant #4 listed congenital defects and genetic abnormalities as the leading causes of death.

For mental illness/conditions for adults in the community, Key Informant #4 listed anxiety, depression, Obsessive Compulsive Disorder (OCD), ADHD, and PTSD (From generational poverty). He said the list was similar for teens, mentioning that there was a little bit less PTSD, a little bit less depression, and more ADHD for teens; additionally, he mentioned that both teens and children experience gender dysphoria.

In talking more about illness among the younger generations, Key Informant #4 mentioned that there is a lot of undiagnosed mental illness within the community. He talked about how mental help is prohibitive and how the cost for care can be expensive. He also talked about some hollers being rural food deserts, and mentioned that this was not necessarily a cause of poor health but was definitely a factor.

Key Informant #4 believes that Urban Appalachians are sometimes getting good healthcare, including mental healthcare. He talked about barriers that cause people in the community to not get good healthcare and mentioned that people need a good job and/or to be wealthy to even afford care, that there are a lot of hoops that a person needs to jump through in order to get government assistance, and that structural inequality acts as a barrier to healthcare. He also mentions cultural barriers including that some people have sociocultural predispositions to not going to the doctor and that they are not socialized to seek preventative care; additionally, he mentions that there are generational predispositions to not going to the doctor.

Key Informant #5

Key Informant #5 is unaffiliated with the Urban Appalachian community and was not asked about perceptions of the health of Urban Appalachians; rather, the focus was on identifying and maintaining contact with multiple generations and research design.

Key Informant #6

Key Informant #6 perceived asthma, cancer, mental illness, addiction, high blood pressure, high cholesterol, and type 2 diabetes as the leading causes of illness for adults in the community. Key Informant #6 also identified mental illness, asthma, and some diabetes (but not in younger teens) as leading causes of illness for teens. For children, Key Informant #6 mentioned mental illness and asthma.

For leading causes of death for adults in the community, Key Informant #6 mentioned stroke/heart attack as a result of high blood pressure and/or high cholesterol, cancer, and deaths of despair (meaning suicide or accidental overdose). For teens and children, she mentioned accidents (car accidents, accidents with firearms where they did not mean to harm themselves or others). Strictly for teens, Key Informant #6 listed suicide, and overdose (though there are fewer overdose deaths for teens than for adults); additionally, she mentioned that homicide is a leading cause of death for teens but that it occurs less often than suicide and overdose.

For mental illness/conditions for adults, teens, and children in the community, Key Informant #6 mentioned depression, anxiety, and ADHD. She made a key point that the ADHD is not necessarily diagnosed for any of the groups due to the costs associated with getting a diagnosis. For adults and teens, Key Informant #6 mentioned addiction.

Key Informant #6 talked about how living in impoverished areas makes children more likely to be exposed to pollution and environmental toxins that lead to them having asthma. She went on to talk about how dental health among teens and kids is not the greatest, mentioning that it is not necessarily something that is going to be caught or treated when they are teenagers and children but may present bigger problems as they reach adulthood. These issues include tooth decay, cavities, bad alignment and Temporomandibular Joint Disorders (TMJ) which can be painful. Key Informant #6 also talked about how even if a person has health insurance, most do not cover dental and that public health resources for dental care are even harder to get than for general healthcare.

Key Informant #6 believes that Urban Appalachians are getting good healthcare some of the time. She talked about barriers that cause people in the community to not get good healthcare and mentioned money as the biggest factor. She mentioned how care is often not affordable for many Urban Appalachians, and specifically mentioned how braces are extremely expensive. The second barrier Key Informant #6 mentioned was access, and transportation/difficulty in getting to appointments as a key aspect. She talked about how it is nearly impossible to get medical appointments after the school day or on the weekends, with most being during the school day; this results in the student missing school and the parent potentially missing work (unless they work outside of an 8:00am – 3:00pm school day). Key Informant #6 emphasized that this is especially ridiculous for orthodontists considering that orthodontists' main clientele are school kids. The third barrier she mentioned was that people are unlikely to seek medical treatment if they know they very possibly will be treated poorly by providers due to how that person talks, their accent, where they are from, their weight, etc. Key Informant #6 told a story of a time she

sought medical care for a problem unrelated to her weight, had a surgery, and the first thing she was given at her follow up appointment for the surgery was a pamphlet about how to lose weight despite the fact that this medical problem had nothing to do with her weight.

Story Circle #1

- **Illnesses Mentioned**

1. Diabetes
2. Cancer
3. Back Issues
4. Babies born addicted due to parental use
5. COVID-19
6. Cirrhosis of the liver

- **Mental conditions mentioned:**

7. Autism
8. Down Syndrome
9. Depression

- **Barriers to Healthcare mentioned:**

10. ***Work:*** One respondent talked about losing their job because of illness.
11. ***Having Children:*** Being a Single Parent adds another level of strain to the situation.
12. ***Not Having Insurance:*** One respondent discussed lacking insurance due to being a student.
13. ***Insurance Company Bureaucracy:*** Respondents explained that the language used in insurance documents and communications is confusing for most people; multiple respondents reported having experienced communication issues about whether or not insurance covers something; Not all insurance companies serve all services and do not clearly list all the services they do serve on their publicly accessible information (such as on their website); Many people don't know what their insurance does or does not cover until they get the bill (for both services and medications); People who are not informed about how to navigate getting

insurance coverage are thus unable to pass on knowledge to the next generation and it is a repeating cycle that results in new generations not knowing how to navigate insurance.

14. ***Lacking Transportation:*** Respondents discussed how some insurance companies provide transport, but often drivers don't show up on time causing people to miss their appointments. Additionally, drivers are only allowed to take the parent and the child with the appointment—they are not allowed to drive other children the parent might have; transportation provided by insurance companies can only go so far, and sometimes the provider a person is seeking is too far away from where the person lives; Because people lack transportation, they call ambulances to take them to the hospital thus resulting in the ambulance not helping people having actual emergencies.
15. ***Trouble Accessing Services:*** Some respondents discussed not knowing exactly what services and care they needed due to communication issues from providers; Respondents mentioned trouble stemming from not knowing where to go to get certain services; Respondents also discussed not knowing the "right people", or not being "somebody's somebody" meaning that they were not seen as important enough by the healthcare system to be a priority in getting care; Respondents mentioned trouble navigating specialists and testing through state insurance; There are a lot of variations of kinds of services and they are spread out far from the neighborhood; Respondents mentioned how people need referrals, they cannot just walk into a specialist to get needed treatment; One specific example provided by a respondent: A local Catholic hospital refused to perform a tubal ligation (though offered an Intrauterine Device).
16. ***Cost of Healthcare:*** Services and medications cost a lot of money, especially if a person does not have health care to cover it.
17. ***Generational Predispositions:*** Many in the older generations are predisposed to not seek healthcare.
18. ***There are more barriers now than ever to seeking care, making even trying to start seeking care daunting***.
19. ***People in positions of power do not know about the barriers to healthcare and thus are not using their power to try to remove the barriers***.

- **<u>How barriers are passed:</u>**

20. One respondent quit their job in order to get on welfare, in order to get a medical card, in order to get the healthcare they needed.

21. Home remedies.
22. One respondent mentioned just paying with a credit card because getting healthcare is seen as more important than owing money.

- **Opinions on Medical System:**

23. Home remedies were seen as "good enough" as opposed to seeing institutional healthcare.
24. As stated above, many in the older generations are predisposed to not seek healthcare.

- **Perceived Changes in the Healthcare System / Perceived Changes in Health Concerns Over the Last 20 Years:**

25. ***Drug activity has increased & is out of control***.
26. ***Mental illness is more visible and present***.
27. ***More Violence:*** Respondents mentioned gun violence—both mass shootings and not—in schools, churches, dance halls, etc.
28. ***Women's Health is Being Talked About More:*** Girls and women are becoming more heard, and are better able to advocate for themselves; the stigma of free tampons is going away.
29. ***Birth Defects are Increasing:*** Respondents mentioned an increase cleft lip and bow surgery; Respondents also discussed an increase in down syndrome and how it used to be people older than their 30s who had children with down syndrome, but now younger parents in their 20s are having babies with down syndrome.
30. ***Changes in sex and relationships:***
    a. People in the past got married younger.
    b. In the recent past people were having more safe sex and having sex later in life than now—respondents thought this was maybe because of Sex Ed and D.A.R.E. (Drug Abuse Resistance Education) programs.
    c. In the present, sex and drugs are back to being a problem in high and middle school—respondents believe kids are being exposed earlier.
31. ***A Lot of Grandparents are Raising Their Grandkids:*** parents are on drugs and/or are still kids themselves so unable to care for their own children so the grandparent is raising both.

32. ***Kids and Young Adults are getting More Screenings for Things These Days:*** Respondents said that, in the past, you only went to the doctor when you needed to; but now there is more emphasis on getting kids screened and on their health, so there is more testing and screening now.

33. ***Reproductive Rights Have Gone in Reverse:*** Respondents discussed how access to birth control has decreased.

34. ***"Old School" Diseases are Coming Back:*** Respondents listed gonorrhea, syphilis, tuberculosis, and Mononucleosis; The respondents did not believe this was due to anti-vaccine mindsets as far as they knew.

35. ***COVID-19 Affected People's Physical, Mental, and Social Health Negatively:***
    a. Depression increased.
    b. People became more introverted.
    c. One respondent developed diabetes during the pandemic.
    d. Another respondent knew someone who developed Cirrhosis of the liver because they were single and worked from home and in isolation turned to alcohol more.

36. ***Access to healthcare has generally improved***.

Story Circle #2

- **<u>Illnesses Mentioned:</u>**

37. Hernias (upper and lower)
38. Botched Surgery
39. Drug Addiction
40. Ruptured Appendix
41. Colon Cancer
42. Urinary Tract Infection (UTI)
43. Fainting (likely because they hadn't eaten/drank much besides an energy drink that day, along with having a UTI)
44. Brain Surgery
45. Cysts (and associated pain)

46. Breathing issues (Asthma)
47. Leukemia,
48. COVID-19
49. Blood Clot
50. Brain Bleeding
51. Brain Damage
52. Blocked Arteries
53. Triple Bypass Surgery
54. Cardiology problems

- **Mental Conditions Mentioned:**

55. Autism
56. Depression
57. Suicidality
58. Dyslexia
59. Eating Disorders

- **Barriers to Healthcare Mentioned:**

60. ***Structural Issues With Rehab Programs:*** Multiple respondents discussed how rehab programs won't take people because they are either too strong or not strong enough for the rehab and that there is no middle ground level of rehab. One respondent discussed how they were not getting clear answers as to what a rehab program for their husband was for specifically and also stated that while he was in rehab the doctor would not see him.
61. ***Lack of Information About Neighborhood Air Quality:*** Unknown whether or not air quality is getting better or worse (Mill Creek smells, they do testing on the air quality but the residents don't get the feedback).
62. ***Having Children:*** It is difficult to get kids in to see the doctor.
63. ***Not Being Listened to by Doctors:*** examples of doctors claiming that disordered eating is just kids being picky, Doctors claim that child's breathing issues are just in their head, some doctors didn't seem like they were listening; one respondent discussed how their daughter was not listened to because she was formerly a drug

addict, daughter was told her colon cancer was just constipation, and was ultimately put on hospice very late when she could have been much sooner.

64. ***Lack of Medical Insurance:*** One respondent hadn't been to a doctor in around 20 years because they did not have medical insurance due to not having the money for medical insurance, so they waited until they were old enough for Medicare.

65. ***Long Wait Times to get Appointments, see Doctors, and have Medical Information/Paperwork Transferred/Reviewed:*** One respondent talked about someone they knew where it took three months before the paperwork to transfer Medicaid coverage from one state to another would be reviewed, the same respondent talked about someone else they knew who was sent back and forth between cardiology and rehab before they told her she was going to need hospice, and she ended up dying in pain because hospice had just started by the time she died. Another respondent talked about how it took a long time for everything to get scheduled and to actually get to the appointment, but the actual appointment itself only lasted 30 minutes. One respondent talked about how scheduling always resulted in appointments being super far out (around six months), that healthcare professionals took a long time getting back about scheduling despite the presence of urgent symptoms, and just how their doctor didn't call back during the scheduling process.

66. ***Lack of Skill in Self-Advocation:*** Many people do not know they can advocate for themselves and/or do not know how to advocate for themselves.

67. ***Medical Malpractice:*** One respondent's son developed hernias (upper and lower) and had surgery to remove them. During the surgery, the surgeon nicked the son's bowel, resulting in the bowel leaking out of the son's bellybutton and in the son needing three more surgeries (four in total). Four months later the son is still leaking out of his belly button from his bowel. A hospital will not fix the mistakes of another hospital, and the doctor that performed the botched surgeries will not perform another surgery on the son, so they are without a clear path forward as to how to solve the medical problem.

68. ***General feeling that they are not taken care of by the healthcare system.***

- **<u>Opinions on Medical System:</u>**

69. There was a general air of frustration around past mistreatment, either experienced personally or by someone they knew, by the medical system.

- **<u>Perceived Changes in the Healthcare System and Changes in Health Concerns Over the Last 20 Years:</u>**

70. ***Effects of Queen City Barrel:*** Queen City Barrel is gone but the community is still feeling the after effects; respondents discussed the increase in illnesses and cancers including people in their 50s and 60s getting cancer more frequently; One respondent talked about how, after the fire, three 34 year olds all died from colon cancer and that the community was having one to two funerals a week for six months after it blew up; one respondent mentioned worries about dust being in the air from replacing all of the dirt at the Queen City Barrel Site when it was cleaned up; One respondent talked about a family who had been living in Lower Price Hill all their lives: one brother passed away from lung cancer, one brother has lung cancer, two brothers have prostate cancer, and one brother has both lung and prostate cancer.

71. ***Lots of Lung Issues:*** Multiple respondents reported that youths are getting a lot of respiratory diseases (including asthma—one respondent reported needing to give the kids the respondent's own inhaler because the kids don't have them) and that some adults are getting lung cancer.

72. **Lack of Good Education:** A few respondents discussed how they believed schools are just passing people up grades because they don't want to deal with them (passing "troublemakers," people with bad grades, and sports figures, who had not actually earned the passing grade).

73. ***Bullying:*** One respondent discussed how the bulling makes the targeted kids physically sick and leads to suicide (referencing bullies who told their targets to kill themselves).

74. ***More Prevalence of Learning Disabilities:*** Respondents discussed an increase in learning disabilities, mental conditions, depression, autism, and dyslexia; One respondent discussed how there is still stigma against getting kids tested for autism as well as stigma against getting metal help; multiple respondents discussed how they believe most teachers are unqualified to teach people with learning disabilities.

75. ***Difficulty Accessing Doctors, Especially Specialists:*** Respondents told of the frustration they have because they can't just go to doctors anymore, they need a referral; One respondent discussed how people can't get referrals from urgent care which is where a lot of people get care; The challenges and frustrations of needing referrals for their kids' medical care were also discussed.

76. ***There is more awareness about the problems facing the neighborhood which means that things can be more easily changed than ever before***.

After the story circles, Pauletta Hansel talked to the increasing difficulty faced by Urban Appalachians (and particularly those without reliable transportation, reliable childcare, or reliable internet) in navigating the health care system. She listed the need for referrals, choosing an insurance provider and figuring out what each provider does and does not cover, and the reliance on specialists rather than family physicians.

Identifying and Tracking Urban Appalachians

Key Informant #1

The questions regarding identifying successive generations of Urban Appalachians or tracking other groups had not yet been added when this interview was conducted.

Key Informant #2

When asked about her ability to identify successive generations of Urban Appalachians, Key Informant #2 answered that they were sometimes able to identify these individuals. She stated that she mostly is able to identify individuals as Appalachian through conversation talking about the individual's life and family history. Key Informant #2 also talked about barriers to identifying the third-, fourth-, and fifth-generation Urban Appalachians which included the language used (e.g., calling someone Appalachian vs. saying they come from the mountains), the fact that there still is some stigma against being Appalachian, and that some of the successive generations do not feel comfortable identifying as Appalachian because they lack the same life experiences as their older Appalachian family members. Key Informant #2 had no experience tracking or identifying other demographic groups.

Key Informant #3

When asked about his ability to identify successive generations of Urban Appalachians, Key Informant #3 answered that he was sometimes able to identify these individuals. He said that he identifies them in conversation through their own self-disclosure for the most part, but that he sometimes will identify them as Appalachian from knowing the person's family. Key Informant #3 had some familiarity with projects that tracked other demographic groups in Dayton, Ohio. He said that these projects identified the younger generations by tracking specific families through time and researching the children of the families.

Key Informant #4

When asked about his ability to identify successive generations of Urban Appalachians, Key Informant #4 answered that he was able to identify these individuals. He said that he identifies them by hearing family stories as well as through genealogical research. Key Informant #4 had no experience tracking or identifying other demographic groups.

Key Informant #5

Key Informant #5 talked about several methods of conducting generational studies. He mentioned that sometimes from non-random samples the only relationship you can learn about is the relationship between respondents. He emphasized that a simple random sample would be a highly effective method of finding relationships and trends for Urban Appalachians of successive generations and their health. This method would require a list of all the housing units and apartments in the geographic area of focus (i.e., Lower Price Hill and other Urban Appalachian neighborhoods); Next, a random selection technique would be used to select a sample of housing

units, those households would be contacted and an attempt would be made to get them to respond to the survey (either using a web based survey, door-to-door, or by phone), and then the data could be statistically analyzed to determine both trends as well as how reliable the sample is compared to the population.

Talking specifically about how to set up a survey, Key Informant #5 mentioned that an accelerated cohort design might be a good fit. The accelerated cohort design is a way of interviewing the same people on multiple occasions over a period of time. For example, you would interview 8-, 10-, 12-, 16-, and 18-year-olds to get an idea of the health issues impacting kids in a span of ten years difference, and then you would reinterview them all 2-6 years later to see how the health conditions of the kids in the ten-year range have changed in the past few years.

Key Informant #5 also talked about the types of questions to ask. Key Informant #5 mentioned that, in trying to understand multigenerational health outcomes, it is useful to ask respondents to talk about one generation above and one generation below themselves in addition to talking about their own health. So that would mean asking respondents to talk about their children (if they have any), plus parents and grandparents. This way you can also conduct retrospective data analysis by asking respondents what they remember from when they were younger and asking if their parents/grandparents had any specific health conditions you might be interested in learning more about.

Key Informant #5 also talked about how to maintain contact with individuals you want to reinterview later. It is important to get data on current residences and phone numbers for

interviewees, but also getting the name(s) of a close friend(s) and their phone number(s) is important. That way if the interviewee can't be found a few years later for a follow up, the researchers have the interviewee's friend to try to find out where the interviewee is, so that the researcher can ask the same questions and get idea of how health and wellbeing have changed over time.

Key Informant #6

When asked about her ability to identify successive generations of Urban Appalachians, Key Informant #6 answered that she was sometimes able to identify these individuals. She stated that she is able to identify individuals as Appalachian if she knows the person or if the person is within her family. Key Informant #6 had no experience tracking or identifying other demographic groups.

V. DISCUSSION

Health Issues

Lung issues and diabetes were the most frequently mentioned physical illnesses. Ludke & Obermiller (2012) also found that Appalachian children had a significant likelihood of having asthma or other respiratory issues, as was mentioned by multiple key informants. Smoking was perceived to be a major cause of illness among Urban Appalachians, which lines up with the results from Pilehvari et al. (2023). Ludke & Obermiller (2012) mentioned that the risk of hypertension and high cholesterol (as mentioned by Key Informant #6) might be increasing among Appalachians. Key Informant #1's perception that there is good maternal healthcare for mothers and infants due to community support contradicts the findings of Seiger et al. (2022).

Depression was the most mentioned mental illness being mentioned by Key Informants #1-#4 and #6; Ludke & Obermiller (2012) mentioned that the risk of depression might be increasing among Appalachians. Anxiety and ADHD were the next most prevalent, followed by Trauma/PTSD as it related to violence, family/life/economic instability, bullying, and veteran status (among other causes). Substance abuse/addiction (including alcohol and tobacco among illicit drugs) was seen as an ongoing and rising concern within the community. Suicidality and overdose (called “deaths of despair” by key Informant #6) were also perceived as major mental issues within the Urban Appalachian community. Ludke & Obermiller (2012) found that first- and second-generation white Urban Appalachians had identical scores to non-Appalachians for mental health, which contradicts what many of the key informants said. This could mean that the mental health of the younger generations is deviating from the general population, which would match the findings of Ludke & Obermiller (2012) that Appalachian children between the ages of 12 and 17 became more likely to have behavioral and emotional health problems, as well as ADHD, when studied between the years of 2000 and 2005.

Multiple Key Informants mentioned poor diet as a major cause of illness which corresponds to the findings of Ludke & Obermiller (2012) that Appalachians were less likely to consume the recommended servings of fruits and vegetables, and were less likely to see their diets as healthy. Key Informants #3 and #4 mentioned that they perceive this as partially an issue of lifestyle choices made both by individuals for themselves as well as by parents for their children. Simply not having access to good food was identified as a major factor contributing to poor diet. Lower Price Hill used to be a food desert which exacerbated the food issues. Key Informant #1 also talked about hunger being an issue among the younger generations. Finally,

Ludke & Obermiller (2012) found that Appalachians were less likely to consume alcohol, which lines up with what Key Informant #1 said about alcohol not being much of a problem with the younger generations.

Barriers

The most frequent areas of concern for the story circles came from struggling to figure out and deal with health insurance, feeling unheard by doctors and like they do not actually care about their patients, and finding/accessing doctors (both primary care and specialists). In Story Circle #1 it was discussed how many Urban Appalachians are not knowledgeable on navigating insurance, and thus are unable to pass on any knowledge to their children, which in turn creates a cycle of each consecutive generation not knowing how to navigate insurance keeping this issue a major problem. Thus, the primary areas of need are finding reliable methods of transportation, education and guidance on navigating health insurance, and education **for** doctors on treating and interacting with Appalachian/Urban Appalachian folks (which lines up with Tripp-Reimer 1982).

The concerns of the story circles regarding insurance were also mentioned by multiple Key Informants who mentioned the difficulty Urban Appalachians have in accessing health insurance. This perception seems to relate to what Ludke & Obermiller (2012) also found: that Appalachian children were less likely to have private insurance coverage than non-Appalachians.

Key Informant #6's perception that weight, and particularly a label of "obese," can be a major barrier to healthcare matches the findings of Weissman et al. (2019) due to the negative perceptions of healthcare providers. Additionally, cultural insensitivity on the part of healthcare providers, as studied in Slusher, Withrow-Fletcher, and Hauser-Whitaker (2010), was mentioned

by Key Informant #6. Similarly, lack of education around healthcare, lack of access to services, cost, and lack of insurance were all mentioned by multiple key informants and was observed in Slusher, Withrow-Fletcher, and Hauser-Whitaker (2010). Key Informant #6 talked about how the way a person talks, their accent, and/or where they are from can lead to a negative experience with professionals which matches up with the findings of the experiences of Appalachian patients with non-Appalachian professionals in Tripp-Reimer (1982).

Multiple key informants mentioned how Urban Appalachians were unlikely to seek preventative care, which matches up with Hayes (2006). Every Key Informant (sans Key Informant #5) mentioned how Appalachians generally live at a comparatively lower socioeconomic status and perceived the cost of healthcare to be too high, which matches what Ludke & Obermiller (2012) found. As mentioned by Key Informants #1 and #6, Appalachians have a hard time accessing dental coverage (and thus care) which corresponds to Ludke & Obermiller (2012) where they found that Appalachians tend to have poorer dental health than non-Appalachians.

Identification and Tracking

For the most part, it appears that Key Informants #1-#4 and #6 used a mix of the place of origin approach, asking about where they and their family come from, and the identity approach, asking people if they identify as Appalachian, as described by Ludke et al. (2010) and Ludke & Obermiller (2012). A few of the respondents also mentioned genealogical records as a method through which they identified Appalachians, such as was mentioned by Ludke et al. (2010) and Ludke & Obermiller (2012) for the place of origin approach. A few of the key respondents

mentioned that, if a person was from a certain area or neighborhood, they would think there is a high likelihood of the person being Appalachian, but the Key Informants would not be able to know for certain unless they talked to that person; this lines up with the place of residence approach described by Ludke et al. (2010). None of the key informants mentioned using the attribute-based approach as described by Ludke et al. (2010) and Ludke & Obermiller (2012). Key Informant #2 talked about how some of the younger generations do not feel comfortable identifying with the Appalachian label, which matches what Obermiller & Philliber (1987) found with later generations of a population (namely, the third), peoples' ethnic ties will weaken because they acculturate into the mainstream culture.

Key Informant #3 mentioned being third generation on one side of his family, and fourth generation on the other side of his family. Balcazar, Grineski, and Collins (2015) discussed a 2.5 generation for Hispanic persons, which was a person with one foreign born parent and one parent born in the U.S., and using this framework Key Informant #3 would be considered in the 3.5 generation.

VI. CONCLUSION AND RECOMMENDATIONS

Health Issues and Barriers

One of the key needs emphasized by the story circles was getting information about the air quality in Lower Price Hill to the people in the neighborhood and doing whatever is possible to clean up air quality. Considering that Key Informants #1-#4 and #6 all mentioned respiratory issues (lung cancer, asthma, mesothelioma, undefined breathing issues, etc.) and/or pollution as being a major cause of illness, this is important information for the community in order to

address their health issues and needs. Lack of dental insurance was mentioned by Key Informants #1 and #6, and that Urban Appalachians often receive insufficient dental care.

While the food desert and lack of education surrounding healthy diet issues are being addressed in Lower Price Hill with Meiser's Fresh Grocery & Deli and other community organizations which are bringing in more healthy food and providing fruits and vegetables for free or cheap on occasion along with providing cooking classes, it is important to maintain the energy behind this initiative.

Getting more educational resources to people about getting and navigating insurance coverage is key. Given that the biggest barriers were insufficient insurance coverage and inability to afford treatment, it is imperative that Urban Appalachians are educated on insurance navigation and are able to pass on knowledge regarding navigating insurance to future generations of Urban Appalachians. Helping Urban Appalachians to find insurance that covers dental is also an extremely important aspect to this issue.

One of the major issues regarding access was just that doctors and healthcare professionals are not located in Lower Price Hill or other Urban Appalachian neighborhoods. I would recommend working on some sort of initiative to try to bring doctors back into the neighborhoods; there is especially a need for primary care physicians. Perhaps this could look like talking to the City of Cincinnati to provide some sort of tax credit or subsidy for doctors who move into these neighborhoods. Getting the doctors into the neighborhoods would greatly increase Urban Appalachian's access to healthcare by reducing the need for transportation. In addition, doctors themselves will need to be trained and educated on how to interact with

Appalachian/Urban Appalachian folks (i.e., developing cultural sensitivity and competency) so that the community members do not feel disrespected by the doctors and are able to build good relationships thus resulting in a greater willingness to seek care. Additionally, since obesity was perceived as a common condition among Urban Appalachians, teaching doctors how to interact with overweight patients in a respectful and productive manner is important. Another important issue to tackle is the fact that many doctors do not have appointments outside of a typical work/school day; perhaps there should be an initiative reaching out to healthcare providers about trying to create time for appointments in the evenings and weekends.

Greater education around mental health and far greater access to mental health care is absolutely essential for Urban Appalachian communities. This includes getting mental health professionals into the neighborhood along with doctors. This could quite possibly be achieved using the same methods of attempting to get the City of Cincinnati to provide some sort of tax credit or subsidy for mental health professionals who move into these neighborhoods. Additionally, mental health professionals should also be trained in cultural sensitivity/competency for Appalachian culture so that they are more able to respect Urban Appalachian patients, build good relationships, and help Urban Appalachians to be more willing to seek care.

Identification, Tracking, and Future Research

Perhaps the half generation framework, as described by Balcazar, Grineski, and Collins (2015), would be useful for people like Key Informant #3 who could be considered in the 3.5 generation having one second generation parent and one third generation parent. Including 1.5,

2.5, 3.5, 4.5, etc. generations could help those of mixed generations to better identify themselves for researchers.

Ludke & Obermiller (2012) and Ludke et al. (2010) discussed that there may not be one best method for identifying Appalachians in general, but they do mention that for studies where the interest is in subsequent generations of Appalachians, self-identification might be the most suitable. Given what the Key Informants said, I believe this to be the best method as well. However, as Key Informant #2 discussed, not everyone might identify with the term 'Appalachian' and so finding some way to include other modes of identification (such as 'hillbilly' or 'from the mountains') could be useful. Additionally, even with other names for identification, some people of Appalachian Heritage might not identify with the Appalachian identity—either because of stigma and/or because they feel a distance from that identity due to be multiple generations down the line from when their family migrated to an urban area from Appalachia (as stated by Key Informant #2 and Obermiller & Philliber 1987); because of the potential for these cases to exist, it might be best to also ask about place of origin (both for the individual and for their family).

Given the two story circles conducted for this project, as well as the history of story circles and CBPR being used in Appalachia (Obermiller 1996; Ludke & Obermiller 2012), I would recommend continuing their use for future research on this topic. Additionally, identifying and interviewing kin sets for these story circles, as were used by Timm (Obermiller 1996), could allow for an easy way to study multiple generations and the change in health status through those generations at one time. Some ideas for future research models and methods could be, as Key

Informant #5 mentioned, using a simple random sampling method to select households in Lower Price Hill and other Urban Appalachian neighborhoods of interest. Then, a mail-based method, such as was used by Balcazar, Grineski, and Collins (2015), to deliver surveys. Additionally, if there was a wish to study Urban Appalachians in a wider geographic area (say, across the United States), then an internet-based model using convenience sampling (such as was conducted by Rosser et al. 2007) on forums/internet groups where Urban Appalachians visit might prove beneficial—at least as a supplement to community-based research—as a way of delivering surveys.

Additionally, the true prevalence of all conditions (mental and physical) perceived by key informants and story circles to be prevalent within Urban Appalachian neighborhoods should be investigated. One key area I think should absolutely be included is the dental health of Urban Appalachians. I believe that an accelerated cohort interview design as was mentioned by Key Informant #5, along with a mail/phone/email survey sent to a simple random sample of households within Lower Price Hill and other Urban Appalachian Neighborhoods within Cincinnati would prove as useful methods of achieving data on these conditions. Additionally, for interviews and surveys, Key Informant #5's idea for gathering the contact information of someone close to the respondents just in case the person moves/gets a new phone number/email address, there is still a possibility to contact them for future participation.

There was not a unified perception of the prevalence of autism, down syndrome, developmental disabilities, and learning disabilities among third, fourth, and fifth generation Urban Appalachians and whether or not there is a disparity between the Appalachian community

and the general population. These mental conditions came up in both story circles, but were not necessarily brought up by the Key Informants and was even perceived to not be more prevalent than in the general population by Key Informant #2. Thus, further research into the prevalence of such conditions, along with whether or not Urban Appalachians with these conditions face specific challenges (i.e., being believed/diagnosed less by healthcare professions) when compared to non-Appalachians should be conducted.

Some more areas of interest, perhaps more broadly than just for Urban Appalachians, is investigating how insurance can be made more accessible and navigable for people and investigating how transportation can be improved (both in ways it can be done in the community as well as the ways where the city would need to step in). After the story circles, Pauletta Hansel brought up a few areas of future inquiry including investigating effects of decreasing reproductive care access; investigating whether or not the perception of "old school" diseases like gonorrhea, syphilis, tuberculosis, and mononucleosis coming back holds truth (and for the Sexually transmitted diseases, exploring if this is related to reproductive care access); generally investigating whether or not there are other diseases that have vaccines but are seeing a rise in cases; and investigating the long-term consequences of COVID-19, including long COVID-19.

In this study, though I reached out, I was unable to talk to any school nurses for schools in Urban Appalachian neighborhoods. I recommend that the UACC Research Committee continue to attempt to make contact with the school nurses in an attempt to get their perspectives on the health of the younger generations of Urban Appalachians.

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APPENDIX A: Key Informant Interview Questionnaire

Urban Appalachian Community Coalition

Key Informant Study

Name: ____

Telephone: ____________________________ **Email:** _________________________________

Neighborhood (If Applicable): ____

City: ____

Demographics

Age:

- ☐ 16 – 19
- ☐ 20 – 29
- ☐ 30 – 39
- ☐ 40 – 49
- ☐ 50 – 59
- ☐ 60 +

Sex:

- ☐ Male
- ☐ Female
- ☐ Other

Family Income:

- ☐ Less than $10,000
- ☐ $10,000 – $25,000
- ☐ $25,001 – $50,000
- ☐ More than $50,000

Ethnicity:

- ☐ Appalachian
- ☐ Hispanic/Latinx
- ☐ British Isles
- ☐ European
- ☐ Other

Race:

- ◻ White
- ◻ Black
- ◻ Asian or Pacific Islander
- ◻ Native American
- ◻ More than one race
- ◻ Other ____________________

Questions

1. Are you able to identify successive generations of Urban Appalachians (i.e., 3rd, 4th, and 5th generations)?
    - ◻ Yes
    - ◻ No
    - ◻ Sometimes

2. If you answered “Yes” or “Sometimes” to question 1, how do you distinguish 3rd, 4th, and 5th generation Urban Appalachians?

3. What are the leading causes of illness in this community?
    a. Among adults:

    b. Among teens:

    c. Among children:

4. What are the leading causes of death?
    a. Among adults:

    b. Among teens:

    c. Among children:

5. What types of mental illness/conditions are frequent?

    a. Among adults:

    b. Among teens:

    c. Among children:

6. Tell us more about illness among the younger generations of Appalachians.

7. Are people here getting good healthcare?

    - ◻ Yes
    - ◻ No
    - ◻ Sometimes

8. What factors cause people not to get good care?

9. If you have never had any experience with Urban Appalachians, or if you have worked with other groups, have you ever performed a study where you tracked succeeding generations throughout time?
    - ◻ Yes
    - ◻ No

10. If you answered "Yes" to question 9, what methods did you use to identify those in succeeding generations?

11. What is your role in this study?
    - ☐ Community resident
    - ☐ Health professional
    - ☐ Appalachian studies
    - ☐ Other ______________________

NOTE: For Key Informant #1, the question form "Key informant survey questions - Nikita" (Key informant survey questions – Nikita.docx) was also used.

APPENDIX B: Health Story Circle Agenda

Health Story Circle Agenda

Pauletta Hansel, Story Circle Facilitator

Introduction to each other and story circle process Theme: Health issues and health care: what are our health concerns for both young people and adults in our neighborhoods and how have these changed?

Review the rules and roles

Basic Rules (Adapted from John O'Neal, Junebug Productions.):

1. Make a real circle so everyone can see each other's face.
2. Don't make too many rules. Less is more.
3. Listening is more important than talking. If we trust the circle to bring our stories to us, we won't be tempted to think about what we will say while someone else is talking.
4. We don't have to like other people's stories but we respect their right to tell them.
5. No one has to tell a story. If you have no story to tell when your turn comes, just pass, you'll get another chance before we close.
6. It saves time in the beginning if the facilitator decides in advance which way to take turns around the circle.
7. Save crosstalk till all the stories are heard.

Roles:

Facilitator: Kicks things off. Keeps time. Makes sure the rules are working. Keeps things moving.

Note taker: Jots down what stories were told and themes that s/he heard, and, when possible, captures a few phrases that really stand out.

Story Circle Round 1: "Tell a story about a time you were concerned about your or your family member's or a neighbor's health."

hour Cross talk round 1

Story Circle Round 2: "Tell a story that shows how the health concerns for your neighborhood has changed in the last ten or so years."

Cross-talk about overall themes and considerations raised in both rounds, including making a list of health concerns and what has changed.

two Close

APPENDIX C: Key Informant Responses

For Questionnaire Responses:

See “UACC Generations Health Study - Key Informant Survey Interview Responses” (UACC Generations Health Study - Key Informant Survey Interview Responses.xlsx)

For Transcripts of Recorded interviews:

See “UACC Generations Health Study - Key Informant 1 Interview Transcript” (UACC Generations Health Study - Key Informant 1 Interview Transcript.docx)

See “UACC Generations Health Study - Key Informant 2 Interview Transcript” (UACC Generations Health Study - Key Informant 2 Interview Transcript.docx)

See “UACC Generations Health Study - Key Informant 3 Interview Transcript” (UACC Generations Health Study - Key Informant 3 Interview Transcript.docx)

See “UACC Generations Health Study - Key Informant 4 Interview Transcript” (UACC Generations Health Study - Key Informant 4 Interview Transcript.docx)

See “UACC Generations Health Study - Key Informant 6 Interview Transcript” (UACC Generations Health Study - Key Informant 6 Interview Transcript.docx)