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EDITORIAL

# Virtual Alternatives and Technological Disparities

### Sheryl L. Chatfield

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It is my pleasure to welcome you to Volume 5, Issue 1 of the *Ohio Journal of Public Health* (OJPH). As I worked with authors to prepare articles for this issue, I was reminded again of the admirable efforts of public health educators, researchers, practitioners, and providers to address new, changing, and ongoing public health challenges during the third year of a pandemic. Since I described the increasing prevalence of the Omicron variant in my January 2022 editorial, circumstances have continued to evolve. Some activities and resources now resemble prepandemic conditions, while others have been modified, suspended, or discontinued. Thus far in 2022, infection rates throughout the world have shown increases and decreases, although experts have expressed concerns that frequent use of home testing may interfere with accurate tracking.

I have observed friends, family members, colleagues, and students struggling to balance engagement in activities enjoyed before the pandemic with perceived infection risk, including the risk of long COVID. Convenience as well as safety may drive some decisions regarding activities. For many individuals, the flexible options for work, study, and leisure have proven not only convenient but cost-effective. Some advantages associated with efficiency of time and resources may be realized by individuals on both sides of an exchange: employers, producers, and educators may benefit along with employees, customers, and students. Although efficiency is typically a good thing, I believe the viability and desirability of sustained reduction of physical presence or in person transactions across a variety of settings remains to be seen. My particular concern is the influence of technological disparities in limiting some individuals' ability to participate in occupational, educational, leisure, and service opportunities. A range of online and virtual opportunities were developed with model users in mind: these include those who have or can access current devices, can purchase and navigate essential programs or apps, and rarely experience extended limitations in connectivity. I also fear technological disparities are most likely to impact individuals who are already at increased risk for poor mental and physical health outcomes. My hope is that organizations and institutions prioritize offering safe opportunities for live engagement, so individuals who prefer these, or those who experience technological constraints, have ample alternatives.

This issue of OJPH includes several articles which explore undersupported areas of individual health that are ongoing concerns to many Ohioans, including mental health, vision care, and hearing loss. Song and colleagues explored the role of mental health gatekeeper training in facilitating mental health referrals among university students at an Ohio institution. Bischof and colleagues' investigation of the association of depression with perceived COVID-19 risk reflects an additional report focused on mental health; in this instance the research is directly related to the current pandemic.

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The commentary by Hinson-Enslin and McClintock describes barriers and burdens associated with hearing loss, and the authors provide recommendations to address this concern. VanNasdale and colleagues used Ohio data from the Behavioral Risk Factor Surveillance System Vision Module to investigate changes in vision care following Medicaid expansion of coverage.

Public health curricula have emphasized disparate health outcomes associated with factors including race, income, and education. In exploring prior research on adverse childhood experiences (ACEs), Gu and colleagues identified lack of diversity among research participants, which may have resulted in incomplete understanding and inadequate intervention efforts. Using data from the Ohio Cancer Incidence Surveillance System, Hood and colleagues described concerning trends in liver cancer care and survival associated with higher degrees of neighborhood depravation. Lanese and Alrubaie explored trends in patients' health care outmigration, often inspired by deficiencies in available services, and potentially a particular problem in low population rural areas. Graham and colleagues also focused on a rural health concern by conducting qualitative interview research with providers working in an integrated care setting. Graham and colleagues suggested integration of medical and behavioral health care has potential to offer rural patients improved access to a broader range of services.

Authors of other articles published in this issue described outreach and community-based efforts. Russell and colleagues contributed case study research about the extent to which federal food service guidelines are applied in community-based permanent supportive housing sites for formerly homeless individuals. Authors of 2 papers carried out projects related to parenting. Clark and DiPietro Mager explored preconception and interconception challenges impacting women in a rural county in Ohio, and Sues-Mitzel and colleagues described encouraging results from a community-based program aimed at improving parental self-efficacy. Leuchtag and colleagues were motivated to discover effective practices in collaborative community development projects. The authors assessed 3 real world examples and present thoughtful recommendations aimed at improving processes, communications, and perceptions of health-promoting development projects. Clearly these articles reflect a broad range of methods and topics. Additionally, it is very gratifying to see individuals who are practitioners, academic faculty members, researchers, and graduate students all represented as contributing authors.

I visited the Columbus area twice in the last month, and one of my favorite places to share with out-of-town visitors is the field of giant corn in Dublin, Ohio. Given the rural focus of several articles in this issue, the cover photo, taken in early June of 2022, seems appropriate.

With the help and support of the Ohio Public Health Association (OPHA) and our online journal publisher, The Ohio State University Library publishing services, some changes are coming to the way OJPH processes, publishes, and promotes articles. Watch OPHA newsletters and the OJPH website for information and updates.



**RESEARCH BRIEF** 

### From Procurement to Consumption: A Model to Understand Nutrition Policy Implementation in Permanent Supportive Housing

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### ABSTRACT

**Background:** Food insecurity has become an increasingly complex public health issue across the United States, particularly among various people battling with current or previous homelessness. This project sought to understand the food system in permanent supportive housing sites (PSH) that serve formerly homeless individuals and to explore the use of nutrition standards, specifically the Food Service Guidelines for Federal Facilities (FSGFFs), in this context.

**Methods:** Participants were members of the administrative staff involved in the food procurement process, food preparation, administrative tasks, and daily operations in a small-intensive program managed by a local nonprofit agency that serves 12 adults over the age of 18 who experience chronic homelessness and persistent mental illness, or substance use disorders, and a second PSH site that helps 41 low-income adults with health conditions experiencing homelessness. The PSH Inquiry Tool (PSH-IT) was developed to better understand the business operations at each site, and the PSH Audit (PSH-A) was created to assess the applicability of FSGFF at each site.

**Results:** Findings suggest that funding mechanisms, staff training, staff capacity, and access to nutrition education were critical barriers to the successful development and implementation of nutrition standards in PSH sites. Furthermore, findings suggest that adaptations to FSGFFs are required before implementation at PSH sites.

**Conclusion:** This report advocates for increased involvement of community stakeholders to support nutrition policy development and implementation, a nutrition policy that impacts all levels of the food system from procurement to consumption, and local, state, or federal policy changes to support improved nutrition in PSH.

Keywords: Homelessness; Food insecurity; Permanent supportive housing; Nutrition policy; Case study

### **INTRODUCTION**

According to the United States Department of Agriculture (USDA), in 2020, over 38 million people in the United States were food insecure.<sup>1</sup> Homelessness compounds the issue of food insecurity, especially for the chronically homeless.<sup>2-4</sup> Chronic homelessness is a state of homelessness for at least 1 year or repeated episodes of homelessness in an individual with a mental illness, substance use disorder, or physical disability. Chronic homelessness is associated with several health conditions and premature mortality.<sup>2-5</sup> The Housing First approach is based on several principles, one of those principles being that safe and affordable housing is the primary solution to homelessness.<sup>6,7</sup> Permanent supportive housing (PSH) is an intervention that incorporates subsidized housing and voluntary support services for people who have experienced chronic homelessness. PSH beds increased by 20% over the past 5 years across jurisdictions, and congress has invested billions in PSH programs.<sup>8</sup>

Despite being a proven solution to chronic homelessness, PSH may not solve the health-related consequences of chronic homelessness.<sup>9</sup> Data have shown that individuals entering PSH may suffer

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from a lower baseline level of health than the general population and thus may need additional health care coordination and health services.<sup>3</sup> In addition, studies have demonstrated that individuals in PSH maintain higher rates of food insecurity than the general population and that placement in PSH may not significantly improve health outcomes.<sup>2,4</sup> Moreover, data suggest that existing food procurement and donation networks may be insufficient to meet all of the nutritional needs of those living in PSH.<sup>2</sup> Therefore, understanding the policy, programming, and operational barriers in PSH may improve its impact on health outcomes and its utility as a housing solution. One such barrier to the success of PSH is the current state of nutrition guidelines for sites that serve persons who are food insecure.

Current nutrition guidelines and policies for sites that serve persons experiencing food insecurity are limited in their scope. Research has shown that food pantries, soup kitchens, and food banks play a pivotal role in providing food for those experiencing food insecurity. Therefore, these may be targets for improving access to more nutritious food among persons with food insecurity living in PSH.<sup>10-13</sup> A recent article identified 42 federal policies on food bank donations; nevertheless, no guidelines addressed the nutritional quality standards for donated foods.<sup>2</sup> Yet, procurement of food is only one component of accessing more nutritious foods. As such, additional policies related to food banks may be needed.<sup>10</sup> Two web-based resources offer information for organizations serving food insecure individuals. Still, when preparing this manuscript (July 2021), the sites had outdated links, a lack of guidance on how to implement recommendations, and no opportunities for technical assistance (TA).14,15 Technical assistance is a strategy used to build an organization's capacity by providing targeted support to an organization with a need or problem. In addition, a limitation of many of the available resources for PSH sites is that they are not endorsed by an existing agency that can provide TA or enforce standards. Furthermore, many resources cover only one aspect of the procurement-to-consumption process (eg, procuring, preparing, ensuring food safety, marketing foods to clients). One central document that guides nutrition policies and best practices is the Food Service Guidelines for Federal Facilities (FSGFFs) tool created by the US Department of Health and Human Services.

The FSGFFs are specific standards for food and nutrition, facility efficiency, environmental support, community development, food safety, and behavioral design in worksites, organizations, or programs.<sup>16</sup> The goal of FSGFFs is to create healthy food environments such as cafeterias, cafes, grills, snack bars, concession stands, and vending machines in areas that serve large populations of people. The standards included in the FSGFFS were determined by the Food Service Guidelines Federal Workgroup, which comprised 60 representatives from 9 federal departments and agencies. The FSGFFs identify 2 levels of implementation: standard and innovative. These levels are supported by the literature to be advantageous to health and the environment. The standard level is considered widely achievable within food service and is expected, whereas the innovative level is regarded as exceptional performance and is encouraged.

We identified PHS facilities as sites that could benefit from implementing nutrition guidelines. Through discussions with community partners, it was determined that nutrition intervention in areas that serve people who have experienced homelessness is limited. Our goal was to explore the food system, conditions, and capacity in PSH and understand the applicability of FSGFFs in this context. The food system was defined as the policies, procurement, and funding that influence nutrition practices in PSH sites in Cuyahoga County, Ohio.

### **METHODS**

### Setting

This study investigated 2 permanent supportive housing sites in Cuyahoga County, Ohio. Site 1, a small, intensive program managed by a local nonprofit agency, serves 12 adults age 18 or over who experience chronic homelessness and persistent mental illness, or substance use disorders. Site 2, a PSH program, serves 41 lowincome adults with health conditions experiencing homelessness. Neither site serves children, families, or individuals who are pregnant.

### Design

This was a cross-sectional case study of 2 permanent supportive housing sites in Cleveland, Ohio. Sites were sampled based on their connection to existing agencies that serve people experiencing homelessness and identified need by stakeholders.

### Participants (inclusion, exclusion criteria), Recruitment Process

Key participants were members of the staff involved in the food procurement process, food preparation, administration, and daily operations of the sites.

### Measures/Outcomes

The PSH Inquiry Tool (PSH-IT) (Appendix I)<sup>17</sup> informed by Koh et al, was developed to explore business operations, staff perspectives on food access, and site needs at 2 permanent supportive housing sites. The PSH Audit (PSH-A) (Appendix II) was developed based on the details of FSGFFs such as prepared foods, packaged snacks, beverages, food safety, and behavioral design. Both sites completed the PSH-IT; site 2 also completed the PSH-A. Site 1 could not complete the PSH-A due to internal staff capacity constraints. Dietary Guidelines for Americans 2015-2020<sup>18</sup> was used as the gold standard for identifying and considering a specific food item to be "healthy."

### Procedures

The Case Western Reserve University institutional review board granted human participant compliance approval for this research. Data for the PSH-IT were collected in an interview format where participants were asked to type their responses into the electronic questionnaire while the examiner read the questions aloud. The

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PSH-A was completed after the PSH-IT on a different day and conducted through discussions with staff and clients, observation of facility spaces, and interviews with staff participants. The researchers selected site 1 and site 2 based on stakeholder interviews and expressed needs by each site.

### **Statistical Analysis**

The case study methodology was used to summarize the data gathered from the 2 sites to understand the food system indepth.<sup>19</sup> The case study approach is an empirical method used to assess an event or phenomena within its natural context.<sup>19</sup> Descriptive statistical analysis was used to explore the data.

### **RESULTS**

The PSH-IT provided information about site operations, staff perspective on food accessibility, and site needs. Data from the PSH-IT showed that neither site was familiar with Federal FSGFFs or Dietary Guidelines for Americans 2015-2020. Moreover, funding varied by location, but client contributions, grants, and private donations were primary sources of support. The local food bank was a primary source of food, followed by local grocery stores, donations of surplus foods from local restaurants, and bulk food suppliers. Both sites moderately agreed that they could request and receive whole grains and low-sugar beverages in the last 6 months, while site 2 strongly agreed that they could ask and receive fresh fruits and vegetables, lean protein, and low-fat dairy products (Table 1). Both sites were moderately satisfied with purchasing healthy food within their budget and accessing healthy donated food from food banks (Table 1). Data showed that both sites considered client dietary restrictions when obtaining food; other considerations included food bank inventory, client desires, and funding limits (Appendix I, Item #22).

Both sites shared that energy-dense and nonperishable food items were more accessible than fresh fruits and vegetables and lean meats and identified a lack of funding as their most significant barrier to accessing healthy foods. Other key barriers to preparing healthy foods were staff training, staff capacity, and staff and client food education. Lastly, neither site had nutrition standards, mechanisms for determining the nutritional value of meals served, or policies to ensure donations and procurement of healthier food options for residents.

The PSH-A provided information about the applicability of FSGFFs within the PSH context and the degree to which the operations of site 2 aligned with these guidelines. The PSH-A of site 2 indicated that they were performing below FSGFFs suggested standards regarding the provision of fruits, vegetables, and protein. In addition, it was discovered that one limitation to using FSGFFs was staff knowledge and capacity. Site 2 staff did not have the training or ability to identify and report information such as the number of trans-fats, sodium content, calorie amount, or nutritional value of foods, all of which are requirements in the FSGFFs. Moreover, site 2 was below FSGFFs standards concerning food safety and behavioral design (eg, how the presentation of food influences individual food choices). Site 2 needed assistance with establishing a comprehensive food safety plan, developing and implementing a written employee health policy, and working with worksite wellness programs or other organizations to promote healthier options. Also, sites needed assistance with executing FDA Food Codes.<sup>20</sup> The PSH-A of site 2 also showed room for improvement around behavioral design strategies such as using marketing strategies to highlight more nourishing food and beverage items or using product innovations and the inclusion of more nutritious options as a default choice at decision points to encourage healthier choices. Lastly, packaged snacks and vending sections of FSGFFs were not regulated aspects of food provision at these sites. Though the PSH-A was completed at 1 site, the similar food serving, preparation, and procurement practices at both sites would make it challenging to systematically implement the FSGFFs.

### **DISCUSSION**

The threat of food insecurity and homelessness for millions of Americans requires focus from multiple sectors to develop best practices and policies that provide agencies with the tools to supply healthier foods. This project identified intersecting factors at

### Table 1. Permanent Supportive Housing Inquiry Tool (PSH- IT) Responses to Food Sourcing

Item	Site 1 response	Site 2 response
On average, over the last 6 months, my facility has been able to request and receive enough of the following items to serve all clients that visit my shelter through the month.		
Fresh fruits and vegetables	Moderately agree	Strongly agree
Lean protein (eg, chicken, turkey, beans)	Moderately agree	Strongly agree
Low-fat dairy (1% or skim milk, low-fat yogurt)	Moderately agree	Strongly agree
Whole grains	Moderately agree	Moderately agree
Low-sugar beverages	Moderately agree	Moderately agree
How satisfied are you with the following?		
Ability to purchase healthy food within site budget	Moderately agree	Moderately agree
Ability to access healthy donated food from food banks	Moderately agree	Moderately agree
Ability to access donated healthy food from community food drives	Moderately agree	Strongly disagree

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permanent supportive housing sites related to procurement, menu and meal preparation, and consumption of foods that ultimately impact the nutrition of individuals living in PSH (Figure 1). We developed a framework for Nutrition Access Intervention in Permanent Supportive Housing (Figure 1) based on the preliminary themes identified by the PSH-IT, PSH-A, and discussion and observations at each site. The findings in Figure 1 enhance many of the conclusions made in previous literature and provide a cohesive model for improving food access for this population. For example, studies have found that meal delivery programs and increasing the income of those living in PSH could solve food insecurity for this population; aspects of nutrition access that fit into the food acquisition umbrella of this project's framework.<sup>2</sup> Moreover, data show that education is negatively associated with food insecurity.<sup>2</sup> In similar ways, this project found that staff and client education was a barrier to nutrition access and could be addressed under meal preparation and consumption. Specifically, consumption refers to the choices individuals make on what foods to consume at any given time. As suggested in Figure 1, educating clients about nutrition could impact their choice to consume healthier foods. The framework provides sites and their collaborators an opportunity to identify specific areas for intervention to improve nutrition services.

Moreover, policy can create far-reaching systemic changes across the food system and have downstream impacts on multiple areas of the above framework. Previous studies have identified a need to understand the policy and program roadblocks that prevent PSH from substantially impacting health outcomes.<sup>4</sup> This study offers foundational insight into PSH facilities' challenges and the relevance of FSGFFs as nutrition standards. Staffing and funding limitations at PSH can result in uneven, inconsistent, and ineffective implementation of nutrition standards and practices. In addition, minor differences in funding sources observed between site 1 and site 2 in our study may account for differences in access to healthy foods and greater reliance on charitable donations and the food bank. Management and technical assistance on behalf of an existing county, state, or national agency could improve site capacity to implement existing nutrition standards while bridging the gaps between procurement sites and PSH. Technical assistance may involve helping permanent supportive housing sites to display and market healthier options to clients, training staff on the 2020-2025 Dietary Guidelines for Americans (DGA) or educating staff on ways to understand the nutritional value of food. These strategies would address staffing capacity and staff training opportunities identified in our framework. These results are consistent with findings from other studies that suggested that PSH programs could benefit from standardization and improved staff involvement.<sup>3</sup> Technical assistance, existing agencies, community, and academic partners could support PSH sites in developing, implementing, and evaluating new standards that align with the DGA.

The FSGFFs were not designed to be used for sites with smaller population sizes or populations with specific dietary restrictions, which may contribute to difficulties in adapting them for PSH sites. While site 2 was compliant with city and county food safety standards, the disconnect between local policies and FSGFFs standards created variability in nutrition standards, resulting in site 1 underperforming concerning FSGFFs. Moreover, data demonstrated that FSGFFs do not address important aspects of how these sites procure or prepare foods nor provide direction to these sites on ways to improve procurement and preparation. These findings are consistent with previous studies that suggest that foodbanks would be more effective when combined with solutions that address operational resources, access to nutrient-dense foods, and client needs and preferences, all of which are discussed in Figure 1.10 Alternative nutrition standards could help procurement sites such as food banks and donation partners prioritize the availability of healthier options while also taking into consideration site-level concerns.

Regardless of the policy structure, careful consideration is needed when working in these settings due to various internal and external factors. Using our proposed framework as a guide can allow for more comprehensive approaches to nutrition access in PSH.

### **PUBLIC HEALTH IMPLICATIONS**

First, nutrition policy is essential because it can create farreaching systemic changes in all food system levels. The FSGFFs



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Figure 1. Interventions for Nutrition Access at Sites for the Food Insecure

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and alternative nutrition standards have a role in improving policies at food banks and donation partners while also addressing site staffing capacity, staff training, and funding limitations. Secondly, the current system places the onus for changing on individual sites, which is challenging to navigate understaffing and funding constraints. Policy intervention on behalf of an existing county, state, or national agency could improve site capacity to create and implement nutrition standards by regulating nutrition standards for various procurement sites, donation partners, and permanent supportive housing sites while also providing technical assistance and coordinating staff training. Lastly, federal food service guidelines are not designed for permanent supportive housing units that operate on limited budgets and staffing capacity and have unique ways of procuring and preparing foods. The limitations of food service guidelines could be counteracted by making the current city, county, and state policies more aligned with FSGFFs standards. In addition, FSGFFs could be improved by considering funding limitations, staff capacity, and staff training, which could be mediated through the provision of technical assistance.

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APPEND	DIX I. PSH Inquiry Tool		main suppliers of food for your facility (Purchases,
	Basic Information	Othe	
	* Required		
1.	Site Type: *		
	Mark only one oval.		
	Food Pantry		
	Mobile Pantry		
	Hot Meal Provider Skip to question 16		n contributes to the food supply of your facility (total should
	Group Home-Meal Provider Skip to question 16	add up to 100)?	
2.	Name of the Facility		
۷.			
3.	Address		
		<ol><li>Does your facility hav</li></ol>	e a monthly food budget and if so, how much?
		Mark only one oval.	
4.	Hours of Operation	\$0-200	
		\$200-400	
		\$400-600	
-	Carterillare	\$600-800	
5.	Contact Name:	\$800-1000	
6.	Contact Phone or Email: *		
7.	Contact Role:	15. In the last year, ho Mark only one oval.	w many people did your facility on average serve per month?
		<100 people 101-500 people	
8.	How long has this facility been in existence?/working with the food insecure?	1001-1500 people	
		More than 1500	
9.	Are you familiar with Food Service Guidelines for federal facilities?	Skip to question 20	
	Check all that apply.		
	Yes	Hot-Meal Provider	
	No	16. How many meals do	bes your facility serve per day?
10.	Are you familiar with "Dietary Guidelines for Americans 2015-2020"?		
	Check all that apply.	17. How many days per	week is your food served?
	Yes		
	No		
-	and Burdent	18. Which meal(s) do yo	bu serve?
FC	bod Budget	Check all that apply.	
11	Where does the overall funding for your food program come from?	Breakfast	
	and program out of the second program out of the second se	Lunch	
		Dinner	
		Other	

8

\_\_\_\_

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19. What is your method of distributing food? Is it restaurant style or cafeteria style?

	~		
Skip to question 11			

### Food Sourcing

 On average, over the last 6 months, my facility has been able to request and receive enough of the following items to serve all clients that visit my shelter through the month.

Check all that apply.

	Strongly Disagree	Moderately Disagree	Moderately Agree	Strongly Agree
Fresh Fruits and Vegetables				
Lean Protein (e.g. Chicken, Turkey, Beans)				
Low-fat dairy (1% or skim milk, low-fat yogurt)				
Whole grains				
Low-sugar beverages				

- 24. What do you see as the biggest barriers to accessing healthy foods sufficiently?
- .

Customer Satisfaction & Services

#### 25. What are the most popular foods among the guests?

26. Are there healthy foods that have been more popular with the guests than others?

21. How satisfied are you with the following? \*

Check all that apply.

	Strongly Disagree	Moderately Disagree	Moderately Agree	Strongly Agree
Ability to purchase healthy food within your budget				
Ability to access healthy donated food from food banks				
Ability to access donated healthy food from community food drives				

22. What factors are considered when obtaining food for your facility?

- 27. Is food education provided in any form to your guests? e.g. Are guests educated about healthy food options? If yes, please expand in more depth.
- 28. How have the guests responded to healthy foods (e.g. whole grains, fresh fruits and vegetables, lean protein, low-fat dairy, low-sugar beverages)?

29. What do you see as the biggest barriers to serving healthy foods?

23. Do you find that certain categories or types of food are more easily accessed than others?

**Current Nutrition Standard Environment** 

- 30. Does your facility have a way in which the nutritional value of the food served is considered or evaluated? If yes, please explain in more depth.
- Does your facility have any policies that require workers to seek out donations of healthy food or purchase healthy food? If so, please describe.
- 32. Are there any nutrition standards that must be met for the food supply? If yes, please expand in more depth.

- Is food education provided in any form to the chefs or kitchen volunteers? If yes, please expand in more depth.
- 34. Is there any attention paid to how healthy food is displayed? If yes, please expand in more depth.
- 35. What services would allow you to provide more nutritious foods to individuals who visit your facility?

### **APPENDIX II. PSH Audit**

### Food Service Guideline Assessment Food Service Guidelines for Federal Facilities

Prevention Research Center for Healthy Neighborhoods at Case Western Reserve University

Site Name:	Site Type:
	Silo IJpo.
Site Address:	
Site Contact Name:	Site Contact #:
Hours of Operation:	Meal Times:
Date of Initial Assessment:	Date of Post-Assessment:
Assessment Completed By:	

### Assessment Sections:

Prepared Foods
Packaged Snacks
Beverages
Food Safety 6
Behavioral Design

Assessment Key:

N/A=	Does	Not	Apply
------	------	-----	-------

- 0= Does Not Exist
- 1 = Below Standard
- 2= Standard
- 3= Innovative

Offer seafood at least two times a week	2			
Desserts				
When desserts are available, offer 25% of desserts containing less than or equal to 200 calories as served	2			
Sodium				
All meals offered contain less than or equal to 800mg Sodium	2			
All entrees offered contain less than or equal to 600mg sodium	2			
All side items contain less than or equal to 230 mg sodium	2			
Trans Fats				
All foods do not include partially hydrogenated oils	2			
Calories and Nutrition Labeling				
Provide calories and nutrition information of standard menu items	2			
Other Considerations				
Limit deep-fried entree options to no more than one choice per day	2			

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative

### Prepared Foods

Standard	Federal Suggestion	Initial Level	Post Level	Notes			
Fruits and Vegetables	Fruits and Vegetables						
Offer a variety of at least 3 fruit options daily, with no added sugars. Fruits can be fresh, canned, frozen or dried.	2						
Offer a variety of at least 3 non-fried vegetable options daily. Vegetables can be fresh, frozen, or canned, and served cooked or raw.	2						
Offer seasonal fruit and vegetables.	2						
Grains							
Offer half of total grains as "whole grain-rich" products, daily	2						
Offer a "whole grain-rich" product as the first (i.e., default) choice	3						
Dairy							
Offer a variety of low-fat dairy products (or dairy alternatives) daily, such as milk, yogurt, cheese, and fortified soy beverages.	2						
When yogurt is available, offer at least one low-fat plain yogurt	3						
Protein							
Offer a variety of non-fried protein foods, such as seafood, lean meats and poulty, eggs, legumes (beans and peas), but, seeds, and soy products, daily.	2						
Offer protein foods from plants, such as legumes (bean and peas), buts, seeds and soy products, at least three times per week	2						
Offer protein foods from plants such as legumes (beans and peas), nuts, seeds, and soy products, daily	3						

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative 2

### Packaged Snacks

11

Standard	Federal Suggestion	Initial Level	Post Level	Notes	
Food and Nutrient Profile					
All packaged snacks contain less than or equal to 200 mg sodium per package	2				
All packaged snacks have 0 grams of trans fat	2				
At least 75% of packaged snacks meet the following food and nutrient standards: - First ingredient is a fruit, vegetable, dairy product, probin - Whole grain-rich grain product - Contains at least ¼ cup of fruit and/or vegetable - Contain less than or equal to 200 calories - Saturated fat limit less than 10% of calories - Sugar limit less than or equal to 35% of weight from total sugars	2				
Calorie Labeling					
All snack foods sold in vending machines are consistent with FDA policies on vending	2				

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative 4

Beverages

Standard	Federal Suggestion	Initial Level	Post Level	Notes
Beverages				
Provide free access to chilled, potable water	2			
When milk and fortified soy beverages are available, offer low-fat beverages with no added sugars	2			
When juice is available, offer 100% juice with no added sugars	2			
At least 50% of available beverage choices contain less than or equal to 40 calories por 8 fluid ounces (excluding 100% juice and unsweetened fat-free or low-fat (1%) milk	2			
At least 75% of available beverage choices contain less than or equalt to 40 clories per 8 fluid ounces (exclusing 100% juice and unsweetened fat-free or low-fat (15) milk	3			

### **Behavioral Design**

Standard	Federal Suggestion	Initial Level	Post Level	Notes	
Placement and Layout					
Strategically place foods and beverages and design the layout of food service venues to foster selection of healthier foods and beverages.	3				
Product Innovations and Defaults					
Use product innovations and the inclusion of healthier options as default choices at decision points to encourage healthier choices.	3				
Pricing and Promotion					
Use price incentives and marketing strategies to highlight healthier food and beverage items.	3				
Tableware					
Promote healthy portion sizes by optimizing the size of plates, bowls, glasses other dishware, and serving ware.	3				
Information					
Use information, displays, decorations, and signage to highlight healthier choices.	3				
Organizational Policy					
Work with worksite wellness programs or other employee organizations to promote healthier options.	3				

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative 5

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative

### Food Safety

	Federal	Initial	Post	Notes	
Standard	Suggestion	Level	Level	Hoica	
Food Code					
Follow the guidance and standards in the most recently published <i>Food Code</i> (and all Supplement) relating to food safety procedures and practices	2				
Food Safety Management System/Ac	tive Manageria	al Control			
Establish a comprehensive written food safety plan that seeks to achieve active managerial control of foodborne illness risk factors	3				
Undercooked Meat, Poultry, and Egg	Products				
Do not serve raw or undercooked meat, poultry, or egg products, even upon request of the customer	3				
Practices to Control Listeria monocyto	ogenes in read	y-to-eat produ	cts.		
Develop and implement written sanitation and temperature control programs that target the control of <i>Listeria monocytogenes</i> in ready-to-eat products.	3				
Sick Employees					
Develop and Implement a written employee health policy.	3				
Certified Food Protection					
Have a least one management/supervisory employee (not necessarily the Person in Charge) who is a Certified Food Protection Manager present during all hours of operation	2				
Food Handler Training					
Develop and implement a written policy that addresses employee food safety training	3				

Assessment Key: N/A= Does Not Apply, 0= Does Not Exist, 1= Below Standard, 2= Standard, 3= Innovative

7



### The Importance of Communication in Collaborative Community Development: Lessons Learned from Three Cases

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### ABSTRACT

Collaborative community development projects aimed at promoting economic vitality, with attendant consequences as a key social determinant of health, necessarily pose questions about how to best communicate between developers, project partners, and community members. Many such projects are taking place across the United States, including in Ohio. This commentary draws on examples from 3 communities (2 outside of our state of Ohio, and another in the Linden neighborhood of Columbus, Ohio) to distill 3 key lessons in the area of communication. First, we argue that communication should be proactive, not reactive. Second, we explain why planners should be consistent in the provision of updates related to progress or lack thereof in real time on websites and apps, all while ensuring that information remains current. Third, though communication remains an under-appreciated aspect of partnership-based community development work, including explicitly health-oriented work, we argue that communicating progress to community members is not only logistically important, but part of a broader effort to build trust within communities in order to create long-lasting and sustainable change. This trust, after all, is a necessary foundation for community-focused work concerned with addressing the social determinants of health.

Keywords: Community development; Communication; Trust; Housing

### **INTRODUCTION**

Despite many moving parts and the involvement of multiple entities, collaborative community development projects aimed at improving health within communities are often introduced as carefully-planned, structured, and multiphased undertakings. Across Ohio, such projects are being carried out, led by individual organizations as well as small and large collaboratives. For example, a collaborative in Miamisburg, Ohio, known as Miamisburg CARES (Community Action for Revitalization, Engagement, and Sustainability), targets building and housing stock, infrastructure, and quality of life in their efforts.<sup>1</sup> Collaborative projects are being carried out in larger cities as well, as in the case of the Buckeye neighborhood in Cleveland, Ohio, where the main focus is to revitalize housing and prevent displacement of Black residents.<sup>2</sup> University Circle, an area less than 15 minutes from Buckeye, has been the focus of a much larger development collaborative, with the involvement of many partners and the local community, planning and completing varying types of projects over a longer period of time.<sup>3</sup>

No matter how well-planned, however, these logistically complex projects are accompanied by challenges. Stakeholders, especially local residents, may reasonably expect not only that the progress of these projects will be tracked and assessed in a coherent, organized, and transparent manner, but also that such progress is communicated effectively to the community staked in its success.<sup>4</sup>

We are a team of health researchers and medical students who, since 2020, have been studying a community development project in Central Ohio in which a children's hospital has played a collaborative role. This commentary uses an examination of publicly



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available accounts of 2 community development projects outside of Ohio (1 in Michigan and 1 New Jersey). These cases, roughly comparable in scope and aim, were chosen to allow for reflection on the challenges and progress of the collaborative project addressing health disparities and other needs in the Linden neighborhood of Ohio's capital city, Columbus. Differences in state locale allowed for reassurance that cases were not shaped by state-level policy dynamics, and set the stage for gaining a better understanding and learning from opportunities and challenges experienced in the varied locations.

We believe that our analysis may prove helpful to community development experts, municipal planners, and administrators such as project managers at organizations involved in collaborative development projects that identify the improvement of health outcomes as key aims. While by no means exhaustive, and with the caveat that each project is unique, these examples provide opportunities for understanding both the aims and challenges of community development plans, especially insofar as they are able to earn and maintain community trust.

### Case 1: Fitzgerald—Detroit, Michigan

Despite possessing assets that could be leveraged for real opportunity, the Detroit neighborhood of Fitzgerald has long grappled with widespread blight, crime, and poverty. Its median household income is about \$3500 lower than Detroit's, and its crime index is 4 times higher than national averages.<sup>5</sup> Amidst a 2017 mayoral race, a \$12 million revitalization plan for the neighborhood was announced with a projected completion of fall of 2019. The project was initially led by the City of Detroit, but was to be carried out in collaboration with real estate developers under the name of 'Fitz Forward.'6 The plan's aim was to "repurpose ten acres of dispersed city-owned vacant land" and to "make life better" through the creation of new opportunities for outdoor recreation, job creation, increasing affordable housing, decreasing food insecurity, enabling the creation of small businesses, promoting clean air and water, and increasing climate change resiliency.7 And yet, despite this focus on economic development, the developers were clear about their ultimate aims, which sit firmly within public health, as one of the project's key planners noted, "In a way, the actual rehab of housing is one of the least significant parts of it. It's really about building a safe neighborhood that brings amenities and economic opportunities that are vital to people's wellbeing."8

Since it commenced, the project's original goals have been scaled back from the initial aim of rehabilitating more than 100 homes. At the time the original goal was reworked, project managers expressed hope that the project would still be completed as planned. That goal was ultimately abandoned, however, as project managers relinquished their right to the remaining properties.<sup>8</sup> Despite this change in scope, the project showed signs of progress, with the rehabilitation of 13 homes, employing 40 residents, and clearing illegal dump sites.<sup>9</sup> Speaking to the difficulty of this ambitious plan, the *Detroit Free Press* noted, "The city's vision for Fitzgerald was bold. The timeline to complete the work was aggressive." Though the decision to scale back the project was disappointing, managers stand behind the project's accomplishments, with one stating that "There's lots of numbers we can throw out to show that this project was anything but a disappointment."<sup>8</sup> Yet, in 2018, some residents publicly expressed disappointment with what they considered a lack of progress, with the *Detroit Free Press* reporting that "There is confusion about jobs that were supposed to be created, and communication with the developer has been uneven."<sup>10</sup>

As a result of changes in the project's scope, tensions between residents and developers have also arisen, underscoring the tentativeness of the existing relationships on which the project depends. Residents have expressed concerns about a lack of communication between Fitz Forward and the community.<sup>11</sup> This problem is compounded by a lack of internet access for many residents, reminding us that urban internet access remains a challenging equity issue and that multiple approaches to media, including fliers and direct mail, may be important in some communities.<sup>10</sup> To aid in communication, a project office was created, however, the timing of the office's establishment suggests that communication was largely reactive instead of proactive.<sup>11</sup>

While there are many variables to be considered in understanding what lessons could be learned from FitzForward, the absence ,at least publicly, of individual benchmarks for developers to meet throughout the project timeline appears to have made it difficult to track progress or provide residents with up-to-date information. Had residents sought out publicly available evaluative information on the plan, they would have encountered outdated developer websites and broken website links. For example, a link on the website for the Detroit Collaborative Design Center inviting users to "Click here for more information about the project!" was broken, and the Fitzgerald-Detroit.com website is now "defunct."<sup>9</sup> Though there are some news articles available with updates on progress, they are limited.<sup>12</sup>

### Case 2: West Ward—Newark, New Jersey

In Newark, New Jersey, the West Ward Neighborhood Development Plan aimed to rehabilitate and redevelop a 21-block radius in a neighborhood with a decaying housing stock and high levels of crime stemming from a long history of neglect and policy failure.<sup>13</sup> Median household income in the neighborhood is about \$2000 less than Newark averages.<sup>14</sup> The West Ward was targeted for development due to its high concentration of blight, while also possessing a "good mix of residential and commercial properties allowing for redevelopment."<sup>15</sup> The plan centers on improving safety, increasing affordable housing, improving public services, and strengthening community more generally. The neighborhood plan was launched in 2016 by the city, in partnership with a group of small local developers. Newark's mayor explained that the choice to work with small developers was intentional and aligns with the goal of ensuring that "...Newark's growth is equitable and that residents benefit from the surge of investment here." The Mayor suggested, as well, that small developers are uniquely positioned to "build wealth in the community, provide jobs for residents, and have a personal stake in shaping a prosperous future for our city."<sup>16</sup> And so while the nominal focus of the West Ward Development Plan is to address entrenched poverty and promote economic growth, the framing of the project specifically recognizes not only that these aims are deeply entwined with improved health, but that communication is critical to the project's success.

As no dedicated websites were developed for the project, news articles are the most widely available resources for tracking the project. Information regarding the plan can also be found on the City of Newark's Facebook page where residents can access a recording of a livestreamed meeting hosted by the Newark mayor, intended to introduce the 6 developers and their individual projects to the neighborhood residents. While this platform is an example of a potentially effective means of communication with community members, it is also important to remember that accessing such platforms requires digital infrastructure and equipment. In addition, this public meeting is almost 90 minutes long. The video's lack of an index makes referencing individual points of information difficult. The event did indicate that there was significant municipal interest in active engagement, as more than 500 residents availed themselves of the opportunity to provide comments to the developers. Most comments pertained to community members' concerns or satisfaction with progress and communication. The comments drove a discussion largely focused on the reasoning behind choosing the plan's developers, possible job opportunities with developers, housing affordability, and the quality of housing.17

### Case 3: Linden—Columbus, Ohio

The One Linden Plan was developed to address health disparities and bring economic stability to the Linden neighborhood of Columbus, Ohio. First conceived in 2017 as a collaboration of local stakeholders, including but not limited to lending and housing institutions, a local children's hospital, faith-based community organizations, and community members, the plan's stated goal was to "create a roadmap for safe neighborhoods, economic development and access to affordable housing, quality health care, education and employment opportunities in Linden."18 Of note, the plan was intended as a list of recommendations and was not necessarily a commitment from specific entities to follow this plan as suggested, which, owing to the concreteness of the word 'plan', could create disconnect between expectations and reality. The plan focuses on an area of Linden that is 2.63 square miles, northeast of downtown Columbus. Demographically, Linden is a primarily Black (63.4%) community with a median household income of \$23,934, and nearly half of its residents live below the poverty level.18

Plan development, grounded in feedback and participation from stakeholders, occurred over the course of 14 months. A planning

team was enlisted to engage residents and other stakeholders of Linden to ensure that their voices were heard and incorporated into the plan's goals. At the end of the planning period, "10 Big Ideas" were announced as the framework for revitalizing the community, with each idea consisting of a broad goal and the elements necessary to achieve those goals. Each of the "Big Ideas" includes a table which presents categorized recommended action items and accompanying information regarding specific outcomes/metrics, potential partners, and a suggested time frame should these recommendations be followed. These time frames vary, but most were intended to be achieved in spans of 1 to 5 years or 6 to 10 years. The language accompanying the plan emphasizes "empowering residents" and "building capacity," both of which are proposed to take place "across the demographic spectrum, from youth to elders and across income and race." Critically, the project leaders promise a focus on neighborhood-level relationships and community engaged development.18

A large collaborative effort, "614 for Linden," was announced approximately 1 year after One Linden's launch. The collaborative is made up of 6 nonprofit organizations and 4 financial institutions (Table 1) that collectively pledged a \$25 million investment aimed at 4 of the "10 Big Ideas" (Table 2) which focused on housing improvement, business development, entrepreneurial support, community investment, and resident health. The "614 for Linden" effort gained a great deal of positive media attention.<sup>19-21</sup>

Although the plan's scope, aims, and objectives are now easy to locate online, updates on the plan's progress were minimal over the past 2 years. The website lay mostly dormant for years and contained broken links leading to "page not found" errors. This included the website's "Our Linden'" email subscription tool, which was nonfunctional for more than a year, as was a form for submitting questions and concerns. Both examples exhibit attempts at community engagement that could have dramatically improved the project's early communication strategy. After a 2-year lull in public announcements, no doubt impacted to some degree by disruptions caused by the COVID-19 pandemic, a 2021 blog post on the Greater Ohio Policy Center website detailed 614 for Linden's progress.<sup>22</sup> In a notable return to iterative communication, the post links to the "614 for Linden" website for further updates, including project and event announcements and a contact form for submitting questions and concerns. In providing such information, the Greater Ohio Policy Center has been tasked as an external evaluator of the project involving the development of impact reports intended to be made publicly available. Tracking and evaluation is required as a condition of JPMorgan Chase's PRO Neighborhood initiative, which invested \$5 million into the project.<sup>22</sup> In other words, from the period when we began our research, to the time of revisions of this manuscript, substantial improvements and a meaningful course correction were made. A brief visit to OneLinden.org also indicates that steady improvement in communication has been made as the website now lists resources available to residents in categories named "Emergency

### Table 1. Nonprofits and Community Development Financial Institutions

### Nonprofits

Saint Stephen's Community House

Community Development for All People

Healthy Neighborhoods Healthy Families

The Affordable Housing Alliance of Central Ohio

**Community Shelter Board** 

Nationwide Children's Hospital

well as other areas relevant to resident wellbeing.23

### Table 2. "Ten Big Ideas"

1. Stabilize and expand housing options*	6. Address early childhood experience
2. Connect residents to employment	7. Reimagine Cleveland Avenue
3. Reduce crime and improve perception	8. Build community investment*
4. Support student success	9. Connect the community
5. Support entrepreneurs and develop business*	10. Support resident health*

Services," "Health and Social Services," "Food," and "Housing" as

\*Areas on which the plan ultimately focused.

### **Lessons Learned**

In the early days when community development was first arising as a coherent concept, it was rare for communication to be a focus, likely because such work tended to be conceived and carried out in a top-down manner.<sup>24</sup> Today, however, it is increasingly understood that communication with communities is essential to the long-term success and sustainable change that such projects aim to create.25 Successful projects start with "people not projects."26 There is also a growing literature on community-based health to guide people-centered development work that takes communication seriously.27 This includes valuable scholarly resources on development and communication, generally,<sup>28</sup> as well as the evaluation of communication practices within projects.<sup>29,30</sup> Though communicative aims can be difficult to achieve, these cases suggest some general principles that might be used by partners for effective communication. Given the need to demonstrate concrete development and progress if community buy-in and trust is to be attained, a range of technical questions about community development plans or projects should be examined.

The success of these collaborations hinges on accessible, up-todate information shared on an ongoing basis with community members, preferably in qualitatively different forums. The Newark case, which lacked a formal website, reminds us of the importance of local news coverage to development work. Predictably, there is significant distrust within long-neglected communities, and failures in communicating during the course of long-term plans may perpetuate this distrust.<sup>31</sup> Updating communities

across multiple media and including members as part of the process regularly is a way to assure residents and key stakeholders that the larger aims remain intact. This is especially true when large disruptions (like a pandemic) interrupt the ability to hold kickoff events, stage high-profile announcements, and carry out face-to-face forums. Effective and regularly updated websites and printed materials distributed within the community are critical in resisting a common cycle of big announcements that then fade into months and years of projects with mixed results. The 3 cases discussed suggest that the cultivation of trust is likely the most enduring effect that these types of large-scale developments and projects can have on communities.<sup>32</sup> Projects like those described above cannot be carried out in a vacuum, however. In addition, this work is never purely forward-looking, as development must simultaneously address the past and the future, especially where there is pervasive distrust.

Our analysis of these communities points to 3 key lessons that collaboratives and municipal planners should heed when undertaking comprehensive and long-term community development initiatives. All concern distinct, though related, insights into effective communication.

1. Communication should be proactive, not reactive.

Communication strategies should be forward-thinking and rigorously adhered to through the stages of development, especially when delays occur. Too often, as in the field of crisis communication,<sup>33</sup> communication becomes a concern only after something has gone wrong, which erodes trust and increases the amount of work community partners will need to do to repair relationships. Stakeholders must avoid making grand promises that are then

### **Community Development Financial Institutions**

**Ohio Capital Finance Corporation** Affordable Housing Trust of Columbus and Franklin County Finance Fund Capital Corporation **Economic Community Development Institute** 

followed up with sparse or disjointed communication. Ultimately, it is not promises but actions, paired with effective communication, that build neighborhood trust. While members of collaborative development efforts may include information on social media and the internet, larger, multi-pronged plans are generally wellknown, at least in their broad strokes, and contain many moving parts. Ideally, these moving parts should be followed and documented appropriately in a single location. Yet, our attempts to identify such information clearinghouses, either in current or past community development projects, turned up empty. The problems we have identified suggest that such clearinghouses should not only be established and maintained, but should be actively promoted to alert communities to their existence. While the presence of such tools is important, a nonfunctional communication tool may be equally, if not more disruptive to trust building than a lack thereof. Such a clearinghouse should be culturally conditioned, linguistically competent, and reflect the broader communicative needs of specific communities, especially if internet access is a barrier for residents.

2. To the extent possible, show progress in real time on websites and apps.

Some of the websites created to showcase and disseminate information about the plans and projects we examined are impressive in scope, but lack updates on incremental progress. Though program partners may have sweeping visions for improving communities, these entities often miss out on opportunities to communicate with community members. Updates, which can be carried out through meetings, web-based communiques, and signage in the community, are critical in the process of communication and trust-building.

Outdated information and broken links may be read by communities as signs that the current project is another instance of being forgotten. Community members and other stakeholders should have easy access to updated and reliable information, rather than needing to search through local news sources or broken links to learn about progress in community development. Wellmaintained websites can be an effective means of communicating with local residents, especially at a time when community members may be just as likely to learn about developments taking place on their street via the internet. For example, the University Circle (Cleveland) website contains a comprehensive news section that provides visitors with extensive information not only regarding development work in the area, but events, community organizations, and other resources.<sup>3</sup> As a counterpoint to this useful resource, nonprofits such as CityWide Development are highly engaged in a range of important development projects in Dayton, Ohio, but it is challenging to get a sense of the state of their important work from publicly available resources.34 Oftentimes, the only available resources about projects of great consequence to communities take a corporate-oriented instead of communityoriented communications approach.

3. Approach ongoing communication as part of trust-building.

Iterative communication is an important means of building trust, not only in community development initiatives but in all public initiatives. Accordingly, communications strategies should be built into plans from the beginning and executed according to plan (and adapted as circumstances change) throughout the process. The initial communication of a plan should be followed by progress updates and continued collaboration with the community to achieve set goals. Ongoing updates via structured communications throughout the life of a plan or project can speak volumes to community members who may require both time as well as concrete proof before they will trust in the collaborative nature of community development projects. Web searches yielded no examples of development projects using dedicated smartphone apps to keep community members apprised of progress in projects, which is unfortunate considering that while internet access may be lacking in poor urban communities, recent data suggest that 15% of Americans access the internet exclusively via smartphone.

While it may be tempting to skip project updates that acknowledge slower-than-anticipated or no progress, such updates are still important, and perhaps especially so, in communities that already feel neglected. Paradoxically, this is particularly true with regard to ambitious projects, as plans that are smaller in scope may be easier to track and communicate to the community. Personnel and entities involved in community development work must understand that while celebrating progress is important, building trust with communities is likely more enduring. Finally, to ensure that communications strategies are working, project managers and planners would be well advised to make communication itself part of project assessment.<sup>35</sup>

### A Note on the Pandemic

17

As it did in clinical medicine and in all sectors of the economy,<sup>36</sup> the arrival of the COVID-19 pandemic in 2020 disrupted many projects like the ones we describe. Despite this interruption, their core mission and importance remain. Yet, it is also true that all critiques of events, projects, and promises made before the arrival of the COVID-19 pandemic must be qualified. It is understandable, even predictable, that community development work would have been disrupted by the pandemic. At the same time, the pandemic provides an additional opportunity for reflection, not only because it serves as a laboratory for critical thinking about health prevention and public health practice, but because the challenges the pandemic has presented once again move the problematic of communication between official entities (governments and both nonprofit and for-profit entities) into stark relief. While before the pandemic many health care institutions had been actively working to improve their communicative and collaborative relationships with communities, the COVID-19 pandemic deepened our understanding of the importance and even imperative of doing this work at an increasingly high level.<sup>26</sup> While much of the conversa-

tion during 2021 has concerned misinformation and disinformation regarding vaccination, the underpinnings of these challenges have once again reminded us of the often low levels of trust that erode the potential of establishing strong relationships between varying types of institutions and communities.<sup>37</sup> As we move into a post-pandemic status quo, the lessons we are learning from the challenges of public health communication should be leveraged far beyond the individual compliance level of public health. As is apparent from our brief discussion of neighborhoods in Detroit, Newark, and Columbus, the most enduring investments will be those that foster trust in general, which can then be leveraged in a myriad of particular ways for public health promotion.

### **CONCLUSION**

The key takeaways from this brief analysis of 3 community development efforts are united by their concern for effective communication. We share these lessons with a reminder that some of the projects we examined are multipronged community development plans, while others are specific and more narrowly focused. Accordingly, our focus is on the distillation of guiding principles, especially regarding communication, rather than a list of specific practices that developers and planners should take. As we noted above, the insights we offer regarding effective communication in community development and economic vitalization projects are applicable to all public projects, especially in historically marginalized neighborhoods where trust is low.

Scholars have noted the importance of effective and active communication between official and corporate entities and their various community constituencies, including in health care,<sup>38</sup> though much of the corporate communications literature is reactive and crisis-oriented instead of taking a more proactive, relationshipbuilding approach.<sup>39</sup> Yet, we have asserted that communication also remains an underappreciated aspect of development work. Our analysis underscores the importance of such practices specifically with regard to large and ambitious community-oriented planning, but also connects to a general ethos for communication that we suggest should exist in health promotion generally.

The One Linden Plan is a bold initiative. Given the longstanding history of promises to develop neglected neighborhoods in American cities, it is likely that community members will wait to see concrete developments before getting too excited. In fact, counteracting such suspended disbelief is an important part of such plans or projects with intentions to provide avenues of change in communities. A consideration of the progress toward implementing the plan's recommendations suggests that there are opportunities for improved communication. It is important to remember that communicating with community members is not only a logistical concern, but part of a broader, more sustained effort to build trust in the larger collaborative process of community development. It is with this trust that successful community development and true collaboration across all stakeholders can and will ultimately occur.

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## Hearing Loss: Applying the Social-Ecological Model for Change

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### ABSTRACT

**Introduction:** The proportion of Ohioans experiencing deafness or serious difficulty hearing is higher than national estimates and is increasing over time.

**Purpose:** The purpose of this study is to describe the burden, risk factors, comorbidities, and financial implications of hearing loss in Ohio as well as discuss approaches to reduce the burden of hearing loss in Ohio applying the Social-Ecological Model

**Methods:** A narrative review was completed to summarize peer-reviewed literature on hearing loss in Ohio. The Social-Ecological Model was applied to identify approaches to reduce the burden of hearing loss in Ohio.

**Results:** The burden of hearing loss on health and economic well-being is substantial in Ohio. While initiatives have sought to reduce costs and increase access, barriers continue to persist impeding people's ability to obtain needed services in Ohio. Approaches were identified on all levels of the Social-Ecological Model to address the burden of hearing loss in Ohio such as creating interventions for prevention, improving access to hearing tests and hearing aids, and changing policies that expand insurance coverage for hearing aids.

**Conclusion:** There is a critical need for public health-initiated programs and policies that reduce barriers and increase access to hearing related services that can be implemented on all levels of the Social-Ecological Model.

Keywords: Hearing loss; Hearing aids; Comorbidities; Insurance

### **INTRODUCTION**

In 2018, 6.4% of adult Ohioans experienced deafness or serious difficulty hearing, which was 0.5% higher than national estimates.<sup>1</sup> From 2016-2018 the percentage of adults with deafness or serious difficulty hearing rose from 6.1% to 6.4% in Ohio.<sup>1</sup> Projections estimate that hearing loss will substantially increase by 2050 because of increased risk factors and comorbidities associated with hearing loss.<sup>2</sup> Hearing aids can improve some health outcomes associated with comorbidities such as reduced mobility restrictions, cognitive decline, and health-related quality of life pertaining to perceived quality of physical health.<sup>3</sup> However, high cost and limited coverage from insurance providers hinders the ability of individuals with hearing loss to obtain hearing aids and needed

services.<sup>4</sup> This commentary aims to describe the burden of hearing loss in Ohio and describes actions that can be taken to reduce this burden by a range of audiences such as practitioners, public health professionals, community members, and other stakeholders through the Social-Ecological Model.

### **Burden and Risk Factors of Hearing Loss**

As described previously, the proportion of adults who were deaf or had serious difficulty hearing is higher in Ohio in comparison with the United States (US) overall (6.5% versus 5.9%).<sup>1</sup> In the US, almost 40 million Americans over the age of 12 years have hearing loss, and it is the third most common reported chronic condition.<sup>5,6</sup> Estimates suggest that by 2030 about 73 million US adults will be impacted by hearing loss.<sup>7</sup> Additionally, hearing loss is one of the



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most common conditions among older adults.<sup>6,8</sup> Almost a third of adults between 65 and 74 years of age, and nearly 50% of adults over 75 years of age, experience hearing loss.<sup>9</sup> Approximately 25% of adults between 20 and 69 years of age experience hearing loss.<sup>10</sup> Moreover, in 2017, 10.4% of infants exhibited hearing loss.<sup>11</sup> In the US almost 2 to 3 out every 1000 children and 1 in 5 teens have some level of hearing loss.<sup>12,13</sup>

Hearing loss has multiple causes and risk factors. Hearing loss can be caused by middle ear infections, genetic factors, disease, health condition, medications, ear abnormalities, or noise exposure.9,14 Unfortunately, some individuals are unaware that noise exposure causes hearing loss. Among adults aged 20 to 69 years who selfreported having good to excellent hearing, about 25% exhibited some level of hearing loss.<sup>6</sup> Additionally, almost 53% of adults reported no noise exposure at work but exhibited signs of noise exposure hearing loss.<sup>10</sup> Yet, other research suggests that noise exposure at work may not be the only cause of hearing loss.<sup>6</sup> A study of Ohio children that live on farms indicated that children living on farms were more likely to experience hearing loss than children in the general population.<sup>15</sup> Considering that food and agriculture is Ohio's primary industry, and over 95% of those farms are owned by families, these families are at a risk of increased exposure.<sup>16</sup> Ohio ranks third in the US for manufacturing which includes developing materials in areas that have the potential for work-related noise exposure.<sup>16</sup> Another potential cause of exposure that Ohioans face is traffic and/or highway noise.17 Therefore, Ohioans may have an increased risk of noise exposure, and there is a need to increase awareness and enhance programs that limit prolonged noise exposure.

### Comorbidities

Individuals with hearing loss have an increased risk of comorbidities that include, but are not limited to, chronic conditions, mental health disorders, psychosocial issues, and other health outcomes.<sup>3,18</sup> Comorbidities increase risk for poor outcomes among persons with hearing loss, and some states, such as Ohio, have a higher average number of comorbidities per person in contrast to other states.<sup>19</sup> However, some studies indicate that using hearing aids can improve some health outcomes, which is discussed further in the upcoming sections. This section provides an overview of the comorbidities associated with hearing loss and implications related to hearing aids.

### **Chronic Conditions**

Several chronic conditions are associated with hearing loss such as visual impairment, diabetes, hypertension, cardiovascular disease, arthritis, and stroke. Besser et al completed a review and estimated that between 3.1% and 18.2% of individuals with hearing loss have visual impairment.<sup>3</sup> Individuals with prediabetes and diabetes had higher rates of hearing loss than those with normal glucose levels.<sup>3</sup> There is an increased risk of hearing loss among patients with cardiovascular risk factors and disease.<sup>20–22</sup> Furthermore,

individuals with hearing loss are at a higher risk of cardiovascular disease, hypertension, and cardiovascular death (eg, stroke) than hearing individuals.<sup>20–23</sup> Arthritis is also associated with hearing loss, and research has noted that specific types of arthritis increase risk of hearing loss.<sup>22,24</sup> Cancer and malignant conditions may require treatments that have side effects of sensorineural hearing loss; a significant association between hearing loss and cancers has been found.<sup>21,22,25</sup> An association between hearing loss and chronic comorbidities is apparent; however, the relationship of causality with each chronic disease is not fully understood.<sup>3</sup> There are few known studies examining if the use of hearing aids improves the health outcomes of comorbid chronic conditions; yet, experts suggest incorporating management of hearing loss into medical treatment.<sup>26</sup>

Additionally, hearing loss is associated with cognitive impairment and increased risk for cognitive decline.<sup>3,18,27</sup> Cognitive decline is associated with hearing loss, but it is unclear how the 2 are related.<sup>3</sup> Along with cognitive decline, hearing loss is also associated with an increased risk of dementia. One study noted that individuals with hearing loss were over 3 times more likely to develop dementia than individuals without hearing loss.<sup>28</sup> More research is needed to determine the impact of hearing aid use on cognitive decline and cognitive impairment because there are studies with varied results.<sup>3</sup> However, a study noted that after an 18-month follow-up individuals with hearing loss using hearing aids had improved cognition, and females exhibited better cognitive outcomes than males.<sup>29</sup> Hearing aid use was also associated with a delay in dementia diagnosis.<sup>30</sup>

As it relates to Ohioans, there is a paucity of research that examines the comorbidities of hearing loss. In 2019 almost half of Ohioans had at least 1 chronic condition.<sup>31</sup> The most prevalent chronic diseases among adult Ohioans are arthritis, diabetes, asthma, chronic obstructive pulmonary disease, cancer, heart disease, and stroke.<sup>31</sup> Almost 12% of Ohioans over the age of 45 years experience cognitive decline.<sup>32</sup> Given that almost half of Ohioans experience a chronic condition and a proportion experience cognitive decline, both correlates of hearing loss, Ohioans could be at a higher risk for having or developing hearing loss.

### Mental and Psychosocial Health

Hearing loss is associated with mental and psychosocial health comorbidities as well. Individuals with hearing loss experience higher rates of depression and anxiety.<sup>3,33–35</sup> In a longitudinal study, individuals with hearing loss were 50% more likely to experience anxiety and 41% more likely to experience depression at 5 years of follow-up.<sup>18</sup> A recent large nationally representative sample of adults in the US found that hearing loss was associated with psychological distress, increased medication use, and utilization of mental health services.<sup>36</sup> Individuals with hearing loss are more likely to self-isolate, stay home, and experience social and emotional loneliness.<sup>35,37,38</sup> Furthermore, some research has found that hearing loss increases the risk for hallucinations and psychosis.<sup>39</sup>

In 2019, a larger proportion of adult Ohioans were diagnosed with depressive disorder compared to the US overall.<sup>31</sup> This appears to be an enduring trend; from 2011-2019 a higher proportion of adult Ohioans reported poor mental health over a 2-week period than adults in the US.<sup>31</sup>

Studies indicate mixed results about hearing aid use and mental or psychosocial health outcomes. In some research hearing aid use and hearing aid training was associated with improved depression symptoms and delays in diagnosis of anxiety and depression.<sup>3,30,40</sup> However, individuals with severe hearing loss who use hearing aids were less likely to stay home than those who do not use hearing aids.<sup>41</sup> Additionally, a 6- and 12-month follow-up study involving adults who obtained hearing aids or cochlear implants found that participants had improved loneliness scores.<sup>42</sup>

### Functioning and Health Care Utilization

Other health issues associated with hearing loss pertain to mobility and injurious falls.<sup>3,22,30</sup> Authors of a review found that individuals with hearing loss were 1.4 to 2.5 times more likely to experience falls than individuals without hearing loss.<sup>3</sup> Recent research has shown that adults with hearing loss have poorer physical activity profiles characterized by less engagement in light intensity and moderate-to-vigorous physical activity, accompanied by more sedentary and fragmented physical activity.<sup>43</sup> Adults with hearing loss are more likely to report worse scores on physical health measures than those without hearing loss.<sup>44-46</sup> Hearing loss is also associated with impaired activities of daily living, instrumental activities of daily living, lower extremity mobility, and reduced engagement in exercise.<sup>47-49</sup>

In Ohio, only 71.7% of adults reported exercising, which was lower than the proportion in the entire US adult population.<sup>31</sup> Additionally, from 2011-2019 the prevalence of adults participating in physical activity among Ohioans is lower than national prevalence; however, no information from this data source indicates whether hearing loss is associated with lack of physical activity.<sup>31</sup> However, hearing loss is associated with an increased risk for physical disability.<sup>48</sup> Thus, persons with hearing loss have been found to have lower age-specific health-related quality of life in physical health.<sup>50</sup> Although, the use of hearing aids among individuals with hearing loss has shown that they can prevent injurious falls and mobility restrictions and improve health-related quality of life.6,30,41,51

To exacerbate the situation further, individuals who experience hearing loss report lower rates of preventative care access and higher rates of health care utilization. A recent investigation reported that persons with hearing loss were less likely to receive preventative care and services such as cancer screenings.<sup>52</sup> Hearing loss is associated with increased mental health services and emergency room utilization.<sup>53</sup> Persons who experienced hearing loss had 47% more inpatient hospital visits and 44% greater risk for a 30-day hospital readmission than individuals without hearing loss.<sup>53</sup> Thus, some research has shown that persons with se-

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vere hearing loss have medical costs that were significantly higher than those without hearing loss.<sup>49</sup> However, use of a hearing aid has been found to reduce emergency department visits and length of hospitalizations as well as total Medicare costs.<sup>54</sup> From January 2018 to June 2021, Ohio had the fourth highest number of hospitalization discharges compared to all other states.<sup>55</sup> Additionally, in 2019, Ohio tied for the eighth highest number of hospital admissions in the US at 122 per 1000.<sup>55,56</sup> Yet, data are unavailable about how many of these hospital admissions are related to hearing loss.

### **Burden of Cost**

Estimates suggest that 28.8 million noninstitutionalized US adults would benefit from hearing aids.9 Despite this, only about 16% of individuals aged 20 to 69 years and 30% of individuals 70 years and over have used hearing aids.<sup>9</sup> One of the barriers to obtaining hearing aids is cost.57 The cost for 1 hearing aid ranges between \$1000 and \$6000 and the cost depends on the technology and features of the hearing aid.58 But, the burden of cost extends bevond the cost of hearing aids. During a 10-year span, individuals with untreated hearing loss had 46% higher health care costs than their hearing counterparts.<sup>36</sup> Another report posits that each year untreated hearing loss costs \$133 billion, which translates to \$9100 yearly per individual.<sup>59</sup> Some research suggests that regulatory change and policy changes could lower the cost of hearing aids making them more accessible to individuals. However, opening the market or allowing over-the-counter hearing aids to be sold could lead to more self-service and could compromise patient safety and quality of care.<sup>60</sup> Little is known about the burden of cost relating to hearing loss for Ohioans. In 2019, the median household income of Ohioans was approximately \$57000, and health care expenditures were increasing to almost \$9000 per capita. Many Ohioans with hearing loss may face more financial burdens in obtaining hearing aids.<sup>61,62</sup> Yet, insurance that provides benefits for hearing services and hearing related technologies also plays a key role in individuals obtaining hearing aids.

### **Insurance Coverage**

In the US health insurance consists of private insurance, Medicaid, and Medicare. Table 1 provides an explanation of each insurance as it relates to obtaining hearing aids. In 2020, only 6.2% of individuals in Ohio were uninsured.<sup>63</sup> Of those that had health care insurance 49.2% received it through an employer, 19.7% received it through Medicaid, 18.4% received it through Medicare, 1.3% received it through military, and 5.1% received health care insurance privately.<sup>63</sup>

Most health care coverage does not cover hearing aids because of multiple factors. Hearing aids are considered by some insurance companies to be an elective rather than a necessary medical device despite the supportive research indicating a decline in quality of life and health among individuals with hearing loss.<sup>64</sup> Only 23 states have state mandates for hearing aid coverage, and each state has different requirements for coverage such as age, amount

### Table 1. Types of Health Insurance and Coverage of Hearing Aids

Insurance	Description	Eligibility	State Level Coverage
Private	Primarily obtained through employer sponsored group plans, occasionally privately purchased <sup>64</sup>	Varies and depends on the insurance; but most do not cover hearing aid costs <sup>64</sup>	Varies by insurance provider
Medicaid	Health coverage for low-income adults, children, pregnant women, and elderly adults with disabilities <sup>65</sup>	Individuals with low incomes, pregnant women, infants, and children, older adults, and individuals with disabilities Must be an Ohio resident and US citizen or meet citizenship requirements, have a social security number, meet the financial requirements <sup>66</sup>	Covers hearing tests and hearing evalu- ations, counseling, ear molds, hearing aids, warranties, batteries, a cleaning kit, and repairs to the hearing aids <sup>66</sup>
Medicare	Medicare is health coverage for individuals over the age of 65 years, some younger individuals with disabilities, and individuals with end-stage renal disease <sup>67</sup>	Medicare does not cover hearing aids; however, some Medicare Part C plans do <sup>67,68</sup>	Some Ohio Medicare Part C plans offer hearing aid coverage; coverage varies <sup>67</sup>

covered, benefit period, and health care provider qualifications; but Ohio is not one of the states. Most private insurance does not cover hearing aids, and Medicare does not cover hearing aids.<sup>64,65,69</sup> However, there are some Medicare Advantage Plans or Part C plans that offer hearing benefits.<sup>70</sup> One Ohio Medicare Advantage Plan covers 1 hearing exam, 3 hearing aid fittings; yet the copay for hearing aids can range from \$700 to \$1000 per hearing aid per year.<sup>68</sup>

Pertaining to Medicaid, an analysis in 2016 of state-by-state coverage revealed that Ohio provides coverage for hearing aids, the initial set of hearing aid batteries, and 3 hours of counseling.<sup>71</sup> In Ohio, Medicaid covers hearing tests and hearing evaluations, counseling, ear molds, hearing aids, warranties, batteries, a cleaning kit, and repairs to the hearing aids and only provides coverage for mild hearing loss.<sup>66,71,72</sup> However, there are limitations. Reimbursement is limited to 1 hearing aid in 4 years unless there is a special circumstance. In addition, only specific types of hearing aids are covered, and only 1 major and 1 minor repair is covered in a 1-year period.<sup>66,72</sup> Furthermore, authorization of benefits is required by Medicaid prior to receiving coverage for hearing aids.<sup>66</sup> Yet, individuals and families may not meet the eligibility criteria for Medicaid because their annual income is over the threshold, but they do not have enough income to offset the burden of cost. Therefore, Ohioans with hearing loss face disparities because of the limitations of health insurance coverage for hearing aids, the cost of hearing aids, and the increased medical expenditures experienced.

### **Call to Action**

The Lancet Commission and World Health Organization aim to continue efforts in preventing and treating hearing loss among populations.<sup>2,73</sup> Current estimates suggest that 1 in 4 people will have some form of hearing loss by 2050.<sup>2</sup> A lack of treatment, such as hearing aids, for hearing loss has a detrimental impact on peo-

ple's ability to function, work, and achieve optimal health. If appropriate early interventions are implemented, then there is potential to mitigate the impacts of hearing loss. Hearing technology (eg, hearing aids) has been identified as a potentially cost-effective approach for addressing hearing impairment.<sup>2</sup> However, financial costs and lack of insurance coverage persist as substantial barriers in access to care for persons with hearing loss globally, nationally, and among Ohioans. Thus, there is an urgent and critical need for the development of policies and programs that reduce barriers to obtaining needed hearing related services and technology.

We frame our call to action for Ohioans in the Social-Ecological Model.<sup>74</sup> The Social-Ecological Model provides a foundation for incorporating a wide range of perspectives into action strategies that promote hearing health. With hearing loss there are several practitioners, professionals, and stakeholders that can be leveraged to promote hearing health equity. The Social-Ecological Model holds that actionable approaches are influenced by a myriad of structures, systems, and groups requiring effective interventions to focus on multiple levels of application.

We are applying the Social-Ecological Model as a framework to identify approaches to reduce the burden of hearing loss. The Social-Ecological Model is tailored to show the different levels of society that are interacting and influencing hearing health. This model is organized into 3 categories: Intrapersonal and Interpersonal, Institutional and Community, and Public Policy and Society (Figure 1). Example actions that stakeholders may participate in to promote hearing health among Ohioans are summarized in Table 2.

### Intrapersonal and Interpersonal

Extensive research has demonstrated that personal characteristics are associated with hearing loss. Many people who develop hearing loss have a genetic disposition and individual behaviors that

hearing loss.

and manage hearing loss.

contribute to the onset and progression of hearing loss over the

life course. An individual's engagement in behaviors that either

exacerbate or protect against hearing loss is related to many fac-

tors such as self-efficacy, knowledge, and locus of control.75 Some

individual level interventions have incorporated a focus on genet-

ic screenings, modifying individual behaviors, or other strategies

showing varying effectiveness in promoting hearing health. For

instance, the Ohio Hearing Conservation Program is a state-level

initiative that aims to increase awareness about preventable hearing loss among school-aged children and to provide information

on hearing conservation programs for school personnel who are

developing local programs.<sup>76</sup> Interventions for individuals can be

beneficial to implement to prevent, screen, diagnose and treat

Interpersonal dynamics play a critical role in understanding the

etiology of hearing loss. Interactions with friends, family, groups,

and other social networks can shape behavioral engagement ei-

ther improving or hindering hearing health. Social support and

relationship interactions with others (eg, spouses, health care

providers) have been identified as important determinants of

health care seeking, engagement in care, and treatment for

hearing loss.<sup>57,77</sup> Several interventions have aimed to incorporate

interpersonal relationships, finding that this expansion of focus

beyond the intrapersonal level can be effective in promoting en-

gagement and improving outcomes.<sup>78</sup> Providers in Ohio may seek

to incorporate both intrapersonal and interpersonal factors when

working to provide adequate care and services to prevent, treat,

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Institutional and Community

Persons with hearing loss spend significant amounts of time within institutional and community environments (eg. work, health care services, school, neighborhoods). These contextual exposures are strongly associated with behaviors and health outcomes among persons with hearing loss. Institutional or community settings can provide the foundation for promoting or hindering hearing health.

One of the factors that impacts individuals from obtaining needed hearing related services and technology is lack of access to resources within institutions and communities. Some opportunities are available to some Ohioans. Individuals who experience hearing loss may qualify for financial assistance through organizations that aim to provide financial resources for individuals to purchase hearing aids. The Ohio Department of Health: Children with Medical Handicaps provides financial assistance and assistance with identifying providers. However, this service is limited to Ohio resident children who are under the age of 21 years, under the care of an approved medical doctor, are financially eligible, and have special health care needs.<sup>79</sup> The Sertoma Hearing Aid Recipient Program by the Lima Noon Sertoma Club is another hearing aid assistance program. It seemingly does not have an age limit for applicants but does require financial information and an agreement to a 1 year follow-up appointment after receiving the hearing aids.<sup>80</sup> There are other similar programs in urban areas; but rural areas are in need of programs to assist in obtaining needed hearing-related services.

Public Policy and Society Institutional and Community Intrapersonal and Interpersonal

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### Figure 1. Social-Ecological Model

### Table 2. Suggested Actions to Improve Hearing Health Outcomes in Ohio

				Institutions and	
Social-Ecological Model Category	Health Care Providers	Public Health Professionals	Politicians	Community Organizations	Community Members
Intrapersonal and Interpersonal					
Plan and implement intrapersonal and interpersonal interventions that promote awareness, self-efficacy, knowledge, and locus of control about hearing health and hearing conservation for high-risk populations.	$\checkmark$	~	$\checkmark$	√	$\checkmark$
Institutional and Community					
Increase access to resources for hearing related services and technology such as hearing screenings and hearing aids in rural Ohio.	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Continue supporting the Ohio Department of Transportation traffic noise exposure.	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	✓
Develop taskforces and coalitions that aim at improving health within communities.	$\checkmark$	✓	✓	$\checkmark$	$\checkmark$
Plan and implement institutional-wide and community-wide programs that increase awareness, self-efficacy, knowledge, and locus of control about hearing health and hearing conservation at places of work, schools, and places of leisure.	✓	✓	✓	✓	✓
Public Policy and Society					
Communicate with state and national level representatives about the need for policy change to improve hearing health outcomes.	√	$\checkmark$	$\checkmark$	✓	✓
Join organizations that aim at creating an equitable policy that improves hearing health for populations experiencing disparities.	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	✓
Create and implement mechanisms of surveillance.	$\checkmark$	$\checkmark$			
Begin surveillance of hearing health status and outcomes among Ohioans.	$\checkmark$	$\checkmark$		$\checkmark$	
Develop policies and laws that protect consumers of hearing technology.	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$

Another program that has been implemented in Ohio pertains to hearing conservation by limiting traffic noise by constructing walls as barriers.<sup>17</sup> The Ohio Department of Transportation conducts noise assessments and builds walls close to roadways and highways to reduce noise exposure to areas that have high noise exposure because of traffic.<sup>17</sup> These programs are helpful for reducing noise exposure of Ohioans at their homes and workplaces.

Other opportunities within the community that practitioners (audiologists, public health professionals, clinicians, grassroots leaders, coalition members, and community-based workers) and stakeholders can participate in is through coalition involvement. Coalitions can work toward a common goal in hearing conservation and implementing interventions to prevent hearing loss as well as implement policy changes within institutions and governments to promote hearing conservation and hearing loss treatments. One such group is the Ohio Coalition for the Education of Children with Disabilities that focuses on children; however, there is little work pertaining to adults.<sup>81</sup>

Institutional programs and community-wide interventions could be key in hearing conservation. The Ohio State University has a Hearing Conservation Program that they implement to protect the hearing of their workers.<sup>82</sup> Also, community-wide programs specifically working with farm families can have a wider reach and promote hearing health education.<sup>83</sup> Incorporating similar interventions into the workplace or in a community setting can promote hearing health and hearing treatment.

### Public Policy and Society

Public policy, through regulatory and legislative channels involving collaborative processes such as lobbying and advocacy, has an impact on persons with hearing loss. Societal engagement through coalition building and strategic plan development is needed to bring about sustainable changes that improve access to and the quality of care for persons with hearing loss. In Ohio political action is ongoing to support the well-being and needs of persons with hearing loss.

### **Recent Political Action**

In 2019, to reduce the burden of hearing aid costs, Ohio House Bill 243 was introduced to the 133rd general assembly.<sup>84</sup> The goal was to have health care plans cover \$1400 every 36 months for insured children up to 21 years of age; however, the bill died in com-

mittee.<sup>85</sup> Yet, efforts persist. In March 2021, the 134th general assembly House Bill 198 was introduced. This bill would require health plan issuers to cover hearing aids and related services for individuals 21 years of age and under with \$2500 per hearing aid every 4 years.<sup>84</sup> One argument is that mandating House Bill 243 or 198 would increase premiums and would be costly. Yet, other states with similar legislation mandates note that premiums have only risen between 5 and 39 cents per insured individual per month.<sup>86</sup> These bills, although beneficial and progressive, only focus on gaining hearing aid coverage and related services for part of the population; there are still individuals over the age of 21 years that would benefit from similar coverage.

Other political action that recently took place in Ohio pertained to hearing protection and consumer protection. In 2020 a law was amended to allow Ohioans who ride motorcycles to wear earplugs to protect their hearing.<sup>87</sup> Also, in response to the US Food and Drug Administration considering a proposal to allow over-the-counter hearing aids, the Ohio Attorney General requested clarification of language to allow the states to protect consumers of the over-the-counter hearing aids by ensuring warranties, refunds, and exchanges of the products.<sup>88</sup>

At the national level, the House of Representatives introduced the Medicare Hearing Aid Coverage Act of 2021 (HR 1118) in February 2021.<sup>89</sup> The aim of the bill is to allow Medicare coverage for hearing examination, hearing aid, and hearing aid-related services as early as January 2022.<sup>89</sup> Further information is required to be gathered by the Comptroller General of the US about the programs and insurance coverage as well as the number of individuals with hearing loss that need hearing aids.<sup>89</sup> Should this bill pass, it would provide hearing aid coverage to individuals over the age of 65; however, there are still young adults and children who will not have insurance coverage.

### Surveillance

Little information has been gathered about the hearing status of Ohioans. There is a need to have in-depth surveillance of this chronic health condition since hearing loss is associated with several comorbidities, poorer health outcomes, and higher expenditures. Appropriate surveillance can lead to identifying the population's need for prevention, management, and treatment of hearing loss. Moreover, surveillance could potentially lead to evidencebased practices to prevent and treat hearing loss as well as guide policy development to improve the hearing health of Ohioans. Societal initiatives, including public policy development and change, are needed to create adequate surveillance systems.

### **CONCLUSION**

Hearing loss exacts a notable toll on health and well-being globally, nationally, and in Ohio. While initiatives aim to improve access to and the quality of care for hearing loss, many barriers such as costs and lack of insurance coverage continue to impede health promotion and care. The Social-Ecological Model provides a Ohio Journal of Public Health, August 2022, Vol. 5, Issue 1 ISSN: 2578-6180

framework to understand and address these barriers. To reduce the burden of hearing loss, initiatives such as intervention strategies addressing interpersonal and intrapersonal factors, institutional and community-based programs and networks, and policy development and modification within all levels of this model need to be implemented.

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**RESEARCH ARTICLE** 

# Depressive Symptoms and Perception of COVID-19 Risk in Ohio Adults

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### ABSTRACT

**Background:** We assessed the relationship between depressive symptoms and perceived COVID-19 risk in the next month.

**Methods:** This analysis used survey data collected during a July 2020 cross-sectional study using a household-based probability sampling design. A total of 615 noninstitutionalized, English- and/or Spanish-speaking adults in Ohio were included. Depressive symptoms screening occurred using the Patient Health Questionnaire-2 (PHQ-2). We applied survey weights so that presented analyses represent the adult population in Ohio. We performed log-risk regression modeling (generalized linear model with binomial distribution and log link) to estimate unadjusted and covariate-adjusted prevalence ratios examining the association between screening positive for depressive symptoms and perceived risk of COVID-19 in the next month.

**Results:** The study population was majority female (59.1%) and White (90.3%). The mean age was 55.9 years (standard deviation (SD)=17.3). About 1 in 20 (4.6%) screened positive for depressive symptoms. A positive depressive symptoms screen was not significantly associated with perceived risk of COVID-19 in the next month (prevalence ratio [PR]=0.75; 95% confidence interval [CI]=0.25–2.24). After confounder adjustment, the adjusted prevalence ratio (aPR) was nearly unchanged (aPR=0.78; 95% CI=0.24–2.55).

**Conclusion:** As depression is often associated with anxiety and pessimism toward the future, the lack of association between depressive symptoms screening and perception of COVID-19 risk in the next month is surprising. Social withdrawal, which is also associated with depression, may have concealed any increased perceived COVID-19 risk, as depressed individuals who remained socially isolated may have had lower perceived COVID-19 risk.

Keywords: COVID-19; Depressive symptoms; PHQ-2; Risk perception

### **INTRODUCTION**

The COVID-19 pandemic has been associated with reduced mental health, including feelings of stress, isolation, and loneliness for many people,<sup>1,2</sup> and a rise in mental illnesses, such as depression.<sup>3</sup> Stay-at-home orders, lockdowns, and social distancing requirements restricted activities in ways never previously experienced by most people alive today. Many continue to endure financial strains from a slowed economy and emotional crises after the deaths of loved ones. In nationally representative data from the United States, the prevalence of depression symptoms was 3-fold

higher during the COVID-19 pandemic compared to 2 years before the pandemic.  $\!\!^4$ 

Globally, depression (characterized by a continual feeling of sadness and a loss of interest in typical life activities<sup>5</sup>) is one of the most common mental health disorders, with nearly 300 million people affected.<sup>6</sup> In the United States in 2019, about 5% of adults experienced regular feelings of depression.<sup>7</sup> Depression is also associated with symptoms of hopelessness and anxiety.<sup>5</sup> These feelings can lead to a general negative outlook on life, including negative attitudes toward the future.<sup>8</sup> One Lebanese study found



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### Recruitment

these pessimistic emotions to be closely linked with cynical feelings of impending doom during the COVID-19 pandemic.<sup>9</sup> A sense of impending doom can often occur while catastrophizing<sup>10</sup>, defined as imagining worst-case scenarios for the future.<sup>11</sup> People who catastrophize generally overestimate their risk for a negative outcome,<sup>12</sup> such as COVID-19. In China, a depressive state was associated with increased perceived COVID-19 risk.<sup>13</sup> Our study sought to examine this association in the United States in the state of Ohio.

Perception of risk for disease during an outbreak is also correlated with how well one follows outbreak-related guidelines.<sup>14</sup> Therefore, we aimed to examine the relationship between screening positive for depressive symptoms and perception of risk of COVID-19 in the next month, as this relationship could impact the success of pandemic control measures. No other study to our knowledge has examined this relationship in Ohio or the United States generally. Using data from a cross-sectional, populationrepresentative study of Ohio adults conducted in July 2020, we characterized the association between screening positive for depressive symptoms (using the validated Patient Health Questionnaire-2 (PHQ-2)) and perceived risk of COVID-19 in the next month.

### **METHODS**

### **Study Setting and Design**

This cross-sectional study was conducted in July 2020 in the state of Ohio.

### Study Sample

We selected the sample using probability-proportionate-to-size cluster sampling (PPS-CS). This sampling method is described in detail elsewhere.<sup>15,16</sup> We sampled 30 census tracts from within each of Ohio's 8 planning regions.<sup>17</sup> From each census tract, we planned to enroll 5 households. Using a marketing database, and to account for expected refusal, we randomly selected a total of 50 household addresses within each sampled census tract to approach for recruitment. Only single- and multi-unit residential addresses were eligible. Post office box addresses were excluded due to the household recruitment design.

Overall, 11974 households were selected for potential recruitment using PPS-CS, although not all were approached (see Analytic Sample under Results). Persons eligible for study inclusion were noninstitutionalized, English- and/or Spanish-speaking adults in Ohio capable of providing informed consent. In total, 727 people enrolled in the study. As this analysis investigates the relationship between depressive symptoms screening and perception of COVID-19 risk in the next month, only the 615 participants with complete data for these variables (84.6% of the enrolled sample) were included in the analysis. All staff wore personal protective equipment during fieldwork. To notify selected households about the opportunity for participation, as well as how to opt out, we mailed a postcard to each home. A household was able to opt out either by declining to participate when a study team visited, by emailing, calling, or texting staff, or by filling out a web form. In the days before the study team planned to visit, the household received an invitation letter providing more detail on study procedures and timeframe.

For safety purposes, field staff visited selected households in pairs. Staff were trained on administering informed consent and the study survey through the Research Electronic Data Capture (REDCap) system.<sup>18,19</sup> All staff underwent COVID-19 polymerase chain reaction (PCR) testing prior to entering the field.

A team of 2 recruiters visited each sampled household to confirm an eligible adult was present. If no adult was home, the team left an informational letter, including an estimated time that they would return. In the first region, a team then attempted another visit, and if again no adult was home, recruiters left a letter with details about a future final visit attempt. All visit attempts took place at different times on different days. If no adult was home after the third attempt, recruiters moved on to another household. Repeated visit attempts in that region were found not to increase recruitment: nearly every person who enrolled in the study did so with the first visit attempt. Therefore, in the remaining regions, if no adult was home during the initial recruiter visit attempt, the team left a flier inviting an adult to contact the study if the household wanted to participate. No further household visit attempts occurred if the household did not contact study staff.

Recruiters recorded the name and birth year for all eligible adults in the household (defined as having slept at least 4 of the last 7 days in the household). If more than 1 adult lived in the household, recruiters randomly selected 1 adult to participate. If the selected adult was home, recruiters asked if this adult was willing to participate. Partial participation was not allowed; the sampled adult had to agree to participate in both the survey and full sample collection (blood and nasopharyngeal swab) to be eligible. If the selected adult declined to participate, recruiters did not sample another adult from the household. Instead, recruiters moved on to the next sampled household.

### **Data Collection**

The field team administered a 10-minute survey via REDCap. The survey gathered information on demographics, symptoms of respiratory illness, history of COVID-19 testing, social distancing and other behavioral practices, the PHQ-2, and other topics.

### **Data Analysis**

All analyses account for the PPS-CS design by applying survey weights, such that all presented analyses represent the adult population in Ohio. We used Stata (IC 16) software for all statistical analyses.

We performed log-risk regression modeling (generalized linear model with binomial distribution and log link) to estimate unadjusted and covariate-adjusted prevalence ratios examining the association between screening positive for depressive symptoms and perceived risk of COVID-19 in the next month. The outcome was captured through the survey item, "how likely do you think you are to get COVID-19 in the next month?" Responses included very likely, likely, unlikely, or very unlikely. For analysis, we collapsed responses into 2 categories: unlikely and likely. Responses of "don't know" (n=100) or "declined to answer" (n=2) were excluded. We defined the primary exposure, positive depressive symptoms screen, using the composite score on the PHQ-2, coded dichotomously (negative/positive). Prior work demonstrates that major depressive disorder is likely with PHQ-2 scores of 3 or high $er^{20}$ ; thus, we dichotomized PHQ-2 scores as < 3 vs 3 or greater. We determined the minimally sufficient adjustment set for the analysis using a directed acyclic graph (DAG), which is most often used for causal relationships but can also aid in visualizing associations between potential confounding variables and the exposure and outcome of interest.<sup>21,22</sup> We selected covariates to include in the DAG based on existing literature<sup>23-34</sup> and hypothesized plausible associations between the exposure, outcome, and covariates.

The minimally sufficient adjustment set included age, gender, race, education, marital status, self-rated health, work status, social distancing behavior, number of adults in the household, and number of children in the household. We performed some consolidation of survey item response categories when including covariates in the regression model: age was coded continuously, race (Black/ African American vs non-Black/African American), education (completed high school or less vs completed at least some postsecondary education), marital status (married vs not married), number of adults in the household (1 adult vs 2 or more adults), and number of children in the household (no children vs 1 or more children). Work status combined data on employment and retirement.

We also assessed whether social distancing behavior modified the association between depressive symptoms and perceived COVID-19 risk in the next month. We assessed for modification first using Pearson's chi-square tests with correction for the PPS-CS design. For variables which appeared to be significant modifiers, we then examined the magnitude of the association between depressive symptoms and perceived COVID-19 risk within levels of the putative modifier. We examined both ratio measures, to identify multiplicative interaction, and difference measures, to identify additive interaction. We added 0.1 to each cell in any contingency table originally containing a zero cell to permit computation and comparison of stratified measures of effect. We repeated this approach for 8 social distancing behaviors over 2 time periods: the past 30 days and during the stay-at-home period from March 15, 2020, to May 25, 2020 (Table 1).

Finally, we performed a sensitivity analysis to assess the robustness of our findings to changes in PHQ-2 score cut-points. We repeated the analyses as previously described but using a PHQ-2 score cut-point of 2 or greater (whereas the primary analysis had used a PHQ-2 cut-point of 3 or greater), which enhances the sensitivity of the PHQ-2.

### RESULTS

### **Analytic Sample**

Of 11974 households selected for potential participation which received postcards and invitation letters, 415 letters were returned as undeliverable, and 1482 households opted out by email, phone, or webform. Of the remaining households, 5347 were not visited because the target enrollment was met for the census tract

 Table 1. Survey Items Used to Investigate Social Distancing as a Potential Modifier of the Effect of Positive Depressive Symptoms

 Screen on Perceived COVID-19 Risk in Next Month

### Survey Item

During the past 30 days, I have stayed home except for going outdoors to exercise, or going to the grocery store, pharmacy, or to get other needed supplies, or getting medical care.<sup>a</sup>

During the stay-at-home period from March 15 to May 25, I stayed home except for going outdoors to exercise, or going to the grocery store, pharmacy, or to get other needed supplies, or getting medical care.

During the past 30 days, I have avoided visiting friends, neighbors, or relatives who don't live with me.

During the stay-at-home period from March 15 to May 25, I avoided visiting friends, neighbors, or relatives who didn't live with me.

During the past 30 days, I have avoided letting friends, neighbors, or relatives who don't live with me come into my home.

During the stay-at-home period from March 15 to May 25, I avoided letting friends, neighbors, or relatives who didn't live with me come into my home.

During the past 30 days, have you attended any gatherings, not including work, with more than 10 people who do not live in the same house as you?

During the stay-at-home period from March 15 to May 25, did you attend any gatherings, not including work, with more than 10 people who did not live in the same house as you?

<sup>a</sup>Social distancing was found to be a potential effect measure modifier in the primary exposure-outcome relationship only when defining social distancing by response to this survey item.

or due to staffing limitations. Therefore, 4730 households were visited in person. After visiting, 585 addresses were considered ineligible due to being vacant/abandoned, inaccessible, a duplicate address, a nonresidential address, or if no adult was home, there was a language barrier, or the selected adult was not competent to consent. Ultimately, 727 households enrolled, resulting in a response rate of 18.5%. The present analysis included n=615 (84.6% of the enrolled sample).

### **Participant Characteristics**

All frequencies and means are weighted to represent Ohio adults. Participant age ranged from 18 to 97 years. The mean age was 55.9 years (standard deviation [SD]=17.3). Most (59.1%) were female. Regarding race and ethnicity, 5.9% reported Black/African American race, 90.3% reported White race, 1.4% reported Asian race, 0.6% reported Native American/American Indian/Alaskan Native race, and 2.6% reported Hispanic/Latinx/Spanish ethnicity. Nearly all (95.3%) had completed high school or additional education. Approximately half (52.2%) were married, but 16.8% were never married. Of those who were not retired, most (59.4%) were employed full-time, and 31.6% were unemployed. Overall, 70% of those who were not employed were retired. Nearly all (94.8%) had health insurance. A plurality (38.2%) self-reported very good health, with only 3.3% reporting poor health. Most (54.0%) reported 2 adults in their household, and 72.2% reported no children in the household. Approximately two-thirds (68.7%) reported they had stayed home during the past 30 days except for going outdoors to exercise, or going to the grocery store, pharmacy, or to get other needed supplies, or getting medical care (Table 2).

We generally observed few differences between those who believed they were likely to get COVID-19 in the next month and those who believed they were unlikely to get COVID-19 in the next month (Table 2). However, about half (48.9%) of those who believed they were likely to get COVID-19 in the next month had no children in the household, compared to three-fourths (75.2%) of those who believed they were unlikely to get COVID-19 in the next month who reported no children in the household. Additionally, 57.7% of those who believed they were likely to get COVID-19 in the next month reported they had stayed home during the past 30 days except for going outdoors to exercise, or going to the grocery store, pharmacy, or to get other needed supplies, or getting medical care, but 70.1% of those who believed they were unlikely to get COVID-19 in the next month reported they had stayed home during the past 30 days. Further, 38.0% of those who believed they were likely to get COVID-19 in the next month reported being in good health, whereas 29.0% of those who believed they were unlikely to get COVID-19 in the next month reported good health. Of those who were not employed, less than half (42.0%) who believed they were likely to get COVID-19 in the next month were retired, compared to approximately three-quarters (72.5%) who believed they were unlikely to get COVID-19 in the next month who were retired (Table 2). The mean age of those who believed

they were likely to get COVID-19 in the next month was 44.9 years (SD=17.8), and the mean age of those who believed they were unlikely to get COVID-19 in the next month was substantially older, at 57.3 years (SD=16.7).

### Depressive Symptoms Screening and Perceived Risk of COVID-19 in the Next Month

About 1 in 20 (4.6%) screened positive for depressive symptoms. A positive depressive symptoms screen was not significantly associated with perceived risk of COVID-19 in the next month. Overall, 11.7% believed they were likely to get COVID-19 in the next month, including 8.8% who screened positive for depressive symptoms and 11.8% who screened negative for depressive symptoms (corrected Pearson's chi-squared test *p* value=0.59).

This finding was reinforced in the log-linear model, which generated an unadjusted prevalence ratio (PR) of 0.75 (95% confidence interval [CI]=0.25-2.24) for the association between positive depressive symptoms screen and believing one is likely to acquire COVID-19 in the next month. After adjustment for age, gender, race, education, marital status, self-rated health, work status, social distancing behavior, number of adults in the household, and number of children in the household, the adjusted prevalence ratio (aPR) was nearly unchanged (aPR=0.78; 95% CI=0.24–2.55) (Table 3).

### Social Distancing as a Potential Effect Measure Modifier

Of the 8 social distancing measures, we observed modification of the primary association of interest by 1 measure ("during the past 30 days, I have stayed home except for going outdoors to exercise, or going to the grocery store, pharmacy, or to get other needed supplies, or getting medical care" (*p* value>4.46)). The PR for the association between depressive symptoms and perceived COVID-19 risk in the next month for those who reported staying home was 1.03 (95% CI=0.34–3.15), whereas for those who did not report staying home, the PR was 0.16 (95% CI=0.00–73.70), providing evidence of modification on the multiplicative scale. We did not observe meaningful differences in the prevalence difference measures and conclude that there was no interaction on the additive scale.

### Sensitivity Analysis

The association between screening positive for depressive symptoms and perceived COVID-19 risk in the next month was sensitive to a change in PHQ-2 score cut-point. When using a PHQ-2 score cut-point of 2 or greater to indicate a positive depressive symptoms screen, 11.7% screened positive for depressive symptoms. (In contrast, in the primary analysis that used a PHQ-2 score cut-point of 3 or greater, 4.6% screened positive for depressive symptoms (Table 2).) When using a PHQ-2 score cut-point of 2 or greater, the unadjusted PR was attenuated compared to the primary analysis (PR=1.02, 95% CI=0.49–2.10). The adjusted PR in the sensitivity analysis was similarly attenuated (aPR=1.12, 95% CI=0.52–2.43) (Table 3).

# Table 2. Characteristics of a Cross-sectional Sample (Overall and According to Perception of Likelihood to Get COVID-19 in the Next Month) of Ohio Adults in July 2020

	Total		Believ	ved they were	Believ	ved they were
	( <i>N</i> =6 N	15) Weighted %	likely in nex (N=8- N	v to get COVID-19 kt month 4) Weighted %		ely to get COVID-19 kt month 31) Weighted %
Depressive Symptoms Screen <sup>a</sup>						_
Negative Positive	579 36	95.4 4.6	80 4	96.5 3.5	499 32	95.3 4.7
Age 18 – 29 years 30 – 39 years 40 – 49 years 50 – 59 years 60 – 69 years 70 – 79 years 80 – 89 years 90 – 97 years	56 75 59 107 172 112 26 8	10.0 13.0 8.8 17.0 27.6 19.0 3.7 0.8	16 16 11 16 15 7 3 0	25.4 20.5 12.3 15.5 14.6 8.2 3.6 0.0	40 59 48 91 157 105 23 8	8.0 12.0 8.4 17.2 29.3 20.4 3.7 1.0
Gender Male Female Nonbinary Other gender identity Missing	253 361 0 1	41.0 59.1 0.0 0.0	30 54 0 0 0	34.8 65.2 0.0 0.0	223 307 0 1	41.8 58.2 0.0 0.0
Race/Ethnicity <sup>b</sup> Black/African American White Asian Native American/American Indian/Alaskan Native Native Hawaiian/Pacific Islander Missing	29 565 6 4 0 3	5.9 90.3 1.4 0.6 0.0	6 72 1 2 0 0	6.6 82.2 2.2 2.2 0.0	23 493 5 2 0 3	5.8 91.3 1.3 0.3 0.0
Hispanic/Latinx/Spanish Missing	14 3	2.6	4 0	7.9	10 3	1.9
Education Less than first grade First through eighth grade Some high school, but no diploma High school graduate or equivalent Some college, but no degree Associate degree Four-year college graduate/bachelor's degree Advanced degree Missing	0 2 20 178 110 76 125 102 2	0.0 0.2 4.5 29.2 16.7 12.3 20.4 16.7	0 0 7 20 10 13 17 17 0	0.0 0.0 9.5 23.5 12.9 14.1 22.5 17.5	0 2 13 158 100 63 108 85 2	0.0 0.3 3.8 29.9 17.2 12.1 20.1 16.6
Marital Status Married Not married but living with partner Widowed Divorced/annulled Separated Never married Missing	326 48 62 82 8 88 1	52.2 8.0 8.7 12.7 1.6 16.8	38 7 5 10 5 18 1	46.3 8.7 5.6 10.1 4.9 24.4	288 41 57 72 3 70 0	53.0 7.9 9.1 13.1 1.1 15.8
Employment Status <sup>c</sup> Employed full-time Employed part-time Unemployed Missing	199 32 108 276	59.4 9.0 31.6	37 6 22 19	58.0 11.4 30.6	162 26 86 257	59.7 8.5 31.8
Retirement Status <sup>d</sup> Not retired Retired Missing	108 252 255	30.0 70.0	22 16 46	58.0 42.0	86 236 209	27.5 72.5
Health Insurance Status Insured Uninsured Missing	581 33 1	94.8 5.2	76 8 0	91.0 9.0	505 25 1	95.3 4.7

## Table 2 (continued). Characteristics of a Cross-sectional Sample (Overall and According to Perception of Likelihood to Get COVID-19 in the Next Month) of Ohio Adults in July 2020

		Total ( <i>N</i> =6 N	15) Weighted %	likely	ved they were to get COVID-19 xt month 4) Weighted %	unlik	ved they were ely to get COVID-19 xt month 31) Weighted %
Self-Rated Health St Excellent Very good Good Fair Poor Missing	atus	106 230 187 67 23 2	17.0 38.2 30.1 11.4 3.3	13 26 30 11 4 0	16.0 33.7 38.0 10.2 2.0	93 204 157 56 19 2	17.2 38.8 29.0 11.5 3.5
Adults in the House 1 Adult 2 Adults 3 Adults 4 Adults 5 Adults 6 Adults 7 Adults 8 Adults 9 Adults 10+ Adults Missing		209 337 39 22 6 0 0 1 0 0 1	33.7 54.0 6.6 3.9 1.5 0.0 0.0 0.0 0.0 0.0 0.0	32 41 5 4 2 0 0 0 0 0 0 0 0	34.2 52.1 5.5 6.3 1.9 0.0 0.0 0.0 0.0 0.0 0.0	177 296 34 18 4 0 0 1 0 0 1	33.7 54.3 6.7 3.6 1.5 0.0 0.0 0.0 0.3 0.0 0.0
Children in the Hous No Children 1 Child 2 Children 3 Children 4 Children 5+ Children Missing	ehold	450 70 53 28 7 3 4	72.2 11.0 10.6 4.6 1.1 0.6	45 18 13 4 0 1 3	48.9 19.5 23.6 6.3 0.0 1.7	405 52 40 24 7 2 1	75.2 9.9 8.9 4.4 1.2 0.4
Social Distancing Be During the stay-at-home period	havior I stayed home I avoided visiting others I avoided letting others into my home I attended gatherings	516 470 459 76	83.7 77.2 78.1 13.1	70 69 64 10	81.8 84.8 79.3 10.8	446 401 395 66	84.0 76.1 78.0 13.4
During the past 30 days	I have stayed home I have avoided visiting others I have avoided letting others into my home I have attended gatherings	416 319 349 218	68.7 53.3 61.3 36.2	49 44 43 33	57.7 46.3 50.2 49.3	367 275 306 185	70.1 54.2 62.8 34.5

<sup>a</sup>Depressive symptoms screen was performed using the Patient Health Questionnaire-2 (PHQ-2).

<sup>b</sup>Race/ethnicity was select all that apply. Therefore, the values shown do not add up to our sample size of 615 and column percentages do not add up to 100%.

<sup>P</sup>articipants who reported they were retired were excluded from our employment status variable and categorized as missing.

<sup>d</sup>Those who reported they were employed were excluded from our retirement status variable and categorized as missing.

#### **DISCUSSION**

Depression is often associated with feelings of anxiety and pessimism toward the future.<sup>5,8</sup> In this study, we investigated the relationship between screening positive for depressive symptoms and perception of COVID-19 risk among Ohio adults in July 2020, a period of increased transmission and prior to the availability of COVID-19 vaccinations. We found that perception of COVID-19 risk in the next month was not significantly different for participants who screened positive for depressive symptoms compared to participants who screened negative for depressive symptoms.

Our sensitivity analysis further confirmed a lack of association between depressive symptoms screening and perception of COVID-19 risk in the next month, as was observed in our primary analysis. When we examined the primary exposure-outcome relationship using a decreased PHQ-2 score cut-point compared to that used in the primary analysis, we still obtained a null association, even though we had expanded the definition for positive depressive symptoms screen to capture more participants in this category.

In some people, depression can lead to social withdrawal, which is when a person minimizes their social contact and activity.<sup>35</sup> Social withdrawal may lead to increased time spent at home to keep away from others—thereby lowering potential exposure to SARS-CoV-2. Even if some participants who screened positive for depressive symptoms had increased perceived risk of COVID-19

## Table 3. Unadjusted and Adjusted Prevalence Ratios and 95% Confidence Intervals for the Association Between Positive Depressive Symptoms Screen and Believing One is Likely to Get COVID-19 in the Next Month<sup>a</sup>

	Primar Unadju	y Analysis <sup>₅</sup> Jsted	Adjust	ed	Sensitiv Unadju	vity Analysis <sup>c</sup> Isted	Adjust	ed
	PR	95% CI	PR	95% CI	PR	95% CI	PR	95% CI
Depressive Symptoms Screen								
Negative	1.		1.		1.		1.	
Positive	0.75	0.25–2.24	0.78	0.24–2.55	1.02	0.49–2.10	1.12	0.52-2.43

PR=prevalence ratio, 95% CI=95% confidence interval

<sup>a</sup>The adjusted PR was adjusted for age, gender, race, education, marital status, self-rated health, work status, social distancing behavior, number of adults in the household, and number of children in the household.

<sup>b</sup>The primary analysis was performed using a Patient Health Questionnaire-2 (PHQ-2) score cut-point of 3 or greater to indicate a positive depressive symptoms screen.

<sup>c</sup>Sensitivity analysis values were generated using a PHQ-2 score cut-point of 2 or greater to indicate a positive depressive symptoms screen.

compared to those who screened negative, others may have believed their COVID-19 risk to be low because of social isolation, and the cumulative effect of these influences may have led to our null finding. Our findings suggest that social distancing has a complex role in modifying the association between depressive symptoms and perceived COVID-19 risk.

As COVID-19 is a novel disease, the relationship between depressive symptoms and COVID-19 risk perception has been studied infrequently. Most related studies<sup>36-38</sup> have concentrated on investigating the opposite association: the effect of perceived risk of COVID-19 on depression and overall mental health during the pandemic. However, a study performed by Zhong et al (2020) in Wuhan, China, found depressive states to be positively related to perception of COVID-19 risk.13 The disagreement between our findings and the results of the Zhong et al (2020) study may be explained by design differences between the 2 projects. Eligible participants in the Zhong et al (2020) study were current COVID-19 patients in Wuhan, China, whereas our study included noninstitutionalized, English- and/or Spanish-speaking adults in Ohio, United States. Additionally, the Zhong et al (2020) study took place in February 2020, only 2 months after COVID-19 was first reported in Wuhan, China.<sup>39</sup> Our study occurred in July 2020, approximately 4 months after COVID-19 was declared a pandemic and confirmed cases began to appear in Ohio.<sup>40,41</sup> Consequently, those with depressive symptoms in Wuhan may have perceived COVID-19 as a greater threat because the Zhong et al (2020) study occurred very soon after the COVID-19 outbreak began in Wuhan. At this early stage, the feelings of anxiety and negative attitudes about the future that are often associated with depression<sup>5,8</sup> were likely elevated in Wuhan study participants. In Ohio, participants with a positive depressive symptoms screen in July 2020 may have perceived a somewhat lower likelihood to get COVID-19 compared to those depressed in Wuhan because social distancing guidelines had been in place already for several months. Zhong et al (2020) also assessed risk perception of COVID-19 in the next year, whereas we assessed risk perception of COVID-19 only in the next month. Finally, Zhong et al (2020) used a modified version of the 20-item Hopkins Symptom Checklist Depression Scale,<sup>42,43</sup> and we used the PHQ-2 to screen for depressive symptoms. It is important to note that the PHQ-2 is a limited assessment measure that only screens for depressive symptoms through 2 questions.

We did not incorporate any component of clinical diagnosis of depression.

As the data were collected in July 2020 during one of the earliest peaks of the COVID-19 pandemic, the applicability of our findings to this multi-year pandemic overall may be limited.

Selection bias may be another potential limitation of our study. It is possible that participants who decided to enroll were more concerned about their health than the average Ohioan and viewed COVID-19 to be a more serious disease than other adults in Ohio. Selection bias may also have resulted from the exclusion of adults who were institutionalized or non-English/non-Spanish speaking. Further, selection bias may be an issue as the participants excluded from study analyses differed in some measured characteristics from the participants kept in analyses. Out of the 727 initial participants that enrolled in the study, approximately 15% were excluded from this analysis because they were missing data for the survey question assessing risk perception for COVID-19 in the next month. We found that those included and excluded from analysis differed in (White) race (90.3% vs 81.3% White race, respectively), education (0.2% vs 5.1% first through eighth grade education), retirement status (70.0% vs 53.7% retired), and social distancing behavior (68.7% vs 50.8% stayed home during the past 30 days) (Appendix I). It is possible that these 2 groups may differ in other unmeasured characteristics as well. Additionally, the study sample was less racially diverse (90.3% (study) vs 81.7% (Ohio) White race) and more educated (37.1% (study) vs 28.9% (Ohio) with a bachelor's degree or higher) compared to the general population in Ohio.44

We have explored the relationship between depressive symptoms and risk perception of COVID-19 in the United States. Our analysis showed that perception of COVID-19 risk in the next month was unrelated to depressive symptoms screening status among Ohio adults in July 2020. As depression is often associated with anxiety and pessimism toward the future,<sup>5,8</sup> the lack of association was surprising. However, social withdrawal may partly explain this result.

#### PUBLIC HEALTH IMPLICATIONS

This study is the first of which we are aware to examine the relationship between depressive symptoms and risk perception of COVID-19 in Ohio or the United States generally. The null association observed in this study between screening positive for depressive symptoms and perception of COVID-19 risk in the next month is an important finding for several reasons.

Perception of risk for disease during an outbreak is often a measure of how well one will follow recommended outbreak safety guidelines.<sup>14</sup> Since lower perception of disease risk often indicates a decreased likelihood to follow outbreak safety recommendations,14 those with depression may be less likely to adhere to safety guidelines during an outbreak. We cannot say for certain whether those with depression truly are less likely to adhere to safety recommendations during an outbreak because reduced risk perception for COVID-19 does not necessarily indicate a lack of awareness about COVID-19. As previously mentioned, depression can present in the form of social withdrawal.<sup>35</sup> Thus, it is possible that those who are depressed may take outbreak safety guidelines (including social distancing) extremely seriously if they are already homebound from depression and could consequently have lower perceived COVID-19 risk. Therefore, social withdrawal could have masked any increased perceived COVID-19 risk in this study.

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#### APPENDIX I. Comparison of characteristics between study respondents who were included compared to excluded from analysis<sup>a</sup>

		espondents = 727)	excluded fi	ts who were rom analysis : <i>112</i> )	Included	nts who were in analysis =615)	
	Ν	Weighted %	(/v- N	Weighted %	(/v- N	Weighted %	p valu
Depressive Symptoms Screen <sup>b</sup>							0.101
Negative	671	94.8	92	91.1	579	95.4	
Positive	45	5.2	9	8.9	36	4.6	
Missing	11		11		0		
Gender	205	41.5	12	42.2	252	41.0	0.724
Male Female	295	41.3	42	43.2	253	41.0 59.1	
Nonbinary	425 0	58.7 0.0	64 0	56.8 0.0	361 0	0.0	
Other gender identity	0	0.0	0	0.0	0	0.0	
Missing	7	0.0	6	0.0	1	0.0	
Race/Ethnicity <sup>c</sup>	,		0				
Black/African American	33	5.5	4	3.4	29	5.9	0.299
White	659	88.9	94	81.3	565	90.3	0.028
Asian	8	1.7	2	3.5	6	1.4	0.251
Native American/American Indian/Alaska Native	4	0.5	0	0.0	4	0.6	0.437
Native Hawaiian/Pacific Islander	0	0.0	0	0.0	0	0.0	
Missing	4		1		3		
Hispanic/Latinx/Spanish	20	3.2	6	6.9	14	2.6	0.052
Missing	4		1		3		
Education	<u>,</u>		-				0.001
Less than first grade	0	0.0	0	0.0	0	0.0	
First through eighth grade	6 23	1.0	4 3	5.1	2	0.2	
Some high school, but no diploma High school graduate or equivalent	23 214	4.2 29.7	3	3.0 32.5	20 178	4.5 29.2	
Some college but no degree	214 129	29.7 16.8	19	32.5 17.1	178	16.7	
Associate degree	88	12.0	19	9.3	76	12.3	
Four-year college graduate/bachelor's degree	149	21.0	24	24.2	125	20.4	
Advanced degree	111	15.5	9	8.2	102	16.7	
Missing	7		5		2		
Marital Status							0.380
Married	388	52.4	62	53.2	326	52.2	
Not married but living with a partner	53	7.1	5	2.2	48	8.0	
Widowed	72	9.1	10	11.3	62	8.7	
Divorced/annulled	98	13.4	16	17.1	82	12.7	
Separated	8	1.3	0	0.0	8	1.6	
Never married	102	16.7	14	16.2	88	16.8	
Missing	6		5		1		0 200
Employment Status <sup>d</sup> Employed full-time	234	57.4	35	48.0	199	59.4	0.308
Employed full-time Employed part-time	234 42	9.7	10	48.0 12.9	32	9.0	
Unemployed	133	32.9	25	39.1	108	31.6	
Missing	318	52.5	42	55.1	276	51.0	
Retirement Status <sup>e</sup>	510				270		0.041
Not retired	133	32.4	25	46.3	108	30.0	
Retired	285	67.6	33	53.7	252	70.0	
Missing	309		54		255		
Health Insurance Status							0.938
Insured	682	94.8	101	94.6	581	94.8	
Uninsured	39	5.2	6	5.4	33	5.2	
Missing	6		5		1		
Self-Rated Health Status							0.948
Excellent	127	17.0	21	16.8	106	17.0	
Very good	270	37.9	40	36.1	230	38.2	
Good	214	30.1	27	30.4	187	30.1	
Fair Poor	82 27	11.4 3.6	15 4	11.6 5.2	67 23	11.4 3.3	
Missing	21 7	3.0	4 5	5.2	23	5.5	
Adults in the Household	1		J		۷		0.170
Adults in the Household 1 Adult	249	34.5	40	38.9	209	33.7	0.170
2 Adults	390	52.3	53	43.0	337	54.0	
3 Adults	52	7.6	13	13.3	39	6.6	
4 Adults	24	3.6	2	1.8	22	3.9	
5 Adults	9	1.7	3	2.9	6	1.5	
6 Adults	0	0.0	0	0.0	0	0.0	
7 Adults	0	0.0	0	0.0	0	0.0	
8 Adults	1	0.2	0	0.0	1	0.2	
9 Adults	0	0.0	0	0.0	0	0.0	
10+ Adults	0	0.0	0	0.0	0	0.0	
Missing	2		1		1		0.04
Children in the Household	E40	74.0	<u></u>	<u> </u>	450	70.0	0.365
No Children	519	71.6	69 12	68.2	450	72.2	
1 Child	82	10.8	12	9.7 16 F	70 52	11.0	
2 Children 3 Children	73	11.5	20 4	16.5	53 28	10.6	
4 Children	32 7	4.4 0.9	4	3.5 0.0	28 7	4.6 1.1	
5+ Children	4	0.9	0 1	2.2	3	0.6	
5+ Ciliaten	4 10	0.0	6	۲.۲	5 4	0.0	

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continued next page

During	ancing Behavior I did <u>not</u> stay home	112	15.9	14	13.4	98	16.3	0.536
the	I stayed home	608	84.1	92	86.6	516	83.7	0.550
stay-at-	Missing	7		6		1		
home								
period	l did <u>not</u> avoid visiting others	177	23.8	32	29.2	145	22.9	0.217
	I avoided visiting others	545	76.2	75	70.8	470	77.2	0.217
	Missing	5		5		0		
	l did <u>not</u> avoid letting others into my home	183	22.3	29	24.4	154	21.9	0.604
	I avoided letting others into my home	537	77.8	78	75.6	459	78.1	0.004
	Missing	7		5		2		
	I did <u>not</u> attend any gatherings	633	87.3	95	89.8	538	86.9	0.438
	I attended gatherings	88	12.7	12	10.2	76	13.1	0.450
	Missing	6		5		1		
During	l have <u>not</u> stayed home	249	34.0	50	49.2	199	31.4	0.003
the past	I have stayed home	473	66.0	57	50.8	416	68.7	0.005
30 days	Missing	5		5		0		
	I have not avoided visiting others	349	48.3	58	57.1	291	46.7	0.095
	I have avoided visiting others	367	51.7	48	42.9	319	53.3	0.095
	Missing	11		6		5		
	I have <u>not</u> avoided letting others into my home	312	39.3	47	42.7	265	38.7	0.506
	I have avoided letting others into my home	409	60.7	60	57.3	349	61.3	0.506
	Missing	6		5		1		
	I have <u>not</u> attended any gatherings	459	63.4	66	61.1	393	63.8	0.658
	I have attended gatherings	259	36.6	41	38.9	218	36.2	0.050
	Missing	9		5		4		
		Weighted Mean	SD	Weighted Mean	SD	Weighted Mean	SD	p value
Age <sup>f</sup>		55.8	17.3	55.3	17.4	55.9	17.3	0.809

<sup>a</sup>Respondents were excluded from analysis if they were missing data for the survey questions assessing risk perception for COVID-19 in the next month or Patient Health Questionnaire-2 (PHQ-2) score. Statistical significance was determined using corrected Pearson's chi-square tests at the  $\alpha$ =0.05 level. 'Missing' categories were not included in analysis. Participants included and excluded from analysis differed in (White) race, education, retirement status, and social distancing behavior Were not included in analysis. Participants included and excluded from analysis differed in (White) race, education, retirement status, and social distancing behave (statistically significant *p* values are bolded). <sup>b</sup>Depressive symptoms screen was performed using the PHQ-2. <sup>c</sup>Race/ethnicity was select all that apply. Therefore, the values shown do not add up to the sample size of 727 and column percentages do not add up to 100%. <sup>d</sup>Participants who reported they were retired were excluded from our employment status variable and categorized as missing. <sup>e</sup>Those who reported they were employed were excluded from our retirement status variable and categorized as missing. <sup>f</sup>To provide a comparison of weighted means for our continuous age variable, a weighted 2-sample t test was performed instead of a Pearson's chi-square test.

# Referrals to Mental Health Services in Ohio: An Exploration of Time to First Referral After Completion of Mental Health First Aid Gatekeeper Training

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#### ABSTRACT

**Background:** The college population is particularly vulnerable to mental health challenges. In 2020 only 46.2% of people with a mental illness received mental health services. Mental Health First Aid (MHFA) is a training course designed to teach people how to connect individuals in need of professional services to the appropriate resources.

**Methods:** Mental Health First Aid (MHFA) trainings were offered to students, faculty, and staff at Kent State University. Data from 343 individuals, who completed the MHFA gatekeeper training, were analyzed to explore the impact of time and participant characteristics on the likelihood of first referral to mental health services after completion of the MHFA. Participants completed a pretraining and posttraining paper questionnaire on the day of MHFA training and received a monthly online follow-up survey to assess self-reported referrals over time.

**Results:** After completing MHFA, the average time until first referral was approximately 3 months. Several participant characteristics were significantly associated with referral to mental health services. African American and Black participants who completed the training were more likely to make a referral as compared to White participants. Extraversion was associated with increased likelihood of making a referral, while emotional stability was associated with a decreased likelihood of making a referral.

**Conclusion:** Participants were 5.7% less likely to first report referring with each passing month following the MHFA training, suggesting that there may be cause for an MHFA or similar gatekeeper "booster" course to highlight the importance of making referrals.

Keywords: Mental health; College students; Referrals; Mental health first aid

#### **INTRODUCTION**

Mental illnesses affect thinking, mood, and/or behavior and include illnesses such as anxiety disorders, depression, and substance use disorders.<sup>1</sup> In 2020 an estimated 52.9 million adults in the United States, nearly 1 in 5, had a mental illness, and only 46.2% of those adults received mental health services in 2020.<sup>2</sup> The college population is particularly vulnerable to mental health challenges due to the stress of coursework and potential separation from family members.<sup>3</sup> For some students, barriers may include low perceived need, stigma, lack of time, financial reasons, etc.<sup>4</sup> The Healthy Minds Survey (HMS) sampled college students and found the most common type of informal help-seeking behavior to support mental or emotional health was from a friend (41%) followed by a family member (37%).<sup>5</sup> The HMS reported the most common factor to cause students who needed services to receive fewer services for mental or emotional health was preferring to deal with the issue on their own or with support from family or



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friends (19%) and not having enough time (19%).<sup>5</sup> In addition, in most states, at age 18 years individuals become responsible for making their own decisions regarding mental health, and a significant proportion of college students with preexisting mental health conditions may stop taking their mental health medication when they arrive at college.<sup>6</sup> Therefore, it becomes vital for college campuses to break down barriers to access professional services (eg, lack of knowledge of mental health challenges, unsure of accessibility and stigma)<sup>7</sup> and utilize mental health gatekeeper trainings to teach individuals how to assist a person in need of mental health support.

Mental health gatekeeper trainings are programs that train individuals to recognize the signs of someone experiencing psychological distress, engage with that person, and help to connect them to services as appropriate. Many gatekeeper trainings focus on recognizing signs of suicide (eg, QPR, LivingWorks safeTALK), but others can be broader in terms of recognizing psychological distress (eg, Kognito). One mental health gatekeeper training is the standardized Mental Health First Aid (MHFA) training, which was created to alleviate some of the potential barriers to seeking mental health treatment.<sup>8</sup> The 8-hour MHFA training provides education on signs and symptoms of mental health challenges and attempts to reduce mental illness stigma. An action plan, which uses the acronym ALGEE, is taught to participants and can be used to assist people experiencing mental health challenges.<sup>8</sup>

Researchers have studied various aspects of the effectiveness of MHFA. Increases in mental health knowledge and confidence in providing help to others, in addition to a reduction in stigmatizing attitudes, have been found after completion of the MHFA training.9-11 However, research exploring referrals to mental health services after completing the training is limited and mixed.<sup>12-14</sup> For example, Eisenberg and colleagues found that after university residential advisors completed MHFA, the number of students they referred to mental health services did not change.14 Furthermore, Lipson and colleagues conducted a randomized control trial with 32 colleges and found MHFA trainings for residential advisors had no impact on students' mental health help seeking.13 However, there was an increase in the likelihood of residential advisors seeking mental health services for themselves. Trainee's self-perceived knowledge, self-perceived ability to identify students in distress, and confidence to help also increased. Additional research is needed to further explore referrals to mental health services after MHFA training.

Mental Health First Aid training provides tools to make referrals to mental health services; however, there is no existing empirical research analyzing the amount of time from MHFA training completion until the first referral is made. Since providing mental health information and resources is a main component of the MHFA action plan, understanding the amount of time it takes to begin making referrals is warranted to assess the effectiveness of the training. Furthermore, studies have not explored MHFA participant factors (eg, demographics). These factors need to be studied to determine their potential effect on referrals as well as their overall influence on the effectiveness of the training. Since this is an exploratory study, a range of variables were assessed that might potentially be linked with making referrals to mental health service (ie, race, sex, faculty/staff or student status, personal and/ or family experience with a mental health or substance abuse problem, average number of students interacted with face-to-face per day, average number of students interacted with electronically per day, and contact with a student on campus in need of help related to mental health or substance abuse prior to training). These variables were selected from prior research and their potential relationship with making referrals.<sup>13, 15-17</sup> The current study aims to: (1) determine the impact of time on the likelihood of first referral to mental health services after completion of the MHFA training and (2) assess the role of MHFA participant characteristics (eg, sex, MHFA knowledge) in making referrals.

#### **METHODS**

#### **Participants and Procedure**

Beginning in the spring of 2016 and ending in the spring of 2018, free MHFA trainings were offered to all students, faculty, and staff at Kent State University. At the beginning of each training, all individuals taking the training were invited, but not required, to participate in a research study. Prior to data collection, the study was approved by the university's institutional review board. The study is a nonexperimental longitudinal design. This means a comparison group was not utilized, and data were collected from participants repeatedly over time. Those consenting to participate in the study were asked to complete the paper-and-pencil pretraining questionnaire immediately prior to the start of the MHFA training. The pretraining questionnaire included questions on demographics (eg, age, race, sex), personality characteristics, personal and family experience with mental health or substance abuse illnesses, MHFA knowledge, personal stigma, confidence to refer to mental health services, previous contact on campus with someone in need of mental health or substance abuse help, average number of students interacted with face-to-face per day, and average number of students interacted with electronically per day.

The majority of the MHFA trainings were led by 2 trainers who were university staff or university faculty or community trainers. Immediately following completion of the MHFA training, individuals were asked to complete a paper-and-pencil posttraining questionnaire that included identical measures of personal stigma, MHFA knowledge, and confidence to refer to mental health services from the pretraining questionnaire.

Information regarding whether participants provided referral information to anyone in the previous 30 days was collected using a monthly online follow-up survey sent through email. Participants received the follow-up survey every month following the date that they completed MHFA training unless they requested to be re-

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moved from the study or were no longer enrolled/employed at the university. Participants could opt out of the follow-up at any time. Surveys were sent every month regardless of whether the person answered previous monthly follow-up surveys. Therefore, an individual may have responded to follow-up surveys every month or responded sporadically. The follow-up survey was sent electronically using Qualtrics<sup>®</sup>.

Of the 730 individuals who completed the MHFA training, 633 (86.7%) individuals consented to participate in the current study. Among the 633 participants who consented to participate in the study, 182 (28.8%) did not respond to any follow-up surveys and were removed from the sample. A total of 108 (17.1%) participants had missing covariate data, which excluded their data from the analysis. The final sample consisted of 343 participants (54% of those who consented to the study) who responded to at least one monthly follow-up survey and replied to each covariate of interest.

#### Measures

#### Pretraining Questionnaire Only

Participant Characteristics. Several items were included to assess participant demographic information and assess experience with mental health or substance use. Items also assessed the type and frequency of contact that participants had with students. Question topics included race, sex, faculty/staff or student status, personal and/or family experience with mental health or substance abuse, average number of students interacted with face-to-face per day,

#### average number of students interacted with electronically per day, and contact with a student on campus in need of help related to mental health or substance abuse prior to training (Table 1).

Prosocial Personality Battery (PSB). The 30-item version of the PSB was administered to participants for the present study.<sup>18</sup> The PSB consists of 7 individual scales: social responsibility, empathetic concern, perspective taking, personal distress, mutual moral reasoning, other oriented reasoning, and self-reported altruism. Previously, these 7 individual scales have been determined to create 2 separate factors: helpfulness and empathy.<sup>18</sup> Empathy combines the sum of social responsibility, empathic concern, perspective taking, mutual moral reasoning, and other oriented reasoning. Helpfulness combines reverse scoring of the personal distress and standard scoring of self-reported altruism scales. Confirmatory factor analysis was used to confirm the fit of these factors for the current study. Participants indicated how frequent-ly they carried out each item (eg, "carrying a stranger's belong-ings") in the past ("Never" = 1 to "Very Often" = 5).

Ten-Item Personality Inventory (TIPI). The TIPI is a short, 10-item measure of the Big Five personality dimensions, including extraversion, agreeableness, conscientiousness, emotional stability, and openness to experiences. Participants indicate the extent to which personality traits apply to them ("Disagree strongly" = 1 to "Agree strongly" = 7).<sup>19</sup> Convergence with the Big Five Inventory<sup>20</sup> has been shown (mean r = .77) across the 5 dimensions, and test-retest reliability for the TIPI is mean r = .72.<sup>19</sup> Cronbach  $\alpha$  scores were low for some several constructs (extraversion,  $\alpha$  = 0.70;

Variable	Number (%)	Average (SD)
Age		32.5 (13.3)
Race		. ,
White participants	274 (79.9)	
African American and Black participants	26 (7.6)	
Other participants	43 (12.5)	
Status		
Student	215 (62.7)	
Faculty/Staff	128 (37.3)	
Sex		
Male	34 (9.9)	
Female	309 (90.1)	
Mental health		
Personal experience	142 (41.4%)	
Family experience	254 (74.1%)	
Daily interactions		
In-person		15.9 (20.1)
Electronic		11.0 (17.0)
Contact with student in need		
Yes	150 (43.7%)	
No	193 (56.3%)	
Referral		
No	98 (28.6)	
Yes	245 (71.4)	
Months to referral		3.1 (2.7)

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#### **Table 1. Participant Demographics**

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agreeableness,  $\alpha = 0.27$ ; conscientiousness,  $\alpha = 0.55$ ; emotional stability,  $\alpha = 0.63$ ; openness to experiences,  $\alpha = 0.35$ ) because the TIPI was created to maximize content validity and only contained a few items per construct.<sup>19</sup>

#### Pretraining and Posttraining Questionnaire

Depression Stigma Scale. The Depression Stigma Scale,<sup>21</sup> an 18item measure comprised of two 9-item subscales, was used to assess stigma. One subscale assesses perceived stigma and the other assesses personal stigma. Cronbach  $\alpha$  for the current study was 0.78 for the personal stigma items, 0.76 for the perceived stigma items, and 0.82 for the total scale.<sup>21</sup> Seven items from the personal stigma subscale were used for the current study, with the items showing good internal consistency ( $\alpha = 0.84$ ). Two question items were not included in the current study, because they were not applicable to the study participants regarding the individuals they interact with directly. Personal stigma questions ask participants how much they agreed ("Strongly Agree" = 1 to "Strongly Disagree" = 5) to 7 statements about "John," a fictional person described in a vignette as having depression. These statements included that John could snap out of it, showed signs of personal weakness, did not have a real medical illness, was dangerous, that it is best to avoid people like John, he is unpredictable, and if I felt like John, I would not tell anyone. Scores from these 7 items were averaged to provide a measure of personal stigma. Mean scores could range from 1 to 5, with higher mean scores indicating greater personal stigma.

Mental Health First Aid Knowledge. Knowledge as a result of completing the MHFA training was assessed by asking participants to define each letter in the mnemonic ALGEE, the 5-step action plan taught during MHFA training.<sup>8</sup> The letters in ALGEE stand for *Assess* for risk of suicide or harm, *Listen* nonjudgmentally, *Give* reassurance and information, *Encourage* appropriate professional help, and *Encourage* self-help and other support strategies.<sup>22</sup> An MHFA knowledge score was computed by summing the total number of action steps correctly defined. Internal consistency of the knowledge items was  $\alpha = 0.67$  for the current study. The

Table 2. Impact of Time and Participant Characteristics on First Referral

knowledge score could range from 0 to 5, with higher scores indicating greater knowledge.

Confidence in Making Referrals. To assess confidence in making referrals, 5 novel question items were developed by the authors for the purposes of the study. Participants were asked to rate their level of confidence in making each referral type: give an informational card/pamphlet, provide a link to a website, provide information about 24-hour hotlines, provide assistance in contacting an on-campus behavioral health provider, and provide assistance in contacting an off-campus provider. Participants could rate each referral from 1 (not at all confident) to 5 (extremely confident). A confidence in making referrals score was computed by averaging the ratings of the 5 items. Internal consistency for the scale was high ( $\alpha = 0.91$ ).

#### Monthly Follow-Up Survey

Referrals Made. To assess number of referrals made each month, participants were asked, "Did you provide referral information about services for mental health or substance abuse problems to [*university*] students in the past 74 days (for example, information about the on-campus health center)?" Respondents selected 'yes' or 'no.' Respondents selecting 'yes' were then asked to report the number of referrals that they made in the past 30 days.

#### **Analytic Plan**

A logistic regression model was conducted to assess the likelihood of referral to mental health services after completing MHFA training (Table 2). Because of the exploratory nature of the study, a stepwise method of variable inclusion was utilized, thus reducing the likelihood of overparameterizing the model. Given that the following analyses focus on outcomes after the training, posttraining scores for personal stigma, MHFA knowledge, and confidence in our models were used. Referral outcomes were derived from responses to the follow-up surveys in the first 12 months after participants completed training. Possible selection variables were race, sex, faculty/staff or student status, empathy, helpfulness, extraversion, agreeableness, conscientiousness, emotional stabil-

Covariates	OR	Confidence Interval
African American and Black participants vs White participants	3.78	(1.977, 7.221)***
Other race participants vs White participants	0.80	(0.452, 1.422)**
Faculty/staff vs student	0.74	(0.521, 1.059)
Personal experience with mental health/substance use	1.38	(0.958, 1.998)
Emotional stability	0.87	(0.758, 0.992)*
Extraversion	1.29	(1.148, 1.438)****
Average number of face-to-face interactions	1.01	(1.001, 1.018) <sup>*</sup>
Mental health knowledge	0.84	(0.67, 1.059)
Seeing student in need prior to training	3.03	(2.135, 4.299)***
Months following training	0.94	(0.883, 0.992)*

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\*Significant at .05 \*\*Significant at .01 \*\*\*Significant at .001

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#### **DISCUSSION**

with a mental health or substance abuse problem, personal stigma, average number of students interacted with face-to-face per day, average number of students interacted with electronically per day, MHFA knowledge, confidence in making referrals, contact with a student on campus in need of help related to mental health or substance abuse prior to training, and number of months since MHFA training occurred. The entry and exit criteria for each variable was a *P* value of  $0.15.^{23}$  All analyses were conducted in SAS  $9.3.^{24}$ 

ity, openness to experiences, personal and/or family experience

#### RESULTS

After stepwise iteration, variables with a *P* value of 0.15 or less were included in the model: race, sex, faculty/staff or student status, average number of students interacted *with* face-to-face per day, contact with a student on campus in need of help related to mental health or substance abuse prior to training, extraversion, emotional stability, conscientiousness, helpfulness, MHFA knowledge, and number of months since MHFA training occurred.

Participant characteristics are presented in Table 1. Most participants are racially White participants (79.9%), and most are females (90.1%). The average age of participants is 32.5 years, and participants reported interacting with an average of 15.9 people in-person and 11.0 people electronically each day. Importantly, among participants, 245 (71.4%) referred someone to services, with a mean time to referral of 3.1 months (SD = 2.7).

The significant covariates in the logistic regression model were race, faculty/staff or student status, emotional stability, extraversion, conscientiousness, helpfulness, average number of students interacted with face-to-face per day, contact with a student on campus in need of help related to mental health or substance abuse prior to training, and number of months since MHFA training occurred (see Table 2). Covariates in the model that were not significant were sex and MHFA knowledge.

Many participant characteristics increased the odds of referral (Table 2). African American and Black participants were approximately 4 times as likely to refer compared to White participants. A person who had contact with a student on campus in need of help related to mental health or substance abuse prior to training was 3 times as likely to refer as compared to someone who had not seen someone in need of help before training. For every additional student someone interacted with face-to-face, the likelihood of referral increased by 1%. For every unit increase in extraversion and helpfulness, participants were 24.2% and 21.1% more likely to make a referral, respectively. Each unit increase in emotional stability decreased the likelihood of referring by 15.4%, and staff/ faculty were 33.8% less likely to make a referral than students. Each unit increase in conscientiousness decreased the likelihood of referring by 21.6%, and each additional month after completion of the MHFA training, decreased the likelihood of first-time referral by 5.7%.

The purpose of the current study was to explore the impact of time and the role of participant characteristics on the likelihood of making a referral to mental health services after completing an MHFA gatekeeper training. The analytical model demonstrates the average time until first referral was approximately 3 months after completing MHFA, and with each passing month the likelihood of a first-time referral decreases. The decrease in referrals may signal a need for a booster component to the MHFA course to reinforce information taught in the initial MHFA training. It is well-established that to maintain the performance of a specific task, such as referring someone to services, it is better learned over a long period rather than a short amount of time. However, in opposition to this is the established conclusion that an amassed amount of knowledge or practice leads to much better initial performance.<sup>11</sup> Self-efficacy, one construct of the Social Cognitive Theory, refers to a person's confidence about their abilities to successfully execute a task.<sup>25</sup> Additional opportunities to practice making referrals could increase the chances of a person making referrals. The juxtaposition of these 2 concepts may be balanced by introducing a booster component to the current MHFA gatekeeper training.

The current study suggests that several participant characteristics predict whether an individual who completed an MHFA gatekeeper training will refer someone in need to mental health resources. African American and Black participants were more likely to make referrals compared to White participants. While we were unable to find other research that directly supports this finding, a large national study examining confidence related to mental health literacy found that African American and Black participants who completed an MHFA training reported higher mental health literacy as compared to White participants who had completed the training.<sup>26</sup> Further, according to the National Institute on Minority Health and Health Disparities, African American and Black participants are more likely to experience serious psychological distress than White participants.<sup>27</sup> Taken together, greater experience with mental health issues and greater mental health literacy may increase the likelihood of making a referral. To explore this further, a subset of the original analysis composed of only African American and Black participants was conducted to compare results to the overall model. Mental Health First Aid knowledge was not significantly related to referrals among African American and Black participants. Further, the covariables of agreeableness and personal stigma were not significant for the overall model. Therefore, the association of these variables with referral may be a reason for the increased association of African American and Black participants making more referrals in comparison to White participants.

Individuals who reported knowing someone in need of mental health services prior to the gatekeeper training were more likely to make a referral following the training. It is quite possible that these individuals signed up for the training specifically to learn

how to assist those in need who were already a part of their social interactions. An increase in referrals among students, compared to staff/faculty, and among those who see more students face-to-face suggests that students and those in direct contact with larger numbers of students may be an important target population for gatekeeper trainings such as MHFA. Additionally, a future direction is to analyze these results separately for faculty/staff and students.

It is not surprising that extraversion and helpfulness were participant characteristics found to be associated with an increased likelihood of referring an individual to mental health services. Extraverted individuals (as compared to introverted individuals) would be more inclined to engage with another individual, especially an individual they are not very familiar with (eg, an acquaintance). While those who indicate higher levels of helpfulness would be more likely to assist a person in need of mental health help and take action in the event of an emergency or crisis. Both emotional stability and conscientiousness have been found to be positively associated with better mental health,28-30 and research has demonstrated both characteristics to be positively related to increased internal locus of control.<sup>31</sup> Consequently, the current study's findings that conscientiousness and emotional stability are associated with less likelihood of making a referral runs counter to our expectations. That said, perhaps individuals who are conscientious and/or emotionally stable, may be primarily focused internally and thus may fail to recognize others around them who may be in psychological distress and may be in need of mental health services. The addition of empathy training may be beneficial and lead to an increase in referrals. Further study is needed to explore this finding.

The present study adds to the existing research on the MHFA gatekeeper training by investigating referrals to mental health services based on time and participant characteristics and experiences. Specifically, the current study contributes by examining how personal characteristics and experiences of gatekeepers are associated with the likelihood to refer an individual for mental health services. A further contribution is this is one of the first studies to examine the permanence of making referrals over time. Although our findings are very preliminary, knowing if and when referrals decrease over time and what factors influence the decrease is important to understand as it relates to any mental health gatekeeper training and its impact to help individuals in need.

One limitation of this study is that the amount of exposure to people in need of mental health assistance and referral could not be controlled. For instance, some participants may have much more contact with individuals, and thus more opportunity to make referrals. Additionally, the analysis does not contain a control group who did not receive the MHFA training. Further, participants who completed the MHFA training but chose not to participate in the study were not evaluated for self-selection bias. In addition, numOhio Journal of Public Health, August 2022, Vol. 5, Issue 1 ISSN: 2578-6180

ber of referrals made required participants to recall and estimate information retrospectively, which potentially introduces error. Finally, social desirability may have led to inaccurate reporting from participants.

#### PUBLIC HEALTH IMPLICATIONS

Even with limitations, the study provides practical implementation applications. Monthly decreases in referrals suggest a need for a potential booster after the initial MHFA training. Since MHFA knowledge was not significant, a booster class focusing on the curriculum of the MHFA would not be necessary. Instead, a booster highlighting the importance of making referrals could be delivered, potentially through email. However, future research is needed to explore potential booster options (eg, length of booster session, delivery format), and the feasibility of using email as the delivery method, which would reduce costs compared to a class session. If resources limit the number of individuals who can be trained as MHFA gatekeepers, results suggest potentially targeting the MHFA training to those with increased face-to-face interactions, which was correlated with increased referrals. Future research and programming can explore ways to increase referral rates based on individual-level characteristics. For example, research tools and educational components can be included in the training or provided after the training to increase the likelihood of those with introverted personalities referring people in need to mental health services. Further research is needed to continue to explore the effectiveness of MHFA on referring individuals to mental health services.

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# Adverse Childhood Experiences, Race, and Health Outcomes: Examining a Synergistic Relationship

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#### ABSTRACT

**Background:** Adverse childhood experiences (ACEs) are potentially traumatic incidents occurring before age 18 years. Adverse childhood experiences include physical or mental abuse, financial stress, home or community violence, substance misuse, familial turmoil, and other factors. Adverse childhood experiences are associated with negative health outcomes in adulthood.

**Methods:** Numerous research studies and systematic reviews were reviewed to assess the breadth and depth of racial and ethnic inclusivity in ACE research.

**Results:** A wide range of ACEs have been investigated, and ample state-level data is publicly available. Early, fundamental ACE studies typically recruited White, educated, and insured participants; racial and ethnic diversity were often neglected.

**Conclusion:** Adverse childhood experiences and race have been found exerting synergistic effects on adult health outcomes. Further evaluation of race is warranted to improve health outcomes. Scrutiny of racial and ethnic equity in health research is paramount for achieving health equity.

Keywords: Adverse childhood experiences; ACEs; Race; Equity; Health outcomes

#### **INTRODUCTION**

In the past few decades, health researchers began examining the impacts of childhood adverse experiences on adult health outcomes. Adverse experiences in childhood have been linked to health risk behaviors and subsequent disease.<sup>1-3</sup> Many of the leading causes of death in the United States are related to individual health behaviors and lifestyle,<sup>3-6</sup> prompting the necessity of identifying these events early in life for long-term health outcomes.

The Adverse Childhood Experiences (ACE) Study<sup>1</sup> was one of the first large-scale studies to examine the long-term relationship between childhood experiences and major health concerns. The adverse childhood experiences (ACEs) addressed in the study included psychological abuse, physical abuse, sexual abuse, and household dysfunction. The assessed health risk factors included

smoking, severe obesity, depressed mood, suicide attempts, physical inactivity, alcohol abuse, drug abuse, STI history, and having a high number of sexual partners. All of the aforementioned risk factors contribute to the leading causes of morbidity and mortality in the United States. A total of 9508 adult patients at a large HMO completed the ACE questionnaire containing yes or no questions about the occurrence of the aforementioned ACE types and a health survey assessing health behaviors and diseases.

The prevalence and risk for all risk factors investigated increased as the number of ACEs increased. Additionally, the breadth of ACEs experienced was found to have a graded relationship with a variety of disease conditions, including cancer, chronic lung disease, and liver disease. The linking mechanism between ACEs and adult diseases was suggested to primarily involve increased engagement



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in health risk behaviors such as smoking, alcohol or drug abuse, sexual behaviors, and overeating as coping mechanisms for the stress of adversity experienced by each individual. Overall, the findings suggested a strong and cumulative impact of ACEs on negative adult health outcomes.

Several subsequent studies further investigated health outcomes, finding links between ACEs and unintended pregnancy, depression, obesity, liver disease, heart disease, and a variety of other health conditions in adulthood.<sup>7-10</sup> These investigations led to the development of a widely adopted cumulative risk model, which states that childhood adverse experiences accumulate over time to give rise to disadvantages in adult health.<sup>11,12</sup> However, although the relationship between ACEs and health outcomes is well-documented, many of these studies factor out race and ethnicity in their analyses. The original ACE study factored out race in their statistical analyses in order to control for its "confounding effects" on the relationship between the number of ACEs experienced and adult health. Additionally, the study sampled mostly White, educated, employed, insured participants.<sup>13</sup>

Disparate health among groups in a variety of health conditions has been widely documented throughout the years. These include conditions such as diabetes, cardiovascular heart disease, obesity, hypertension, and overall mortality.<sup>14,15</sup> One of the major pathways through which these discrepancies arise is through ACEs. Black, Hispanic, or Asian youth are often at a greater risk of being exposed to ACEs, due to a complex blend of cultural, environmental, and socioeconomic factors.<sup>16</sup> The types of ACEs experienced by minority youth may also differ from those experienced by White youth. Minority youth may experience covert and overt forms of discrimination and racism on a daily basis. Compared to Whites of low socioeconomic status, a significantly greater proportion of minority groups of low socioeconomic status, especially Black youth, live in communities of concentrated poverty.17 Consequently, minority youth who live in these communities face a higher risk of exposure to community-level ACEs such as witnessing neighborhood violence, experiencing neighborhood adversity (eg, feeling unsafe, lack of support from community members), and peer victimization.

Unfortunately, the current ACE model is limited in its assessment of individual ACE experiences. The cumulative risk model for ACEs only measures the frequency of ACEs, assuming that all included adversities influence health outcomes equally and through the same mechanisms. Additionally, ACEs that are experienced in higher frequencies by minority youth (eg, racial discrimination, community violence, and incurring financial stress) were not included in the original ACE assessment. Questions addressing racial discrimination and community-based ACEs have since been included in more recent ACE questionnaires, such as the ACE-IQ from the World Health Organization and the 2020 National Survey of Children's Health. However, research on the moderating effect of race on ACEs and adult health using data from these questionnaires is still limited. These limitations further support the need for analyses of ACEs and adult health outcomes through racial and cultural lenses.

We highlight the relationships between race, ACEs, and health outcomes in an effort to better inform our colleagues of this often overlooked public health concern and emphasize the importance of racial equity in research. Addressing these differences early in life may help diminish health disparities between racial and ethnic minority groups and Whites.

#### In-Depth Description of Issue

#### Impacts on Lifespan

Racial disparities between White and minority populations are evident in lifespan measures. According to the 2017 National Vital Statistics report from the Centers for Disease Control (CDC),<sup>18</sup> the average life expectancy at birth is 81 years for non-Hispanic White females, 78.1 years for non-Hispanic Black females, 76.1 years for non-Hispanic White males, and 71.5 years for non-Hispanic Black males. Overall, White people have a higher life expectancy at birth than Black people. Interestingly, Hispanic women and men had higher life-expectancy estimates than both non-Hispanic White and non-Hispanic Black men/women (84.3 years and 79.1 years, respectively).

The observed gap between Black and White life expectancies may be moderated by ACEs. The 1998 ACE Study proposed a cumulative lifetime model for the influence of ACEs throughout life. This model suggested that ACEs would lead to social, emotional, and cognitive impairment during development. These developmental changes could subsequently increase the likelihood of adopting health-risk behaviors, which could cause diseases, disabilities, and social issues, potentially contributing to early death.

Follow-up studies have supported this model, finding that ACEs lead to a reduction of lifespan overall.<sup>19</sup> A strong association exists between the number of ACEs experienced and subsequent reduction in lifespan.<sup>19</sup> Jia and Lubetkin (2020) found that adults who reported multiple ACE types had lower estimated quality-adjusted life expectancies (QALE).<sup>20</sup> Specifically, those with 3 or more types of ACEs experienced a significant loss of quality-adjusted life years (QALYs) compared to those with 0 or 1-2 ACE types. Patterns of QALE estimates across racial groups are consistent with CDC findings.<sup>18</sup> Within any ACE frequency group, Black men and women have lower QALEs than White men and women, respectively.<sup>20</sup> Once again, Hispanic men and women had the highest QALEs.<sup>20</sup> Laditka and Laditka (2018) also found that across all examined racial and ethnic groups, individuals with high adversity had decreased lifespans.<sup>21</sup>

Adults who experienced greater adversity in childhood have been found to spend a greater portion of their life impaired than those with more advantaged upbringings.<sup>22</sup> Despite living longer, Hispanic individuals experience more functional impairment than White individuals,<sup>23</sup> a phenomenon which may be linked to childhood adversity. This, coupled with the higher frequency of ACEs among Hispanic and Black youth, suggests potential differences in the types of ACEs experienced or the pathways by which these experiences influence health among racial and ethnic groups.

#### Socioeconomic Status

According to the National Center for Children in Poverty (2016) and the Kids Count Data Center, higher percentages of Black and Hispanic children live in poverty compared to White children.<sup>24,25</sup> Children in poverty are more likely to experience ACEs due to increased stress on family members, environmental hazards, and reduced accessibility to resources. In addition, according to the 2016 National Survey of Children's Health, Black children are disproportionately represented among children with ACEs.<sup>26</sup> Over 6 in 10 Black children have experienced ACEs, comprising 17.4% of all US children with ACEs. These findings suggest that race and socioeconomic status interact in complex ways to influence ACEs.

The effects of socioeconomic status on ACEs may differ by race and ethnicity, as institutionalized systems of racism and classism pose additional challenges for racial minority groups. Since children in poverty are more likely to incur ACEs, the observed higher prevalence of ACEs in Black and Hispanic children may be in part mediated by the racial wealth gap. According to data from the Federal Reserve's Survey of Consumer Finances, Black and Hispanic families have considerably less mean and median net worth than White families.<sup>27</sup> The mean and median net worth of White families in 2016 was \$933700 and \$171000, respectively. The mean and median net worth of Black families was less than 15% of that of White families: \$138 200 and \$17 600, respectively. The mean and median net worth of Hispanic families was more than Black families, but still significantly less than White families: \$191 200 and \$20 700, respectively. Additionally, patterns of residential segregation create communities of concentrated poverty in which disproportionate numbers of racial minorities live. A 2014 report from the US Department of Health and Human Services found that 4 out of 5 people living in metropolitan concentrated poverty communities are Black or Hispanic.28

Children living in these communities may have increased exposure to neighborhood/community-level ACEs such as community violence, peer victimization, perceived racism/discrimination, and lack of neighborhood safety. Individually and in combination with family-level ACEs, neighborhood/community-level ACEs have been associated with childhood and adult health issues. For example, one study found that racial discrimination indirectly increased the risk for insulin resistance among African American youth through elevated body mass index (BMI).<sup>14</sup> Another study found that childhood and adolescent adversities significantly predicted greater risk for adult cardiovascular disease through multiple pathways, including financial stress, educational attainment, lack of medical/dental care, and health behaviors.<sup>15</sup> The existing findings on socioeconomic status, race/ethnicity, ACEs, and adult health support programs that address financial hardship, housing segregation, community investment, and other conditions that may put children, especially minority youth, at a higher risk for ACEs.

#### Mental Health/Disorders

ACEs have been found to have profound effects on mental health in adulthood. The original ACE study found a cumulative effect of ACEs and increased risk for developing depression, attempting suicide, and substance abuse.<sup>1</sup> The study also suggested that health-risk behaviors such as smoking, overeating, and sexual behaviors may be interpreted as attempts to better regulate the anger, anxiety, and depression stemming from these adverse experiences. Subsequent studies have found links between ACEs and a variety of other mental conditions, including post-traumatic stress disorder (PTSD), anxiety disorders, bipolar disorder, and cognitive impairment.<sup>29</sup>

As with physical health conditions, racial disparities are also observed in mental health conditions. According to a 2017 report by the American Psychiatric Association, racial and ethnic minorities experience the same mental disorders as Whites, and lower numbers of reported cases are observed in racial/ethnic minority groups compared to Whites (except American Indian/Alaska Natives).30 However, the report also suggested that racial/ethnic minorities may experience longer-lasting consequences from mental disorders. Rather than a true difference in prevalence of mental disorders between racial/ethnic demographics, the observed disparities in mental health diagnoses likely result from a combination of sociocultural factors and lack of access to mental health primary care services in minority groups. Instead of specialty primary care, racial/ethnic minority youth are more often referred to the juvenile justice system for behavioral issues. Racial and ethnic minority groups are disproportionately represented in the criminal justice system, and 50% to 75% of youth in the juvenile justice system meet criteria for a mental health disorder.<sup>30</sup> Instead of getting the help they need, minority youth may be exposed to further adversity through these practices, further aggravating the negative mental health consequences of ACEs. Lack of cultural understanding by medical providers may also lead to misdiagnoses and/or underdiagnoses of mental disorders in racial and ethnic minority groups. Additionally, cultural stigmas against mental illness and seeking help for mental illness in racial and ethnic minority groups may contribute to the lower numbers of reported mental illness cases in these groups.

Despite the severity of these issues, few studies have examined the relationships between race, mental illness, and ACEs. The studies that have examined the relationships have produced mixed results. In a 2016 study, Zhang et al examined the role of adverse experiences in childhood and other factors in adulthood in observed racial disparities between Black and White older Americans in cognitive impairment.<sup>31</sup> Using data from the Health and Retirement Study (HRS), the study found that not only was cognitive impairment significantly more prevalent in Black individuals than White individuals, but it also reached high prevalence at earlier years than in White individuals. The odds for experiencing the onset of cognitive impairment for Black individuals were more than double that of White individuals. A significant reduction in these odds was observed for Black individuals after factoring in childhood adversity, childhood health, being born in the South, and education. Comparatively, only a slight reduction in odds was observed when factoring in adult socioeconomic status and wealth. From these results, Zhang et al concluded that at least part of the racial gap in cognitive impairment can be explained by the racial difference in childhood conditions. In another study examining the effect of racial and ethnic differences in the relationship between childhood adversity and mental disorders, however, Ahern et al found that the examined childhood adversities did not play a significant role in racial/ethnic differences in mental disorders.32

#### Health Behaviors

One major pathway by which ACEs lead to reductions in adult health is through health-risk behaviors. Commonly examined risk behaviors include smoking, drug abuse, alcohol abuse, sexual behaviors, exercise, and eating behaviors. The original ACE study found that ACEs increased the prevalence and risk for engaging in health-risk behaviors.<sup>1</sup> A variety of follow-up studies have also found a similar relationship between ACEs and health-risk behaviors.

Racial disparities for common health-risk behaviors also exist. A 2011 study by Dubowitz et al identified several racial/ethnic differences in health-risk behaviors.<sup>33</sup> Diet differences, such as a higher consumption of fruits and vegetables and a lower percentage of calories from fat in Mexican Americans, were observed. A higher proportion of Blacks and Hispanics were found to lead sedentary lifestyles than Whites. A higher proportion of Mexican American and Black males also engaged in binge-drinking compared to White men. Interestingly, the trend was reversed for females in the same racial/ethnic groups. A higher percentage of Blacks engaged in smoking, compared to Whites (second highest) and Mexican Americans (lowest percentage).

Despite observed differences in health-risk behaviors and diseases associated with these behaviors, few studies have examined the relationship between ACEs, race, and health-risk behaviors. Existing literature connecting the 3 has suggested that race does have some effect on the relationship between ACEs and health-risk behaviors. Lee and Chen (2017) found that the impact of ACEs on heavy drinking differed by race/ethnicity, with ACEs increasing the odds for heavy drinking in some racial/ethnic groups.<sup>34</sup> Specifically, the odds were significantly higher for Hispanics who reported household challenges and abuse as children than Whites with the same adverse experiences. Further research may be needed to better define the moderating effect of race/ethnicity on the relationship between ACEs and health risk-behaviors. Such information could help better inform intervention programs for alcohol abuse, substance abuse, and programs promoting general healthy habits.

#### Genetics

Another pathway by which ACEs lead to reductions in adult health is through epigenetic effects. Childhood adversity has been linked to a number of genetic changes affecting proinflammatory genes, genes associated with obesity risk, and the glucocorticoid gene. The observed effect of ACEs on genetics usually involves DNA methylation, leading to blunted expression of genes.<sup>35-38</sup> This may seem counterintuitive, as one might expect an elevated cortisol response in an individual experiencing ACEs, and thus high levels of stress. However, despite initial elevated HPA axis activity, a blunting of the cortisol response occurs over time in response to chronic stress from ACEs.<sup>38</sup> Several studies have reported lower levels of diurnal cortisol secretion in children exposed to early adversity.<sup>35-38</sup> Evidence also suggests that the effect may last into adulthood, manifesting as lower cortisol responses to stress.

The existing body of literature on this topic includes a fair number of studies examining the effects of race on ACEs and epigenetic effects of ACEs. Janusek et al (2017) examined the extent to which ACEs impacted the psychological, cortisol, and proinflammatory response to acute stress in young African American men.<sup>39</sup> Specifically, the study focused on interleukin-6 (IL-6), which acts as a proinflammatory cytokine. Individuals with greater exposure to childhood trauma and neighborhood violence were found to have a blunted cortisol response, greater IL-6 response to the laboratory stress test, and less methylation of the IL-6 promoter. Less methylation of the IL-6 promoter results in a hyperproduction of IL-6 in response to stress, which may contribute to higher levels of anxiety and negative affect in response to stress for those with more ACEs. In a related study, Nikulina and Widom (2014) found that growing up Black predicted elevated levels of C-reactive protein, an inflammatory protein, and hypertension.<sup>40</sup> This effect persisted after controlling for neglect and poverty.

#### PUBLIC HEALTH IMPLICATIONS

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The welfare of our youth strongly influences multiple facets of health as they mature. The effects of race, behavior, community, socioeconomic status, genetics, and mental and physical health in childhood can have severe consequences on adult health outcomes. Ohio youth incur ACEs at an alarming rate, the most common of which are economic hardship (27%), parental divorce (23%), exposure to neighborhood violence (13%), and living with someone who had a problem with alcohol or drugs (12%).<sup>41</sup> Over 400 000 Ohio children reported experiencing  $\geq$ 2 ACEs between 2017-2018.<sup>42</sup> The crisis of childhood trauma continues to plague many of our communities, which prompted the introduction of

HCR 25 earlier this year urging the governor to declare a state of emergency on childhood trauma in Ohio.<sup>43</sup>

Increased awareness of ACEs experienced by minority youth, as well as early intervention through support structures in schools and health care settings, and informed child welfare programs may help reduce the effects of ACEs on lifespan in racial minority groups. Programs such as parent-focused interventions, home visits, and parent-child psychotherapy have been effective for prevention or reduction of ACEs.<sup>44</sup>

While the risk for incurring ACEs exists among all racial and ethnic groups, some minorities are at a greater risk. These minority youth are subsequently more likely to have worse health outcomes as they mature. Unfortunately, racial disparities persist in health research. Greater emphasis on race in study design, recruitment, and analysis is paramount for achieving health equity.

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# Vision Care Utilization and Insurance Coverage Prior to and Following Medicaid Expansion in Ohio

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#### ABSTRACT

**Background:** Increased access and utilization of vision care services has the potential to reduce preventable vision loss. The state of Ohio has been uniquely proactive when collecting vision-oriented data through population health surveys, including the Behavioral Risk Factor Surveillance System (BRFSS). These data can be used to better understand vision care utilization patterns and access to insurance.

**Methods:** Responses to 3 items administered in the Ohio BRFSS that assess vision care utilization and insurance coverage were compared between 2 different administration periods, 2005-2011 and 2018-2019, using chi-square tests. Comparable data from 2 items assessing eye care utilization were available in 2005-2011 and 2019. Comparable data for insurance coverage were available in 2005-2011 and in 2018-2019. Responses were further stratified by population characteristics, including age, gender, household income, and education level.

**Results:** The percentages of those reporting eye exams in the previous year were not significantly different between 2005-2011 and 2019 (chi-square, p = 0.06). In Ohio, the primary reason for not seeing a vision care provider in the past 12 months was "No reason to go" in 2005-2011 and in 2019. The second most common reason for not seeing a vision care provider in the past 12 months was "Cost/insurance," which decreased between 2005-2011 and 2019 (chisquare, p < 0.001). Insurance coverage for eye care increased between 2005-2011 and 2018-2019 (chi-square, p < 0.001). Important differences were found within the demographic stratification.

**Conclusion:** Population health surveillance data provide useful insight into vision care utilization and insurance coverage. Despite the increase in insurance coverage, eye care provider utilization remains relatively stable.

Keywords: Vision; Epidemiology; Surveillance; Insurance; BRFSS; Trend analysis

#### **INTRODUCTION**

Vision impairment represents a serious public health challenge driven by high prevalence, increased morbidity, economic costs, and poorer health and quality of life.<sup>1,2</sup> Prevalence rates for vision impairment vary, depending on case definitions and sampling methodology,<sup>3</sup> but data from the Behavioral Risk Factor Surveillance System (BRFSS) estimate an overall crude prevalence of 4.9% in the state of Ohio in 2018.<sup>4</sup> Recent estimates indicate the prevalence of vision loss is increasing in Ohio with an estimated economic burden of \$6.1 billion annually.<sup>5</sup> Public health surveillance data have demonstrated that those with vision impairment are twice as likely to fall as people without vision impairment,<sup>6</sup> are more likely to report higher levels of psychological distress,<sup>7</sup> poor-



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er quality of life,<sup>8</sup> and overall poorer physical health than people without vision impairment.<sup>9</sup> Those experiencing vision loss are also at greater risk for premature death.<sup>10</sup> Despite the negative impact of vision loss in multiple domains, vision health lacks sufficient recognition as a population health priority.<sup>11,12</sup>

Prevention of vision loss requires attention to several overlapping factors.<sup>11</sup> Generally, prevention strategies are predicated on access and utilization of vision care services,<sup>13</sup> as most vision loss can be addressed through refractive error correction<sup>14</sup> or is avoidable through timely diagnosis and effective management.<sup>15</sup> Unfortunately, those at greatest risk for vision loss remain least likely to access and/or utilize needed vision services.<sup>13,16</sup> Factors contributing to inadequate vision care utilization include cost,17 availability of vision care providers,<sup>18</sup> and health literacy.<sup>19</sup> Underlying reasons for the lack of vision care access and utilization remain only superficially understood, however, and downstream effects of vision impairment on health and social outcomes are well-documented, including decreased educational achievement, poorer physical health, and depression.<sup>20</sup> Identifying and understanding more upstream barriers would likely improve delivery of eye care services to those in greatest need and result in broader improved health outcomes across disparate populations.

Population health surveillance can identify risk factors associated with vision loss. Stratification of vision impairment by demographic characteristics hints at a wide range of disparities, determinants, and associated outcomes.<sup>21</sup> Population health surveillance data have demonstrated that vision impairment is more common with advancing age, and females are more likely to report vision impairment than males.<sup>3</sup> Individuals living in poverty and those with less formal education also report higher rates of vision impairment.<sup>22</sup> National and state-specific vision surveillance mechanisms collect data on factors associated with vision care utilization patterns and unmet need for services,<sup>23</sup> indicating that most individuals who have not received eye care in the previous 12 months cite "no reason to go" as their primary reason for not accessing care,<sup>24,25</sup> followed by cost, and lack of insurance.<sup>25</sup>

The expansion of Medicaid in Ohio in 2014 resulted in increased coverage for eye care services. Ohio Medicaid benefits include 1 exam and 1 pair of eyeglasses every 12 months for individuals younger than 21 years and adults over 60 years, and 1 eye exam and 1 pair of eyeglasses every 24 months for all other adults. Coverage also includes glaucoma screenings, contact lenses with prior authorization, and medical and surgical services when medically necessary. Copays for services include \$2 per refractive exam and \$1 for dispensing eyeglasses.<sup>11</sup>

The Behavioral Risk Factor Surveillance System (BRFSS) is a national surveillance mechanism that collects information related to multiple domains of health, including vision impairment. Optional modules can be included at a state's discretion, and are typically supported by the US Centers for Disease Control and Prevention (CDC) for a limited time. The CDC supported additional vision-

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oriented questions between 2005-2011 for any state that elected to include the module. To better understand the trajectory of vision health in the state of Ohio, a collaborative group of stakeholders, including The Ohio State University, the Ohio Department of Aging, and the Ohio Affiliate of Prevent Blindness, successfully advocated for items from the vision module to be reintroduced into the BRFSS as state-added questions in 2018 and 2019. The goal of this effort was to assess any changes that may have taken place as a result of advocacy efforts and policy changes, including the implementation of the Affordable Care Act.

Ohio BRFSS data from 2005-2011 and 2018-2019 can provide insight into Medicaid expansion's impact on vision health and access to services. To assess this impact, we analyzed responses from the 3 questions included in the BRFSS vision module from 2005-2011 with responses to those items included as state-added questions in 2018-2019, measuring differences across pre- and post-Medicaid expansion, and assessing different population demographic characteristics to identify potential care access disparities.

#### **METHODS**

#### **Data Source:**

#### The Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a state-based cross-sectional survey collecting data through continuous, random digit dialed telephone interviews of noninstitutionalized US civilians aged  $\geq$  18 years, administered by states and territories in collaboration with the CDC. Participants are selected through a multistage cluster-design procedure. The BRFSS contains deidentified, publicly available data. Details regarding the survey methods, questionnaires, data, and reports can be found at https://www.cdc.gov/brfss/about/index.htm. The governing institutional review board considers studies based on publicly available, deidentified data to be exempt from review and oversight.

The BRFSS consists of 3 parts: core questions, optional modules, and state-added questions. Health departments must ask the core component questions and optional modules without modification. Optional CDC modules include topics that states elect to include in their survey. A 10-question vision-related module, "Vision Impairment and Access to Eye Care Module," often referred to as the vision module, was supported by CDC between 2005-2011. In addition to the required core questions, the Ohio BRFSS typically includes a set of optional modules each year reflecting program and stakeholder interest. Only a limited number of modules are implemented because of cost and time constraints. The inclusion of a module one year does not guarantee its use in following years.

#### The Behavioral Risk Factor Surveillance System Vision Module

Items related to vision loss, age-related eye diseases, and access and utilization of eye care services were included in the 10-question vision module implemented in 23 states (https://www.cdc.gov/ visionhealth/programs/vision-health-toolkit/section-one/brfssquestions-app.html). The vision module included participants aged  $\geq$  50 years in 2005. After 2005, the module questions were asked of people aged  $\geq$  40 years. In 2011, BRFSS survey methodology changed to include cell phone and landline; however, in 2011, the questions from the vision module were only conducted using landline. The BRFSS vision module incorporated questions regarding vision care access barriers and the magnitude of those factors. From 2005-2011, the CDC formally supported the incorporation of the vision module in the BRFSS, and Ohio and 22 other states elected to include the additional optional questions.

#### The Behavioral Risk Factor Surveillance System State-Added Questions

Three questions from the vision module were included as stateadded questions in Ohio's survey in 2018-2019 and administered to noninstitutionalized adults aged  $\geq$  18 years:

 "When was the last time you had your eyes examined by any doctor or eye care provider?" Response categories included "Within the past month (anytime less than 1 month ago)," "Within the past year (1 month but less than 12 months ago)," "Within the past 2 years (1 year but less than 2 years ago)," or "2 or more years ago." In 2019 "Never" was a response option, but it was not a response option in 2018.

Those who responded either "Within the past 2 years (1 year but less than 2 years ago)," "2 or more years ago," or "Never" were asked a follow-up question regarding the reason for not accessing vision care services.

2. "What is the main reason you have not visited an eye care professional in the past 12 months?" Response categories included "Cost/insurance," "Do not have/know an eye doctor," "Cannot get to the office/clinic (too far away, no transportation)," "Could not get an appointment," "No reason to go (no problem)," "Have not thought of it," "Other," "Don't know/Not sure," "Not applicable (Blind)," or "Refused."

Respondents were also asked 1 question regarding insurance coverage.

 "Do you have any kind of health insurance coverage for eye care?" Response categories included "Yes," "No," "Don't know/Not sure," "Not applicable (Blind)," or "Refused."

#### Participants and Eligibility Criteria

Our analysis includes answers by respondents to the Ohio administration of the BRFSS between 2005-2011 and 2018-2019. The vision module, administered between 2005-2011, was only administered to those aged 50 years and over in 2005 and those aged 40 years and over in 2006-2011 to more precisely evaluate the influences and outcomes associated with age-related eye diseases. Determinants of vision impairment and outcomes associated with vision loss can vary considerably by age, and even though the state-added questions, administered between 2018-2019, sampled all adults aged 18 years and over, only responses from those aged 40 years and over were included. This ensured more direct comparisons between the 2 time periods. Because there were minor modifications to the eye care utilization question in 2018, which subsequently impacted the sampling for the follow-up item assessing the most recent eye exam, we could not make direct comparisons with the 2005-2011 data. This limited our analysis of the eye care utilization and most recent eye exam items, which could only be directly compared using 2019 data. However, the vision insurance item could be directly compared between both 2018 and 2019 and the 2005-2011 data.

#### **Statistical Analysis**

#### **Descriptive Statistics**

Responses to each of the 3 questions were stratified by population characteristics, including age, sex, household income, and education level. The statistical software, SUDAAN, version 11.0.1 (RTI International, Research Park Triangle, NC), was used for the analysis to account for the complex sampling design. Mean response values with 95% confidence intervals (CI) were calculated for each demographic category.

# Statistical Comparisons Pre-Medicaid and Post-Medicaid Expansion in Ohio

Chi-square was used to compare responses from the 3 vision module questions between 2005-2011 and the 2018-2019 surveys, where direct comparisons were possible. Age categories used for comparison were 40-49 years, 50-64 years, and ≥65 years, to remain consistent with previous BRFSS vision module analyses.26 The full vision module sampled only those 50 years and over in 2005 and those 40 years and over between 2006 and 2011. For our analysis, only data that allowed for direct comparisons across age categories were used. Because the sampling frames differed between the full vision module and the state-added question administrations, direct comparisons could not be made for those under the age of 40 years. "Never" was not a response category for most recent vision care provider visit in 2018, so direct comparisons for this question and the question assessing rationale for not seeking care could only be made between 2005-2011 and 2019 data. Those who selected "Don't know/not sure" or "Refused" for the item assessing the reason for not seeking vision care and for the item assessing insurance coverage were excluded from the analyses. Due to the 3 statistical comparisons included in this analysis, we applied a Bonferroni correction to a 0.05 significance level, which resulted in a statistical significance cutoff of p = 0.0167.

There was an insufficient sample size for some of the race/ ethnicity categories to yield precise estimates and reliable statistical results. As a result, race/ethnicity was not included in this analysis.

#### **RESULTS**

Table 1 summarizes the demographic characteristics of respondents of the 2005-2011 vision module as well as respondents for the 2018-2019 state-added BRFSS questions in Ohio. Respondents were included if they responded to all 5 demographic questions, were at least aged 40 years, and did not respond to any of the vision module questions with "Not applicable (Blind)." Respondents were not included if they answered all 3 vision questions with "Don't know/Not sure," "Refused," had missing responses, or if they were not asked these questions. This totaled 1641 respondents that were excluded across both administration periods. The results from the question "When was the last time you visited ANY eye care professional?" were excluded in 2018; therefore, the 2018 response rate only considers the remaining 2 vision module questions. With those criteria, response rates for at least 1 vision question ranged from 94.5% to 98.2% for the 2005-2011 vision module and 87.2% to 91.0% for the state-added questions in 2018 and

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2019. This resulted in 22 265 respondents from 2005-2011 and 7588 respondents from 2018-2019. When stratified by race/ ethnicity, the sample size was too small to produce reliable estimates for the majority of racial/ethnic categories. As a result, we could not assess the individual item responses based on race/ ethnicity, but include the relative proportion of respondents in Table 1.

Table 2, Table 3, and Table 4 summarize the responses to the 3 vision care access questions by administration periods, 2005-2011 and 2018-2019. Overall, the percentages of those reporting eye exams in the previous year did not significantly increase from 2005-2011 to 2019 (chi-square, p = 0.06). In 2005-2011, 60.7% (95% CI, 59.7-61.7%) of respondents reported having an eye exam in the previous year, compared to 64.3% (95% CI, 61.3-67.2%) in 2019. In Ohio, the primary reason for not seeing a vision care provider in the past 12 months was "No reason to go" in 2005-2011 (45.4%, 95% CI, 43.7-47.1%) and in 2019 (48.1%, 95% CI, 45.3-

#### Table 1. Respondent Demographics 2005-2011 and 2018-2019 Administration of the BRFSS in Ohio

Demographic		2005-2011 % of Subjects (n= 22 265)	2018-2019 % of Subjects (n= 7588)
Age			
	40-49 years	32.6	23.7
	50-64 years	42.0	43.0
	65+ years	25.4	33.3
Gender			
	Male	48.6	48.1
	Female	51.4	51.9
Race			
	White only	88.4	86.0
	Black or African American only	7.5	9.4
	Asian only	0.7	0.5
	Native Hawaiian or other Pacific Islander only	0.0	0.0
	American Indian or Alaskan Native only	0.5	0.8
	Other race only	0.5	0.2
	Multiracial	1.1	1.7
	Hispanic	1.2	1.4
Income			
	Less than \$15 000	9.2	8.7
	Less than \$25 000 (\$15 000 to less than \$25 000)	15.8	17.1
	Less than \$35,000 (\$25000 to less than \$35000)	11.9	10.5
	Less than \$50,000 (\$35 000 to less than \$50 000)	15.3	14.0
	\$50 000 or more	47.9	49.7
Education level			
	Did not graduate high school	8.6	8.6
	Graduated high school	36.5	33.5
	Attended college or technical school	25.5	30.7
	Graduated from college or technical school	29.5	27.3

Demographic characteristics of respondents of the 2005-2011 vision module as well as the demographic characteristics of the respondents for the 2018-2019 state-added BRFSS questions in Ohio.

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#### Table 2. Percentage Last Visited Any Eye Care Professional in Previous Year

		2005-2011	2019
Overall <sup>*</sup>		60.7 (59.7, 61.7)	64.3 (61.3, 67.2)
Age			
	40-49 years	53.3 (51.2, 55.3)	57.4 (49.6, 64.7)
	50-64 years	58.5 (57.0, 60.0)	60.7 (56.1, 65.1)
	≥65 years	74.0 (72.5, 75.4)	73.6 (69.7, 77.2)
Gender			
	Male	57.7 (56.1, 59.2)	62.6 (58.1, 66.9)
	Female	63.6 (62.4, 64.9)	65.9 (61.9, 69.7)
Income			
	Less than \$15 000	54.7 (51.5, 57.7)	61.9 (52.2, 70.7)
	\$15 000-\$24 999	59.0 (56.7, 61.3)	60.6 (53.5, 67.4)
	\$25 000-\$34 999	60.7 (57.8, 63.4)	68.5 (59.4, 76.3)
	\$35 000-\$49 999	59.5 (56.9, 62.0)	64.6 (56.7, 71.7)
	\$50 000 or more	62.9 (61.4, 64.4)	65.2 (60.8, 69.4)
Education level			
	Did not graduate high school	56.4 (52.5, 60.2)	58.4 (46.3, 69.5)
	Graduated high school	58.4 (56.8, 60.1)	60.4 (55.1, 65.4)
	Attended college or technical school	60.6 (58.6, 62.6)	65.6 (60.1, 70.8)
	Graduated from college or technical school	64.9 (63.2, 66.6)	69.2 (64.0, 74.0)

Responses to the BRFSS item assessing the eye care utilization divided by administration periods, 2005-2011 and 2018-2019. \* The percentages of those reporting eye exams in the previous year were not significantly different between 2005-2011 and 2019 (chi-square, p = 0.06).

51.0%). The second most common reason for not seeing a vision care provider in the past 12 months was "Cost/insurance," which decreased from 26.0, 95% (CI, 24.6-27.5%) in 2005-2011 to 20.6% (95% CI, 18.5-23.0%) in 2019 (chi-square, p < 0.001). In 2005-2011, 60.2% (95% CI, 59.2-61.1%) reported having insurance that covered eye care, which increased significantly to 70.7% (95% CI, 69.2-72.1%) in 2018-2019 (chi-square, p < 0.001).

#### Stratification by Age

In both 2005-2011 and 2019, those in the  $\geq 65$  year age category had the highest percentage of exams in the previous 12 months, followed by those aged 50-64 years, and those aged 40-49 years (Table 2). The primary reason for not seeing a vision care provider in the past 12 months was "No reason to go," and "Cost/insurance" was the second most common response for each age group. For each of the 3 cohorts, the percentage of respondents reporting any kind of health insurance coverage for the eye increased.

#### Stratification by Gender

In both 2005-2011 and 2019, females reported the highest percentage of exams in the previous 12 months (Table 2). The primary reason for not seeing a vision care provider in the past 12 months for males and females was "No reason to go" in both periods. The second most common reason for not seeing a vision care provider for both groups was "Cost/insurance" in 2005-2011 and remained the second most common response for females in 2019. For the male cohort in 2019, "Cost/insurance" was the third most common response, slightly behind "Other," cited by 16.8% (95% CI, 14.0-19.9%) of male respondents. The difference in reported insurance coverage was higher in 2018-2019 compared to 2005-2011 for both cohorts.

#### Stratification by Household Income Level

In 2005-2011, the percentage of those reporting eye exams in the previous 12 months was highest in the  $\geq$  \$50 000/year household income cohort and lowest in the < \$15 000/year household income cohort (Table 2). In 2019, the percentage reporting eye exams in the previous 12 months was highest in the \$25 000-\$34 999/year household income cohort and lowest in the \$15 000-\$24 999/year household income cohort. In 2005-2011, the primary reason for not seeing a vision care provider was "Cost/insurance" for the <\$15 000 household income cohort and the \$15 000-\$24 999 income cohort. "No reason to go" was the primary reason for not seeing a vision care provider remained "Cost/insurance" for the <\$15 000 income cohort and "No reason to go" was the primary reason for all of the other income cohorts. There was an increase

#### Table 3. Main Reason for Not Visiting Eye Care Professional in Previous Year

<b>o</b> "			2005-2011	2019
Overall	**			
	Cost**		26.0 (24.6, 27.5)	20.6 (18.5, 23.0)
	lo reason to go		45.4 (43.7, 47.1)	48.1 (45.3, 51.0)
Age				
	40-49 years			
		Cost	27.5 (24.9, 30.3)	21.6 (16.8, 27.3)
		No reason to go	45.5 (42.5, 48.5)	49.2 (42.8, 55.7)
	50-64 years			
		Cost	28.0 (25.9, 30.1)	22.2 (19.1, 25.6)
		No reason to go	42.3 (39.9, 44.6)	45.9 (42.0, 49.9)
	≥65 years			
		Cost	17.5 (15.0, 20.3)	16.7 (13.7, 20.3)
		No reason to go	53.2 (49.9, 56.5)	51.0 (46.5, 55.6)
Gender		Ū.		
	Male			
		Cost	20.7 (18.6, 22.9)	16.1 (13.3, 19.2)
		No reason to go	50.5 (48.0, 53.0)	54.8 (50.8, 58.9)
	Female	5		
		Cost	31.9 (29.9, 34.0)	25.5 (22.2, 29.1)
		No reason to go	39.7 (37.6, 41.8)	41.1 (37.2, 45.0)
Income		5-		
	Less than \$15000			
		Cost	55.5 (50.8, 60.2)	31.5 (24.5, 39.5)
		No reason to go	24.4 (20.8, 28.4)	28.2 (22.0, 35.4)
	\$15 000-\$24 999	ge	(,,	(,)
	\$13000 \$£1333	Cost	41.5 (37.7, 45.3)	35.0 (29.2, 41.2)
		No reason to go	34.8 (31.3, 38.6)	38.6 (32.7, 44.8)
	\$25 000-\$34 999	No reason to go	3 1.0 (3 1.3, 30.0)	50.0 (52.17, 11.0)
	¥23000 ¥34333	Cost	32.1 (27.6, 36.9)	22.0 (15.6, 30.0)
		No reason to go	39.6 (35.2, 44.3)	46.3 (37.9, 54.9)
	\$35 000-\$49 999	No reason to go	33.0 (33.2, 11.3)	10.0 (01.0, 01.0)
	Ψ <u>-</u>	Cost	23.2 (19.7, 27.0)	22.3 (16.7, 29.0)
		No reason to go	45.6 (41.3, 49.9)	48.6 (41.5, 55.8)
	\$50,000 or more	No reason to go	+3.0 (+1.3, +3.3)	-30.0 (+1.3, 33.0)
	\$30,000 OF MOLE	Cost	12.9 (11.3, 14.7)	11.2 (8.7, 14.2)
		No reason to go	55.5 (53.0, 58.1)	57.0 (52.6, 61.2)
Education level			55.5 (55.0, 50.1)	57.0 (52.0, 01.2)
Laucation level	Did not graduate ł	high school		
	Bia not graduate i	Cost	39.0 (33.2, 45.0)	29.5 (21.4, 39.2)
		No reason to go	36.0 (30.4, 41.9)	31.1 (22.8, 40.7)
	Graduated high sc	5	50.0 (50.4, 41.5)	51.1 (22.0, 40.7)
	Graduated myll SC	Cost	29.9 (27.5, 32.4)	22.4 (18.9, 26.3)
		No reason to go	43.7 (41.0, 46.3)	46.2 (41.8, 50.7)
	Attended college	5	43.7 (41.0, 40.3)	40.2 (41.0, 20.7)
	Attended college of	Cost	28.5 (25.5, 31.8)	22.1 (18.0, 26.8)
		No reason to go	42.8 (39.5, 46.2)	49.5 (44.1, 55.0)
	Graduated from co	ollege or technical school		
		Cost	13.3 (11.5, 15.3)	11.9 (9.0, 15.6)
		No reason to go	53.7 (50.5, 56.8)	57.5 (52.1, 62.7)

Responses to the BRFSS item assessing "Cost" and "No reason to go" as reasons for not seeking vision care services in the previous 12 months, divided by administration periods, 2005-2011 and 2018-2019. "No reason to go" remained the most common response.

in those reporting health insurance for the eye between 2005-2011 and 2018-2019 in all of the household income cohorts.

#### **Stratification by Education Level**

In 2005-2011 and in 2019, the percentage of those reporting eye exams was lowest in those not graduating high school and highest in those reporting graduating college or technical school (Table 2). In 2005-2011, the primary reason for not seeing a vision care provider was "Cost/insurance" for those not graduating high school. "No reason to go" was the primary reason for all other education

cohorts. In 2018-2019, the primary reason for not seeing a vision care provider was "No reason to go" for all education cohorts. There was an increase in those reporting health insurance coverage for the eye between 2005-2011 and 2018-2019 for all education cohorts.

#### **DISCUSSION**

A critical factor in developing effective interventions to reduce vision loss is an understanding of the utilization patterns of vision care services. Using BRFSS data from 2 different time periods,

#### Table 4. Has Any Kind of Health Insurance for Eye Care

		2005-2011	2018-2019
Overall <sup>**</sup>		60.2 (59.2, 61.1)	70.7 (69.2, 72.1)
Age			
	40-49	66.3 (64.3, 68.2)	78.4 (74.9, 81.6)
	50-64	62.3 (60.8, 63.7)	72.4 (70.0, 74.6)
	≥65	48.7 (47.1, 50.4)	62.8 (60.6, 65.0)
Gender			
	Male	60.6 (59.0, 62.1)	68.9 (66.6, 71.1)
	Female	59.8 (58.5, 61.0)	72.3 (70.4, 74.1)
Income			
	Less than \$15 000	42.0 (39.0, 45.1)	69.8 (64.3, 74.8)
	\$15 000-\$24 999	42.3 (40.0, 44.6)	60.4 (56.5, 64.2)
	\$25 000-\$34 999	53.4 (50.5, 56.2)	59.0 (54.1, 63.7)
	\$35 000-\$49 999	58.6 (56.1, 61.1)	64.4 (60.2, 68.3)
	\$50 000 or more	71.6 (70.2, 72.9)	78.5 (76.6, 80.3)
Education level			
	Did not graduate high school	50.4 (46.6, 54.3)	68.3 (61.6, 74.4)
	Graduated high school	55.8 (54.2, 57.5)	65.5 (62.8, 68.1)
	Attended college or technical school	60.9 (59.0, 62.9)	70.7 (67.9, 73.4)
	Graduated from college or technical school	67.6 (65.9, 69.2)	77.5 (75.2, 79.7)

Responses to the BRFSS item assessing insurance coverage for eye care, divided by administration periods, 2005-2011 and 2018-2019. \*\*Insurance coverage for eye care increased between 2005-2011 and 2018-2019 (chi-square, p < 0.001).

2005-2011 and 2018-2019, we found that the percentage of those receiving vision care services remained relatively stable in Ohio, despite efforts by advocates actively promoting greater vision care access. The primary reason for not obtaining care from an eye care professional remained the same, but insurance coverage that included eye care increased over time. These findings underscore the complex interaction between insurance coverage, vision care access, and utilization and provide insight into aspects of vision health that need prioritization.

Stratification by demographic characteristics using BRFSS data provides important insight into those seeking eye care and the frequency of eye care visits. It is encouraging that the oldest cohort reported the highest rates of vision care in the previous 12 months, as that age group is at highest risk for vision loss, comorbidities that include vision loss, and other associated health outcomes,<sup>27-29</sup> including falls.<sup>6</sup> We found lower examination rates in younger age cohorts, indicating further work is needed to identify barriers resulting in this disparity. This is particularly important because the leading causes of permanent vision loss are predominantly asymptomatic in the earliest stages, and early detection combined with effective management can significantly reduce irreversible vision loss in sight threatening eye diseases such as glaucoma<sup>30</sup> and diabetic eye disease.<sup>15</sup> When stratified by household income, there were small increases in the frequency of vision care services in all of the income cohorts between 2005-2011 and 2019. Those reporting the lowest rate of eye care provider visits for both time periods were those with incomes <\$15 000. This finding is important because previous studies indicate preventable vision impairment is correlated with lower socioeconomic status.<sup>22,31</sup>

The questions included in the BRFSS also assess the reasons why individuals did not seek or receive eye care services in the previous 12 months. In both time periods, the most common reason cited for not seeing an eve care professional was "No reason to go." This finding is consistent with reports from other states implementing the vision module<sup>24,25</sup> and is particularly troubling, given the asymptomatic nature of the most common sightthreatening diseases. Interestingly, the primary reason for the \$15 000-\$24 999 cohort changed in 2019 from "Cost/insurance" to "No reason to go," while the percentage reporting "Cost/ insurance" in the <\$15000 income group decreased between the time periods, indicating a potential shift in the affordability of vision care services in this specific demographic cohort. "No reason to go" was also the primary reason for not seeking vision care for all educational cohorts, with the exception of those not graduating high school, where "Cost/insurance" was the primary reason. This finding indicates that inadequate health care literacy with respect Ohio Journal of Public Health, August 2022, Vol. 5, Issue 1 ISSN: 2578-6180

to vision care is not limited to those with lower formal educational attainment.

Given Medicaid's expansion in Ohio, we anticipated that individuals in the Medicaid-eligible income cohorts would report an increase in care utilization. Since this was not the case, more complex influences involving vision care access for this population must be at play. These influences are likely multifactorial in nature, with previous studies suggesting that health literacy, transportation, and distribution of vision care providers may all play some role.<sup>32</sup> Additional factors likely include conflicting messaging regarding the recommended frequency of vision care, lack of coordination with primary care providers and medical homes, lack of providers accepting Medicaid reimbursements, lack of convenient hours for providers accepting Medicaid, lack of practices providing services in convenient locations, and lack of understanding of vision care benefits under Medicaid and by other insurance carriers. This complexity is supported by research in Ohio by Hurley et al<sup>33</sup> studying the relationship between county-level estimates of vision impairment, reported unmet need, and optometrist distribution. In Ohio, reported unmet vision care need did not correlate with the number of providers at the county level, indicating that individuals may not be far from providers but nonetheless report lack of access to care.33 This discrepancy between unmet need and provider distribution was significant in the Medicaid-eligible population, indicating that Medicaid coverage alone may be insufficient in addressing barriers to vision care access. Even with insurance, out-of-pocket costs for vision care and materials may excessively strain the resources of individuals not covered by Medicaid,<sup>34</sup> and it is possible that the residual cost of vision care services or materials, including glasses, contact lenses, and visual assistive devices, may preclude some from seeking care.35,36

While the findings of this study provide considerable insight into vision care utilization and insurance coverage, there are a number of important limitations that must be considered. Constraints inherent in self-report population health surveillance include recall and social desirability bias. Additional limitations include the lack of standardization in the design and administration of vision questions across years, complicating comparisons. For example, the 2005-2011 version of the CDC vision module only sampled individuals 50 years and over in 2005 but expanded the sampling frame to include those 40 years and over from 2006-2011. Additionally, response categories for the question asking about the last eye exam differed between the 2018 and 2019 administration of the state-added BRFSS questions. In 2018, the response categories did not include the option of "Never." While a seemingly minor omission, this complicates the compatibility between all other years the question was administered, potentially biasing the results, and preventing any direct comparisons for this study. As a result, the follow-up question inquiring about the reason for not seeking care in 2018 was also excluded from our analysis in order to make responses as directly comparable as possible. Finally, some of the racial/ethnic demographic categories had an insufficient sample size to allow valid statistical comparisons, making it difficult to fully appreciate any racial/ethnic disparities to care access and insurance coverage. To address this shortcoming, additional emphasis needs to be placed on sampling populations from diverse race/ethnic backgrounds, particularly since there are well-documented racial/ethnic disparities in vision health outcomes.<sup>22</sup>

Despite limitations in the current study, the underlying findings have significant public health implications and can provide unique guidance for advancing vision care access and utilization in Ohio. The findings of this study should be considered in the context of the complex array of determinants that impact the utilization of vision care services and in turn influence the rate of vision loss in the United States. While insurance coverage may be a convenient surrogate for access to vision care services, the current study suggests the assumption that insurance coverage necessarily equates to vision care access is likely misplaced. The fact that the percentage of respondents reporting care utilization remained relatively stagnant between the 2 collection periods is problematic and indicates a need for sustained and consistent messaging to improve health literacy around vision and eye health. This messaging should also target other health care providers, including primary care physicians, who demonstrate the greatest influence when recommending eye exams<sup>37</sup> and are the providers most likely to see patients in younger age groups where increased awareness is needed. Primary care providers could also be important facilitators in more comprehensive approaches to chronic disease management where vision is a relatively common comorbidity.38

To our knowledge, Ohio is the only state where BRFSS vision module questions were included as state-added questions following the implementation of the vision module. Similar work is needed in other states to better understand the impact of Medicaid expansion, or lack thereof, on insurance coverage, access to care, and care utilization. Future work should be concentrated on standardizing the collection of these and similar data. Additional longitudinal analyses with sample sizes large enough to provide insight into more population demographics are also needed, but this study represents a useful foundation for future work.

While we cannot assert a causal relationship between Medicaid expansion and changes observed in responses to the BRFSS, it can be reasonably assumed that a significant proportion of those in the lower income categories who report a higher percentage of insurance coverage would be covered by Medicaid. Increased insurance coverage for the medically vulnerable is important, as these are the individuals most likely to experience vision loss and develop vision impairment. Nevertheless, insurance coverage is only beneficial if individuals actively seek and are able to obtain care. The overarching goal of this research is to improve vision health surveillance in order to detect trends in determinants and health disparities. This will allow the public health and clinical communities to identify the most at-risk and medically vulnerable populations and develop interventions to address those needs. To

accomplish that goal, ongoing inclusion of vision-oriented questions in health surveillance mechanisms is necessary, with support for future analyses of those data. Defining populations where vision health literacy is lacking would be beneficial in developing more directed messaging to improve vision health awareness. The inclusion of vision module items as state-added questions in other states is also needed and would help improve our understanding of vision health influences and outcomes associated with vision loss.

#### PUBLIC HEALTH IMPLICATIONS

Vision care utilization is dependent on a complex set of factors. Improved population health surveillance can be used to better assess utilization, rationale for not seeking care, and impact of insurance coverage. Understanding the upstream factors that influence vision loss, including access to care, is important in reducing avoidable vision impairment.

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# Health Disparities in Liver Cancer: An Analysis of the Ohio Cancer Incidence Surveillance System

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#### ABSTRACT

**Background:** We explored associations between neighborhood deprivation and tumor characteristics, treatment, and 5-year survival among primary hepatocellular carcinoma (HCC) patients in Ohio diagnosed between 2008 and 2016.

**Methods:** We used data from the Ohio Cancer Incidence Surveillance System and limited our analysis to adult (>18 years of age) HCC patients with known census tract information based on address at diagnosis. Using principal components analysis, we created a neighborhood deprivation index (NDI) using 9 census tract-level variables. We examined associations between tumor characteristics (stage and tumor size) and NDI quintile using chi-square tests and analysis of variance (ANOVA). Associations between guideline-concordant care and NDI using log-binomial regression adjusted for sex, race, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis were conducted. For 5-year survival, we utilized Cox proportional hazards models with a similar adjustment set.

**Results:** Neighborhood deprivation index was not associated with stage or tumor size. Individuals living in the most deprived neighborhoods were 16% less likely to receive guideline-concordant care as compared to individuals living in the least deprived neighborhoods (adjusted prevalence ratio [PR]: 0.84; 95% confidence interval [CI]: 0.74-0.94). Similarly, individuals living in the most deprived neighborhoods were 15% less likely to survive 5 years compared to individuals living in the least deprived neighborhoods (adjusted Hazard Ratio: 1.15; 95% CI: 1.01-1.29).

**Conclusion:** Our results suggest a negative association between neighborhood deprivation on guideline - concordant care and survival among HCC patients. Interventions targeting disparities of HCC should focus not only on individual-level factors but address larger neighborhood level factors as well.

**Keywords:** Neighborhood deprivation; Hepatocellular carcinoma; Guideline-concordant care; Mortality; Five-year survival

#### **INTRODUCTION**

In the United States (US), liver cancer ranks fifth in cancer mortality and by 2030 is projected to be the third leading cause of cancer mortality.<sup>1</sup> Several epidemiological studies have demonstrated disparities across liver cancer incidence, treatment, and mortality.<sup>2-5</sup> In particular, disparities according to race, ethnicity, and nativity have become apparent. Hispanics and Asian Americans tend to have the highest incidence of liver cancer.<sup>2</sup> Additionally, Black men and women have higher mortality rates from primary liver cancer when compared to non-Hispanic White men and women.<sup>3-5</sup> While these disparities are known, it is less clear how socioeconomic status is related to liver cancer treatment and mortality.<sup>6-9</sup> Most studies of socioeconomic status and liver cancer focus on incidence rather than treatment or mortality.<sup>6,8,9</sup>

One-dimensional socioeconomic status, variously defined according to income (individual or household), employment, educational attainment, and housing, as well as a myriad of other variables,<sup>10</sup> generally demonstrates inverse associations with liver cancer mortality.<sup>7,11,12</sup> The contribution of multidimensional socioeconomic risk factors at the neighborhood-level, while increasingly



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recognized to be important, is absent from the literature.<sup>6-9</sup> The use of deprivation indexes such as Townsend material deprivation index, Krieger's index, or Messer's index, which combine several census-measured variables, are extensively used in other diseases including low birth weight and infant mortality<sup>10,13,14</sup> but are used less in liver cancer research. These studies demonstrate that multidimensional measures of socioeconomic status provide a more complete picture when trying to understand how socioeconomic status influences health when compared to a one-dimensional measure.

Understanding the contribution of neighborhood deprivation on liver cancer survival would lead to greater clarity regarding the context in which liver cancer occurs. Additionally, a better understanding of neighborhood deprivation would allow for public health and medical providers to target the social determinants of health rather than place the entire burden on the individual patient. To investigate the role of neighborhood deprivation on liver cancer, specifically hepatocellular carcinoma, we obtained data from the Ohio Cancer Incidence Surveillance System (OCISS) from 2008 to 2016. We explored the association between tumor characteristics at diagnosis, treatment course, and 5-year survival of hepatocellular carcinoma and neighborhood deprivation.

#### **METHODS**

#### Setting, Design, and Participants

We obtained data on primary hepatocellular carcinoma patients diagnosed from 2008 to 2016 from across the state of Ohio (n = 5984). We excluded 22 cases of hepatocellular carcinoma in patients less than 18 years of age since we sought to generalize to adult liver cancer patients rather than pediatric cases. Hepatocellular carcinomas were identified based on the following ICO-3 histology codes: 8170/3, 8171/3, 8172/3, 8173/3, 8174/3, and 8175/3.

Liver cancer includes several different subtypes, which may not progress at the same rate and require different treatments as well. Therefore, to reduce confounding by liver cancer subtype, we restricted the sample to hepatocellular carcinoma. In addition, hepatocellular carcinoma is the most common liver cancer type and provides the largest homogenous sample among all types of incident liver cancers. Data collected from OCISS include some individual patient demographic characteristics and clinical information such as age at diagnosis and tumor characteristics. According to the North American Association of Central Cancer Registries, Ohio was considered a certified gold standard for cancer registries in 2013, 2014, and 2016.<sup>15</sup> Additionally, Ohio was a silver certified registry in 2008, 2009, 2011, and 2012.<sup>15</sup> Ohio was not ranked in 2010, and data on 2016 certifications are not available.<sup>15</sup>

#### Measures—Outcomes

We examined 2 hepatocellular carcinoma characteristics, specifically, stage and tumor size. Stage was categorized as 1) localized, 2) regional (including various degrees of lymph node involvement), 3) distant, and 4) unstaged. Tumor size was measured in millimeters and examined as a continuous variable. Tumor size was missing among 39.5% of the study population (n = 2353).

We examined whether patients received guideline-concordant care based on recommendations published on UpToDate. Briefly, UpToDate provides evidence-based clinical information for health care providers. Based on published recommendations, specifically the Barcelona Clinic Liver Cancer (BCLC) system,<sup>16</sup> we assumed that patients with lower stage cancers would receive surgery while patients with regional tumors would require a mix of surgery and chemotherapy or radiation while individuals with advanced tumors should receive chemotherapy or radiation. Guideline-concordant treatment was classified as missing for 1180 (19.8%) patients with unstaged disease. We examined 5-year overall survival among patients diagnosed between 2008 and 2013; we used 2013 as the last date because 2018 was the last year of follow-up available. Patients' vital status was recorded as alive or dead and survival time was recorded in months.

#### Measures—Exposure

We obtained census data at the tract level from the 2010 Census and the American Community Survey (ACS). Census tracts are large geographic areas but tend to be more stable estimates over time when compared to census blocks.<sup>10</sup> We obtained the following 9 variables from the US Census Bureau: percent of the tract with less than high school diploma, percent of the tract with less than a college degree, percent of the tract living below the federal poverty line, percent of individuals 16 years and older who are unemployed in the tract, median household income, percent of housing units vacant, percent of housing units not owned, median value of mortgage, and percent of individuals self-identifying as African American or Black. We selected these variables based on previous studies exploring associations of these variables or similar measures at the individual level with liver cancer.<sup>6-9,11,12,17-20</sup> We then created a neighborhood deprivation index using similar methods described in detail elsewhere.<sup>10</sup> Briefly, we utilized principal component analysis to create weights for each of the nine variables. We then combined these weights to create a single index and created quintiles of deprivation with higher quintiles indicating greater deprivation.

#### **Measures**—Covariates

We selected covariates by identifying the minimal adjustment set of variables using a direct acyclic graph (DAG).<sup>21,22</sup> Our covariates included sex assigned at birth (male vs female), race (White, Black, Other), age at diagnosis in years (continuous), metropolitan status (urban vs rural), stage, and year of diagnosis. Metropolitan status was defined using the 2003 Beale codes to create a dichotomous categorization where nonmetropolitan areas were those with a Beale code between 4 and 9 and metropolitan areas were those with a Beale code between 1 and 3.

#### **Statistical Analysis**

Tumor Characteristics by Neighborhood Deprivation

We compared the distribution of hepatocellular carcinoma stage and mean tumor size by quintile of neighborhood deprivation using chi-square and ANOVA tests, respectively.

#### Treatment by Neighborhood Deprivation

We used unadjusted and adjusted log-binomial models with receipt of guideline-concordant treatment as the outcome and quintile of neighborhood deprivation index as the exposure. We used the least deprived neighborhoods (ie, quintile 1) as the reference category. In our adjusted model, we included sex, race (as a proxy for racism), age at diagnosis, metropolitan status, cancer stage, and year of diagnosis. In addition to utilizing a model with all patients, we stratified the models by race to examine potential racial disparities in treatment because racial disparities are known to exist for liver cancer. However, we could not fit the full model for individuals who did not report their race as either White or Black because the sample size was too small.

#### Five-Year Survival by Neighborhood Deprivation

Finally, we examined 5-year survival by quintile of neighborhood deprivation index using Cox proportional hazards models for liver cancer patients diagnosed from 2008 to 2013. Individuals diagnosed after 2013 were excluded from this analysis. We used the least deprived neighborhoods (ie, quintile 1) as our reference for our models, and a DAG to identify the minimally sufficient adjustment set identified<sup>21,22</sup> sex, race (as a proxy for racism), age at diagnosis, metropolitan status, cancer stage, and year of diagnosis as relevant covariates for which we adjusted. Similarly, we stratified the model by race, in addition to utilizing a model with all subjects, to examine potential racial disparities in 5-year survival. Again, we were unable to fit the full model for individuals who did not report their race as either White or Black due to sample size constraints.

#### Missing Data Analysis

To assess the impact of missing data on the results of the guideline-concordant treatment models and the 5-year survival models, we utilized multiple imputation using fully conditional specification (FCS) to impute missing data for neighborhood deprivation quintiles, outcomes, and covariates. We specified 100 imputations with 20 burn-in iterations. Results were combined across imputed datasets using the standard multiple imputation combining rules. Stata version 15 (StataCorp LLC, College Station, TX USA) was utilized to create the neighborhood deprivation index. All other analyses were conducted using SAS 9.3 (SAS Institute, Cary, NC USA). All results presented are from the available case analysis unless otherwise stated.

#### **Ethical Statement**

This study was approved by the institutional review boards at The Ohio State University and the Ohio Department of Health.

#### **RESULTS**

#### **Neighborhood Deprivation**

From 2008 to 2016, a total of 5962 adult hepatocellular carcinoma cases were diagnosed. Among these patients, 2364 Ohio census tracts were identified. Approximately 2.9% of patients (n = 173) lacked census tract information and could not be assigned a neighborhood deprivation index quintile. Means and standard deviations for each of the 9 component variables followed expected patterns across the neighborhood deprivation quintiles (Supplemental Table 1). The neighborhood deprivation index was slightly skewed and ranged from -4.18 to 1.36. The mean value for the least deprived quintile (quintile 1) was -1.68 (standard deviation [SD]: 0.72) while the mean value for the most deprived quintile (quintile 5) was 0.98 (SD: 0.13).

#### **Patient and Tumor Characteristics**

Similar to national trends,<sup>23</sup> a majority of the patients with hepatocellular carcinoma were male (n = 4577; 76.8%) and had an average age at diagnosis around 65 years. However, unlike national trends which find that liver cancer is more common among non-Hispanic Asian/Pacific Islanders and non-Hispanic American Indian/Alaskan Native,<sup>23</sup> the sample was predominately White (n = 4503; 75.5%) (Table 1). Approximately 41% of the patients had a localized tumor while almost 20% of cancers were unstaged. Among all hepatocellular carcinoma patients, 76.7% (n = 4574) were deceased in 2018. Neither cancer stage (*P* value = 0.19) nor tumor size (*P* value = 0.80) differed by quintile of neighborhood deprivation.

#### Guideline-Concordant Treatment by Neighborhood Deprivation

In the unadjusted model, the prevalence of patients living in the most deprived neighborhoods receiving guideline-concordant care was 12% lower (PR: 0.88; 95% CI: 0.78, 1.00) than the prevalence of patients living in the least deprived neighborhoods receiving guideline-concordant care (Table 2). Similarly, when comparing patients in lower quintiles of deprivation (ie, quintiles 2, 3, and 4) to patients in the least deprived neighborhoods (quintile 1), these patients were less likely to receive guideline-concordant care although these associations were not significant. After adjustment, the prevalence of patients living in the most deprived neighborhoods receiving guideline-concordant care was 16% lower (PR: 0.84; 95% CI: 0.74, 0.94) when compared to patients living in the least deprived neighborhoods.

When the model was stratified by race, in the adjusted model, the prevalence of White patients living in the most deprived neighborhoods receiving guideline-concordant care was 14% lower (PR: 0.86; 95% CI: 0.75, 0.99) than the prevalence of White patients living in the least deprived neighborhoods receiving guideline concordant care (Table 3). The prevalence ratios for the other quintiles of deprivation were similar for White patients when compared to the full model. In the adjusted model, the prevalence of Black patients living in the most deprived neighborhoods re-

#### Table 1. Sample Characteristics Adult Ohioans Diagnosed with Primary Hepatocellular Carcinoma 2008 to 2016 (n=5962)

Characteristic	Ν	%
Sex		
Male	4577	76.8
Female	1385	23.2
Race		
White	4503	75.5
Black	1261	21.2
Other	181	3.0
Missing	17	0.3
Metropolitan status		
Metropolitan	5063	84.9
Nonmetropolitan	899	15.1
Stage		
Localized	2458	41.2
Regional	1533	25.7
Distant	803	13.5
Unstaged	1168	19.6
Guideline-concordant treatment		
Nonconcordant	3216	53.9
Concordant	1566	26.3
Missing	1180	19.8
Vital status		
Alive	1388	23.3
Deceased	4574	76.7
	Average	SD
Age (years)	64.6	11.1
Tumor size	62.8	70.3
Missing (n, %)	2353	39.5%
Survival time (months)	9.5	12.7
Missing (n, %)	497	8.3%
Neighborhood deprivation index		
Quintile 1 (Least deprived)	-1.68	0.72
Quintile 2	-0.25	0.23
Quintile 3	0.31	0.12
Quintile 4	0.65	0.09
Quintile 5 (Most deprived)	0.98	0.02

Table 2. Prevalence Ratio Patients Receiving Guideline-Concordant Care by Neighborhood Deprivation Index among Ohioans with Primary Liver Cancer Diagnosed 2008-2016 using log-binomial regression

	<b>Unadjusted</b> PR <sup>b</sup>	95% CI <sup>c</sup>	<b>Adjusted <sup>a</sup></b> PR <sup>b</sup>	95% CI <sup>c</sup>
Neighborhood deprivation index <sup>d</sup>				
Quintile 1 <sup>e</sup>				
Quintile 2	0.90	0.79, 1.02	0.90	0.81, 1.01
Quintile 3	0.95	0.84, 1.08	0.91	0.81, 1.02
Quintile 4	0.90	0.79, 1.03	0.89	0.79, 1.01
Quintile 5	0.88	0.78, 1.00	0.84	0.74, 0.94

<sup>a</sup>Adjusted for sex, race, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis.

<sup>b</sup>PR: prevalence ratio

<sup>c</sup>95% CI: 95% confidence interval

<sup>d</sup>Higher quintiles indicate higher areas of deprivation. <sup>e</sup> Quintile 1 is the lowest deprivation and the reference category.

#### Table 3. Prevalence Ratio Patients Receiving Guideline-Concordant Care by Neighborhood Deprivation Index among Ohioans with Primary Liver Cancer Diagnosed from 2008-2016 using log-binomial regression stratified by race

	White		Black	Black		
	Unadjusted	Adjusted <sup>a</sup>	Unadjusted	Adjusted <sup>a</sup>		
Neighborhood deprivation index <sup>d</sup>	PR <sup>b</sup> (95% CI <sup>c</sup> )	PR <sup>b</sup> (95% CI <sup>c</sup> )	PR <sup>b</sup> (95% Cl <sup>c</sup> )	PR <sup>b</sup> (95% CI <sup>c</sup> )		
Quintile 1 <sup>e</sup>						
Quintile 2	0.95 (0.82, 1.10)	0.98 (0.86, 1.11)	0.77 (0.52, 1.13)	0.71 (0.50, 1.00)		
Quintile 3	0.97 (0.84, 1.11)	0.93 (0.82, 1.06)	1.05 (0.74, 1.50)	0.95 (0.70, 1.31)		
Quintile 4	0.92 (0.80, 1.07)	0.93 (0.81, 1.06)	0.98 (0.70, 1.38)	0.94 (0.70, 1.27)		
Quintile 5	0.87 (0.74, 1.01)	0.86 (0.75, 0.99)	1.11 (0.82, 1.50)	0.97 (0.74, 1.27)		

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<sup>a</sup>Adjusted for sex, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis. <sup>b</sup>PR: prevalence ratio <sup>c</sup>95% CI: 95% confidence interval <sup>d</sup>Higher quintiles indicate higher areas of deprivation.

<sup>e</sup>Quintile 1 is the lowest deprivation and the reference category.

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ceiving guideline-concordant care was 3% lower (PR: 0.97; 95% CI: 0.74, 1.27) than the prevalence of Black patients living in the least deprived neighborhoods receiving guideline concordant care (Table 3). However, this association was not statistically significant. The prevalence ratios for the other quintiles of deprivation were closer to null for Black patients when compared to the full model.

#### **Five-Year Survival by Neighborhood Deprivation**

Prior to adjustment, individuals living in the most deprived neighborhoods had a 16% decrease in survival (Hazard ratio [HR]: 1.16; 95% CI: 1.03, 1.30) compared to individuals living in the least deprived neighborhoods (Table 4). A similar trend emerged in the other quintiles of deprivation, with greater deprivation associated with decreasing survival; the trend was almost linear apart from quintile 4. After adjustment, individuals living in deprived neighborhoods still had approximately a 15% decrease (HR: 1.15; 95% CI: 1.01, 1.29) in survival when compared to individuals in the least deprived neighborhoods.

When the model was stratified by race, in the adjusted model, White patients living in the most deprived neighborhoods had a 16% decrease in survival (HR: 1.16; 95% CI: 1.00, 1.34) compared to White patients living in the least deprived neighborhoods (Table 5). The hazard ratios for the other quintiles of deprivation were similar for White patients when compared to the full model. In the adjusted model, Black patients living in the most deprived neighborhoods had a 9% decrease in survival (HR: 1.09; 95% CI: 0.84, 1.41) compared to Black patients living in the least deprived neighborhoods (Table 5). The hazard ratio for the other quintiles of deprivation were wider for Black patients when compared to the full model.

#### **Missing Data Analysis**

Generally, the characteristics between the available (n = 4711) and incomplete cases (n = 1251) were similar for the guideline-concordant care analysis (Supplemental Table 1). Among the incomplete cases, the characteristics with the highest percent of missingness were guideline-concordant treatment (n = 1180, 94.3%) and neighborhood deprivation quintile (n = 173, 13.8%). Incomplete cases were likely missing guideline-concordant care because their cancer was unstaged or they were missing information on the treatment they received.

After imputing missing values, we observed associations that were closer to the null value when compared to the results from our available case analysis (Supplemental Table 2). Additionally, none of the prevalence ratios were statistically significant after multiple imputation.

For the 5-year survival analysis, there were a few key differences in characteristics of the available (n=3271) and incomplete cases (n = 486) (Supplemental Table 3). Generally, a higher proportion of the cancers in the incomplete cases were unstaged compared to the available cases (87.4% vs 12.1%). Additionally, incomplete cases on average were about 2 years older (66.0 vs 64.1 years) and a higher percent were dead (97.7% vs 84.4%). Survival time was also slightly shorter in the incomplete cases compared to the available cases (10.0 vs 11.7 months). The characteristics with the

 Table 4. Hazard Ratios Five-year Survival Liver Cancer by Neighborhood Deprivation Index among Ohioans with Primary Liver Cancer

 Diagnosed 2008-2013 using Cox proportional hazards regression.

	Unadjusted	95% CI <sup>c</sup>	<b>Adjusted <sup>a</sup></b> HR <sup>b</sup>	95% CI <sup>c</sup>
Neighborhood deprivation index <sup>d</sup>				
Quintile 1 <sup>e</sup>				
Quintile 2	1.11	0.98, 1.25	1.11	0.98, 1.25
Quintile 3	1.13	1.00, 1.25	1.12	0.99, 1.28
Quintile 4	1.04	0.92, 1.17	1.05	0.92, 1.19
Quintile 5	1.16	1.03, 1.30	1.15	1.01, 1.29

<sup>a</sup>Adjusted for sex, race, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis.

<sup>b</sup>HR: hazard ratio

<sup>c</sup>95% CI: 95% confidence interval <sup>d</sup>Higher quintiles indicate higher areas of deprivation.

<sup>e</sup>Quintile 1 is the lowest deprivation and the reference category.

## Table 5. Hazard Ratios Five-year Survival Liver Cancer by Neighborhood Deprivation Index among Ohioans with Primary Liver Cancer Diagnosed 2008-2013 using Cox proportional hazards regression stratified by race.

	White		Black	Black		
	Unadjusted	Adjusted <sup>a</sup>	Unadjusted	Adjusted <sup>a</sup>		
Neighborhood deprivation index <sup>d</sup>	PR <sup>b</sup> (95% CI <sup>c</sup> )	PR <sup>b</sup> (95% CI <sup>c</sup> )	PR <sup>b</sup> (95% Cl <sup>c</sup> )	PR <sup>b</sup> (95% Cl <sup>c</sup> )		
Quintile 1 <sup>e</sup>						
Quintile 2	1.15 (1.00, 1.32)	1.16 (1.01, 1.33)	0.95 (0.71, 1.29)	0.94 (0.69, 1.27)		
Quintile 3	1.14 (0.99, 1.30)	1.13 (0.99, 1.30)	1.13 (0.83, 1.54)	1.14 (0.84, 1.56)		
Quintile 4	1.01 (0.88, 1.17)	1.02 (0.88, 1.17)	1.18 (0.89, 1.56)	1.19 (0.89, 1.59)		
Quintile 5	1.17 (1.01, 1.35)	1.16 (1.00, 1.34)	1.15 (0.90, 1.49)	1.09 (0.84, 1.41)		

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<sup>a</sup>Adjusted for sex, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis.

<sup>b</sup>HR: hazard ratio

<sup>c</sup>95% CI: 95% confidence interval

<sup>d</sup>Higher quintiles indicate higher areas of deprivation.

<sup>e</sup>Quintile 1 is the lowest deprivation and the reference category.

highest missingness included survival time (n = 340, 70.0%) and neighborhood deprivation quintile (n = 159, 32.7%).

The association between neighborhood deprivation and survival were similar after using multiple imputation (Supplemental Table 4).

#### DISCUSSION

Among Ohioan adults diagnosed with hepatocellular carcinoma between 2008 and 2016, we observed lower likelihood of receiving guideline-concordant treatment among those living in the most deprived areas compared to those living in the least deprived neighborhoods. Furthermore, individuals living in more deprived areas had lower 5-year survival than patients living in the least deprived neighborhoods. However, in this analysis, neighborhood deprivation was not associated with worse tumor characteristics (ie, later stage at diagnosis or larger tumor size), indicating that neighborhood deprivation influences survival through mechanisms unrelated to tumor characteristics. We also

#### Supplemental Table 1.

Comparison of characteristics between available <sup>a</sup> and incomplete cases for adult Ohioans diagnosed with primary hepatocellular carcinoma from 2008-2016 (n = 5962). observed limited evidence for racial disparities in receiving guideline-concordant care as well as 5-year survival. However, this may be the result of small sample size.

To our knowledge, this is the first study examining associations between neighborhood deprivation, hepatocellular carcinoma treatment, and survival. However, studies of other cancers such as breast and prostate provide some context. In one study of patients with an abnormal screening for breast cancer in Ohio, patients residing in areas of higher deprivation had a longer time to resolution for their abnormal test, potentially indicating less access to treatment.<sup>24</sup> Other components of the deprivation measure, including lower educational attainment, lower household income, and greater unemployment, may indicate that a lack of health literacy and income prevent people from seeking care in a health care system that is prohibitively expensive. In addition, it is reasonable to hypothesize that lower odds of receiving guidelineconcordant care may be linked to more advanced disease because of nonoptimal treatment options or delay in treatment that may

	Available	Available Cases <sup>a</sup>		Incomplete Cases (n = 1251)	
	• •	(n = 4711)			
Characteristic	n	%	n	%	
Sex					
Male	3614	76.7	963	77.0	
Female	1097	23.3	288	23.0	
Race					
White	3558	75.5	945	75.5	
Black	997	21.2	264	21.0	
Other	156	3.3	25	2.0	
Missing	0	0	17	1.4	
Metropolitan status					
Metropolitan	4006	85.0	1057	84.5	
Nonmetropolitan	705	15.0	194	15.5	
Stage					
Localized	2410	51.2	48	3.8	
Regional	1508	32.0	25	2.0	
Distant	793	16.8	10	0.8	
Unstaged	0	0	1168	93.4	
Age (Years) – Average, SD	64.1	10.9	66.5	11.5	
Guideline-concordant treatment					
Nonconcordant	3171	67.3	45	3.6	
Concordant	1540	32.7	26	2.1	
Missing	0	0	1180	94.3	
Neighborhood deprivation index	c				
Quintile 1 (Least deprived)	883	18.7	164	13.1	
Quintile 2	936	19.9	212	17.0	
Quintile 3	938	19.9	223	17.8	
Quintile 4	937	19.9	228	18.2	
Quintile 5 (Most deprived)	1017	21.6	251	20.1	
Missing	0	0	173	13.8	

<sup>a</sup>Available cases had complete data for the log-binomial models examining the association between quintiles of neighborhood deprivation and receiving guideline concordant care.

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allow the tumor to progress. Indeed, in a study of prostate cancer, Zeigler-Johnson et al (2011) observed that neighborhood deprivation was associated with higher Gleason score.<sup>25</sup> However, in this analysis we did not observe an association between neighborhood deprivation and worse tumor characteristics.

This analysis also demonstrated a decrease in survival when neighborhood deprivation increased, and these results are consistent with previous findings. In one study of chronic liver disease and hepatocellular carcinoma, higher area deprivation was associated with lower survival from chronic liver disease when compared to less deprived areas.<sup>6</sup> However, this study did not observe an association between area deprivation and hepatocellular carcinoma survival.<sup>6</sup> Our study differs slightly by examining all-cause mortality rather than cause-specific mortality and we do not adjust for other area-level factors such as alcohol retail outlets. In other cancer sites such as lung cancer, others have observed that greater neighborhood deprivation is associated with lower survival.<sup>26</sup> The results from our analysis may differ from previous liver specific research due to the underlying population,

#### Supplemental Table 2.

Prevalence ratio for patients receiving guideline-concordant care by neighborhood deprivation index among Ohioans with primary liver cancer diagnosed from 2008-2016 using log-binomial regression and multiple imputation.

Neighborhood deprivation index <sup>d</sup>	<b>Unadjusted</b> PR <sup>b</sup>	95% CI <sup>c</sup>	<b>Adjusted</b> <sup>a</sup> PR <sup>b</sup>	95% CI <sup>c</sup>
Quintile 1 <sup>e</sup>				
Quintile 2	0.98	0.89, 1.07	0.99	0.95, 1.02
Quintile 3	1.01	0.92, 1.11	0.99	0.95, 1.02
Quintile 4	0.99	0.90, 1.09	0.98	0.95, 1.02
Quintile 5	0.99	0.90, 1.08	0.98	0.94, 1.01

<sup>a</sup>Adjusted for sex, race, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis.

<sup>b</sup>PR: prevalence ratio

<sup>c</sup>95% CI: 95% confidence interval

<sup>d</sup>Higher quintiles indicate higher areas of deprivation.

<sup>e</sup>Quintile 1 is the lowest deprivation and the reference category.

#### Supplemental Table 3.

Comparison of characteristics between available <sup>a</sup> and incomplete cases for adult Ohioans diagnosed with primary hepatocellular carcinoma from 2008-2016 (n = 3757).

	Available Cases <sup>a</sup>		Incomplete Cases			
	(n = 3271)		(n = 486)			
Characteristic	n	%	n	%		
Sex						
Male	2504	76.5	387	79.6		
Female	767	23.5	99	20.4		
Race						
White	2457	75.1	354	72.8		
Black	708	21.6	110	22.6		
Other	106	3.3	9	1.9		
Missing	0	0	13	2.7		
Metropolitan status						
Metropolitan	2766	84.6	419	86.2		
Nonmetropolitan	505	15.4	67	13.8		
Stage						
Localized	1441	44.0	33	6.8		
Regional	926	28.3	19	4.0		
Distant	510	15.6	9	1.8		
Unstaged	394	12.1	425	87.4		
Age (years) – Average, SD	64.1	11.5	66.0	11.9		
Vital status						
Alive	509	15.6	11	2.3		
Dead	2762	84.4	475	97.7		
Missing	0	0				
Survival time (months)	11.7	14.9	10.0	15.9		
Missing	0	0	340	70.0		
Neighborhood deprivation index						
Quintile 1 (Least deprived)	509	18.0	57	11.7		
Quintile 2	673	20.6	65	13.4		
Quintile 3	663	20.3	69	14.2		
Quintile 4	635	19.4	66	13.6		
Quintile 5 (Most deprived)	710	21.7	70	14.4		
Missing	0	0	159	32.7		

<sup>a</sup>Available cases had complete data for the Cox proportional hazards models examining the association between quintiles of neighborhood deprivation and 5-year mortality.

#### Supplemental Table 4.

Hazard ratios for 5-year survival of liver cancer by neighborhood deprivation index among Ohioans with primary liver cancer diagnosed from 2008-2013 using Cox proportional hazards regression and multiple imputation.

			- 10 - 13	
	Unadjusted		Adjusted <sup>a</sup>	
	HR <sup>b</sup>	95% CI <sup>c</sup>	HR <sup>b</sup>	95% CI <sup>c</sup>
Neighborhood deprivation index <sup>d</sup>				
Quintile 1 <sup>e</sup>				
Quintile 2	1.12	1.00, 1.26	1.12	0.99, 1.26
Quintile 3	1.13	1.01, 1.27	1.14	1.00, 1.28
Quintile 4	1.05	0.50, 1.18	1.06	0.93, 1.20
Quintile 5	1.15	1.03, 1.29	1.16	1.02, 1.31

<sup>a</sup>Adjusted for sex, race, age at diagnosis, metropolitan status, cancer stage, and year of diagnosis.

<sup>b</sup>HR: hazard ratio

695% CI: 95% confidence interval

<sup>d</sup>Higher quintiles indicate higher areas of deprivation. <sup>e</sup>Quintile 1 is the lowest deprivation and the reference category.

different adjustment sets, and differing neighborhood deprivation scales.

Based on these results, clinicians and other health care providers should be made aware of potential disparities that may exist by neighborhoods with regard to hepatocellular carcinoma treatment and mortality. Health care providers should be aware that several other cancers such as breast, prostate and lung cancer, in addition to hepatocellular carcinoma, have been associated with neighborhood deprivation.<sup>24-26</sup> Taken together this evidence suggests neighborhood-level factors play an important role in human health. Understanding these disparities by neighborhood may help to explain why individual-level factors cannot solely predict cancer risk. Neighborhoods can be both helpful and harmful to health depending on the conditions (ie, stress, physical conditions, environmental exposures, safety, etc). People spend a significant amount of time in their neighborhoods, and if the neighborhood is not optimized for people's health it can be detrimental. If health care providers are made aware of potential disparities, clinicians could provide additional resources to help lessen these disparities by, for example, connecting patients with social workers to assist them in accessing food, income, and housing assistance. At the same time, disparities in neighborhood resources and access need to be made more equitable to protect human health which should be the goal of sound public policy and advocacy.

Our study is not without limitations. Our main limitation was missing data for tumor characteristics, specifically stage and tumor size. We addressed this by using multiple imputation to assess the impact of missing data on our results and found that our results were robust to the missing information. Additionally, we lacked some clinical information about the patient's tumor such as the Child-Pugh score and the operability of a patient's tumor. Without this information we may have oversimplified the guideline-concordant variable, potentially introducing nondifferential misclassification. However, as this would bias our results toward the null, our findings may be viewed as conservative. Additionally, we utilized a simplified version of the BCLC guidelines, but the most commonly used guidelines come from the National Comprehensive Cancer Network (NCCN). However, the BCLC guidelines

have been validated extensively<sup>16</sup> and may not differ from NCCN guidelines in clinically meaningful ways. Next, our measure of neighborhood deprivation has not been extensively validated but similar methods have been used in other contexts. However, we built the deprivation index using variables that have been previously linked with cancer outcomes, and we were able to tailor the index to our specific population and outcome. The NDI also has the advantage of partially incorporating the racial composition of a neighborhood which is linked to redlining and structural racism; something that is absent from many other indices. Additionally, we utilized census tracts rather than smaller units such as a census block group or block, which means there could be heterogeneity in the variables used to build the NDI. However, we selected the census tracts because they are generally more stable over time and heterogeneity within a census tract would likely lead to nondifferential bias, which means our findings would be conservative. Due to sample size constraints, we were unable to fully explore potential racial disparities that exist for hepatocellular carcinoma treatment and mortality in Ohio. Lastly, our results may not be generalizable to other states or cancer types, warranting a cautious interpretation.

#### **PUBLIC HEALTH IMPLICATIONS**

In summary, we observed greater deprivation associated with worse treatment and survival outcomes. Clinicians and other health care professionals should be aware of the context in which people live and how it may impact one's health. Future analyses are needed to confirm these results and understand potential mechanisms between neighborhood deprivation and liver cancer outcomes.

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#### DISCLAIMER

This study includes data provided by the Ohio Department of Health which should not be considered an endorsement of this study or conclusion.

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## Patient Access to Care: In-Network and Out-of-Network Utilization of Services

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#### ABSTRACT

**Background:** Access to health care is impacted by several key factors such as urbanization, insurance coverage, availability of health care facilities, specialists, and equipment. For an in-depth understanding of Portage County area residents' health care utilization location choices, a study was conducted to identify the main factors and assess health care outmigration.

**Methods:** A total of 125 292 patients were identified using 2019 administrative health data from University Hospitals Portage Medical Center in Portage County, Ohio. A descriptive analysis, t test, and chi-square tests were used to examine 3 primary outcomes: (1) patients' demographics (age, gender, insurance, etc.), (2) time and distance patients are willing to travel for care, and (3) health services demand that is causing outmigration.

**Results:** An analysis of 119 034 patients showed 66% of patients stayed in network and 34% went out of network. In-network participants had an average travel time of 30 minutes [95% Cl, 29.5 to 29.8] and an average distance of 19.4 miles [95% Cl, 15.9 to 16.1]. Conversely, out-of-network participants averaged 43 minutes [95% Cl, 43.1 to 43.5] and 30.8 miles [95% Cl, 30.4 to 30.8]. Outmigration was mainly influenced by the need for radiology services (66.3%), specifically mammograms (12.7%), computerized tomography (CT) (39.2%), and lab (18.2%).

**Conclusion:** Outmigration can negatively impact a county's health care infrastructure and growth and contribute to a loss of revenue to the local hospitals. In this case, out-of-network services are more commonly used for radiology and lab work than for chronic conditions. It is recommended that both physicians and patients become knowledgeable about the impact of seeking out-of-network care.

Keywords: Outmigration; Out-of-network; In-network; Access to care; Hospital service area

#### **INTRODUCTION**

Outmigration of health care services is a widespread issue that causes many challenges, especially in rural areas. Outmigration means that patients travel out of their primary service areas to receive health care services in other geographical locations.<sup>1</sup> Outmigration occurs in different patterns observed in patients with varying health needs.<sup>2</sup> Multiple factors have contributed to outmigration such as seeking better health services, health system reputation, convenience, insurance coverage, social networking, and many other reasons.<sup>3,4</sup> Patients may also have negative perceptions about care delivered by certain institutions. Negative perceptions may result from past negative experiences by patients or family members due to limited resources, lack of privacy, mistrust, and communication challenges.<sup>3</sup> Patients may choose to travel to regional health institutions if the required health care services are unavailable in local institutions.

Existing data indicate outmigration is a growing problem in the United States. According to Miller, outmigration is a challenge to health institutions within a 75-mile radius of large US cities.<sup>2</sup> A survey by Swanston in 2019 found that 86% of community hospitals experienced outmigration, with 25% to 30% of these hospitals ranking outmigration among their top challenges.<sup>5</sup> The Institute for Public Policy and Economics found that in 1 rural Pennsylvania county 25% of the residents traveled to other counties for patient care. Rural Ohio counties, which in many ways are similar to rural Pennsylvania counties, are likely to experience the same issues. In



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approximately 50% of those who traveled, the decision for outmigration was driven by a perceived quality disparity.<sup>6</sup> Furthermore, the rate of outmigration is higher in rural areas than in urban settings.<sup>6</sup> According to Mosley and colleagues, approximately 76% of patients in rural counties out-migrated for health care compared to 23% in urban areas.<sup>1</sup> Rural outmigration was common across several services, including general care (22%), surgery (13%), orthopedics (17%), heart disease (11%), pulmonary medicine (8%), and neuroscience.<sup>1</sup> On average, 67.1% of gastrectomy patients traveled 17 miles from the nearest health care institution.<sup>7</sup> Likewise, 61% of individuals with ovarian cancer traveled approximately 50 miles for care.<sup>8</sup> These statistics underscore the need for further research and health care policies to tackle outmigration.

Patients traveling for care can cause severe consequences such as financial loss and poor health outcomes. Patient outmigration led to approximately \$1 billion in losses for hospitals in just 2 counties.<sup>2</sup> There is a link between longer-distance traveling patients and how medical initiatives improve medical conditions, disease prevention, and disease management; although hospital distance influences medical programs, rural inhabitants are unlikely to access these programs to improve chronic illness management.<sup>9</sup> As a result, many people wait to seek medical care until it is an emergency. Another study investigated the geographic and social aspects of engagement in the chronic illness self-management initiatives and diabetes.<sup>10</sup> The study concluded that involvement in self -management programs depends on initiative, class size, and on traveling shorter distances.

The physical distance between a patient and a hospital influences patients' choice when selecting surgical service location.<sup>11</sup> On the same note, other aspects besides the inherent risk and care distance influence traveling for elective surgery.<sup>12</sup> Even though improved results at high-end surgery hospitals facilitate the centralization of intricate operation facilities, admission into the deluxe facilities often requires extended travel distances. A study sought to assess the travel patterns among esophagectomy clients to determine the willingness to travel for surgical care.<sup>13</sup> The study concluded that more patients prefer traveling to high-volume surgical centers regardless of their distant location. Conclusively, the travel problem is an essential aspect in conceptualizing physical reach to medical facilities. Probst et al aimed to assess the topographic and ethnic-based disparities in destination covered and how long it takes to access health care.14 The researchers concluded that both people from rural regions and African Americans face greater travel burdens than urban inhabitants or Whites accessing medical services.

Even though outmigration trends are a growing problem overall, limited research exists that covers the matter in detail. To our knowledge, there is no published research on this topic specific to any Ohio counties. Portage County is a good place to start because it has 1 major hospital with several networked facilities and service providers. Portage County is located in northeast Ohio, approxi-

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mately 30 miles south of Cleveland. Of the 88 counties, it is the 15<sup>th</sup> most populated county in Ohio and is a mostly rural county with proximity to the larger cities of Akron and Cleveland. The demographics of the county are displayed in Table 1. The Portage County Community Health Needs Assessment (CHNA) revealed 9 "Areas of health need." "Access to care" and "Chronic disease" were listed as numbers 2 and 3 on that assessment. As previously mentioned, these are both issues that are exacerbated by patient outmigration, and reducing patient outmigration can improve both access to care and health outcomes related to chronic disease.

There is a need for empirical research on which service lines are most likely to lose patients to outmigration and the distances those patients are willing to travel for care. The research gaps establish the need for additional research on the problem so that health centers can better address the issues. Research shows limited information regarding what programs individuals travel for and lack of evaluating electronic health records (EHR) that include countylevel data with demographics and insurance coverage.<sup>6</sup> This paper aims to examine University Hospitals Portage Medical Center in Portage County, Ohio, in-network versus out-of-network health care utilization, identify out-of-network travel time and mileage, and detect the most common health services utilized out of network.

#### **METHODS**

#### Setting

University Hospitals Portage Medical Center is a 302 licensed-bed community hospital in Northeast Ohio. It primarily serves the residents of Portage County and is the only hospital in the county. University Hospitals Portage Medical Center has a level III trauma emergency department, 2 urgent care facilities, imaging centers, outpatient centers, and a network of physician practices.

#### **Study Design**

We conducted a retrospective cohort study of 125 292 Portage County, Ohio, patients using patient-level administrative data that included 140 metrics from University Hospitals Portage Medical Center in Portage County, Ohio. Data included demographics (age, gender, ethnicity), health insurance network status, procedure codes, ICD–9 diagnosis codes, provider city and specialty, patient risk level, medical diagnosis, spend and cost, drive time, and drive mileage. Drive time and mileage (distance) were calculated using geographical information system (GIS) techniques by mapping patient home addresses to the health care facility.

#### Participants

The initial cohort for this study included 125 292 patients for 2019. The study excluded patients outside the hospital service area (HSA); hospitals typically predetermine an HSA for their patients who come from specific area codes, zip codes, or other determining factors. Patients outside of the HSA were excluded because the focus of this project is to analyze patient travel for those inside Ohio Journal of Public Health, August 2022, Vol. 5, Issue 1 ISSN: 2578-6180

the University Hospitals Portage Medical Center HSA who were seeking services outside the HSA. The final analysis after exclusion yielded 119 034 patients.

#### Measures/Outcomes

The primary measured outcomes were the rates of out-of-network services and which groups would most likely out-migrate for service. The secondary outcome was estimating how much time and distance patients are willing to drive for care. Finally, the last outcome measure was identifying the primary service line(s) for which out-of-network patients are traveling. Based on prior research, we determined a priori the following were potential predictors of out-of-network migration: age, insurance type, patient risk level, and medical diagnosis. Patient risk score is an internal measure calculated by the University Hospitals Portage Medical Center using the patient's age, diagnoses, and gender.

#### **Statistical Analysis**

Descriptive statistics included means and standard deviations (SDs) for continuous variables and frequencies for categorical variables. Network status was the primary outcome; thus, each predicator's bivariate association was analyzed using the chi-square test ( $\chi$ 2). The t test was used to compare the drive time and miles in network to out of network. Statistical significance was assessed at  $\alpha$  = 0.05. All analyses were conducted using SAS

(version 9.4; SAS Institute). The study has been reviewed by the University Hospitals review board (IRB) and received a determination that it was not human subjects research (IRB Number: STUDY20211210).

#### **RESULTS**

Table 1 shows descriptive analysis of 119 034 patients. Eighty percent of the patients were aged 50 years and over, 60% were female, 40% were male, and 92% were White. The largest number of patients (50.5%) were insured under the Medicare program, followed by patients with private health care coverage at 46%. Sixty-six percent of patients stayed in network, and 34% went out of network, migrating to bigger cities. Statistically significant differences (P < 0.01) were found between in-network and out-of-network groups regarding travel time, mileage, and health services.

In-network patients had an average travel time of 30 minutes [95% CI, 29.5 to 29.8] and an average distance of 19.4 miles [95% CI, 15.9 to 16.1] (Table 2). Conversely, out-of-network patients averaged 30.8 miles [95% CI, 30.4 to 30.8] and 43 minutes of travel time [95% CI, 43.1 to 43.5].

Outmigration was mainly driven by the need for radiology (66.3%), computerized tomography (CT) (39.2%), and lab (18.2%); for the sub-services, organ/disease panel (15.2%) and

#### Table 1. Population Demographic Characteristic, n=119034

	In-network (66%)	Out-of-network (34%)	Chi-square P value
Gender			<.0001
Male	32 390 (27.2%)	14 760 (12.4%)	
Female	46 231 (38.8%)	25 653 (21.6%)	
Age			<.0001
0-19 years	2359 (2.0%)	1146 (1.0%)	
20-39 years	6254 (5.2%)	2531 (2.1%)	
40-54 years	14 270 (12.0%)	5991 (5.0%)	
55-74 years	38 816 (32.6%)	18 162 (15.2%)	
75 years and over	16 922 (14.2%)	12 583 (10.7%)	
Ethnicity			0.1855
Asian	412 (0.2%)	169 (0.1%)	
African American	2472 (2.1%)	1241 (1.1%)	
White	72 988 (63.2%)	36 217 (31.7%)	
Others	706 (0.5%)	364 (0.5%)	
Insurance			<.0001
Commercial	40 056 (33.6%)	14 500 (12.2%)	
Medicaid	851 (0.7%)	684 (0.6%)	
Medicare	35 710 (30.0%)	24 433 (20.5%)	
Medicare advantage	2004 (1.7%)	796 (0.7%)	
Risk Level			<.0001
High risk	26 367 (22.1%)	12 064 (10.2%)	
Highly complex	24 950 (21.0%)	17 303 (14.5%)	
Low risk	11 038 (9.3%)	4729 (4.0%)	
Rising risk	16 266 (13.6%)	6317 (5.3%)	

#### Table 2. Mean Difference in Drive Distance and Drive Time

	In-Netw	ork		Out-of-N	Out-of-Network			
	n	Mean	95% CI	n	Mean	95% CI	Pr >  t	
Drive distance in miles	78615	19.4	15.9-16.1	39 358	30.7	30.4-30.8	<.0001	
Drive time in minutes	78615	29.7	29.5-29.8	39 358	43.3	43.1-43.5	<.0001	

mammograms (12.7%) were the most utilized services out of network (Table 3). Also, when looking at provider taxonomy, we found that the most visited out-of-network physicians were radiology-diagnostic (46.5%) and general acute care (23.4%). Finally, respiratory related diseases were considered high for both innetwork and out-of-network patients, in which 75% of out-ofnetwork and 68% of in-network patients were diagnosed with pulmonary disease.

#### **DISCUSSION**

This study was conducted to better assess health care service outmigration in Portage County, Ohio. We believe this work will be of particular interest to health care administration leadership, as well as health care providers and policy makers. Outmigration is influenced by cost and insurance coverage, quality of care, convenience, access to information and services, perceived reputation, and social networking. Additionally, patients are more likely to travel if they have higher education and income.<sup>3</sup> These factors influence patients' willingness to travel for care and imply that those without resources are likely less able to travel for care.

Health care outmigration is a common challenge particularly in smaller and more rural counties, and this study confirmed that outmigration to bigger cities within a 75-mile radius is a valid concern. The study found that travel time and distance were notably higher among out-of-network patients than those within the network group. Previous work indicated that up to 75% of patients in rural areas out-migrated for care.<sup>1</sup> This does not seem to be the situation in Portage County where that number was only around 34%. Also, it seems that some of the more complex and high-risk cases are staying in the service area for care, which is not typically the case.<sup>1</sup> What is happening, however, is that there are specific services for which patients are very likely to travel.

As data indicated, respiratory-related diseases and radiology services, particularly in specific sub-services such as CT and mammograms, were the most utilized services out of network. The findings also show 46.5% of patients going out of network for diagnostic radiology. This can be explained by facility location and a shortage of pulmonologists in the county. Fewer facilities that provide CT and mammograms can cause a lack of appointment availability and longer wait times, which may contribute to patients seeking care elsewhere. Other factors contribute to outmigration as well; mammogram services are influenced by social networking.<sup>15, 16</sup> If patients have a good experience at a particular location, this anecdotal evidence can be highly influential in driving patients to that location.<sup>15</sup> It is important for health care leadership to know which service lines in their HSA are prone to outmigration because it allows them to use this information when making decisions regarding the placement of facilities and recruitment of spe-

	In-network (n=78 621)	Out-of-network (n=40 413)	Chi-square P value
Most utilized service lines			
Radiology	21 916 (27.9%)	26 803 (66.3%)	<.0001
Lab	35 124 (44.7%)	7354 (18.2%)	<.0001
Cardiology	7664 (9.7%)	1317 (3.2%)	<.0001
Most utilized sub-services			
Organ/Disease panel	29 349 (37.3%)	6156 (15.23%)	<.0001
СТ	10 726 (13.6%)	15 849 (39.2%)	<.0001
Mammography	6428 (8.2%)	5131 (12.7%)	<.0001
MRI	3316 (4.2%)	4248 (10.5%)	<.0001
Most visited provider by taxonomy			
General acute care hospital	37 137 (47.2%)	9468 (23.4%)	<.0001
Radiology - diagnostic radiology	804 (1.02%)	18 785 (46.5%)	<.0001
Clinical medical laboratory	13 051 (16.6%)	2009 (4.9%)	<.0001
Most common medical diagnosis			
Pulmonary disease	53 473 (68%)	30 075 (75%)	<.0001
COPD	17 410 (22.1%)	11 278 (27.9%)	<.0001
Asthma	13 383 (17%)	7843 (19.4%)	<.0001
Respiratory failure	8578 (10.9%)	7370 (18.2%)	<.0001
Chronic bronchitis	9136 (11.6%)	6303 (15.6%)	<.0001

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#### **Table 3. Selected Services Features**

cialists. Other rural counties in Ohio and elsewhere can conduct similar analyses.

The current study has notable strengths and limitations in its identification of and potential causes of outmigration. The main strength is the use of EHR data. The EHRs have significant value to research as they provide detailed information collected during patient care.<sup>17</sup> The EHR data facilitated the inclusion of a large sample of the patients utilizing University Hospitals Portage Medical Center. With the large sample size, the current study's findings can be generalized to other counties by ensuring adequate representation.<sup>16</sup> The EHR data also allows the identification of the services being utilized as well as the location of these services. Another strength is the inclusion of Medicare and non-Medicare patients, which provides a comprehensive approach to capturing patients with different insurance coverage. However, a limitation of this study relates to the lack of consideration of patients' perspectives. The analysis of outmigration only accounts for factors captured in the EHR data, and it is difficult to identify the true nature of patients' travel decisions. Some patients may prefer to seek health care services closer to their employer rather than their home. Further studies using patients' perspectives are needed to determine why patients might travel for care.

#### PUBLIC HEALTH IMPLICATIONS

Health care services outmigration can have critical consequences if it remains unresolved. First, outmigration can negatively impact the county's health care infrastructure and growth. As previously stated, the Portage County CHNA listed "access to care" and "chronic diseases" as 2 of the 9 main health issues. In the CHNA, University Hospitals Portage Medical Center (formerly known as Robinson Memorial Hospital) is identified as 1 of the public health assets in Portage County.

The care institutions and associated facilities can be negatively affected if outmigration increases. The high rates of patient travel out of network may affect the health care infrastructure by triggering widespread provider shortage and limited investment in the local health care industry.<sup>1</sup> Outmigration can reduce demand for health care services, leading health care organizations to reduce workforce, which then could lead to even higher levels of outmigration due to long wait times and quality of care concerns. Also, some health care workers may move to work for competing institutions in neighboring counties, leading to greater provider shortages. The more that outmigration occurs within a specific HSA contributes to facility closures, which then further decreases access to care for patients. Outmigration may cause limited investment in the county's health care sector due to reduced demand for health care utilization as many patients move to other counties.<sup>9</sup>

Another impact of outmigration is the potential economic losses for health care institutions in the county. As patients travel to other geographical areas, hospitals will incur financial losses which will impact operational costs and reduce cash flow.<sup>6</sup> The economic losses may trigger additional outmigration of health care providers from the county. The popularity of health care service outmigration shows real or perceived disparities in the quality of care offered by different facilities. Other factors such as the cost of care also come into play because financial constraints will limit patients' desire and ability to visit a given institution. Patients seeking care elsewhere impacts upon the facility's revenue, which inhibits the ability to afford specialized or upgraded infrastructure and equipment.

Multiple solutions to reduce outmigration have been recommended. One solution is the integration of all health systems in a particular area. Integration would allow providers to make referrals to in-network service providers.<sup>18</sup> Also, providers can improve the patient experience to influence them to remain within local hospitals by making in-network referrals easier. Likewise, educating patients on the advantages of staying in network and establishing positive relationships with consumers is crucial to tackling outmigration.1 Staying in network also potentially allows medical providers to view a patient's history and medical treatments in a unified health record system. Given the influence of anecdotal evidence for certain services, health systems may want to use patient vignettes or cases to help promote their services.<sup>15</sup> Outmigration does not necessarily mean that patients will receive the quality of care they want. Instead, it potentially exposes them to more risks and expenses such as traveling and the challenge of getting timely assistance when one must cover long distances to acquire it. These consequences underline the need for policy interventions to tackle health care outmigration in the county.

Policymakers are encouraged to investigate and address health care outmigration by proposing a policy that increases funds for small counties. Currently, the Health Resources and Services Administration (HRSA) allocates more funds for large counties.6 At the same time, small counties can use the fund to facilitate their health care infrastructure growth. The policy would ensure that the health care providers in these smaller counties can deliver quality and competitive health care services.<sup>6</sup> At the same time, hospitals and health system responsibilities involve educating patients on the impact of out-of-network care. There is a high need to keep patients informed about health care services in their local health care institutions.8 Addressing health care outmigration would support the growth of health care infrastructure in small and rural counties. Determining which services are of greatest need in the county, and for which services patients are most likely to travel is a vital first step in addressing outmigration.

#### Conclusion

The findings in this study demonstrate that patient outmigration is a significant issue for rural areas with far-reaching repercussions. Resolving such an issue requires a reconsideration of decisions around health care administration and patient care. Ensuring that the best possible care is offered at minimal costs may discourage

patients from seeking assistance elsewhere. Such efforts require significant investment in infrastructure, equipment, and personnel training. This initiative should also be supported by policy changes that promote the development of high-quality care facilities. Similarly, subsidizing care can ensure that patients do not have to look for cheaper care elsewhere. Lastly, efforts should be made to educate the citizens about the care offered in local hospitals and the benefits from visiting the local hospitals instead of traveling elsewhere. Nonetheless, further studies are needed to help develop more sustainable solutions that promote access to care while ensuring that more institutions are adequately equipped to provide quality health care.

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## Perceptions of How Integrated Care Impacts Treatment in Rural Settings

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#### ABSTRACT

**Background:** In light of the changing face of health care, it is important that practitioners and researchers begin to think strategically regarding comprehensive and accessible care. The purpose of this research study is to provide a deeper understanding of change among health care providers who work on multidisciplinary teams and the impact on patient outcomes.

**Methods:** This research was designed as an exploratory phenomenological research study. The experience of interest was how providers described changes in care when working in an integrated care context. Eight semistructured in-depth interviews were conducted with physicians, nurse practitioners, social workers, and psychologists from locations in Southern Ohio, Central Maine, and Eastern Tennessee. Data were analyzed using qualitative coding to find patterns with and across participants associated with their perceptions of health integration.

**Results:** Final developed themes described provider perceptions of working in an integrated care environment, and included access to care, interprofessional education, communication between providers.

**Conclusion:** Through interviews and a review of the literature, we have found that as integrated care is employed throughout the country, patients have better health outcomes and providers experience efficient and effective work environments. Providers have adapted to the changing environment of integrative medicine; through this study we see that these changes have been for the benefit of the patients. Patients who disproportionately suffer from a lack of health care resources, such as those in rural areas, may benefit greatly from an integrated care model.

Keywords: Integrated health care; Qualitative methods; Interview research; Behavioral health

#### **INTRODUCTION**

National health care initiatives have continued to focus on increasing efficiency of health care outcomes. Both the Substance Abuse Mental Health Services Association (SAMHSA) and Health Resources and Services Administration (HRSA) emphasize the importance of preventive care in contributing to optimal health for the public.<sup>1</sup> These agencies and the US Department of Health and Human Services (HHS) share the common goal of improving public health in order to increase efficiency and quality health outcomes.<sup>2</sup>

The World Health Organization (WHO) provides a succinct justification regarding the importance of integrated health care to improve quality of care:

- 1. The burden of patients who have mental disorders is heavy.
- 2. Difficulties between mental and physical health problems are intertwined.
- 3. There is a large treatment gap for mental health disorders.
- 4. Access to care is increased by having mental health services in primary care.
- 5. Patient stigma and discrimination is decreased by offering mental health programming into primary care settings.
- 6. Treatment of behavioral health illness in primary care practice is cost-effective.
- There is evidence of positive outcomes for patients who have been diagnosed with mental health difficulties who are treated in primary care sites.<sup>3</sup>

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As health care continues to evolve, there are growing concerns about quality and efficiency. Integrated health care potentially adds a further dimension to quality assessment. Therefore, it is advantageous for the researchers and practitioners to gain knowledge regarding the benefits and challenges in integrated care, in order to facilitate optimal planning.

Preventive medicine includes wellness checkups and patientcentered health homes. As medicine continues to move toward integrated care, preventive medicine will become normal practice, ultimately increasing coordination of care and reducing overall health care costs.<sup>4</sup> The new medical models attempt to decrease the high costs of emergency department utilization and chronic conditions that oftentimes end up in costly, long-term treatments (ie, untreated type 2 diabetes). Further, integrated health care improves quality of patient outcomes by providing a place for shared information and a means to treat complex issues that face health care practitioners, particularly mental health care.<sup>5</sup> Having a 'warm hand-off' allows the patient to have specialty care incorporated into maintenance and preventive medical practice.<sup>6</sup> As health care continues to advance to this approach, it is imperative that research presents a collective understanding of what improves quality care.

The Agency for Healthcare Research and Quality (AHRQ) conducted a robust meta-analysis in 2008 of over 942 abstracts and citations of integrated health. As a result of this systematic review of findings, limitations, and recommendations, the team found 13 priority areas for future research. The importance of both rural integrated practices and qualitative analyses was cited in the study. In order to create sustainability and long-term systems of care, the AHRQ recommends conducting further research into what works.<sup>7</sup> Current research suggests that providers enjoy the benefits of integrated care because it decreases physicians' tendency to "live in silos," allows collaboration to help with complex patient needs, increases provider retention, and increases job satisfaction.<sup>8</sup>

Most previously published research on integrated care focuses on patient outcomes, or chronic care conditions and how they are treated in teams.<sup>9,10</sup> There is a scarcity of research that focuses on change within the health care practitioner (either as a primary care practitioner (PCP) or as a behavioral health professional) and, in particular, how practitioners perceive integrated care and how it may influence practice. As focus on integrated care continues, study of practitioner perceptions and practices will provide beneficial insights to continue to improve efficient use of time, coordination, patient satisfaction, and financial outcomes.

This study explores qualities that change a health care provider's practice as a result of working in multidisciplinary teams. We explored how the implementation of integrated care changes the quality of services delivered to the patient from the practitioner perspective. The basis of an exploratory study is to capture common themes among interviewees rather than having a set number

of hypotheses as often used in more traditional scientific research. Therefore, the main objective for exploration in this study was to uncover patterns of experience when comparing interviews among rural practitioners in multidisciplinary teams.

#### **METHODS**

The questions for this phenomenological, qualitative research focused on the nature of change of practice as a result of the practitioner's participation on a multidisciplinary team. The primary question of interest was: "What about working on a multidisciplinary team changes the way you treat patients?" This question was formulated to fit the population of interest, as recommended in prior research.<sup>11</sup>

Phenomenology is the process of seeking to uncover the essence and structure of a particular thing of interest, the phenomenon. Often participants are similar in terms of the experience and other attributes.<sup>12,13</sup> The researcher seeks to describe the essence of the experience, make sense of it, and record the data retrospectively through in-depth interviews.<sup>12</sup> According to phenomenological methods, the interviewer, in this instance the first author, is the primary instrument of research. The primary author has previous experience working on multidisciplinary teams and has extensive experience working with rural patients. Additionally, all 3 authors are experienced in either behavioral health or primary care.

The desired participants for this study consisted of both primary care practitioners (PCPs; medical doctors, doctors of osteopathic medicine, family nurse practitioners) and behavioral health clinicians (BHCs; clinical psychologists, counseling psychologists, licensed social workers, independently licensed counselors) working in designated HRSA underserved areas. Participants were identified in advance of interviews via referral or snowball sampling with key contacts at each research site and were directly recruited through phone and email requests. The interviews consisted of 12 semistructured questions exploring the nuances that result in a change in the practice of care. The interview questions were tailored to address practitioners that work with both medical and mental health patients. As part of the process of conducting interviews, the author developed rapport with participants through use of a respectful, empathetic, and culturally appropriate approach.14 Prior to data collection, a submission of research exemption request was requested and granted from the Ohio University institutional review board (IRB).

#### **Data Collection**

Each interviewee received the list of questions prior to the interview for preparation (see Appendix). Data collection consisted of a series of semistructured interviews lasting between 60 and 90 minutes. The interviewer also documented field notes within 48 hours of contact with the interviewee. The interview component of this research was concluded when the authors determined, based on preliminary data analysis, that the standard of data saturation was met. This occurred after interviews with 8 participants. For

this research, the authors followed guidance which specifies that data saturation is achieved when there is enough interview data to propose adequate inferences about the phenomenon of interest.<sup>15</sup>

#### Data Analysis

All interviews were recorded using a digital recording handheld device. A typed transcript was created from each audio recording. Field notes were collated. Data were deidentified and stored in a secure location locked files with deidentified names. The authors followed these steps for data analysis. Transcripts were read and reread by the authors along with the primary interviewer's scripted field notes regarding the observation of details not captured in the digital recording.

Next, a process of axial coding was conducted. This process included the following steps: 1) reduction of data 2) coding of data 3) creation of categories, and 4) analysis of themes. Reduction of data refers to identification of excerpts of interest. Coding refers to associating excerpts with a summarizing word or phrase. Categories are comprised of multiple similar codes. These are further abstracted into higher order themes that run through the data and address the question of interest. Two additional coders were recruited from Ohio University Heritage College of Osteopathic Medicine to provide an additional source of validity beyond the authors. All data were coded by 3 analysts. Codes were assessed for reliability by measuring consistent application of each code. The criteria used for reliability was agreement by 2 of 3 coders.

#### **RESULTS**

The final developed themes included access to care, interprofessional education, and communication between providers.

#### Access to Care

Access to care is an issue that the medical profession continues to deal with, particularly in rural areas. Integrating psychiatry, even telepsychiatry in rural communities, has helped bridge this gap.<sup>7</sup> Many patients are unable to make their appointments due to finances, lack of transportation, or even proximity of health care providers. This was supported by a statement made by a provider interviewee who said, "Transportation is sometimes difficult, and money, and things like that, so being able to, at the same time, capture all of their needs, all of their family's needs...that definitely can make a big difference."

One interviewee described: "In a rural setting, you may never get them back! Get them when you can and do as much as you can at one time." Another stated: "So much in the rural community is so isolated and fragmented that integrated care makes it unified for the patient."

Providers consistently reported that patients are often reluctant to follow up to receive psychiatric care; however, when they are already in the clinic, they are more willing to receive that care. Receiving psychiatric care in a place that is familiar and comfortable to patients helps reduce the stigma surrounding mental health.<sup>6</sup> An interviewee stated, "The patients were very pleased to attend counseling sessions at the primary care site as opposed to the stigmata they had attached to the other institution."

#### Interprofessional Education

Through integration, PCPs have realized that their treatment and diagnosis of mental health issues weren't as thorough or accurate as they had initially believed. The interaction between providers associated with integration has given them the tools they need to treat their patients efficiently and confidently.<sup>5</sup> One PCP illustrated this, stating, "You did the best you could, but I see in retrospect that I probably wasn't doing as much good as I thought I was because I wasn't really able to accurately diagnose." Another participant observed: "I think it has made a great deal of difference both in terms of our ability to educate, residents and medical students, and our ability to better take care of patients, and I think that we are more successful at engaging patients in behavioral health treatment."

Behavioral health clinicians have also benefited from their interactions with PCPs. A BHC discussed how this integration has allowed them to link information from a mental health perspective as well as a physical health perspective. A participant described how integration has been "really educational for me, because I hadn't worked in a primary care setting before, so, a lot of that medical information I didn't have before, I have now, and can better link the information I have about mental health/behavioral health."

The combination of shared physical space and combined electronic health records provides an ongoing educational framework that blends the disciplines of medicine and behavioral health. The ability to understand and share health care language contributes to a more seamless coordination of care for each patient, enhancing positive, quality outcomes. According to one behavioral health provider: "I think I'm definitely even more holistic than I was before, because I have more of that medical understanding now."

#### **Communication Between Providers**

When the doctor is down the hall from the psychologist who is just down the hall from the social worker, the influences related to social determinants of health (SDOH), associated with the environments where patients engage in everyday activities, are more readily and efficiently addressed by the care team. Communication between each provider is timely and not bogged down with complicated referral systems and unanswered phone calls. One medical provider described: "Say they are seeing us the same day, I can identify immediately the issues, I can task the behavioral health provider—this is going on, I'd like to do this medicine, will it conflict?"

If patients disclose important information about unaddressed SDOHs to a provider, this gap can be communicated to a different provider who may not have been aware and can provide that patient with resources. Patients can be discussed in a holistic man-

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ner putting into consideration multiple health factors, rather than in separate pieces. This was described by one participant: "I'll interview a patient; the behaviorist will interview and get other information. Together we can get a better picture of the patient together." One PCP expressed, "It's been very helpful having the psychologists and psychiatry in the same building to be able to shoot questions or consult with...I've always got somebody there trained in psychiatric behavioral services to back me up." Another noted: "It's very easy to communicate—there's no barriers to communication, you know, we have access to—primary care has access to behavioral health, and vice versa."

#### **DISCUSSION**

To address the purpose of this research, it was necessary to explore the perceptions of providers working in integrated care settings. To gain a deeper understanding of the benefits, challenges, and future steps surrounding the multidisciplinary care team model, interviews with providers who work on such teams were conducted and analyzed. Throughout these interviews, several themes arose that supported the idea that an integrated health care model is beneficial to all involved entities of the health care system. These themes included access to care, interprofessional education, and communication between providers. Access to care was important among multiple dimensions including mental health concerns. Patients experienced increased access and decreased stigma in the integrated care environment which led to patients receiving treatment before their psychiatric symptoms were exacerbated. Regarding interprofessional education, interviewees described benefits with providers reporting they felt more well-rounded and better equipped to resolve issues that were not covered within their training programs. This is consistent with prior research; previous researchers concluded nearly all psychiatrists working in integrated environments stated that they provided educational support for PCPs and BHCs.<sup>16</sup> Communication among providers is enhanced, and this is beneficial for patients as well as the providers, and facilitates more comprehensive, timely care.

Integrated care facilities have become more numerous over the past several years, but they are not yet the standard. Through interviews and a review of the literature, we have found that as this model is employed throughout the country, patients have better health outcomes and providers experience efficient and effective work environments. Providers have adapted to the changing environment of integrative medicine; through this study we see that these changes have been for the benefit of the patients. Based on the results of our research, we suggest that this model should be the standard. Our findings show that integrated care facilities are an invaluable method to improving patient outcomes, especially in communities and areas that are underserved.

#### PUBLIC HEALTH IMPLICATIONS

Through discussions of individuals working in integrated care models, we found that patient access to care, provider comfort, and positive outcomes increased and were supported by the model. One PCP described the explicit advantages of integrated care: "We have such problems with patients with very limited transportation, so that, to have as many services in one place as you can...makes it so much better for the patient. Because if they can get that one van ride, or one tank of gas they can buy to come...we can get their behavioral health appointment, their general medical care, and their OB/GYN appointment care all on one day!"

Patients who disproportionately suffer from a lack of health care resources may benefit greatly from an integrated care model. For facilities that are in urban or rural underserved areas, we recommend that steps be taken toward development of medical homes that reflect an integrated primary and behavioral health model. Although the medical home can be beneficial to patients of all economic backgrounds, it is even more beneficial to the socioeconomically disadvantaged; socioeconomically advantaged patients have an increased ability to pay for services, travel to distant specialists, pursue private psychological services, and support healthy and safe lifestyle measures. In our view, this is an issue of justice and the equitable allocation of resources.

More recently, the emergence of COVID-19 has highlighted the importance of integrative care, particularly in rural communities. COVID-19 mortality rates have been considerably higher in rural counties, meanwhile testing has been shown to be lower when compared to urban communities.<sup>17</sup> The higher death rate is also in part due to the increased frequency of comorbidities in rural communities. With increased anxiety surrounding visits to clinics and hospitals, decreasing the number of times a patient must risk exposure is helpful. Additionally, the health care infrastructure in these areas may be unable to handle the volume of care that is required during these times.

We intend this research to add to the body of literature backing the support and funding of health care initiatives that holistically and efficiently care for all patients, especially those who are most burdened by a lack of resources and socioeconomic privilege. Incorporation of integrative health care would reduce the number of doctors' visits and allow for more of their health care needs to be met, providing patients with the opportunity to most effectively manage their health and reduce future issues.

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#### **APPENDIX. Interview Guide**

- 1. What has been your experience working on integrated teams?
- 2. What positive changes have you seen among your patients as a result of a multidisciplinary approach to treatment?
- 3. What challenges, if any, have arisen for your patients as a result of a multidisciplinary approach to treatment?
- 4. How has your practice changed as a result of working among other health care professionals?
- 5. In your (Medical/Psychology) training, were you exposed to experiences working with integrated health? If so, what were they?
- 6. What do you think are the advantages of multidisciplinary care in a rural setting?
- 7. Is there anything you would like to add in regard to your current rural practice as a result of integrated care?
- 8. How has communication of patient treatment changed as a result of working on a multidisciplinary team?
- 9. Do you think health care integration is critical in rural settings? If so, why?
- 10. Is there anything else I forgot to ask, or anything you'd like to share with rural integration practitioners and researchers?



## "How do we get to them?" Insights on Preconception and Interconception Health for Women in Rural Northwest Ohio

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#### ABSTRACT

**Background:** Rural women in the United States are at increased risk for poor preconception and interconception health. In a previous study, women living in Hardin County, a Primary Care Health Professional Shortage Area and maternity care desert in rural northwest Ohio expressed their concerns and their need for more resources to improve their health. As a follow-up study, key informants of Hardin County were interviewed to provide further insight on current resources for preconception and women's health available to community members, barriers and challenges community members face, and interventions could be implemented in the county to improve health and pregnancy outcomes.

**Methods:** A purposive sample of 14 key informants from community assets in Hardin County were recruited and individually interviewed with semistructured questions from 2 domains: perceived needs and barriers to care. Interview recordings were transcribed, precoded, and thematically analyzed. Participants received a \$20 gift card as a token of appreciation.

**Results:** Three themes were characterized from the data: current resources available, community observations, and suggested intervention strategies. Key informants identified the federally-qualified health center and YMCA, among others, as potentially underutilized resources for reproductive-age women. The small-town culture was described as both an advantage and disadvantage when trying to raise awareness about preconception/interconception health. Interventions built on partnerships and utilizing various outlets were suggested. Childcare, intergenerational knowledge transfer, and trust were issues crossing multiple themes.

**Conclusion:** Key informants gave direction on available resources for reproductive-age women and potential approaches to provide education and outreach regarding preconception/interconception health and care.

Keywords: Preconception care; Women's health; Female; Rural population; Qualitative research

#### **INTRODUCTION**

Preconception and interconception health are wide-ranging concepts that encompass overall health for nonpregnant girls and women of reproductive age. The term "preconception" is applied to nulliparous women while "interconception" is used for multiparous women. Preconception and interconception health encompass biomedical, behavioral, and social issues that may harm a woman or future baby. Optimizing preconception and interconception health is key to improving women's personal health and reducing risk factors for adverse pregnancy outcomes.<sup>1.4</sup> However, women in the United States (US) currently report high rates of chronic disease and low rates of prepregnancy health care interventions, indicating a need for better preconception and interconception health and care.<sup>5-7</sup>



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#### Design

Rural women in the US are at even greater risk for poor preconception and interconception health due to the social determinants they often face. These may include lower socioeconomic status, geographic isolation, and limited access to health care providers, healthy food options, and transportation. Each of these contributes to health disparities.<sup>8-13</sup> Furthermore, studies have found that women living in largely rural areas in the US had concerning preconception health risk behaviors, such as high rates of smoking, overweight/obesity, and physical inactivity.<sup>14-16</sup> Governmental agencies, including the US Department of Health and Human Services and Centers for Medicare and Medicaid Services, have raised awareness for the need to improve rural maternal health.<sup>17,18</sup> Rural experts rank maternal and infant health as a top concern, with calls to better study rural women's health.<sup>10,19</sup>

However, to date, literature detailing preconception and interconception health and care for reproductive-age women specifically in the rural Midwestern US has been scant. Therefore, a series of studies has been conducted to better understand preconception and interconception health and care among women in rural northwest Ohio.<sup>20-22</sup> During interviews with reproductive-age women in Hardin County, Ohio, as part of a qualitative study to better understand their most pressing health needs, it became apparent that most were not aware of community assets they could utilize to improve or maintain their health.23 Consequently, it was decided to conduct a second qualitative study with key informants in the county knowledgeable about such resources. The primary objective of this study was to gather information regarding resources available in the county for reproductive-age women. Secondary objectives were to characterize the challenges they observe reproductive-age women facing and intervention strategies they believe would be beneficial for reproductive-age women in Hardin County to improve preconception and interconception health.

#### **METHODS**

#### Setting

Hardin County, Ohio, has a population of approximately 31 000. The county is considered to be a non-core county, the most rural classification, with no cities, towns, or urban clusters of 10 000 residents or more.<sup>23</sup> The county is additionally labeled as a Primary Care Health Professional Shortage Area (HPSA) and a maternity care desert, without proper resources and facilities for preconception and women's health care.<sup>24,25</sup> While there are a few primary health care facilities in Hardin County, some have restricted hours or are not open each day of the week. A free mobile health clinic has started in the county, providing limited secondary preventive care services, such as diabetes and hypertension screening, as well as disease state management to patients on certain days of the month; uptake among reproductive-age women has been minimal to date.<sup>26</sup> Some sources of care, such as the family planning clinic at the local health department, have recently closed.

Prior to designing the study, a literature review was performed to identify gaps and determine potential design models for structuring interview questions. The study was designed to be phenomenological after bracketing that it was expected to identify resources and barriers.<sup>27</sup> The semistructured interview (Appendix) consisted of 9 questions from 2 domains: perceived needs and barriers to care. Interview questions included probes and follow-up questions for gathering additional information when needed, and all questions were open-ended. Interviews were thematically analyzed to identify reoccurring patterns in the data and characterize key informants' beliefs.<sup>28</sup>

#### **Participants and Procedures**

Key informants representing community assets and stakeholders in the county were purposively recruited to participate in individual interviews to identify what resources are available in the county for reproductive-age women, what challenges they observe reproductive-age women facing, and what intervention strategies they believe would be beneficial for reproductive-age women in Hardin County. First, an email describing this study was sent to members of the Healthy Lifestyles Coalition of Hardin County, a group representing organizations involved in prevention initiatives to improve the health of Hardin County residents.<sup>29</sup> Members interested in participating in the study were asked to contact the investigators to arrange the interview. After seeing which organizations were represented by those volunteers, the investigators used personalized email messages or phone calls to individuals at agencies that they were aware of in the county that engage with reproductive-age women but had not been reached through the Healthy Lifestyles Coalition listserve. Despite multiple contact attempts, certain key informants the investigators had hoped to interview were not able to be reached.

Interviews were conducted individually using audio phone calls and video calls in June 2021. Prior to the interview questions, basic information regarding how long they have worked at their current organization and how long they have worked or lived in Hardin County were collected. The duration of the interviews was 15 to 60 minutes per participant, and each received a \$20 Dollar General gift card as a token of appreciation following the interview. Upon informed consent, interviews were recorded with a Sony-PX Series digital voice recorder and manually transcribed verbatim. Transcripts were labeled sequentially so as to not explicitly identify each key informant. Interviews were conducted until saturation was reached.

The Ohio Northern University Institutional Review Board exempted the study.

#### Analysis

Before analysis, the transcripts were reviewed to gain familiarity with the data. The interview transcripts were precoded based on primary expectations and ideas to identify and highlight the key

data wanted from the question script for the initial analysis. A concept map of the initial parent codes was made in order to see where there were differences and similarities in the data, leading to the identification of the emerged child codes. No analysis software was used and the coding process was done manually. For consistency, one researcher conducted the theoretical thematic analysis and interpretation of the interview data, while the other researcher ensured validity of the data codes by reviewing the analysis findings. Before the code tree was finalized, codes were redefined, modified, and discussed until discrepancies were resolved. The parent and child codes identified the reoccurring patterns in the data and became the 3 overarching themes and 8 subthemes due to the overlaps in the smaller data set (Table 1).

#### **RESULTS**

Fourteen key informants were interviewed, representing a variety of organizations and stakeholders in Hardin County. Participants had worked at their current organization in Hardin County for 1 to 35 years (mean = 8.7 years, standard deviation = 8.3 years). Twelve were residents of the county (4 to 50 years, mean = 27 years, standard deviation = 14.7 years). All but 1 of the participants were female, which gave a unique perspective as not only a key informant but also, in many cases, as a resident of the county themselves.

Organizations Represented by Key Informants (n=14)
Chamber of commerce
Church
Community center
Critical access hospital
Federally qualified health center
Head Start
Health department
Law enforcement
Ohio Northern University
Ohio State University (OSU) Extension
Pregnancy resource center
United Way
Special Supplemental Nutrition Program for Women, Infants,
and Children (WIC)
YMCA

Three main themes were characterized from information the key informants shared during the interviews. Table 1 displays the 3 overarching themes, subthemes of each main theme, and exemplar quotes.

#### **Theme 1: Current Resources Available**

Hardin County is known to be a maternity care desert and HPSA; however, there are some valuable resources in the county. Participants discussed the resources the county has readily available and sometimes not routinely tapped into, such as the federallyqualified health center, mobile health clinic, YMCA, and OSU Extension. Figure 1 shows the resources in Hardin County that the participants specifically named as potentially helpful for repro-

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ductive-age women and designates the location of Kenton and Ada, the 2 communities with the largest population in the county.

While mentioning the current assets in the county, key informants also recognized there are many resources missing from both inside and outside the health care system in Hardin County that are necessary for all members of the community. For instance, one participant said:

We have no pediatricians in the county—so it's not only the health of women but it's the health of girls as well. (KI-14)

She went even further to expand on how the lack of resources can hinder the community and said:

...access is a problem, education is a problem. Unless we change generationally, it will continue as a cycle, then the children pick up the cycle and we are back to where we are before....(KI-14)

Several participants indicated that many women had to go outside of the county to access health care services or did not get needed care due to cost or transportation issues.

#### **Theme 2: Community Observations**

Many participants mentioned their observations of needs in the community or the hardships in Hardin County resulted from being a rural community and small-town culture. Some of the barriers or challenges mentioned were social determinants of health including poverty and low educational attainment, as well as geographic issues from lack of access or transportation. As a participant explained:

Our number one disparity is poverty in the county—but the health care system in the county is not going to overcome poverty itself. There are so many different players to improve the poverty within the county.... (KI-14)

Compounding these challenges is a lack of childcare options. Several participants mentioned this as a barrier preventing women from obtaining services or participating in events to improve their health. A participant shared:

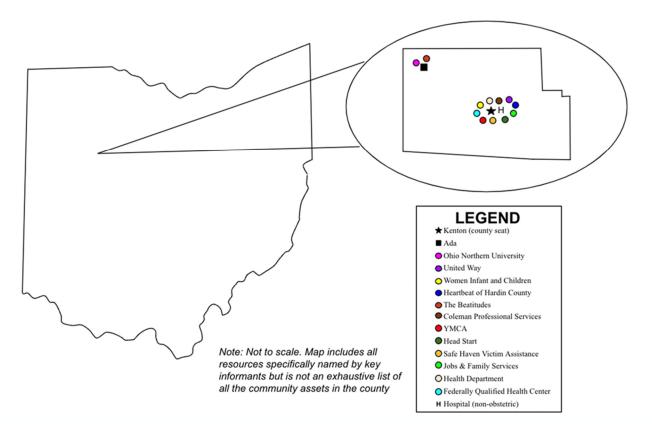
...they don't always have someone to watch their kids. So you know maybe that is a stumbling point—they don't have anyone to watch their kids, so they don't even think about going to things. (KI-3)

Low health literacy and difficulty in reaching members of the community were also brought up by multiple participants. One indicated:

...we get that quite often that people believe that they are educated enough and they don't need more education. I don't know if that's a learned behavior from past generations....I think it comes down to not being educated enough about what you do 6 months prior to getting pregnant is just as important as what you do while you are pregnant. (KI-12)

#### **Table 1. Thematic Analysis**

Theme	Subtheme	Representative quotes
Current resources available	Inside the health care system	"when you are in a very rural area and you don't have access to maybe big health organizations for care, you can still seek that care[with the pandemic there are] virtual visits for everything I think that's been a good effort that will continue postpandemic." (KI-2)
	Outside of the health care system	"We have the Heartbeat of Hardin County which provides some things like car seats, smoking [ <i>sic</i> ] detec- tors, courses to help new moms with raising children. We have reading programs in the county, we have a GED program in the county as well that has been very beneficial in trying to help women." (KI-14)
Community observations	Determinants of health	"I think a lot of it kind of correlates when you live in a lower income community and you have lower edu- cation status I don't think we are a very future-minded cultureand we don't think about how those things will affect our future or our kids' future." (KI-11)
	Barriers and needs	"I think access to care is definitely probably at the top, as far as not having professionals we need at a rea- sonable distance, we do have a pretty large issue with poverty here. Even if they [health care professionals] were in the county, I still think we would run into issues with transportation We only have 2 grocery stores [in] Kenton and 1 in Ada, besides dollar stores and suchwe're kind of in a desert area." (KI-12)
	Small-town culture	"They are not very good in the county about someone coming from outside of the county and being an expert on something and telling them how it goes. They are more likely to trust a grassroots effort coming in from neighbors, friendspeople that they knowa community member they trust." (KI-14)
Suggested intervention strategies	Partnerships	"a couple of my ideas would be to partner with other agencies such as the Kenton Community Health Center, or um partnering with um ob/gyns to spread the information or hold clinics and/or um post short videos on Facebook that link with the hospital and things like that." (KI-6)
	Education and outreach	"They are going to go to some of the more entertainment components than they are to a health fair. So if we can sort of capture some of those in those areas where they are showing up because of entertainment, or they are showing up because of a club like 4H or Girls [ <i>sic</i> ] Scoutswe may be able to get to women there because that's where we have women participating in the county." (KI-14)
	Clinical	"I think women are much more comfortable with some of the women's health services when they see women health care providers or they know it's dedicated to women." (KI-14)



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Figure 1. Resources Identified by Key Informants for Reproductive-Age Women in Hardin County, Ohio

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#### Another said:

It's so hard with Hardin County, to try to get the word out about things is so hard. So, even if there are things available, most people don't know it.... Those of us who know what the strengths are, we can't get the information out.... How do we get to them? (KI-3)

In addition to the hardships, there was also mention of the benefits of small towns, such as their close-knit relationships and trust of other community members. A participant observed:

I think in general the community really wants to help each other, and there's a lot of people in the community that care...and want it to be better—and you don't get that everywhere, so I think that if people realized that and took advantage of that, our community would be a lot better off. (KI-11)

#### **Theme 3: Suggested Intervention Strategies**

Some key informants from Hardin County have attempted interventions to improve health and mentioned their success and failures to suggest what interventions may be best for Hardin County in the future. Suggested intervention strategies included partnerships between organizations, improving education and awareness outreach, and increasing access to clinical facilities and services. Table 2 organizes the recommendations based on the socioecolog-ical model.<sup>30</sup>

Participants went on to provide additional perspectives regarding their proposed intervention strategies. One participant suggested using the small-town culture of the community as a foundation of intervention strategies and said:

I think that because there are so many close families here...if you can convince one family member, you're in [laughs], because a lot of people in the county have family in the county...if you connect with someone about their health, that they likely will share it with their family members. So I think if you can get into one person it could spiral in a positive way. (KI-2) Several participants mentioned that incorporating entertainment would be helpful to capture and maintain residents' attention. Others reiterated the importance of childcare to enable women to utilize services, or that organizations should provide on-site activities for children. As one participant stated:

If there was something for their kids to do when they came, they'd probably come more. If they have kids already, it's all about their kids—so if they've got to deal with their kids, they're not going to come...[you need] something for the kids to do. (KI-3)

Finally, many participants indicated that in their experience, providing education and outreach at an event already attended by women, such as fairs or high school football games, increased participation as compared to stand-alone events where it was hard to attract attendance.

#### **DISCUSSION**

To our knowledge, this is the first qualitative study to interview representatives of community assets to better understand the landscape regarding health among rural, reproductive-aged women in the US. The results of this study provide important insights from key informants to improve or maintain health for reproductive-age women in rural northwest Ohio. Three themes were characterized from the data: current resources available, community observations, and suggested intervention strategies.

Key informants identified resources both inside and outside of the health care system currently available in the county. This is significant as many residents who live in rural areas have low health literacy<sup>10</sup>; further compounding this challenge is that many do not know the resources available to them.<sup>22</sup> Raising awareness about such resources is paramount to increasing their utilization and impact. However, when examining Figure 1 it becomes apparent that many of the resources cited by the key informants are concentrated in the county seat of Kenton which may limit their accessibility to women living in the outlying areas. This demonstrates a continued need to establish more assets across the county. In ad-

Table 2. Intervention Strategies Suggested by Key Int	ormants
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Socioecological Model Level	Suggested Intervention Strategies
Individual	Provide education on the importance of preconception/interconception health and care Provide information on women's health including common diseases, symptomatology, and preventative care guidelines
Community	Create partnerships between organizations and other resources in the county Perform education/outreach in-person at events such as football games, fairs, etc and utilize media such as billboards, social media, flyers, etc Develop transportation services Provide free and low-cost clinical services Recruit more female health professionals Recruit more clinical services to be based in the county Recruit clinic staff (nurses, receptionists, etc) from the county Establish a women's health center (not exclusively focused on reproductive health) to provide comprehensive care to women Expand existing clinics' hours Provide childcare options
Policy	Adapt health education standards in schools to include further depth into women's health and preconception health and care

dition, all but 3 of the resources named by the key informants had direct links to provision of or access to clinical health services. Although key informants often mentioned issues related to social determinants of health during their interviews, they did not tend to list resources addressing such challenges (such as food banks or other charitable organizations) when asked about available resources for reproductive-age women. Key informants also mentioned important deficits in the county. For example, the lack of pediatricians may mean that girls are not receiving the clinical care they need and may be entering their reproductive-years in suboptimal health. The life course perspective must be taken into account, realizing that the foundation for good preconception health begins far earlier than the onset of puberty and involves resources both inside and outside of the health care system.<sup>31</sup>

Key informants also shared their observations about Hardin County. Consistent with previously-published literature,<sup>8-13</sup> key informants indicated poverty as well as limited access to health care resources, transportation, and healthy foods as potential barriers to optimal health for reproductive-age women. Furthermore, many stated the difficulty in making residents aware of the resources available to them, because they may not perceive the need to avail themselves of the resources and there is not one medium readily available to communicate about the resources to all members of the community. However, there was a sense that there were strengths that the community derived from its small-town culture that could be better utilized to improve or maintain women's health.

Additionally, key informants made recommendations to improve preconception and interconception health at the individual, community, and policy levels. This is valuable as it can be used to inform the development of needed interventions. Many spoke of the need for a multipronged approach built on partnerships and utilizing both traditional and social media outlets as well as established venues that women already attend. When developing these interventions, planners should take care to ensure they are comprehensive and address both upstream (social and policy issues) as well as downstream (biomedical and lifestyle issues) factors that impact health.<sup>31-33</sup>

Finally, 3 issues emerged that crossed multiple themes, indicating these may be priority areas to address. One of these was lack of childcare readily available in the county that serves as a barrier for women to receive services or attend programming. Another regarded the intergenerational cycle where women use older generations in the family as knowledge sources. This was indicated to be, at times, both a barrier (eg, when women have the perception that they do not need any education about a particular topic) and a benefit (eg, recognizing that information is likely to be shared among family members) when trying to raise awareness about preconception/interconception health. The third was trust, with a recognition that improving women's health in the county will likely not be successful if it is not a grassroots effort or if residents don't see their peers represented.

There are 2 major limitations to this study. The key informants consulted were extensive, but not exhaustive. For example, there was not an opportunity to speak with a physician or with staff from certain nonprofit organizations, such as food banks, who may have been able to provide further insights. In addition, the population of Hardin County is not racially or ethnically diverse<sup>34</sup>; therefore, while these findings and recommendations may be helpful to counties with similar demographic profiles, they may not be applicable in rural communities with more diversity.

Future studies could utilize the methodology described here to ascertain barriers and recommendations for preconception and interconception health in other type of communities, such as urban areas, or other rural areas such as rural Appalachia, which has distinct cultural differences when compared to northwest Ohio. This information could then be used to guide potential interventions to improve preconception/interconception health at the individual, community, and policy level. Once the interventions are implemented, repeating interviews with key informants may yield insights into their effectiveness, needed changes, and new gaps to be addressed.

#### PUBLIC HEALTH IMPLICATIONS

Good preconception/interconception health is important for all reproductive-age women, regardless of their intent to conceive, as it reflects their personal health.<sup>1-4</sup> In addition, given that fact that nearly half of pregnancies in the US are unintended,<sup>35</sup> ensuring good preconception/interconception health can help to mitigate risks that could adversely affect a pregnancy.<sup>1-4</sup> However, women may not know of or utilize local resources that can improve or maintain their health.<sup>22</sup> Key informants can be consulted in order to collate information regarding community assets. Furthermore, they can provide perspectives regarding new strategies or services. The findings from this study will be helpful not only to Hardin County but also for similar rural communities. Communities that are different than Hardin County can utilize the methodology shared here to do their own studies to gain insights relevant for them.

#### ACKNOWLEDGMENTS

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#### APPENDIX. Key Informant Interview Guide

#### INTRODUCTION

Thank you for taking the time to participate in this interview. During the next half hour, I will be asking questions about women's health in Hardin County. First, I would like to hear about your beliefs on the health needs of your community. I will then ask questions about health care access for women in your community. We will end our discussion by asking you to provide any information that you feel is important that we may have missed.

The information you give us will allow us to better understand what women in Hardin County believe to be their most important health needs. It will also give us information on how to best provide education about prepregnancy health.

We would like to audio record our discussion today so that I can go back and listen to make sure we don't forget anything you say. You may ask for the recorder to be stopped at any time.

At the end of the interview, we will gather your contact information so we can send you a \$20 Dollar General gift card as a thank you for your time. We will not use your name or give any information that would allow someone to recognize you. Do you give us permission to interview you for this study and share your anonymous answers publicly?

Do you have any questions before we begin?

#### **Begin Recording**

Please state your current job title and the name of the organization you work for.

How long have you worked at [insert name of organization]?

How long have you lived in Hardin County?

Follow-up: If you do not live in Hardin County, how long have you worked in Hardin County?

I will ask questions about "prepregnancy health" and "prepregnancy care". "Prepregnancy health" is the state of health and well-being during the years when women can become pregnant, usually up to age 45 or so. "Prepregnancy care" refers to health care services that improve women's health and the health of the baby before becoming pregnant. When we ask questions about your thoughts regarding health for women in Hardin County, we are talking about younger women who are under 50 years old.

Do you have any questions?

We are going to begin with talking about the needs of women in your community.

#### PERCEIVED NEEDS

1. What do you think is the most important health need for women in Hardin County?

Follow Up: What do you think are the causes of the health problems that you mentioned?

Follow Up: How are women affected by these needs or problems?

2. Is there anything being done to solve the health problems that you talked about? If so, could you explain them to me?

Follow Up: What specific activities or services are targeted at women? If so, what are they? If not, what could there be? Follow Up: Do you think more can be done for women in the community, and if so, what could be done?

3. A recent study identified high blood pressure, overweight/obesity, smoking, and lack of exercise as problems for women in Hardin County. Do you think these are important issues to be addressed? Why or why not?

**Probe:** Do you think these problems are bigger than the ones you told me? Why or why not?

4. Many women we talked to in Hardin County did not want information on how to be a healthy woman or how to have a healthy baby. Why do you think that might be?

Follow Up: What do you think is the most important information to educate and talk to women about?

Follow Up: What do you feel like is the best way to educate and talk to women in Hardin County about women's health?

Probe: When is the best time to inform women and why?

Now that we have talked about the health needs, we are going to talk about the access to health care and the barriers that women in your community face.

#### BARRIERS TO CARE

1. What barriers or challenges do women face when trying to use health care services?

**Probe:** Would you say the barriers/challenges for women are more because of personal reasons like not having the time, reasons out of their control like transportation, or reasons regarding the providers or clinics themselves?

Follow Up: What do women do if they cannot access care in your community?

2. Why do you think so many women are turning to doctors and midwives only after they get pregnant or if they are having trouble getting pregnant, and not before?

Follow Up: How do you think we can talk to women about utilizing other health services prior to pregnancy/trying to get pregnant?

3. What do you see as the strengths in your community that can help people be healthy or stay healthy?

- Probe: Are there services, organizations, resources, or facilities there? If so, what do they provide?
- Follow Up: How do you think we can talk to women about utilizing these strengths [insert their response]?

4. Are you aware of the mobile health clinic from Ohio Northern, called HealthWise?

Follow Up: Have you recommended women ages 18-45 in the community use it? Why or why not?

Follow Up: How do you think we could increase use of HealthWise services among women ages 18-45?

5. What support do you think women in your community need for improving their health (whether that's from a partner, other family member, community, organization, etc)?

#### CLOSING

Those are all of the questions I have for you today. Before we end, is there anything that you feel is important that we missed and you would like to tell me? Are there any questions you have for me?

Thank you again for taking the time to participate!

#### **End Recording**

#### Collect address to send gift card.

#### Note:

Questions 2 under "Perceived Needs" and "Barriers to Care" were adapted from Bortolus R, Oprandi NC, Rech Morassutti F, et al. Why women do not ask for information on preconception health? A qualitative study. BMC Pregnancy Childbirth. 2017;17(1):5. https://doi.org/10.1186/s12884-016-1198-z

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# Increasing Parenting Self-Efficacy Through a Community Partnership in Akron, Ohio

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#### ABSTRACT

**Background:** The Nurturing Family Program (NFP) is a family-centered educational curriculum designed to equip parents with tools and techniques to support a nurturing relationship with their child. While there have been many evaluations of the NFP, no evaluations to date measure how the curriculum may influence parenting self-efficacy, how confident a caregiver feels about their ability to foster their child's development and success, or parenting stress.

**Methods:** This community-based interventional study used a convenience sample of families recruited from community agencies or within a pediatric medical center. Families with one or more children aged 0 to 5 years, premature infants or an infant discharged from the neonatal intensive care unit (NICU), and/or adolescent parents were invited to participate in NFP. Participants were recruited from community agencies that were most likely to work with populations meeting program eligibility criteria. The NFP was offered as in-home and community-based sessions.

The primary outcome of interest was perceived parental self-efficacy, measured using the Tool to Measure Parenting Efficacy (TOPSE) at weeks 1, 5, and 10. The secondary outcome of interest was perceived level of stress, as measured by a visual analog scale each week.

**Results:** Participants of community-based sessions (n = 45) experienced a significant increase in parenting self-efficacy at week 10, compared to week 1 and week 5 (p < 0.01). Overall, participants of the community-based sessions experienced an average increase of 17.7 points on the TOPSE scale (p = 0.014). Across all participants (n = 79), each session attended resulted in a modest, but significant, 3% reduction in stress (p = 0.021).

**Conclusion:** The NFP improved parental self-efficacy among participants of the community-based sessions and reduced perceived stress for all participants.

Keywords: Nurturing family program; Parenting; Community; Self-efficacy; Stress

#### **INTRODUCTION**

Early life experiences matter not only in terms of early childhood development but also because of the impact on educational, health,

and economic outcomes across the lifespan.<sup>1,2</sup> Programs, policies, and practices most likely to improve child and family health outcomes are those that include a focus on supporting responsive relationships for children and adults, strengthening core life skills,



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and reducing sources of stress in the lives of children and families. Research has shown that these principles are strongly interconnected; strengthening core life skills in parents can decrease stress and increase responsive parent-child interactions.<sup>1</sup>

Parenting is influenced by multiple factors across the individual, interpersonal, community, and societal levels.<sup>3</sup> Parenting self-efficacy can be defined as how confident a caregiver or parent feels about their ability to successfully foster their child's development and success.<sup>4,5</sup> Parental self-efficacy is a core life skill that has been found to be associated with promoting positive child behavioral, emotional, physical health, and social outcomes.<sup>6,7</sup> Parenting difficulties are a major source of stress for parents, and parenting self-efficacy has been shown to be an important buffer against parenting stress. Individuals with strong parental self-efficacy are able to guide their children through the developmental stages they face without serious problems or undue strain on their relationship with their spouse or partner. Individuals low in parental self-efficacy may struggle to meet familial demands and are at risk of stress and depression.<sup>8</sup>

Programs that seek to support and build parental self-efficacy are critical opportunities for promoting relational health characterized by safe, stable, and nurturing relationships (SSNR). The American Academy of Pediatrics (AAP) suggests that such programs are an important component of adopting a comprehensive public health approach, and require effective collaboration between the pediatric health system, families, and community partners.<sup>2</sup> This article describes outcomes of the Nurturing Family Program (NFP) offered through a partnership between a pediatric medical center, families, and key community partners. The NFP is a parenting program that provides tools and techniques to parents to support nurturing relationships.9 While the NFP has been found to reduce the likelihood of being reported for maltreatment among program participants, specifically those who attend a high number of sessions,10 no NFP evaluations to date have examined the potential effects of the curriculum on parenting self-efficacy,<sup>11-14</sup> and almost no studies have looked at stress reduction as an NFP outcome.

The primary objective of the study was to explore whether participation in the NFP changed parent perceptions of self-efficacy. Our secondary objectives focused on understanding whether participation in the NFP changed parents' perceived level of stress.

#### **METHODS**

All study methods were reviewed and approved by the Akron Children's Hospital institutional review board (IRB # 17-2160).

#### **Procedures/Program Description**

The NFP, also referred to as the Nurturing Parenting Program, is a family-centered educational curriculum designed to equip parents with tools and techniques to support a nurturing relationship with their child.<sup>9</sup> The NFP can be customized to needs of specific populations, such as children with special needs or parents who are incarcerated.<sup>15,16</sup>

Parents and their children participated in weekly NFP sessions for 10 weeks, with each session lasting approximately 2.5 hours. A description of topics discussed during each session is outlined in the Appendix. Both the in-home and community-based groups received the same curriculum. Families in both the in-home and community-based groups were also provided a kit, which included developmentally appropriate toys and books, educational materials, and a community resources guide. This program was offered 7 times over 2 years (n= 10 sessions x 7 programs = 70 total sessions) and all participants were invited to engage in the research study component. The program facilitators were employees of the pediatric medical center, and the community partners provided the space for the group sessions. Importantly, all parents who participated in NFP received the same intervention. Only parents who elected to participate in the research study component were asked to complete assessments to measure parenting self-efficacy and stress.

This was the first time NFP was administered in Akron. The NFP was chosen to respond to increasing rates of child abuse and neglect, identified as a community health need through recent assessments.<sup>17,18</sup>

#### Setting

Akron is an urban city with a strong, cross-sector collaborative approach to improving community health. As the fifth largest city in Ohio, slightly more than 190 000 people live in Akron.<sup>19</sup> According to the 2020 Census, 6% of residents are under 5 years of age, with 21% of residents under the age of 18 years.<sup>19</sup> Nearly 60% of people living in Akron self-identify as White, 30% as Black or African American, and 5% as Asian.<sup>19</sup> About half of the homes in Akron are owner-occupied and median monthly rent is \$759.19 Neighborhoods throughout Akron experience multiple poor outcomes that endanger relational health and support the need for parenting programs, including preterm birth, low birthweight, lead exposure, social isolation, changing family structure, chronic poverty, parenting stress, family disorganization, violence, parent history of neglect and abuse in family of origin, and parental beliefs and knowledge about the role that they play in the development of their children.20

#### **Community, Participant Characteristics, Recruitment**

Members of the collaborative clinical, community, and local governmental partnership played an active role in recruitment and implementation. Families were referred to the NFP through community agencies, as well as through Akron Children's Hospital's Maternal and Fetal Medicine (MFM) and Neonatal Intensive Care Unit (NICU). Families (also referred to as participants) were invited to participate in the program if they met one or more inclusion criteria: (1) were parents of one or more children aged 0 to 5 years, (2) were parents of a premature infant or an infant discharged from the NICU, and/or (3) were adolescent parents. Families involved with the court system, or child protective services, were excluded due to challenges in obtaining consent to partici-

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pate in either the NFP or the research study component. Additionally, families for whom English was not their primary language were also excluded due to lack of accurately translated and validated teaching materials.

Families recruited through community partners selected their preferred location for NFP, either individual sessions in their home or group sessions at a community partner site, depending on which was most convenient for their family. Parents who were recruited through hospital providers and staff were offered individual sessions in their home, also referred to as the in-home NFP program, but could also choose group sessions at a community partner site, referred to as the community-based NFP program. Parents recruited through both strategies were invited to participate in the research study component of the program. Participation in NFP was voluntary and engagement in the research study component was optional. At the beginning of the first session, informed consent was obtained by research staff from parents who elected to participate in the study. Staff reviewed the entire consent form with each parent and answered any questions before obtaining their signature. The research study component began October 1, 2017, and concluded September 30, 2019.

#### Measures/Outcomes

Demographic data were collected at week 1, and attendance was tracked weekly. Outcome data focused on changes in perceived parenting self-efficacy and changes in reported stress. Parenting self-efficacy was measured at weeks 1, 5, and 10 by the Tool to Measure Parenting Efficacy (TOPSE).<sup>21,22</sup> Based on self-efficacy theory, the TOPSE instrument consists of 48 items divided into 8 subscales/parenting dimensions: emotion and affection (I am able to show affection towards my child); play and enjoyment (Playing with my child comes easily to me); empathy and understanding (I am able to comfort my child); control (I can remain calm when facing difficulties); discipline and setting boundaries (I am able to reason with my child); pressures (It is difficult to cope with other people's expectations of me as a parent); self-acceptance (I can manage the pressures of parenting as well as other parents do); and learning and knowledge (I am able to learn and use new ways of dealing with my child).<sup>21,22</sup> Internal reliability for the subscales ranges from 0.80 to 0.89 with the overall reliability at 0.94.22

Stress was measured weekly through the use of the visual analog scale (VAS), an efficient, empirically based method widely used to measure perceived stress.<sup>17</sup> As participating families filled out their attendance form at each session, they were asked to *"Indicate on this scale how stressed you feel at this time"* by marking on a 10 cm line. The left endpoint was labeled "no stress" and the right endpoint was labeled "high stress." Trained research staff measured the number of centimeters starting from the left endpoint to the nearest quarter of a centimeter. All data were collected through paper and pencil, and acquired prior to the start of the NFP session. Data were then entered by trained research staff

into an Excel database for analysis. A table outlining the data collection timeline is available in the Appendix.

#### **Statistical Analysis**

Data were imported into SPSS statistical software<sup>23</sup> and analyzed via 2-sided statistical testing with p < 0.05 considered statistically significant. Participant characteristics were summarized by program location using frequencies and percentages for categorical data and means and standard deviations for numeric data. Comparisons of the distribution of categorical data between program locations were performed via Pearson chi-square or Fisher exact test depending on cell sample size. For analysis of a possible effect of the program location (in-home versus community-based), TOPSE scores were compared via repeated measures ANOVA with a between group effect for program location. The repeated measures analysis of variance (ANOVA) model had an unfulfilled assumption of sphericity verified via significant Mauchly test of sphericity. A Greenhouse-Geisser correction for non-sphericity was then employed in determining the effect of study time point on the TOPSE score outcome.

Since the effect of time was significant in the repeated measures ANOVA model, data were compared across locations at each of the study time points. Data were compared for rank equivalence between location at each of the week 1, 5, and 10 study time points via Mann-Whitney U tests. These tests were employed due to failed normality assumptions required for independent samples t tests. Data were subsequently aggregated across the 2 program locations due to insignificant location main effects. Pairwise leastsignificant difference tests determined which study time points were significantly different in mean TOPSE scores. The primary analysis of the mean change in TOPSE scores from week 1 to week 10 study time point was performed on the aggregated cohort across locations. A paired samples t test compared the mean change for equality to zero since the aggregated sample size allowed for invocation of the central limit theorem. A sensitivity analysis was also performed to determine the relative influence of outliers and those who dropped out prior to week 10. Missing data were imputed using the week 5 TOPSE value or week 1 TOPSE value if unavailable carried forward to week 10 for those subjects with missing week 10 TOPSE values. Changes in specific domain scores of the TOPSE from week 1 to week 10 were also analyzed similarly to the overall change score.

The other measures involving numeric metrics (demographics, attendance, VAS stress) were correlated with the change in TOPSE score to week 10 to determine factors that might have significantly influenced gains in self-efficacy. Changes in VAS stress from week 1 to week 10 were assessed using a paired samples t test and the correlation with class attendance determined. This significant correlation prompted the use of a linear regression model to determine the influence of class attendance on reductions in parental stress.

#### **RESULTS**

#### Participant Characteristics

Over two-thirds of families participating in the NFP also elected to participate in the research study component (79/117 = 68%). Characteristics of families who participated in the research study component are presented in Table 1. Across both groups, the majority of participants were single (in-home: 84%, community-based: 80%), had a high school diploma (in-home: 50%, community-based: 55%), and an annual household income less than \$15 000 (in-home: 83%, community-based: 67%). The in-home and community-based groups did not differ significantly on marital status (p = 1.000), education level (p = 0.335), or annual household income (p = 0.269). However, the percentage of participants currently pregnant was significantly different between the in-home and community-based groups (25% vs 50%, p = 0.031).

#### Attendance

The average (SD) class attendance out of 10 classes was 6.8 (3.29) classes across the 2 groups. There was a significant difference in the mean (SD) attendance between the in-home and community-based groups (8.1 (2.23) vs 5.8 (3.63), p = 0.001).

#### Parental Self-Efficacy

Changes in self-efficacy were measured by the changes in TOPSE overall scores from week 1 to week 10. In-home participants were significantly less likely to drop out early (p < 0.001, Table 2). The

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effect of program location on the total TOPSE score across the three study time points was insignificant (p = 0.799, partial eta squared effect size = 0.02) so analysis was conducted on the aggregated program data across study arms. However, the repeated effect for time was highly significant, indicating that TOPSE scores differed across the 3 measurement time points (p = 0.003 via Greenhouse-Geisser adjustment for sphericity violation).

A post hoc least-significant differences (LSD) procedure was performed to determine pairwise distinction across the 3 time points. Weeks 1 and 5 were comparable on average (p = 0.642); however, each differed significantly from week 10 (p < 0.01 for each). Participants exhibited a significant increase in parenting self-efficacy during the second half of the program. The significant mean (SD) increase of 17.7 (46.55) (p = 0.014, Table 2) reaffirms the repeated measures results to indicate significant improvement in TOPSE for those participants completing the week 10 assessment. A sensitivity analysis was also performed imputing a value of zero improvement for those not completing the week 10 assessment to reveal similarly significant results (p=0.015). The sensitivity analysis indicates that the conclusions of significant improvement in TOPSE are consistent even after adjustment for the influence of attrition. The significant gains in TOPSE at week 10 relative to week 1 were further probed by looking at the specific domains that comprise the validated metric. Each of the 8 domains exhibited mean improvement; significant gains were determined specifi-

#### Table 1. Characteristics of Nurturing Family Program Participants in Akron, Ohio (n=79)

	In-Ho (n=34		<b>Comm</b> ( <i>n</i> =45)	unity-Based	P value	<b>Total</b> (n=79	
Characteristic	n	<i>`</i> %	n	%		n	<i>`</i> %
Children residing in the home, mean (SD) Classes attended (out of 10), mean (SD)	1.6 8.1	(0.99) (2.23)	1.4 5.8	(1.21) (3.63)	0.349 0.001	1.5 6.8	(1.12) (3.29)
Marital status Single Married Partnered Divorced Separated Missing	26 4 1 0 0 3	(83.9) (12.9) (3.2) (0.0) (0.0)	32 5 1 1 1 5	(80.0) (12.5) (2.5) (2.5) (2.5)	1.000	58 9 2 1 1 8	(81.7) (12.7) (2.8) (1.4) (1.4)
Education level GED High school diploma Associates degree Bachelor's degree Trade Other Unknown	4 13 3 0 3 3 8	(15.4) (50.0) (11.5) (0.0) (11.5) (11.5)	2 18 4 1 4 1 4 12	(6.1) (54.5) (12.1) (12.1) (3.0) (12.1)	0.335	6 31 7 4 4 7 20	(10.2) (52.5) (11.9) (6.8) (6.8) (11.9)
Annual household income Less than \$15000 \$15 000 < \$20 000 \$20 000 < \$25 000 \$25 000 < \$30 000 \$30 000 + Missing	25 2 3 0 0 4	(83.3) (6.7) (10.0) (0.0) (0.0)	22 6 2 1 2 12	(66.7) (18.2) (6.1) (3.0) (6.1)	0.269	47 8 5 1 2 16	(74.6) (12.7) (7.9) (1.6) (3.2)
Currently pregnant No Yes Missing	24 8 2	(75.0) (25.0)	20 20 5	(50.0) (50.0)	0.031	44 28 7	(61.1) (38.9)

SD: standard deviation

Note: P value for children in home, classes attended from independent samples t test. P value for marital status, education level, household income from Fisher's exact test. P value for current pregnancy status from Pearson chi-square test.

#### Table 2. Outcomes of the Nurturing Family Program in Akron, Ohio (n=79)

	In-Home			inity-Based	P value	Total	
	(n = 34)		(n = 45)			(n = 79)	
Outcome	Mean	SD	Mean	SD		Mean	SD
TOPSE					< 0.001		
Total score data availability, n (%)							
Baseline	34	(100.0)	45	(100.0)		79	(100.0)
Week 5	29	(85.3)	26	(57.8)		55	(69.6)
Week 10	28	(82.4)	19	(42.2)		47	(59.5)
Baseline total score	403.0	(51.85)	395.6	(51.47)	0.387	398.8	(51.42)
Week 5 total score	413.2	(36.84)	399.1	(56.55)	0.656	406.6	(47.24)
Week 10 total score	423.0	(46.31)	435.3	(44.41)	0.344	427.8	(44.41)
Change in total score (Week 10 - Baseline)	16.0	(44.94)	20.4	(50.38)	0.842	17.7	(46.55)
P value	0.063		0.079			0.014	
n	28		17			45	
Change in total score (Week 10 - Baseline) with imputed values of 0 for all dropouts					0.015	10.1	(36.05)
VAS							
Baseline score						3.74	(3.28)
Week 10 score						2.48	(2.81)
Change in score (Week 10 - Baseline) Percentage change					0.041	-1.26 33.69	(4.05)
Correlation between number of classes and score					0.021	-0.100	
Linear regression slope of VAS regressed on class					0.021	-0.109	

SD: standard deviation

TOPSE Notes: *P* value for all between group numeric comparisons via Mann-Whitney U test. *P* value for all within location group comparisons via signed rank test. *P* value for all cohort within group change comparison to 0 via paired samples t test. *P* value for TOPSE Total data availability via Pearson chi-square test. Time is a significant within group factor in TOPSE Total Score (p=0.003 via Greenhouse-Geisser adjustment, partial eta squared effect size=0.139). Study Arm interaction with time interaction was insignificant (p=0.691) and subsequent main effect only model (p=0.799) and both were removed from the model. Pairwise comparisons of time using protected LDS procedure revealed baseline and week 5 to be comparable (p=0.642) however comparisons to week 10 were significant (p<0.01 for each).

VAS Notes: P value for all cohort within group change comparison to 0 via paired samples t test. Only those participants with both baseline and week 10 values are included in baseline and week 10 summaries.

cally for discipline and boundaries, control, and empathy and understanding (p < 0.001, p = 0.011, p = 0.023 respectively).

#### **Parenting Stress**

Parenting stress significantly decreased from week 1 (mean=3.74) to week 10 (mean=2.48; p=0.041, Table 2). This reduction represents a 34% decrease in stress over the 10-week study period for those providing week 10 data. The correlation between number of classes and VAS scale was calculated to explore a per class trend in stress reduction to include all participants and not just those who provided week 10 data. A significant negative correlation (r = -0.100, p = 0.021) indicates that class attendance was significantly associated with reduced stress, regardless of whether the participant completed the program. Each class attended contributed a modest but significant reduction in stress of 0.109 (3%) as measured by the VAS.

#### **DISCUSSION**

The purpose of this study was to evaluate the effects of a parenting program offered through a collaboration between a pediatric hospital and community agencies that included local housing authorities and a mental health agency. The study looked at changes in 2 key parenting variables shown to be critical determinants of relational health: self-efficacy and stress. Parenting self-efficacy in both program locations improved significantly over time. Changes were especially strong in 3 domains: empathy and understanding; control; and discipline and boundaries. Parenting stress in both locations also significantly decreased from week 1 to week 10. The increases in self-efficacy and the reduction in stress over time reflect the interconnectedness among the 3 principles to improve child and family outcomes: supporting responsive relationships, strengthening core life skills, and reducing sources of stress for children and adults.<sup>1</sup>

Program attrition rates have consistently been a challenge in evaluating parenting programs serving vulnerable populations. Multiple studies have indicated attrition rates ranging from 30% to 70%.<sup>24</sup> In this study, the use of sensitivity analysis indicated that the changes in TOPSE scores continued to be significant even after adjusting for the influence of attrition. However, attrition was indeed higher in the community-based group, suggesting possible barriers such as transportation, child care, or feeling uncomfortable in a group setting.

The findings did show that the more sessions parents attended (or the greater the "dosage" of intervention), the greater was the increase in self-efficacy scores and the greater the decrease in parenting stress levels. The significant changes appeared to have occurred between week 5 and week 10. Perhaps the changes were due not only to simply "showing up" week after week, but also due to increased *engagement* over time with the program. Engagement is affected by a variety of provider, parent, program and neighborhood characteristics, and is more multidimensional than "showing up;" it includes aspects such as listening, asking questions, asking for advice, and applying the information between Ohio Journal of Public Health, August 2022, Vol. 5, Issue 1 ISSN: 2578-6180

sessions.<sup>25</sup> Any future parenting program evaluation should consider a closer look at potential engagement factors and measure more than attendance.

While this study has many strengths, results should be considered in light of its limitations. First, as described in the Methods section, the study used a convenience sample to evaluate the program. Next, collection of additional demographic data from participants might have identified additional mediating engagement variables that could have helped explain, for example, why the inhome group and community-based group differed in terms of length of participation. Long-term follow-up after session 10 was not possible, so it is not known if participants were able to maintain the short-term significant changes in self-efficacy and stress in the months after program completion. Additionally, the study was completed in a single geographic and urban area and may not be generalizable to communities across the state. Lastly, analyses were limited by consistency in program participation. Nevertheless, the finding that increased participation in a parenting program led to stronger outcomes such as self-efficacy and decreased stress is consistent with other recent research.<sup>26</sup> As a result, the collaborative partners continued the program throughout the pandemic and continue to offer the program today. Importantly, the NFP was administered in a virtual environment at the onset of the pandemic and continues to be administered in virtual individual and group sessions today. Future evaluations should explore whether the same positive outcomes will be experienced by families participating in a virtual setting.

#### PUBLIC HEALTH IMPLICATIONS

The 2021 AAP Policy Statement (*Preventing Childhood Toxic Stress: Partnering with Families and Communities to Promote Relational Health*) describes a vision for a comprehensive public health approach to building "relational health," a key predictor of many aspects of wellness later in life.<sup>2</sup> The AAP vision emphasizes a public health approach that not only addresses toxic stress but also addresses, promotes, and repairs relational health, and is collaborative in nature so that a variety of interventions are integrated both vertically (within the health care system) and horizontally (with community agencies). A public health approach is crucial since no one system alone can successfully reduce the burdens of toxic stress and promote or repair relational health in vulnerable communities.<sup>27</sup>

Although small in size, the study can be seen as a promising step toward building a successful and comprehensive community public health approach to improve outcomes for children and families. The development and implementation of the program was in response to data from a community-wide public health assessment that identified neighborhoods experiencing poor outcomes for children and families. The effort was led by the pediatric hospital in collaboration with community partners serving those neighborhoods. The parenting program was chosen based on its focus on building relational health and SSNRs. Although outside funding supported training for the session leaders and the initial implementation and evaluation of the program, the program is now financially supported by the hospital. The collaboration with community partners continues to grow.

This study describes an approach and model for building "relational health" not only between parents and children, but also between a medical center and surrounding community agencies. Communities considering replicating such an approach will have many decisions to make: What does our community needs assessment data tell us? What population shall we serve? What program or intervention shall we choose? Who will take the lead? Who will work in partnership with the lead? How can we recruit families and keep them engaged? How will we know if our approach is successful? Such an effort is not without its challenges and bumps in the road; however, the hard work involved in designing a response to community needs assessment data can have long-lasting positive effects for children, families, and communities.

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#### APPENDIX

Detailed Curriculum

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#### Session 1: Welcome

**Session 1** introduces the program themes, discusses nurturing parenting principles and how parents impact a child's emotional development, describes personality traits and how they relate to parenting, defines ways parents can become nurturing parents, and encourages parents to discuss their hopes and fears.

#### Session 2: Building Joy and Praise

**Session 2** is designed to improve parents' and children's self-worth and self-concept. Participants discuss the definitions of self-concept, self-esteem, and self-worth; realize their ability to impact a child's overall feeling of worth; learn about labels and how they hurt children; and explore ways parents can improve their children's self-concept, self-esteem, and self-worth.

#### Session 3: Discipline

**Session 3** is designed to increase parents' awareness of the other ways to discipline besides spanking. Participants discuss why parents spank their children, learn how spanking is detrimental to children, and identify alternatives to spanking.

#### Session 4: Warmth, Needs and Nurturing

**Session 4** is designed to increase parents' skills in developing family morals, values, and rules. Participants discuss family morals, give examples of family morals, relate family morals to family discipline, define family values, define the purpose of family rules, and practice making family rules.

#### Session 5: Problem Solving

Session 5 focuses on brain development and the functions of the brain. Parents learn methods on how to problem solve using a series of techniques and how to handle conflict.

#### Session 6: Ages and Stages

Session 6 is designed to increase parent's awareness of appropriate expectations of children. Participants increase their knowledge of age-appropriate expectations of children and stages of child development.

#### Session 7: Handling Stress and Anger

**Session 7** is designed to increase parents' ability to recognize and handle stress. Participants explore the meaning of stress, identify ways adults create stress, learn about stressors children face and how to help them cope, and learn ways to help parents and children reduce stress.

#### **Session 8: Feelings**

**Session 8** is designed to help parents recognize and understand their feelings and the feelings of their children. Participants discuss feelings of comfort and feelings of discomfort, learn how to help their children understand feelings, learn to recognize feelings in children, and learn how to teach children how to manage their feelings.

#### **Session 9: Communication**

**Session 9** is designed to help parents recognize and communicate their feelings and the feelings of their children. Participants practice how to communicate their feelings in a healthy way, define I-Statements and You Messages, learn negotiation skills and ways to confront without criticizing, and learn to model appropriate communication styles.

#### Session 10: Safety

**Session 10** focuses on how to keep children safe. Participants explore what to look for and how to communicate safety to their children. Tips are suggested based on age and areas of the house, car, babysitter, school, peers, etc.

**NFP Session Number** 7 1 2 3 4 5 6 8 q 10 **Demographic data** х **TOPSE Instrument** х х х VAS for stress х х х х х х х х х х

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Timeline of Data Collection Across Nurturing Family Program (NFP) sessions.



