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# **Examining the Home Interventionist Model of Care in Pediatric Asthma**

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

by Katherine Dempster Lohr

M.S., Virginia Commonwealth University, 2019 B.S., Pennsylvania State University, 2015

Chair:

Robin S. Everhart, Ph.D. Associate Professor, Department of Psychology

Virginia Commonwealth University Richmond, Virginia

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#### Abstract

# EXAMINING THE HOME INTERVENTIONIST MODEL OF CARE IN PEDIATRIC ASTHMA

By Katherine D. Lohr, M.S.

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

Virginia Commonwealth University, 2023

### Chair:

Robin S. Everhart, Ph.D. Associate Professor Department of Psychology

Pediatric asthma disproportionately affects children living in urban areas and within families reporting an income below the poverty threshold. Home interventionist models of care, utilizing interventionists from the communities they serve, have been found to improve pediatric asthma symptoms and reduce Medicaid costs. Home interventionists, such as community health workers (CHWs) and Healthy Homes assessors (HHAs), focus on connecting care among schools, providers, and homes, and empowering families in accessing resources to overcome barriers to care. However, research is just beginning to understand how home interventionists create positive change among families within low-income, urban communities. This dissertation study used a qualitative data approach outlined in the author's NHLBI-funded F31 training grant (PI: Dempster, F31HL158196) and secondary data analysis of an NHLBI-funded Asthma Empowerment grant that tested a randomized clinical trial of the community-based asthma program, RVA Breathes (PI: Everhart, U01HL138682).

Participants in RVA Breathes identified predominantly African American or Black, resided in public housing, and reported an income below \$25,000 a year in Richmond, VA. This

mixed-methods dissertation examined the processes by which interventionists in RVA Breathes assisted families in managing their children's asthma control over an 18-month period. Session notes and internal records from the RVA Breathes intervention were qualitatively analyzed in conjunction with caregiver and interventionist focus groups. Secondary data analyses used multilevel modeling to assess associations among caregiver stress, depressive symptoms, stressful life events, barriers to care, and asthma control over 18-months controlling for group assignment.

Findings highlighted the positive impacts of RVA Breathes on families of children with asthma, even in the face of COVID-19. Caregivers and interventionists also provided recommendations for future intervention efforts. Quantitative analyses found improvements in caregiver stress, depressive symptoms, stressful life events, barriers to care, and asthma control over time. Using multilevel modelling, improvements in caregiver stress and stressful life events were associated with improvements in asthma control over time regardless of group assignment. Findings highlight the benefits of the RVA Breathes program for families of children with asthma and provide evidence for future models of care incorporating home interventionists.

### Introduction

Pediatric asthma, a respiratory disease characterized by chronic inflammation of the airway, is a major public health concern that negatively impacts children living below the poverty threshold (Azmeh et al., 2020). Asthma can be controlled by taking prescribed medications and avoiding environmental triggers that exacerbate coughing, wheezing, and breathlessness (Akinbami et al., 2016; Centers for Disease Control and Prevention, 2022; Shankar et al., 2018). Families of children with asthma often experience missed days of school and work, activity limitations, increased emergency department (ED) visits and hospitalizations, lower quality of life, and increased financial burden (Everhart et al., 2015; Lozier et al., 2019; Pacheco et al., 2014; Sicouri et al., 2017). Children with asthma living in low-resourced areas also experience more asthma-related hospitalizations and school absences compared to children living in higher-resourced areas (Shankar et al., 2018). When COVID-19 began in mid-March 2020, additional barriers to care were introduced to families of children with asthma (e.g., no access to school nurses, increased mental health symptoms, decreased income). Examining these barriers and how they are addressed in a home interventionist model is paramount to minimizing asthma disparities within the context of a pandemic.

Research has suggested that individuals reporting an income below the poverty threshold have higher rates of asthma diagnosis, morbidity, and mortality (Akinbami, 2012; Cardet et al., 2022; Chen et al., 2017; Forno and Celedón, 2012; Hughes et al., 2017), and report worse asthma outcomes compared to those in higher income brackets (Cardet et al., 2018; Keet et al., 2015). Research has also shown that children with poorly controlled asthma are about 2.5 times more likely to have an asthma-related healthcare visit compared to children with an asthma control score in the well-controlled range (Shaw et al., 2022). Furthermore, the odds of asthma-related

healthcare utilization are higher for participants who live in neighborhoods with a median family income <\$50,000 compared to those in higher income neighborhoods (Shaw et al., 2022). It is possible these health disparities based on income are due, in part, to lower health literacy, more mental health challenges, provider bias, and limited healthcare access among low-income caregivers (Canino et al., 2009). In fact, asthma disparities are driven by multiple, overlapping factors.

Research has also documented a high risk of asthma morbidity and mortality among families living in urban areas (i.e., defined as census tracts in large metro center areas with at least 20% of households below the poverty line) (Mak et al., 1982; McConnochie et al., 1999). In a study by Keet and colleagues (2015), children aged 6-17 living in urban areas had a 40% higher risk of asthma-related ED visits and 62.5% higher risk of asthma-related hospitalizations compared to children living in other areas. A child's exposure to environmental triggers often found in low-income housing (e.g., mold, cockroaches, smoke, bleach, humidity) can negatively impact asthma prevalence and symptomatology (Alicea-Alvarez, 2016; Keet et al., 2015; Keet et al., 2017). Pediatric asthma interventions have attempted to minimize children's exposure to environmental triggers in an effort to improve asthma symptoms (Bryant-Stephens et al., 2019; Everhart et al., 2021). Interventions have also targeted a multitude of barriers to asthma care in low-resourced communities to further improve asthma symptoms (Everhart et al., 2021; Swartz, Banasiak, and Meadow-Oliver, 2005).

#### **Barriers to Asthma Care**

It is well documented that childhood asthma is negatively impacted by persistent exposure to environmental triggers often found in low-income housing, inconsistencies in quality healthcare, including long wait times and unavailability of appointments, lack of transportation,

care giver mental health, beliefs about asthma care, and societal disparities in access to asthma care that stem from poverty and cultural differences (Butz, Kub, Bellin, & Frick, 2013; Swartz et al., 2005). These barriers to care are well ingrained in society and can have deleterious effects on children with asthma. Caregivers reported that family characteristics, health beliefs, and their physical environment were the top barriers to childhood asthma care in a low-income, urban population (Mansour, Lanphear, and DeWitt, 2000). Focus groups also found that family health beliefs, financial constraints, and psychological distress negatively impacted children's asthma care routines (Laster et al., 2009), and caregivers emphasized that families in low-income, urban communities need asthma interventions tailored to their specific needs. Barriers to pediatric asthma care are numerous and pervasive, spanning from difficulty getting medical appointments to lack of adequate housing, clothing, and food. Some of these barriers to care can be addressed by home-based asthma interventionists, such as community health workers (CHW), individuals who typically reside in the communities they serve and can often relate to the lived experiences of families.

# **Pediatric Asthma Interventions**

Home interventionists, such as CHWs and Healthy Homes assessors (HHAs; i.e., home assessors embedded within a local health district), help families in their communities by providing asthma education, identifying environmental triggers that exacerbate asthma symptoms, providing relevant resources to address barriers to asthma care, supporting families with other social needs impacting asthma care, and providing coordination of care among school, work, home, and healthcare providers. A CHW is one of many types of home interventionists that support families of children with asthma. In fact, pediatric asthma interventions with asthma education, environmental trigger remediation efforts, and/or coordination of care have used

various terms to describe home interventionists including: CHW, home health worker (Turcotte et al., 2014), lay health educator (Bryant-Stephens et al., 2009), trained environmental educator (Eggleston et al., 2005), peer health educator (McConnell et al., 2005), home evaluation team (Morgan et al., 2004), community environmental specialist (Parker et al., 2008), and asthma counselor (Evans III et al., 1999). This dissertation utilizes information gathered by two types of home interventionists, CHWs and HHAs; both were part of the RVA Breathes home intervention team that provided family-based care in managing child asthma. Regardless of the term used to describe home interventionists, programs utilizing such interventionists have been shown to improve health outcomes and decrease healthcare costs for children with asthma. Living and working in the same communities as their clients, home interventionists have extensive knowledge of local resources and healthcare systems that can benefit the families with whom they work (Katigbak et al., 2015). This unique knowledge of the communities they serve allows home interventionists to tailor referrals to address both health and social needs.

Findings suggest that CHWs, a type of home interventionist, can serve as integral components of effective community intervention programs (Bryant-Stephens et al., 2019), addressing families' barriers to asthma care. Home interventionists provide social support, assist with adopting healthy behaviors, leverage cultural congruence with clients, and employ interpersonal communication to build trust and minimize health disparities in their communities (Katigbak et al., 2015). Because asthma disparities are multi-determined, effective interventions must extend beyond routine health care and invest in social and community resources (Rehman et al., 2020). Specific educational curriculums, the implementation of self-management skills, and the use of behavior change plans have been identified as effective components of the home interventionist model of care, specifically utilizing CHWs (Martin et al., 2016).

Home-based asthma interventions utilizing home interventionists have been linked to decreased asthma symptoms, improved asthma control, increased daytime activity limitations, decreased emergency and urgent care use, and environmental trigger reduction (Marshall et al., 2020; Postma, Karr, & Keikhefer, 2009). In a pediatric asthma intervention study conducted in Massachusetts, home health workers (another type of home interventionist) improved household safety, provided targeted environmental interventions to decrease asthma triggers, and provided asthma education which led to a significant decrease in asthma-related healthcare utilization and medication usage, as well as improved physical and emotional health over the 12-month intervention period (Turcotte et al., 2014). In fact, over the past two decades, several asthma intervention programs utilizing home interventionists have yielded decreases in asthma-related healthcare utilization (Bryant-Stephens et al., 2008; Bryant-Stephens et al., 2009; Evans III et al., 1999; Krieger et al., 2005; Krieger et al., 2009; Levy et al., 2006; Parker et al., 2008; Walders et al., 2006), the presence of home asthma triggers (Bryant-Stephens et al., 2009; Eggleston et al., 2005; McConnell et al., 2005; Morgan et al., 2004; Parker et al., 2008; Williams et al., 2006), and asthma-related school absences (Bartholomew et al., 2006; Clark et al., 2004; Halterman et al., 2011; Levy et al., 2006). These interventions are also linked to increases in asthma knowledge (Bartholomew et al., 2006; Gerald et al., 2006; Levy et al., 2006; McConnell et al., 2005) and symptom free days (Evans III et al., 1999; Halterman et al., 2011; Krieger et al., 2009; Morgan et al., 2004).

Several studies also found that asthma interventions can decrease healthcare costs.

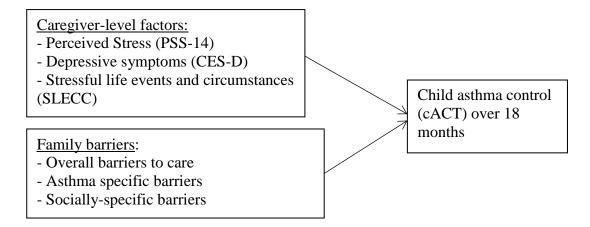
Marshall and colleagues (2020) saw a positive financial return on investment for participants who had 2 or more ED visits one year prior to the first home visit, suggesting the intervention decreased Medicaid costs. Furthermore, Turcotte and colleagues (2014) showed that their 12-

month home health worker intervention provided a medical savings of about \$71,000 over a 4-week period, estimating a yearly medical savings of about \$821,000. It is possible that home interventionists can alleviate some of the financial burden that pediatric asthma places on the healthcare system.

The home interventionist model of care, however, has not been widely adopted by health care systems mainly due to limited coverage by insurance companies (Morley et al., 2014). Further understanding how a home interventionist model contributes to improved child asthma control has the potential to minimize healthcare costs (Figure 1), especially among children most likely to receive care from the ED. Asthma control was chosen as the main outcome of interest for analyses in this study given its links to other outcomes, such as asthma-related ED use.

Moreover, asthma control is used in clinical practice as a strong indicator of how well a child's asthma is being managed (Liu et al., 2007). This dissertation aimed to demonstrate the utility of the home interventionist model in improving asthma control among children from a low-income, urban setting.

Figure 1. Model predicting asthma control



# Caregiver Stress, Depressive Symptoms, Stressful Life Events, and Asthma

As mentioned previously, asthma disproportionately impacts children living in families reporting an income below the poverty threshold (Akinbami, 2012; Azmeh et al., 2020). In addition to being associated with worse asthma outcomes, living in poverty has been associated with high stress levels (Cardet et al., 2022; Kopel et al., 2017). In fact, perceived stress has been shown to mediate the association between socioeconomic status and asthma control scores among adults with asthma enrolled in a randomized trial assessing reliever-triggered inhaled corticosteroid strategies across the United States (Cardet et al., 2022). The authors found that stress partially explained the association between socioeconomic status and asthma control, suggesting that low socioeconomic status may cause stress which might then negatively impact asthma control.

Furthermore, research shows that caregivers of children with asthma can experience more anxiety and depressive symptoms compared to caregivers of children without asthma (Easter et al., 2015). In a recent study conducted among low-income, urban, Black caregivers of children aged 3-12 years with uncontrolled asthma, nearly a third reported clinically significant levels of depression, and caregiver depressive symptoms predicted decreased medication adherence (Margolis, Dababnah et al., 2022), as well as fewer symptom free days (Margolis, Shelaf et al., 2023) across the one-year study period. Caregiver mental health can negatively impact child medication usage and asthma symptomatology (Morillo-Vanegas, Sanchez-Salcedo, and Ariño, 2020). The association between caregiver mental health and negative asthma symptoms might be due to less engagement in daily care behaviors, such as not picking up necessary asthma prescriptions (Margolis, Bellin et al., 2022), and by caregivers utilizing maladaptive coping skills, such as smoking, that exacerbate asthma symptoms (Jasal et al., 2020).

Stressful life events, such as a recent accident or illness, can also negatively impact pediatric asthma symptoms, especially when the child's caregiver is depressed (Margolis, Shelef et al., 2023). Stressful life events can include medical, financial, legal, psychological, or physical occurrences that can leave lasting impacts on a family. In a study of adolescents residing in a city in the US, stressful life events were associated with having an asthma diagnosis, as well as a greater number of asthma symptoms, asthma-related school absences, and asthma-related doctor visits and hospitalizations (Turyk et al., 2008). Furthermore, a prospective study of children with asthma found that within the first two days of a stressful life event occurring, the risk of an asthma exacerbation increased by a factor of 4.69, and 5-7 weeks after the stressful event, the risk of an asthma exacerbation increased by a factor of 1.81 (Sandberg et al., 2004). Stressful life events can have both immediate and lasting negative impacts on children with asthma.

Other than a single occurrence like an accident or death in the family, stressful life events can be related to neighborhood violence or limited financial resources that can be ongoing and chronic, stressful factors in a child's life. For instance, lower neighborhood safety and more caregiver stress and depressive symptoms have been associated with more child asthma symptoms (Rodriguez et al., 2022). Furthermore, caregiver stress partially mediated the association between neighborhood safety and children's asthma symptoms (Rodriguez et al., 2022), such that caregiver stress helped explain why unsafe neighborhoods were associated with negative asthma outcomes in children. Living in unsafe neighborhoods can negatively impact children's health and caregiver mental health may worsen this association. Global events, such as the COVID-19 pandemic, can also be considered a chronic stressful life event that may have negative impacts on pediatric asthma.

#### **COVID-19 and Asthma**

Although the impact of COVID-19 on families is not entirely known yet, there was a decrease in ED use among children with asthma shortly after the onset of COVID-19 (Kenyon et al., 2020); this under-utilization for families that typically visit the ED for their child's care could have a profound impact on asthma control. It is critical to understand families' barriers to care both in the acute pandemic period and in the time after the pandemic in order to optimize family-based interventions to improve child asthma outcomes.

A notable increase in mental health problems has occurred as a result of the COVID-19 pandemic (Adams et al., 2021; Russell et al., 2020). Caregivers and children report more stress due to pandemic-related factors (e.g., school and employment closures, increased caregiving demands, limited social interaction) that are negatively contributing to caregivers' capacity (Cluver et al., 2020). A longitudinal study by Adams and colleagues (2021) found that parental stress (as measured by the Perceived Stress Scale-10) increased during peak stay-at-home mandates compared to pre-COVID-19, and then decreased when children returned to school. Interestingly, even with the decrease, stress levels for parents remained elevated above pre-COVID-19 levels (Adams et al., 2021).

Caregiving duties during the COVID-19 pandemic were likely to be particularly stressful for caregivers of children with asthma, considering their children have specific medical needs relative to their peers (Sicouri et al., 2017). Nevertheless, limited research has examined COVID-19's influence on families of children with asthma, particularly in regards to caregiver stress, depressive symptoms, stressful life events, barriers to care, and asthma control. In one study of caregivers of children with asthma (Clawson et al., 2021), Black families reported greater food insecurity, discrimination, resource losses, reductions in healthcare access, worries

about resources losses, and distress about COVID-19 compared to non-Hispanic White families. Given the negative effects of the pandemic on families of children with asthma, the current study asked caregivers specifically about their experiences during COVID-19.

# **Current Study**

This dissertation builds off an NHLBI-funded Asthma Empowerment grant that tested a randomized clinical trial of the community-based asthma program, RVA Breathes (PI: Everhart, U01HL138682). RVA Breathes used a home interventionist model (utilizing both CHWs and HHAs) to coordinate asthma care across multiple domains of a child's life. The program directly addressed concerns raised in a community needs assessment (Everhart, Haley et al., 2020). CHWs and HHAs, who resided in the communities they served, delivered evidence-based asthma education, advocated for families, assessed homes for environmental triggers, provided appropriate resources, and facilitated coordination among families, schools, and children's medical providers. This mixed-methods dissertation study examined the processes by which home interventionists in RVA Breathes assisted families in improving their children's asthma control.

CHW session notes from RVA Breathes, internal records from the Institute for Public Health Innovation (IPHI; CHWs were hired and supervised by IPHI for RVA Breathes), as well as four focus groups with caregivers and one focus group with home interventionists conducted as part of the author's F31 grant, were qualitatively analyzed. CHW session notes often detailed relevant information from both the CHW and HHA as a home interventionist team, even if the work fell under the scope of a home assessment (e.g., desire to move, household mold and/or cockroaches, humidity concerns, contaminated furniture). In fact, CHWs often followed up on a family's household needs if they were able to provide relevant resources, such as new furniture

or a housing referral. Thus, within the scope of this dissertation study, only CHW session notes and IPHI internal records were analyzed given that both CHWs and HHAs worked together during study sessions and notes detailed information relevant to both interventionists. This study categorized barriers and resources to asthma care as either asthma-specific or socially-specific, given that both categories impact child asthma outcomes, possibly in different ways (Trent et al., 2015).

Specific aims were addressed through secondary analysis of a rich longitudinal dataset collected as part of RVA Breathes, and focus groups conducted as part of the author's F31 grant. This study used multilevel modeling to examine how barriers to care impact asthma control over time. Furthermore, this study examined caregiver-level factors (e.g., stress, depressive symptoms, stressful life events) associated with changes in asthma control throughout the duration of RVA Breathes.

# **Study Aims and Hypotheses**

<u>Aim 1</u>: To identify barriers to care among families in RVA Breathes and examine interventionist-provided resources targeting such barriers.

To address this aim, CHW session notes from 152 participants (intervention families in RVA Breathes) were qualitatively analyzed using rigorous analytic methods to identify and compare asthma-specific and socially-specific barriers to asthma care and resources provided. Community referral information was obtained from IPHI's internal records to add to session note findings. Using a more comprehensive coding scheme, five focus groups (four caregiver and one home interventionist) were analyzed to provide an in-depth understanding of unique and pervasive barriers to asthma care and provided resources. The Spanish-speaking focus group only included two caregivers, and therefore, was not formally coded. The transcript was treated

as a semi-structured interview and quotes were used to bolster themes identified across the other four caregiver focus groups.

<u>Aim 2</u>: To examine the associations among caregiver-level factors, type of barrier to care (e.g., asthma-specific, socially-specific), and asthma control.

Using multilevel modeling, the association of caregiver level factors (stress, depressive symptoms, and stressful life events) with child asthma control was examined. To explore possible associations of asthma-specific and socially-specific barriers to care with asthma control trajectories, multilevel models were fit to assess changes in asthma control over time.

<u>Hypothesis 1:</u> More caregiver stress, depressive symptoms, and stressful life events would be associated with worse asthma control over time.

Hypothesis 2: More barriers to care would be associated with worse asthma control over time. Due to the exploratory nature of the examination of type of resource with asthma control, no hypothesis was generated as to which barrier type was more strongly associated with asthma control over time.

#### **Methods**

This study involved both quantitative and qualitative data analysis from RVA Breathes and focus groups conducted as part of the author's F31 grant. Families in RVA Breathes were randomized to either an active intervention group or an enhanced standard of care (control) group (see Figure 2), with 9-month intervention and 9-month follow-up phases. The author conducted five caregiver focus groups (four English speaking and one Spanish speaking) and one home interventionist focus group to categorize and facilitate in-depth understanding of barriers to asthma care and study interventionist provided resources to address those barriers. These data were analyzed as a part of this dissertation study.

# **RVA Breathes**

**Population**. Two hundred and fifty children in Richmond area elementary schools with asthma were enrolled in RVA Breathes; there were 187 families in the intervention groups. This dissertation used data from 152 intervention families that completed at least one intervention session. Most caregivers and children in RVA Breathes reported an income below \$25,000 a year and identified their race and/or ethnicity as Black or African American (n=201 caregivers; n=194 children), Latinx (n=23 caregivers; n=22 children), or Mixed/Multiracial (n=12 caregivers; n=28 children).

Recruitment and eligibility. Children were recruited from community sites (e.g., PCP offices, community centers), local hospitals, and schools. Inclusion criteria included child aged 5-11 years, physician-diagnosed asthma, residing in Richmond City, attending an elementary school in Richmond Public School (RPS) and having an asthma-related hospitalization/ED visit, unscheduled doctor appointment, or being prescribed an oral steroid for asthma in the past 2 years. Caregiver inclusion criteria included status as the child's legal guardian (parent or caregiver), and living in the same home as the child for the last 6 months. Exclusion criteria for all participants included a severe medical or psychiatric condition that would preclude effective study participation. We did not have specific inclusion criteria related to race/ethnicity.

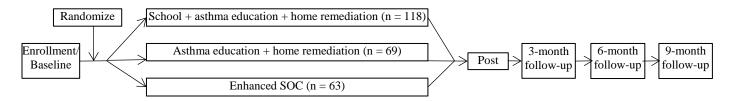
**Randomization.** As RVA Breathes included a school nurse component, families were randomized at the school level. In consultation with Richmond Public Schools, we matched elementary schools based on demographics and location; 8-9 schools were included in each condition.

**Data collection and procedures.** Figure 2 outlines the RVA Breathes study timeline. Once a family screened eligible, a baseline session was scheduled within 2 weeks. Caregivers

and children completed the consent/assent process and questionnaires assessing healthcare utilization, asthma symptoms and control, home environment, demographic information, and psychosocial characteristics. After the visit was complete, the project coordinator randomized the family to one of three conditions based on the child's school. Two weeks after the baseline session, families in the intervention arms completed the first home visit with CHWs and HHAs working as a team to provide both family-based asthma education and a home assessment. This was the first of four home visits with both CHWs and HHAs that occurred every 2-3 months. In this dissertation, the CHW session notes from intervention sessions were coded to identify barriers to asthma care, as well as resources provided by CHWs and HHAs. In these notes, CHWs detailed what they did in the session in conjunction with HHAs, outlined how they addressed the participants' concerns, and created a plan of action. Furthermore, internal records from IPHI were examined to categorize more community referrals and participant engagement in those referrals. For children in the school nurse component of RVA Breathes, CHWs ensured that families submitted their child's asthma action plan and medication release form to the school nurse. These interactions were also captured in CHW session notes. School nurses in intervention schools were also provided with asthma education materials and used a standardized protocol with participants.

After each home visit, CHWs worked with the project coordinator to update providers on the family's participation in the intervention and information related to symptoms, asthma control, missed school days, and healthcare utilization since the last home visit. Within 2 weeks of completing the 9-month intervention program, children and caregivers completed a post-intervention session, and 3-, 6-, and 9-month follow-ups.

**Figure 2.** RVA Breathes study timeline (taken from U01 grant)



Data collection in COVID-19: Prior to the COVID-19 pandemic, all study sessions occurred in family homes. In mid-March 2020 when COVID-19 quarantine began in Richmond, VA through mid-April 2020, no study sessions were conducted as remote and safe protocols were being developed with the study team. Starting late April 2020 through the end of June 2022, all study sessions were conducted over the phone or using video conferencing. This change in protocol ensured the safety of participants and staff during study sessions and research visits.

# **Explanation of Parts 1 and 2:**

The rest of this dissertation is divided into two parts. Part 1 focuses on the caregiver and interventionist focus groups, CHW session notes, and internal records from IPHI. The methods, results, and discussions included in Part 1 are focused on the rigorous coding and qualitative analyses conducted as part of this dissertation. Part 2 focuses on the secondary data analyses utilizing data collected as part of the RVA Breathes program including caregiver perceived stress, depressive symptoms, stressful life events, and child asthma control. It also includes quantitative analyses examining count scores of barriers to care, interventionist-provided resources, and average engagement in resources based on coding from Part 1. The methods, results, and discussions included in Part 2 are focused on all the quantitative analyses conducted as part of this dissertation. A combined summary of main findings is included at the end of the dissertation to highlight important findings from both parts.

# **Dissertation Part 1:**

Qualitative

# <u>Part 1</u>

Part 1 of the dissertation focused on the qualitative methods, results, and discussions of dissertation aim one. This section examined findings from the caregiver and interventionist focus groups, as well as content from the CHW session notes. Additional information about community referrals and participant engagement in referrals was gathered from internal records at the Institute for Public Health Innovation (IPHI). All findings in Part 1 are results from qualitative coding procedures.

# Methods: Part 1

Caregiver Focus Groups: Caregivers from the intervention arms of RVA Breathes were invited to participate in focus groups via phone calls and/or text messages. A number generator was used to assign each eligible participant a number for the order of recruitment calls.

Caregivers were called in the order created by the random number generator. If a caregiver agreed to participate, reminders about the group were sent via email and text message both three days and one day before the group. Four of the focus groups included English-speaking participants and were led by the primary researcher. Discussions focused on barriers to asthma care, the impact of COVID-19 on such barriers, and how CHWs and HHAs assisted families in overcoming barriers to care. Focus group participants were compensated \$25 for their time.

Focus groups were completed on November 18<sup>th</sup>, 2021, December 8<sup>th</sup>, 2021, January 20<sup>th</sup>, 2022, and February 9<sup>th</sup>, 2022. The first two groups included Group 1 participants and the next two groups included Group 2 participants. All English-speaking focus groups included 4-6 caregiver participants in each. The fifth "focus group" included Spanish-speaking participants and was conducted on July 13<sup>th</sup>, 2022. It was led by a bilingual Latina doctoral research assistant (RA) and assisted by a bilingual Latina post-baccalaureate RA.

Nineteen Spanish speaking individuals participated in RVA Breathes; 17 participants were still enrolled when focus group recruitment began. When recruiting participants for the Spanish-speaking focus group, only two participants agreed to attend. Since the group discussion only consisted of two participants, the session was considered a semi-structured interview, and quotes were compared to the four other caregiver focus groups. Pertinent speech samples from the semi-structured interview were used to bolster identified themes from the other focus groups.

Interventionist Focus Group: RVA Breathes' CHWs and HHAs were asked to participate in one hour-long focus group. Five interventionists (3 CHWs and 2 HHAs) participated in the discussion. Interventionists in the focus group discussed their experiences in the program and how they addressed barriers to care with families. The primary researcher led this focus group on September 3<sup>rd</sup>, 2021; the last day of the intervention phase of RVA Breathes was September 30<sup>th</sup>, 2021. Focus group participants were compensated \$25 for their time.

Transcriptions and Translation: All focus group sessions were conducted on Zoom and audio recorded. Participants had the option to leave their cameras on or off, but videos were not recorded. English transcriptions were completed and checked for accuracy. The Spanish transcription was completed by a Spanish-speaking RA, and was checked for accuracy by another Spanish-speaking RA. The transcript was translated to English and the English translation was checked by another bilingual RA for accuracy. Then, the English transcript was back-translated to Spanish for comparison with the original transcription.

**Member Checking**: After focus group results were compiled, all focus group participants (n=25, 20 English-speaking caregivers and 5 interventionists) were contacted by phone (by either the primary researcher or the second coder) for member checking. Spanish-speaking "focus group" participants were not contacted since their discussion was not formally

coded. During this phone call, a summary of focus group findings was shared with participants using Synthesized Member Checking (SMC) (Birt et al., 2016). SMC employs a four-step procedure to minimize participant burden: 1) the author prepared a synthesized summary of emerging themes, 2) participants' willingness to engage in member checking procedures prior to the phone call was confirmed, 3) findings were sent out ahead of time in English and/or Spanish, and 4) each participant shared their feedback on the results and whether it accurately captured focus group discussions during the individual phone call. Participants were compensated \$10 for participating in the phone call.

CHW Session Notes: CHWs took notes after every intervention session with a family.

CHWs asked a series of open-ended questions at each visit related to parent goals, asthma control, barriers to care, and COVID-19 impact. In their notes, CHWs often included barriers to care and provided resources relevant to the HHA as both home interventionists worked as a team during study sessions.

Community Referrals: To supplement the data gathered from session notes, the primary researcher received a list of community referrals by ID number from the CHWs' supervisor at IPHI. This list of community referrals also included information about whether a caregiver engaged in that referral. Referrals and caregiver engagement in those referrals were added to results from CHW session notes to create a comprehensive account of interventionist referrals and caregiver engagement during the program.

# **Qualitative Research Team**

Creswell and Proth (2018) highlight the importance of acknowledging a qualitative researcher as a "multicultural subject" with a background and identity that inform beliefs and research practices. Therefore, it is important to note that the primary researcher is a White,

middle-class female in her 30s enrolled in a doctoral program at a large, predominately White institution in the southeastern United States. She does not share many identities with the families enrolled in RVA Breathes. She recognizes her privilege and took steps to minimize her biases during focus groups discussions and qualitative coding procedures (see Data Integrity, page 24).

Each English-speaking focus group was led by the primary researcher, and was assisted by another graduate student from the same institution who had less experience with the RVA Breathes intervention program. For the interventionist focus group and the first two caregiver focus groups, the primary researcher was assisted by a Black male in his 30s whom had only completed a handful of follow-up sessions for RVA Breathes. For the second two caregiver focus groups, the primary researcher was assisted by a White female in her early 30s whom completed follow-up sessions for RVA Breathes in its final year. The Spanish "focus group" was led by a Latina woman in her 30s enrolled in a doctoral program at the same institution as the primary researcher whom had little experience with RVA Breathes, and was assisted by a Latina woman in her 20s who had just graduated with her Bachelors in Psychology from the same institution. The Spanish-speaking focus group assistant worked closely with the Spanish-speaking families in RVA Breathes for the study duration.

The primary researcher's committee chair and research advisor is a White woman in her 40s who served as the Primary Investigator on RVA Breathes. The primary researcher was also advised and supported for all qualitative analyses by another committee member who is a Latina woman and Co-I on RVA Breathes. All coders had extensive backgrounds in qualitative data collection and analysis as well as pediatric asthma research with communities reporting an income below the poverty threshold and identifying as Black and/or Latinx.

# **Data Analyses: Part 1**

Barriers to care, interventionist-provided resources, and caregiver engagement collected through CHW session notes, focus group coding, and IPHI provided community referrals were compiled throughout the intervention period. The content of barriers, interventionist-provided resources, and caregiver engagement were summarized.

Coding Procedures for Focus Groups: Separate caregiver and interventionist focus groups identified unique and pervasive barriers to asthma care, which did not emerge during intervention sessions. The caregiver focus group coding schema was developed using data from all five focus groups, and the interventionist focus group coding schema was developed using data from the one group discussion. Two graduate students independently evaluated the transcripts for initial theme development and discussed the resulting codes to obtain consensus with the study team. Using a bottom-up approach from grounded theory (Glaser & Strauss, 1999), each topic that emerged during focus group discussions was noted and then categorized into major topics/themes (e.g., program takeaways and overall response, challenges and barriers, interventionist interactions and responses, and COVID-19 impact). Using constant comparison analysis, content from each group was subsequently reviewed to identify themes and determine whether themes from one group emerged across the four other groups. The remaining caregiver transcripts were then reviewed, and the thematic framework was refined to incorporate data from all four focus groups. For the interventionist group, the coding team worked collaboratively to ensure all data were appropriately coded. After consensus on the coding schemas, two coders independently coded each transcript. Codes were reviewed on a regular basis with research team members to reconcile discrepancies. We calculated item level inter-rater reliability kappa coefficients on developed themes between coders ( $\kappa$ =.96).

Coding Procedures for CHW Session Notes: Coding procedures used in our study with school nurses (Everhart, Corona, et al., 2020) were applied to CHW session notes to categorize barriers to asthma care, interventionist-provided resources to address those barriers, and engagement in resources. Home interventionists met with participants four times across the 9month intervention phase. We coded all session notes from the 152 intervention participants whom competed at least one intervention session with a home interventionist team. In general, session notes were no more than half a page. The codebook was collaboratively generated with the study team and explicitly outlined barriers, resources, and engagement that were either asthma-specific (e.g., transportation to healthcare visits, health insurance, medication adherence) or socially-specific (e.g., employment, finances, housing concerns). Barriers to care were determined to be asthma-specific if they were directly related to a child's asthma. Published research on asthma barriers to care from the Centers for Disease Control and Prevention (Centers for Disease and Prevention, 2014), American Lung Association (American Lung Association, n.d.), and American Academy of Allergy, Asthma, and Immunology (Presnell, 2019) were used to develop asthma-specific codes. Barriers were categorized as socially-specific if they mentioned any social determinants of health (Butz, Kub, Bellin, & Frick, 2013; Espaillat et al., 2023) that were indirectly related to a child's asthma, but may have negative downstream health impacts on children.

Session notes were coded by two graduate students (the primary researcher and a graduate RA). Notes from the first five participants were coded collaboratively by both graduate students. Once the coding procedures were learned using a collaborative coding of 5 sets of notes, coders independently coded the next 15 sets of notes. Upon completion of independent coding, inter-rater reliability was calculated to be 94%. Since the reliability score was greater

than 90%, the two coders divided the remaining notes evenly and independently coded the remaining notes. However, all discrepancies were discussed among the first 15 sets of notes until coders reached consensus to ensure coders did not have remaining questions. Any questionable codes in the remaining note sets coded independently were discussed amongst the coders to ensure the correct code was assigned.

Data integrity: The primary researcher, a White, middle class woman whom is an outsider to the community that participated in her research, acknowledges her position and took steps to ensure the integrity of the data and analytic process. The first step was the use of an audit trail, which mapped out thinking processes, activities, and decisions about data collection and analysis, and was maintained throughout coding procedures (Lewis, 2015). Second, the researcher consulted with a professor whom identifies as Latina and has done extensive work with qualitative research to ensure all processes were done correctly, and focus group probes and codes were appropriate. Third, during the development, collection, and coding of data, the primary researcher included team members from different age, financial, and racial and ethnic backgrounds to ensure other voices were heard and incorporated. She also engaged in post processing discussions after each focus group with the focus group assistant/note taker to discuss observations, the experience of the group, and reflections on how the group compared to prior groups. Fourth, all coding discrepancies were discussed between coders until a consensus was reached, and codes from CHW sessions notes were brought to the group if the coder was not positive of the correct code. Lastly, member checking procedures were conducted on focus group results to ensure focus group participants agreed with the identified themes and had an opportunity to provide additional thoughts or concerns based on their experience.

# **Results: Part 1**

# **Caregiver Focus Group Themes**

Using a bottom-up approach from grounded theory, four topics of discussion/themes were identified across caregiver focus groups: 1) program takeaways and overall response, 2) challenges and barriers, 3) interventionist interactions and responses, and 4) the impact of COVID-19. Each topic/theme had between 2-4 sub-themes that further categorized caregiver discussions. Table 1 visually depicts caregiver focus group themes and sub-themes. Open-ended focus group probes specifically asked about thoughts related to the RVA Breathes program, interventionist interactions (including barriers to care and interventionist provided resources), and how COVID-19 impacted their child's asthma care. Representative quotes are presented within each sub-theme description. The Spanish "focus group" only included two caregivers. Therefore, the "focus group" was not formally coded. Topics discussed across the four English-speaking focus groups arose in the Spanish-speaking discussion as well. Representative quotes can be found in the section titled, "Spanish-speaking semi-structured interview."

**Table 1**. Caregiver focus group themes and sub-themes.

Program Takeaways and Overall Response	Challenges and Barriers	Interventionist Interactions and Responses	COVID-19 Impact
Addressing home environmental triggers/ tangible materials (Tang)	Exposure to triggers outside of control, asthma exacerbations (Expo)	Validation and Support (VS)	Emotional impact (EI)
Utilizations of asthma education (UAE)	Mental health concerns and stressors- non- COVID-19 (MH-NC)	Skills/information learned (SL)	Behavioral impact and activity restriction/social isolation (BI)
Positive thoughts about the program (Pos)	Medication use/ adherence (MA)		Asthma impact (AI)
Future program improvements (FPI)	Caregiving discussions (CD)		Economic impact (Econ)

# Theme 1. Program Takeaways and Overall Response

Caregivers discussed the RVA Breathes program in general, how the components of the program were helpful/not helpful, and overall reactions to the program. During conversations about the program, caregivers focused on how RVA Breathes helped them address environmental asthma triggers, how they utilized the education they received, positive thoughts about the program, and how the program can be improved in the future. Select quotes across the focus groups are embedded in sub-theme descriptions.

Addressing Home Environmental Triggers/Tangible Materials (Tang). This sub-theme focused on what tangible materials caregivers were given during the program and how they utilized those resources. In general, caregivers appreciated the Seventh-Generation cleaning supplies, hyperallergenic pillow cases, and air purifiers supplied by interventionists.

"I really appreciated the air purifier. I still use that. The cleaning products that they showed me... like new generation. I still use those because like, that was one of the things that was triggering for her. So, I think that was a big help" (FG January 2022).

\*Utilization of Asthma Education (UAE). Caregivers described the knowledge they gained from the program and how they utilized that knowledge. For instance, caregivers discussed actions resulting from asthma education,

"I found out myself recently using certain cleaning products that I love. I was like, "What?" They was like, "Yeah, that's a trigger." I was like, "Oh my goodness!" So, I've been trying to be more careful, even down to what my landlord uses for a pesticide. So they've given me help with that." (FG Jan 2022);

a shift in thinking about their child's asthma management,

"Yeah, it made him more aware that he doesn't have to rely on Mommy, heal his body, and he runs and gets his medication" (FG Nov 2021);

a better understanding of communication and asthma management in general,

"You have to tell me how you feel, because asthma's an internal thing. I can see it and I can hear a wheeze, but to you that's an everyday noise because that's how you breathe every day. That's what you hear all day long. To me, that's a concern. That's an item for me to, and I'm like, "Wait a minute. That sounded a little heavier, are you okay?" You know, and he's like, "No, but imma take my medicine." "Okay, well get your medicine, let's take your meds, see how you feel, you know, hour or so after that." Or, "It's not getting any better Mom and I need to go." "Okay well let's go."" (FG Feb 2022); and advocacy efforts based on gained asthma knowledge both in school and with housing,

"So we had to get that removed, and now I'm fighting to get the carpet removed because I know the carpet still is holding all that mold." (FG Nov 2021).

*Positive Thoughts about the Program (Pos)*. This sub theme encompasses any positive words stated about the program and how the community accepts/needs the RVA Breathes program.

"No, everything, they are all information they gave me, I mean, it worked. It helped, I mean, whatever program they told me to call, or whatever number they told me to call, I always got through. I mean every, I didn't get nothing, nothing they gave me, nothing never worked. I mean, I mean everything work. I mean, they were on point with everything." (FG Nov 2021).

"I can't speak for nobody but myself, but it wasn't, you know, I said yes and I was nervous cause I was like "I don't know," like open up your homes and stuff to a stranger is something to you know, you know, protective of your kids and things like that. But it

wasn't, it put my fears at ease. Everybody was nice and personable and it didn't make me feel like "Oh, I'm on the spot for every little thing I'm doing as a parent." It's hard enough, you know, there's no book with raising your kids and then you got a child with a medical condition, you know. So I will say I'm grateful for that. Because I was a little nervous and wondering like "Are they gonna be fussing at me for every little thing I'm doing?" You know, judging. So it was nothing like what I thought. So I'm glad I did get the chance." (FG January 2022).

Future Program Improvements (FPI). Caregivers reported possible program changes for the future including the inclusion of teen support groups,

"Maybe the teenagers with the asthma, would be able to get on the phone and talk about what they go through and what they think would help them, instead of us coming up with it trying to enforce it." (FG Dec 2021).

interventions in school,

"Yeah, they should educate them more at the schools. There should be more programs in the school in general, rather than kids have asthma and that because they always coming in contact with people with other health issues." (FG Feb 2022).

and providing more resources,

"More resources. More resources...as needed...more resources." (FG Dec 2021).

"Except I didn't get no humidifier. I wanted one of them. That's it." (FG Jan 2022). as well as topics they do not wish to be included in future programs.

"For me, it's too personal of a decision [COVID-19 vaccination] to ask everyone because it's such a personal decision. So, I personally wouldn't want it to be included in it, because it's a personal decision." (FG Nov 2021).

# Theme 2. Challenges and Barriers

Caregivers discussed barriers to asthma care and challenges that families faced prior to the program, during the program, and after the program ended including discussions of triggers, mental health concerns (without mention of COVID-19), and medication adherence. Select quotes across the focus groups are embedded in sub-theme descriptions.

Exposure to Triggers, Asthma Exacerbations (Expo). Caregivers discussed asthma triggers that they did not have control over both outside (school, weather, public places) and inside of their homes (if renting).

"See the triggers might not even be at home, it's because my son has never messed up at home yet no problems soon as he get into school. He couldn't breathe. He got sick. I got one time my son threw up because he couldn't breathe. He had a headache so bad in school, and that's not fair to our kids to have to deal with illnesses due to going to school trying to learn." (FG Dec 2021).

"And the weather change really affects my younger kids going in and out and the weather being hot and then cold. There's nothing much I can really do. So sometimes I have to keep them home because I don't want them feeling like their coughing or sneezing is from it's cold, when really it's allergies and asthma mix." (FG Feb 2022).

These triggers can cause asthma exacerbations and caregivers reported that they had difficulty removing these triggers without systemic changes within the schools and public housing sectors.

"Just like the school and the mold in our houses here at RRHA apartments, and then the schools are gonna mess with our kids' breathing for life." (FG Dec 2021).

"Richmond, they changed the hours from 9 o'clock to 8 o'clock, or yeah so now that meant that my son will be outside at like 7 something waiting for the bus. And I didn't

really think about it in the beginning. Until it started getting cold, and I'm like, "Well wait a minute. The sun not even up yet, and you want him to go stand out here in this freezing cold." And he's a child that if you hit the door too fast, the cold air will have him wheezing trying to catch his breath." (FG Feb 2022).

Mental Health Concerns and Stressors, Non-COVID-19 (MH-NC). This sub theme focuses on any stressors or mental health concerns brought up by caregivers that they did not attribute to COVID-19. It is important to note that all FGs occurred after the onset of COVID-19, so it is possible that the pandemic exacerbated mental health symptoms; however, caregivers did not explicitly state the pandemic in quotes categorized by this sub-theme.

"It came to me, they were asking me about...when we were doing the survey, you know, and the time where it asked about your emotions and things. How have you dealt with, how are you dealing with things. They were points where I wasn't happy, you know.

There were times I had to be honest, I wasn't happy." (FG Jan 2022).

"See that's the thing what I'm saying. 'Til you jump off a bridge or you do something crazy, that's when they listen to you. And that's not right. When I'm telling you, I'm stressed and there is something wrong with me. "Can you see I'm stressed; can you just help me." (FG Dec 2021).

Medication Use/Adherence (MA). Across all groups, caregivers reported their child's problems with medication adherence,

"I had a problem with the chamber. (Child's Name) does not like using the chamber but I don't care how much they tell her it's gonna help her — She don't want to use a chamber. She feels comfortable just pulling her little pump out and pumping her, you know." (FG Dec 2021).

difficulties with medications at school,

"But now, going into the schoolhouse, he prefers to keep his medicine on him, personally. And the nurse and I had to have a conversation about it, because she was like, 'Well, you know, we really like for him to leave the medicine in the nurse's office.' And I'm like, 'No, because if he upstairs and there's an issue, by the time he get all the way downstairs, who knows what may have happened. So, I really prefer that he have his own meds. He understands how to administer it. He knows what he needs to do."" (FG Jan 2022).

and medication beliefs that may stop them from using recommended medications.

"I am on the fence. I personally, my personal feelings were, me and my older children took it to protect my younger son. Just in case we get it, at least one of us is not as hit badly for it, this is just me personally, that someone is there to protect them because I'm a single mom. So, I only have them and me. Although I do have family around here, but I can't put him at risk in another household. Because if he has the, if he's asymptomatic, you know, he might pass it to them. So, I'm still on the fence about him getting it. I'm like, (Participant 2), is just not enough data for me for a kid." (discussing COVID-19 vaccine which is recommended for children with asthma) (FG Nov 2021).

"Yeah, but I understand that cause my daughter, she take the same thing and it don't work. It works for a minute, but it's a like they get immune to it so. It's a struggle trying to find the right medication." (FG Feb 2022).

Caregiving Discussions (CD). Caregivers engaged in discussions of general parenting difficulties,

"Well I need to ask them about Christmas cause I sure, usually I get on top of it but me not being in my home all year, wandering from the hotel to somebody else's house to the hospital. I don't have anything for Christmas." (FG Dec 2021).

"I was dealing with my child having asthma as they say, and I was also having to deal with the rest of my life." (FG Jan 2022).

having another child with asthma,

"but all my kids in general have asthma." (FG Feb 2022).

advocating for child needs outside of current supports (this relates to general advocating for the child, not explicitly using learned skills/information from the program),

"I'm, I'm the type of mother that you can't tell me no. I'll find a way around you, and if one doctor that tells me nothing. Okay, no problem, write that in his chart, I move on to the next doctor. And when I tell them write it in their chart, they get nervous, because I look up the rights of my child. And when they see that I am not playing around with his health. You might think I'm crazy but that's okay. I'll be the crazy mother. Just make sure my child is okay." (FG Nov 2021).

"Yeah, I had the curtains pulled out at (*Child's school*). I had the curtains pulled." (FG Dec 2021).

and sharing resources with others by providing an endorsement for services that that they have found helpful.

"Participant 2: Yeah the deadline for the Angel Tree the Mother Tree is still until the 15th. Participant 4: Okay, thank you. Participant 2: You're welcome. Cause I'm doing, that's what I had, I just finished filling my paperwork out last Friday." (FG Dec 2021).

### Theme 3. Interventionist Interactions and Responses

Across all focus groups, caregivers discussed feeling supported by their interventionists, connections their interventionists had with the community, and skills/information they learned based on interactions with their interventionists. Select quotes across the focus groups are embedded in sub-theme descriptions.

Validation and Support (VS). Almost all caregivers reported feeling validated and supported by their interventionists. Several caregivers even mentioned that interventionists were like "family."

"I love the two ladies that always they came to my house. I mean they were wonderful. Like she would come when she didn't have to..." (FG Nov 2021).

"And that's the one thing that really stuck out, it was the fact that, it was like okay we met them but then they treated my baby like family. She was really, you know, very family-oriented. And really, it was close to me." (FG Feb 2022).

"They treat you more like family, it didn't feel like it was like an appointment. Like when they came over they were chill and they talked real good with my daughter. And she was really comfortable with them, she got excited and she would bring her little stuff...It was real nice." (FG Feb 2022).

Caregiver also had conversations about community referrals given by their interventionist team and if those referrals were helpful.

"Well, mainly they were, she was helping me get connected. It took months for me to get in touch with the Virginia Unemployment Commission. So, she helped me with her phone number to actually reach to someone else. It was another line that I had to call and it didn't directly go to anybody per say, but it went, it was a better option for me to call.

So that helped out a lot and I was able to get through and finally find out what was going on with my claim." (FG Jan 2022).

"And also, we, it was, I think it was last year, I think we had a bit of issue like, with food and because we were like going through rough times, a little rough patch. And she had, you know, she provided us resources for like places to get food and stuff like that. And she knew places where she could bring some to us. So that was, that was really helpful too." (FG Feb 2022).

Skills/Information Learned (SL). Caregivers discussed the skills and information they learned from interventionists during the program without discussing actions taken based on the information they learned. The fact that caregivers were able to regurgitate information they learned from the program proved they retained valuable information from their interventionists.

"You know the roach carcass that makes asthma bad for kids, the roach stuff that they leave behind and that stuff makes people's asthma flare up." (FG Dec 2021).

"I did learn a lot about what triggers asthma that I didn't know. As far as like dust. And then, I like that the lady when she, before it became, before COVID came, she would like check around and like show me stuff to look out for, things that I missed. We had a little mold coming at the bottom of one of my faucets in the shower and I didn't see it. So she had seen that and told me that can affect asthma..." (FG Jan 2022).

# Theme 4. COVID-19 Impact

COVID-19 occurred part-way through RVA Breathes and had a profound impact on the families enrolled. This theme encompasses all discussions with RVA Breathes intervention caregivers about the impact of COVID-19 on emotions, behavior, development, asthma, and finances. Select quotes across the focus groups are embedded in sub-theme descriptions.

Emotional Impact (EI). Across all groups, caregivers reported on the emotional toll COVID-19 had on themselves and their families. Discussions included reporting increased anxiety, depression, stress, and fear for caregivers and children alike.

"It was, it was scary it was. It was like really really scary." (FG Nov 2021).

"But once he started getting too much rest, he started getting depressed. He sit up in that room all day playing that video game, and I gotta get some type of sunshine for him because he's getting depressed." (FG Dec 2021).

"Right? Yeah, and it breaks some of them down. And it does, sometimes depending on the child, it'll lead to depression or you know, loneliness and things like that. It can trigger a lot of stuff, anxiety and everything." (FG Jan 2022).

Behavioral Impact and Activity Restriction/Social Isolation (BI). Not only did COVID impact emotions, caregivers discussed social isolation, increased caution, and a lack of ability to go outside. Caregivers reported how behavioral changes due to COVID-19 negatively impacted mental and physical health.

"So, it put a damper in a lot of things, especially for my kids. We like to travel back home. So, we couldn't, because of COVID. And I didn't want to, can't, you know, decide to get sick, and something happening to her. And then I'm working in retail, and I have to go home to her." (FG Nov 2021).

"Well, (Child's Name) about her being a teenager. It was hard for her, she told like, "Man I'm stuck in this house. I can't go nowhere I can't do nothing. Grandma won't let me go to my friend's house." Because I told her no you ain't going to nobody's house I don't know nothing about them. And you need to be at home so you don't get sick from

nobody, because if you go around somebody and you come bring it back to me, I'm 67 years old." (FG Dec 2021).

"it's sad because it's like right as she started to come out of her shell and make friends and not be so shy, and she was a little plus-sized, and she hit a growth spurt and she started losing weight and feeling confident and making friends. And she was doing cheerleading and extracurricular activities. I was just still being cautious with her asthma, making sure that her coaches had her inhalers and everything that we needed. And we got hit with COVID and now it's like, we would go out there for certain games. We would go out on the field for a game and then last minute we find out oh, our game is cancelled because XYZ has COVID or, you know, we got a couple of players that tested, you know, inconclusive. So, it really has stunted her there because that was her, and actual other kids, her being an only child. Other than having her cousins to play with, it really put us back into our little bubble, and she's like right back into being by herself." (FG Jan 2022).

Asthma Impact (AI). Through focus group discussions, caregivers reported how their child's asthma symptoms improved during COVID-19, possibly due to social isolation, not being in the school building with mold and other asthma triggers, and wearing a mask when around others.

"But it honestly seems better because he doesn't have as much asthma attacks as he used to at school before this even happened. So, I honestly think the masks are good, you know, for the kids with asthma sometimes. Everybody different but I think it does keep a lot of stuff down, you know. Germs and stuff that they gotta breathe in. I think it does help. Yeah." (FG Jan 2022).

"Yeah, the previous year my kid was sick every other day before COVID started. Every other week they were sick. They even were sick for two, three, weeks they were out of school. From wheezing and they got the flu shot and got sick and all that. But once they get at home schooled, they didn't even get sick not one time. But as soon as school started back, the wheezing and the coughing started back." (FG Feb 2022).

While caregivers reported that asthma symptoms improved, they also mentioned having difficulty getting a doctor's appointment since COVID-19 began, and in some cases, being forced to pay out of pocket for visits that should be covered by insurance due to not being able to get an appointment.

"Yeah. Hard to get an appointment you know, still hard to get an appointment. You have to wait months and months to get an appointment." (FG Nov 2021).

"I've been having problems with my child's doctor...Me too...With the nurse. I've been like through with the nurse, I'm on file with the nurse. But the doctor, the doctor is really ticking me off....Trying to get a hold of them...They kept saying they full...Making up excuses for every time I try to take. My son just went to school physical. Do you know I have to call the doctor for a physical....On the Zoom?...They talking about they booked up. They booked up. So then, I had to take my son to Patient First to wait three hours for his physical, a sports physical, because I couldn't take him to his regular doctor...I had to pay \$35 for his physical at Patient First. Yep." (FG Dec 2021).

*Economic Impact (Econ)*. Another impact of the COVID-19 pandemic that was discussed in two focus groups revolved around job loss and decreased finances that may have had a downstream impact on a family's wellbeing.

"Like my job closed because of it. Because I work for a cleaning service or whatever and it's like we just completely closed down or whatever." (FG Nov 2021).

"I did, I went through, I ended up losing my job during COVID. Last year. And it was really rough, you know. Trying to piece things together. And I think that was the primary focus, you know." (FG Jan 2022).

### Spanish-Speaking Semi-Structured Interview

The caregiver Spanish-speaking semi-structured interview used the same probes as the English-speaking focus groups. Caregivers reported liking the program "I felt it was good. I felt good. The program was fine. I did enjoy it" and learning important information "I didn't know that stuffed animals caused asthma attacks. And, me too, before I used to like to have a lot of stuffed animals on my bed...so they had to slowly be discarded." A caregiver also reported liking her interventionist, "Oh no, she's a sweetheart. She is a nice person," and appreciating the community referrals that their home interventionist provided them, "Yes, with me yes (referring to community resources). She gave me a lot of advice. She shared a lot of information that was very helpful to me."

Both caregivers reported not having any illness or asthma difficulties once COVID-19 began, "Well, looks it went well with her thank God. I didn't have any problems...She didn't even get the flu." They also reported other perceived benefits to social isolation and remaining at home with their families such as getting more sleep, and being with their families for more time. "They no longer had to get up very early and well- I really liked it." Overall, the two Spanish-speaking caregivers had similar thoughts and feedback compared to the discussions in the English-speaking focus groups.

# Caregiver Member Checking Results

All caregiver focus group participants (n=20) were contacted for member checking to ensure focus group results aligned with their thoughts and experiences. Twenty English-speaking caregivers across four focus groups were contacted over a week at various times throughout the day. A detailed message describing the intent of the phone call was left if caregivers did not answer. Caregivers from the Spanish-speaking "focus group" were not contacted since their discussion was not formally coded. Of the 20 caregivers contacted, 9 (45%) completed member checking procedures.

Five of the caregivers had no thoughts or comments and agreed with all results. Four caregivers agreed with all results, and emphasized the importance of specific topics identified. One caregiver emphasized a need for continued interventions in schools with school nurses. The caregiver specifically talked about partnering with parents to determine whether the child or nurse should hold on to the child's inhaler at school. Another caregiver emphasized that she really enjoyed the focus group component of the study because it allowed her to talk to and connect with other caregivers of children with asthma. A third caregiver added final thoughts about making sure the program is turned into a sustainable community program, because it will greatly improve health outcomes in children with asthma. The fourth caregiver stressed the role of subsidized housing conditions (e.g., lack of ventilation, mold, age of the units and lack of updates) in her child's asthma exacerbations. She also emphasized the usefulness of air purifiers. Based on member checking procedures, no additional themes were added to focus group results.

# Percentage of Caregiver Focus Group Discussions by Theme

Across the four English-speaking caregiver focus groups, some groups discussed certain topics more than others. Table 2 outlines the number and percent of codes given by theme for

each focus group. The focus group in November of 2021 focused discussions on utilization of asthma education and caregiving difficulties. Caregivers in the December 2021 focus group had conversations about challenges and barriers, specifically caregiving difficulties and exposure to asthma triggers outside of their control. The focus group in January 2022 mainly discussed the impact of COVID-19 on their families, as well as the positive impacts of RVA Breathes. Finally, the focus group in February of 2022, similar to the focus group in December 2021, discussed challenges and barriers, specifically general caregiving difficulties.

**Table 2.** Number of codes given in each focus group by theme and sub-theme.

Theme Sub-Theme	FG1 (Nov 2021) n (%)	FG2 (Dec 2021) n (%)	FG3 (Jan 2022) n (%)	FG4 (Feb 2022) n (%)
Program Takeaways	29 (29.6)	25 (11)	29 (33.7)	24 (21.2)
Tang	4 (13.8)	1 (4)	7 (24.1)	4 (16.7)
UAE	16 (55.2)	9 (36)	4 (13.8)	9 (37.5)
Pos	7 (24.1)	3 (12)	14 (48.3)	10 (41.7)
FPI	2 (6.9)	12 (48)	4 (13.8)	1 (4.2)
Challenges and Barriers	30 (30.6)	164 (71.9)	13 (15.1)	51 (45.1)
Expo	4 (13.3)	48 (29.3)	2 (15.4)	11 (21.6)
MH-NC	6 (20)	26 (15.9)	1 (7.7)	3 (5.9)
MA	8 (26.7)	8 (4.9)	3 (23.1)	8 (15.7)
CD	12 (40)	82 (50)	7 (53.8)	29 (56.9)
Interventionist Interactions and Responses	15 (15.3)	9 (3.9)	13 (15.1)	26 (23)
VS	12 (80)	1 (11.1)	7 (53.8)	20 (76.9)
SL	3 (20)	8 (88.9)	6 (46.2)	6 (23.1)
COVID-19 Impact	24 (24.5)	30 (13.2)	31 (36)	12 (10.6)
EI	8 (33.3)	2 (6.7)	10 (32.3)	1 (8.3)
BI	8 (33.3)	10 (33.3)	9 (29)	5 (41.7)
AI	7 (29.2)	18 (60)	10 (32.2)	6 (50)
Econ	1 (4.2)	0 (0)	2 (6.5)	0 (0)
<b>Total Codes</b>	98	228	86	113

Note. The abbreviations are tied to each sub-theme. Tang is Addressing Home Environmental Triggers/Tangible Materials, UAE is Utilization of Asthma Education, Pos is Positive Thoughts about the Program, FPI is Future Program Improvements, Expo is Exposure to Triggers/Asthma Exacerbations, MH-NC is Menta Health Concerns and Stressors, Non-COVID, MA is Medication Use/Adherence, CD is Caregiving Discussions, VS is Validations and Support, SL is

Skills/information Learned, EI, is Emotional Impact, BI is Behavioral Impact and Activity Restriction, AI is Asthma Impact, and Econ is Economic Impact.

## **Home Interventionist Focus Group Themes**

The home interventionist focus group occurred in September 2021 and included 5 interventionists (3 CHWs and 2 HHAs). Similar to coding procedures for caregiver focus groups, using a bottom-up approach from grounded theory, four topics/themes were identified in the interventionist focus group: 1) continued client challenges, 2) interventionist resources, 3) thoughts on being a home interventionist, and 4) the impact of COVID-19. Each theme had between 2-3 sub-themes that further categorized interventionist discussions. Table 3 shows interventionist focus group themes and sub-themes. Open-ended focus group probes specifically asked about client challenges, community referrals and targeted resources, the impact of COVID-19 on the families they worked with and the program at large, and thoughts about being a home interventionist. Representative quotes are presented within each sub-theme description.

**Table 3**. Interventionist focus group themes and sub-themes.

Continued Client Challenges	Interventionist Resources	Thoughts on being a home interventionist	COVID-19 Impact
Barriers to asthma care (BC)	Connections to community/tangible resources/community referrals (CR)	Likes (L)	Impact on families (COVID)
Caregiving stress (CS)	Asthma planning with families (AP)	Dislikes (D)	Impact on intervention components and resources provided (COVID Res)
	Rapport is essential (Rap)	Ideas for future program improvements (FI)	

Theme 1. Continued Client Challenges

Interventionists discussed challenges that families reported during and after the program including barriers to asthma care and general caregiving stresses.

Barriers to Asthma Care (BC). Interventionists had conversations about barriers that may directly impact a child's asthma symptoms and management routines including transportation difficulties to doctor's appointments, "Transportation, a lot of them don't have transportation," accessibility issues for asthma care (lack of internet service, need for in-person medical support, lack of finances, insurance difficulties, lack of phone minutes), "Yea some of the families, they have, they, they...government phone. And they have seven minutes a month," insistence on using fragrant cleaning products in the home, "And I get it because I use their cleaning products and it doesn't give you that bleach smell, that Fabulos, you know, you know when you clean you wanna smell that you cleaned," and caregiver smoking, "Um, so I would say the smoking and cleaning would probably be the top two issues."

Caregiving Stress (CS). Interventionists discussed other challenges that their families have faced that may have downstream impacts on a child's health. Challenges included difficult conversations with landlords, "one call from us, we can usually get them...get a fire lit under leasing offices and under landlords. But it shouldn't really take that. They should go ahead and do what they're supposed to do, especially if it's in the lease," concerns with partners/violence in the home, "domestic violence...In one of them where they had a stalker and the stalker was bothering them so they had to relocate and everything," lack of education, "so that comes hand in hand with the jobs because a lot of them might not have a GED or high school diploma," other children in home with or without asthma who may need to provide childcare, "sometimes there might be issues in the home with the children...not getting along well. Also, like you said, child care. A lot of the mothers, they might not have a job so they're relying on like maybe an older child you know to help out. And sometimes the older child can't help," mental health concerns, "this anxiety to drug abuse (pipeline), ya know It's a, it's a different category and they, and we

have somebody for every category," crowded homes, "multi..multi-family households... we've all, we've all experienced that with one another, one or another um...client," and lack of finances "they don't have money to pay for the childcare as well."

#### Theme 2. Interventionist Resources

During focus group discussions, interventionists reported on the resources and community referrals they provided to families, the asthma planning techniques they used in their work, and the importance of rapport building and maintaining with families in order to help make a difference.

Connections to Resources, Tangible and Community (CR). Interventionists had conversations about resources and materials they provided families including tangible supplies such as the air purifiers, Seventh Generation cleaning supplies, and hyper-allergenic pillow cases as well as connections to community resources to address any reported client challenge directly or indirectly related to asthma care. "Well, we try to contact their doctor or um, or have them-that's when they have a patient come in and they finding out the right information that they can do: hospital, doctor or pharmacy. And you know, um, you get to do the – you get them what they need." They also mentioned the resources and materials that they liked and favorited, (including "Caritas, Code Enforcement, Medicaid transportation, the Doula Project, Capital Area Biker Bank, Richmond Behavioral Health Association (RBHA), and River Road Baptist Church"), as well as those they did not like "with one of our clients they were saying that they like the cleaning products that we gave them but it just doesn't have the smell that they desire." Interventionists also discussed their wish to provide financial assistance to families. "For me, it was really challenging to try to help them, like my coworkers say with money for the car

payments or insurance for the car payments assistance. There was another realization that we can't help with those two topics."

Asthma Planning with Families (AP). During the focus group, interventionists discussed engaging in asthma planning with families including attaining an asthma action plan, setting up doctor's appointments, updating medications, and getting an allergy test if needed. "I want to make sure that they completely have the asthma action plan renew, they have been likely checked out by the doctors, they have all the medication refills. So, make them ready in order for them to return to school and have extra medication at school in case the kid's going to need it, then they are at school

Rapport is Essential (Rap). All interventionists emphasized the importance of establishing and maintaining rapport with families, even if it was difficult. "Some of them, some of them you just gotta, just keep checking with them and eventually you know at the end, most of the time at the end it's a whole different ball game from the beginning."

"Yes, working right beside the family, help them to try to whenever they... you show them results, show them that you can help them out and once you show them, they trust you and they start working with you. They start doing them self, learning how to do what what to go, and become patients. You gotta guide them. Yeah. But, but to get that trust, you gotta show them that if someone gets consistent that my coworkers say, you're gonna get good results"

#### Theme 3. Thoughts on Being a Home Interventionist

Interventionists were asked about their experience in the program and reported on what they enjoyed, what they did not enjoy, and ideas for future program improvements including possible trainings interventionists would benefit from.

Likes (L). Interventionists reported enjoying the service field, "I would have to say, just being able to service the people in my community with um with the knowledge that I have, and that's coming from anywhere, that's coming from mental health and that's coming from case management," working with their own communities, "I've always helped out my community in whatever way I could. It's just who I am," getting to know the families they work with, "I enjoy um getting to know new families and new kids. I feel like every child that I met has a different personality and I like getting to know them and just seeing how they change over the four sessions," developing strong relationships, "I do love the bonds that we build and connect with um because we have a lot of similarities as well that we can all connect on," and getting to see client growth, "So, that's what I really enjoy, is really the, just again getting to meet the families and being able to help them and seeing the growth over the four sessions."

Dislikes (D). While all interventionists reporting liking their jobs, they also reported some areas they did not like including not being able to help families financially, "Mine was like everyone said, the financial part, like you really want to help them when you, ya know, talk to them and they're, let you know what they need help with...But you can't help them financially," having some families lost to follow up, "of course you want to help people out you know, ones that you miss in the cracks, they fall through the cracks and different things like that, that hurts your feelings," and having difficulties with supervisors and lack of perceived support, "would have to be um my supervisor, I'm sorry to say I, it's just that I don't think we get the recognition and the support, you know, until they feel like it."

*Ideas for Future Improvements and Trainings (FI)*. Having worked with families in the RVA Breathes program for several years, interventionists reported possible improvements for future asthma interventions based on their experiences. Ideas included trainings on Medicaid,

"Medicaid is a very valuable piece, especially for our low-income families and I think that being able to, you know, give them, you know, some knowledge about the services that we can help them with, not just pass them on....I've already asked for, you know, training and um a class, webinar, whatever," being able to attain an asthma certification, "Asthma certification. I've been looking everywhere and I couldn't find organizations, someone who can give us that training," more IT and virtual technology trainings, "The internet and stuff. Like you know because we're using it more, so it's more advances that's coming up, like the zoom and the teams and all of those things. Those will be like miniature, you know, I mean those things can be like one to two hours of training and things of how to connect better and, you know, with the internet, have more resources up, place things together, yeah," mental health trainings, "maybe more training about mental health um so like give them more information. Cause sometimes they can't reach out to any providers for that and also something close to social work," and additional assistance with documentation and case management skills, "documentation and all that...Uh like case managers, case managing."

### Theme 4. COVID-19 Impact

All interventionists started working with the RVA Breathes program prior to COVID-19 and aided in procedural changes when COVID-19 began such as moving to a virtual format and families needing additional resources. During focus group discussions, interventionists reported on the impact of COVID-19 on families, as well as the impact of the pandemic on the resources and community referrals they provided to families.

COVID Impact on Families (COVID). COVID-19 began during the RVA Breathes intervention program, and according to home interventionists, negatively impacted families through job loss, "with the threat of being homeless and different things because of the um

pandemic not being able to work and um you know their jobs and everything. And so then, they're behind in different, in their bills and everything," food insecurity, "...not just think but it's been hard out there to try to um maintain, to try to cause, you know even trying to get food bring to your house. It's um a fee, it's ya know. So, things aren't always adding up for the convenience. We didn't ask for the convenience. If we could go to the store safely, we would go to the store, but when this first happened, that wasn't the case," lack of childcare, "lack of child care because the schools close and they don't...the child care expenses are too much," worsened mental health, "it's a whole different ball game like oh my gosh, like it's so much that the kids have like their anxiety and depression and a lot of our kids, they have, like some of them are a little of depression and anxiety and other health disorders. It's just, we're gonna have to help them with that as well," failing school subjects, "with the virtual learning, you know a lot of kids didn't pass. A lot of kids had to repeat their grade because either one, they didn't have the supervision needed to um you know for, from their parents and parents couldn't really help them the way, you know, they get their help in school," and family deaths due to COVID-19 illness, "having other family members who have contracted it either passing away or being sick because of it...you know finished it. So those are some of the things over the last year."

additional challenges for families enrolled in RVA Breathes, it also impacted community resources and referrals that interventionists recommended to families. For instance, interventionists received a lot more requests for food assistance, "the food pantries um with the COVID going on, the food pantries...um the uh, the-the-the school lunches for the children. We provided flyers in different places when it first started, of the COVID," mental health services, "I would say mental health. A lot of the kids went like some things we went through as adults, the

children had um went through as well," and assistance for accessing medical care remotely, "Um tela-telamaid uh telemaid. Resources like let them know that you can get on the phone... for us doctors appointments." Interventionists also reported that they had to regularly update their go-to referrals because resources would shut down "some of them had closed and you wouldn't hear that because some people were leaving their offices so like a lot of different changes so that thing just," take longer to respond, "some resources, um some of the um resources, they either um it would take longer to give the resources or even because of the pandemic," or run out of funds and energy, "In my experience, a lot of organizations was helping the beginning of COVID but has been drying out now and even the organization are tired with COVID. They don't have any more money, funds, and uh places to go but the COVID is still here and the new variance is still coming so and a lot of people is getting infected for the second, third time already. And so COVID is not over, but the organizations are tired."

### Interventionist Member Checking Results

Interventionist focus group participants (n=5) were contacted for member checking to ensure focus group results aligned with their thoughts and experiences. All conversations occurred in English. Of the five interventionists, 4 participated in member checking procedures. Two interventionists agreed with all results and had no comments. The other two interventionists agreed with all results, and emphasized the importance of specific topics. One interventionist emphasized the importance of case management and helping families with all their challenges, even those that are not directly related to a child's asthma management. The other interventionist emphasized that the experiences that home interventionists had with community resources/referrals is important information for future pandemic responses.

## Percentage of the Interventionist Focus Group Discussion by Theme

During the interventionist focus group, topics were discussed for various durations based on the engagement of the interventionists in that topic. Table 4 outlines the numbers and percentages of codes given by theme. Interventionists focused discussions on interventionist resources, specifically conversations about community referrals and tangible materials they gave to the families they worked with. Interventionists also discussed continued client challenges with a focus on caregiver stresses that may have indirectly impacted a child's asthma.

**Table 4**. Number of codes given for the interventionist focus group by theme and sub-theme.

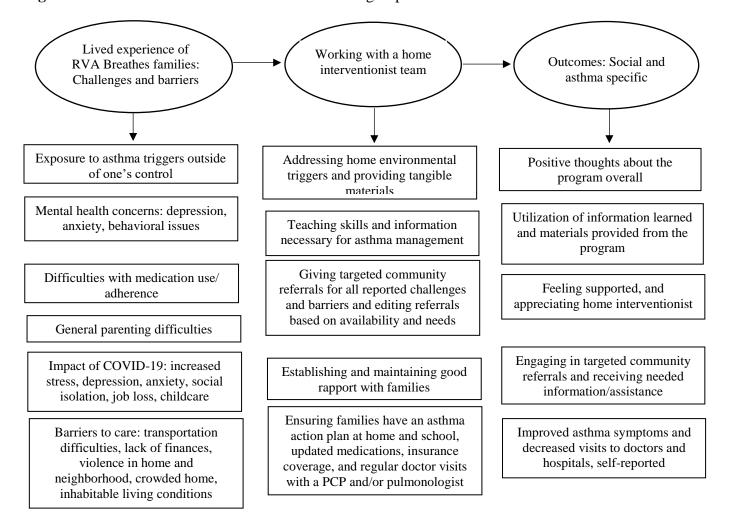
Theme Sub-Theme	FG (Sept 2021) n (%)
<b>Continued Client Challenges</b>	38 (22.9)
BC	18 (47.4)
CS	20 (52.6)
<b>Interventionist Resources</b>	67 (40.4)
CR	38 (56.7)
AP	10 (14.9)
Rap	19 (28.4)
Thoughts on being a home interventionist	28 (16.9)
L	6 (21.4)
DL	7 (25)
FI	15 (53.6)
COVID-19 Impact	33 (19.8)
COVID	20 (60.6)
COVID Res	13 (39.4)
<b>Total Codes</b>	166

*Note*. The abbreviations are tied to each sub-theme. BC is Barriers to Asthma Care, CS is Caregiving Stress, CR is Connection to Tangible and Community Referrals, AP is Asthma Planning with Families, Rap is Rapport is Essential, L is Likes, D is Dislikes, FI is Future Improvements, COVID is COVID-19 Impact on Families, and COVID Res is COVID-19 Impact on Intervention Components and Resources Provided.

A map was generated to visually depict how RVA Breathes and home interventionists positively impacted the families with whom they worked. Figure 3 was created by synthesizing

interventionist and caregiver focus group discussions into a care model. This model provides a general overview of reported family challenges, how interventionists assisted families, and perceived positive outcomes based on home interventionist support. The model supports the notion that home interventionist support can lead to positive social and asthma-specific outcomes for families with a child with asthma.

Figure 3. RVA Breathes Care Model based on focus group discussions



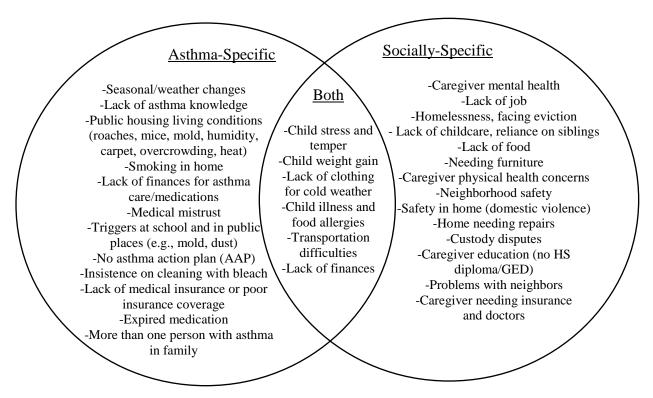
# CHW Session Notes and Institute for Public Health Innovation (IPHI) Summary of Codes

#### **Barriers** to Care

CHW session notes were coded for barriers to care, interventionist provided resources, and engagement in provided resources. The content of each code was organized further into

asthma-specific and socially-specific categories using the information provided. Asthma-specific barriers and resources were directly related to a child's asthma care based on published guidelines from the CDC, American Lung Association, and American Academy of Allergy, Asthma, and Immunology (such as access to providers, medication refill difficulties, insurance issues, environmental triggers in school/public places that caregivers cannot address, lack of knowledge about triggers and/or medications), whereas socially-specific barriers and resources were factors that may influence a child's broader system and have possible downstream impacts on their health (such as lack of food, clothing, housing, or finances, job loss, need for furniture, mental health concerns, concerns about the school (other than trigger/asthma-related), COVID-19 and other global/national/local events, adverse childhood experiences, incarceration, caregiver or sibling illness and/or death, etc.). Barriers to care coded from session notes were organized into asthma-specific and socially-specific categories and placed in a Venn diagram (Figure 4).

**Figure 4**. Asthma-specific and socially-specific barriers to care based on session notes.



### Community Referrals/Resources

To further augment the community referrals and resources, IPHI provided a list of community referrals and client engagement in those referrals by ID number derived from the CHW's internal record keeping system. This information was not tied to specific intervention sessions, however, and provided an overview of resources and client engagement in resources throughout the intervention period. Client referrals were added to information gathered from CHW session notes. Table 5 outlines asthma-specific and socially-specific resources based on identified barriers from both CHW session notes and IPHI internal records to give an overall picture of interventionist-provided community referrals throughout RVA Breathes.

IPHI's internal records outlined more community referrals than CHW session notes alone. Nevertheless, 63 out of the 152 families (41.4%) that completed at least one RVA Breathes intervention session had no referrals listed in IPHI's records. Some of those families may not have needed community referrals; however, it is plausible that others received community referrals that were not documented. Documentation challenges are discussed in the limitations section of the discussion in Part 1 on page 68. At this time, there is no way to differentiate between a family not receiving community referrals and referrals not being documented. Based on the available data, all resources listed in CHW session notes were also listed in IPHI's internal records. Additional family barriers that were addressed through interventionist referrals outlined in IPHI's internal records included legal assistance, safety, and utility support. Numerous community referrals were able to assist families with an array of needs, and therefore, may appear in the table across several categories. Furthermore, utility support can be seen as a sub-category of financial assistance, since all referrals aided families in paying utility bills.

 Table 5. Asthma-specific and socially-specific resources

Barriers	Interventionist-Provided Resources	
Asthma-Specific		
No doctor for child	Pulmonologist and PCP referrals to VCU Health, VCU Children's Pavilion	
Smoking (in home/around child)	Quit Now, referral to primary doctor for smoking education	
Socially-Specific		
Food	List of food pantries, dropping off food, giving school lunch locations, SNAP benefit assistance, Waymakers Foundation, Shipt, Store delivery, Grub Hub, Door Dash, Feed More, Feed my People (Crusade for Christ Church), Belmont United Methodist Church, St. Augustine Catholic Church, La ROCA Food Pantry, Latinos en Virginia empowerment center, Secret Heart Center, The Rock Church, Resource Mother, Mosby Resource Center, First Baptist Church of South Richmond, Hillside mobile Food Pantry, New Life Deliverance Tabernacle Church, Celebration Church and Outreach Ministry, Bainbridge Community Ministry, Celebration Church and Outreach Ministry, First Baptist Church of South Richmond, CAP Up, NO Kid Hungry, CCHASM alliance for social ministry, The Give Back, Victory Tabernacle, Richmond Public Schools (RPS- COVID lunches), Antioch Baptist Church, Fishes and Lovers food pantry, Neighborhood Resource Center, Youth With A Mission Pantry, Northside Outreach Center, St John Baptist Church, St Thomas Episcopal Church, Twenty-first St Church of God, Ebenezer Baptist Church, First Baptist Church Monument, Moore Street Baptist Church, Saint Marks, Second Baptist Church, Homeward Project Connect at the Convention Center, ICNA food pantry delivery	
Mental Health	Richmond Behavioral Health Authority, in-home counseling referral, Daily Planet, Health Brigade, Eastern Henrico Health Department, Children's regional crisis, COPES, Lighthouse Behavioral Health Center, J Group Counseling, WHO Counseling services, CPSD (VCU Center for Psychological Services), Bridging the Gap Family Services, Child Savers, CHoR VCU Mental Health Family Navigator and tele counseling appointments, Replay Counseling Center, Greater Richmond Regional Hotline, Safe Harbor, Latinos en Virginia Empowerment, Family Lifeline	
Employment	Employment referrals, VEC, Michael and Son, Richmond Career Center, Henrico Career Center, Race Track Midlothian, Careers in Motion Warehouse logistics, Community Wealth Building, Career Station and Randstad office community wealth building, All Team (Hospitality and Janitorial), Career in Motion (CDL drivers, Laborers, Services Technicians, Material Handlers, Shipping, Reciters) SERVPRO, Fire, water cleanup restoration, Scotties (Glass/Metal Maintenance restoration and cleaning), Papa John's Pizza, Rock Solid Janitorial, Shamin Hotel, SMI Hotel Group, The results company, Career Advantage, Goodwill, Glean LLC, Lynchburg, Registered Apprenticeship, Virginia Dept of Labor and Industry, Hillside Resource Center Job Fair, Integrity Staffing Solutions Recruitment event, provide the web page for job search for spouse, bonds4jobs.com, federal bonding program for a risk job seekers, exoffenders.net/employment-job-for-felons (job placement services) and jailtojob.com/WordPress/, Aerotek Job Agency, Virginia Career Works—Capital Region Workshops/Events, Arthur Ashe Athletic Center, T Mobile Customer Care	
Home Repairs	Common Help Virginia for cooling assistance, two floor fans by Diversity Thrift, space heaters, DSS Emergency heating assistance, Habitat for Humanity, VA Dept of Health Development, Project Homes, Urban Hope, Eviction hotline, legal aid	

Adult Education	Information about GED and online HS programs, South Side Community Career Station, RPS Adult Education, Adult Career Development Center, Travis Woods, Human Service Analysts, Office of Community Wealth Building,
Medical, (caregiver, sibling, and undefined)	Parent Educational Advocacy Training Center  PCP referral, Capital Area Health Network (Dr. Vango), DSS Richmond medical, Hayes E. Willis Medical Center, Crossover Ministries, COVID-19 testing, Access Now, Center of Healthy Hearts, Norma Ryan, Virginia Health Care Foundation, Give Kids a Smile, Medicaid application specialist, Cover Virginia, Goodrx, Care-a-van, Cetaphil corporation (for lotion)
Furniture	Caritas, Diversity Thrift voucher, Mercy Mall, Habitat for Humanity, Love if Jesus Thrift Store, Goodwill
Housing	Southside Community Development Corporation, Urban Hope, St. Luke Apartments, Coventry Gardens, Walmsley, St. Luke's, Kingsridge apartments, VA Housing authority (VDHA), Armstrong Renaissance, Housing resource line, Dominion Place, Richmond redevelopment and housing authority, Randolph village apartments, ACTS, Southside community development center, Catholic Charities, Better housing coalition, Andrew's townhomes, Virginia poverty law and eviction legal helpline, Jefferson Mews, The Goodwyn at Union Hill, Winchester Greens, Section 8 housing, RCHD Creighton coaches, Henrico arms
Holiday Needs	Referrals for Turkey baskets and Christmas gifts, Tabor Baptist Church Christmas, Salvation Army, Christmas Angels, Toys for Tots, Branches community Thanksgiving, Arthur Ashe Turkey Basket, Peter Paul Thanksgiving basket giveaway
Childcare	YMCA childcare assistance, mentorship (Big Brother, Big Sister), Preschool Kick-off, The Doula Project, Capital Child Care, SOAR 365 summer camp
Legal Assistance	OMA, Latinos en Virginia/Empowerment Center, VCU Legal Partnership Assistance, Medical/legal partnership, Legal aid justice center, Bilingual Family Support specialist
Safety	Broad Rock Community Center, Richmond Animal Care and Control, YWCA, Latinos en Virginia Empowerment, 911/Agent JA Uribe
	Both
Transportation	Medicaid Transportation, Boaz and Ruth Inc., and Peter Paul, Optima Family Care (Medicaid), Humankind, Vehicles for Change, www.freehcaritycars.org, how to set up virtual appointments, Richmond Public School Department of Pupil Transportation Telephone Directory, medical transport company
Finances	Assistance paying for medications, gas money, utility assistance (CAPUP), Commonwealth Catholic Charities, Financial Opportunity Center, assistance filling out COVID stimulus, rental assistance, RVA Strong through OMA, Sacred Hearth Center (rent assistance), DSS assistance to receive money as caretaker, Temporary Assistance for Needy Families (TANF), LULAC, Ways to Work, Faith Landmark, Sacred Heart Center, Richmond Public Library North Ave, Robins Family Foundation, Creighton Resource Center, Dominion Energy, St Paul Episcopal Church, RVA Strong Family Crisis Fund, Crisis assistance, Southside community center, Amazing Grace World Fellowship church
Utility Support (sub-category of finances)	Water bill assistance, DPU Cares Program, Commonwealth Catholic Charities, Salvation Army, Her Church, Faith Landmark, River Road Baptist, Dominion let the company know your son has asthma with a note from doctor, Capital Area Partnership Uplifting People (CAPUP), Common Help, The Salvation Army of Central Virginia, ACTS, Richmond Public Utilities CARES Program, TANF, Sacred Heart Center
Clothing	Mercy Mall, New shoes for back to school Ministry, Carol Adams Foundation, Diversity Thrift Store, First Baptist Church, Grace and Holy Trinity Church, Sixth Mt. Zion Baptist Church, Tabernacle Baptist Church, Third Street Bethel AME Back to School event, Belmont United Methodist Church, Bethlehem

Baptist Church, Churchill Christian Wellness Center, First Baptist Church
South Richmond, Fish (Eastern Henrico), Ginter Park United Methodist Church,
Grace and Holy Trinity Church,, Sixth Mt. Zion Baptist Church, Pregnancy
Resource Center, Second Baptist Church, Tabernacle Baptist Church, Trinity
Baptist Church, Victory Tabernacle Church of God, Thrift store, Capital Diaper,
Urban Baby Bank

## Engagement in Referrals/Resources

Client engagement in resources was coded as "yes" or "no" utilizing information included in session notes. Only 13 asthma-specific and 10 socially-specific engagement phrases were found in session notes, all of which were coded as "yes" since they described client engagement in provided resources. Asthma-specific engagement included attempts to stop smoking, pest control efforts above and beyond program norms, and attendance at a child's doctor's appointment set up by interventionist team. Socially-specific engagement included caregivers keeping their doctor's appointments set up by interventionists, connecting with Caritas for furniture, speaking to a housing referral called Urban Hope, following up with Code Enforcement for housing concerns, and obtaining social service benefits for a loved one.

Each community referral within IPHI's internal records also outlined whether or not a family engaged in the provided resource. Notes were coded as: "yes"- the family engaged in the referral, "no"- the family did not engage in the referral, "partial"- the family reached out to the referral, but may not have been eligible or may not have utilized it, or "unknown"-the family's engagement efforts are unknown. All community referrals in IPHI's system were assigned one of the four engagement categories. Of the 529 listed referrals across 91 unique families in IPHI's system, 44 referrals were categorized as no engagement, (8.3%), 47 referrals were categorized as partial engagement (8.9%), 193 referrals were categorized as yes engagement (36.5%), and 245 referrals were categorized as unknown (46.3%). Results of family engagement in community referrals can be found in Table 6.

**Table 6**. Family engagement in interventionist-provided referrals using IPHI's internal records.

<b>Engagement Category</b>	n (%)
No	44 (8.3)
Partial	47 (8.9)
Yes	193 (36.5)
Unknown	245 (46.3)

**Discussion: Part 1** 

Families of children with asthma, particularly families reporting an income below the poverty threshold, have high rates of asthma diagnosis, missed school days, activity limitations, increased financial burden, lower quality of life, increased ED visits and hospitalizations, and mortality (Akinbami et al., 2017; Cardet et al., 2022; Everhart et al., 2015; Hughes et al., 2017; Sicouri et al., 2017). Research also shows that pediatric asthma is negatively impacted by continued exposure to environmental triggers, and persistent barriers to care that are, unfortunately, systemic in our society (Butz, Kub, Bellin, & Frick, 2013; Swartz et al., 2005). Nevertheless, pediatric asthma home interventionists work closely with families in their communities, directly address environmental triggers and barriers to asthma care, and have been linked to decreased asthma symptoms, improved asthma control, and decreased emergency and urgent care use (Marshall et al., 2020; Postma, Karr, & Keikhefer, 2009). Home interventionists have also been shown to decrease healthcare costs (Marshall et al., 2020).

Even though utilizing home interventionists has been associated with positive health and financial outcomes, the home interventionist model has not been widely adopted by health care systems due to limited insurance coverage (Morley et al., 2014). This study aimed to provide further evidence of the benefits of home interventionists for families of children with asthma by gathering qualitative data on the caregiver and interventionist experience in a community pediatric asthma intervention program. Notably, COVID-19 began halfway through the RVA

Breathes intervention, and created additional barriers and challenges for families and interventionists. Therefore, we had the unique opportunity to gather family and interventionist feedback about the home interventionist model of care during a pandemic.

Data were gathered from five caregiver FGs (4 English-speaking and 1 Spanishspeaking), one interventionist FG, 152 sets of CHW session notes, and IPHI's internal records of community referrals and client engagement. Through coding procedures, we developed an RVA Breathes Care Model (Figure 3) as well as a Venn diagram highlighting asthma-specific and socially-specific barriers to care that RVA Breathes families reported (Figure 4). Furthermore, we summarized focus group themes (Tables 1-4) and interventionist-provided resources (Table 5). Client engagement in resources based upon IPHI internal records was summarized in Table 6. The use of multiple qualitative data sources allowed for a rich understanding of the interventionist and caregiver experiences to inform future pediatric asthma intervention efforts and policy changes. Findings highlight the benefits of the pediatric asthma home interventionist model of care for providing necessary support, helping to improve asthma outcomes, and giving targeted assistance for family challenges (both directly and indirectly related to asthma). The following sections further discuss focus group themes and the categorization of barriers to care, interventionist-provided resources, and family engagement based on session notes and internal records.

#### **Focus Group Themes**

Using both caregiver and interventionist focus groups, we were able to examine the home interventionist model of care utilized in RVA Breathes, identify family and interventionist challenges and barriers, discover interventionist techniques to address client concerns, and examine how COVID-19 impacted the program and enrolled families.

#### Interventionists Interactions and Resources

In focus group discussions, caregivers reported feeling supported by their interventionists, and in some cases, even considered them to be "like family." Interventionists emphasized the importance of rapport for establishing trust and maintaining a positive relationship throughout the intervention period. Both caregivers and interventionists recognized the importance of establishing trust, consistently showing up, and making one another feel supported. Recent qualitative research examining engagement-promoting strategies for CHWs in a school-based mental health intervention identified rapport building and responsive delivery as the two main engagement strategies that CHWs utilized (Gustafson et al., 2021). Rapport was built and established through non-judgmental supportive listening, increasing social proximity, praise, privacy and confidentiality, and leveraging relationships, while responsive delivery was achieved by flexibility, consistency, advocacy, incentives, and meeting needs (Gustafson et al., 2021). In line with published findings, focus group discussions established that the relationship between a home interventionist and the family they serve is essential in promoting positive outcomes, and interventionists acknowledged the need to be flexible and consistently show up for the families with whom they worked.

In addition to building strong rapport, caregivers and interventionists reported the importance of community referrals and asthma education. Caregivers reported learning important information about their child's asthma triggers and asthma management routines. Some caregivers were surprised at certain identified triggers in their homes, such as roaches, black mold, cleaners with bleach, and dust in stuffed animals. Interventionists reported a sense of accomplishment when providing families with tangible materials to address identified triggers. They also discussed community referrals they used often such as Caritas, Code Enforcement,

Medicaid transportation, the Doula Project, Capital Area Biker Bank, Richmond Behavioral Health Association (RBHA), and River Road Baptist Church, that all continued to help families through COVID-19.

### Positive Feedback about the Program

Caregivers expressed positive thoughts about the program, continued to utilize the asthma education they learned from interventionists, and praised the tangible materials they were provided to address home environmental triggers (e.g., air purifier, cleaning supplies, hyperallergenic pillow cases). Similar to past home interventionist programs, caregivers supported the idea that home interventionists serve as an integral part of an effective community intervention program by providing targeted educational curriculums, addressing specific barriers, and implementing behavior change plans for maladaptive behaviors (e.g., smoking, using bleach for cleaning) that may worsen asthma symptoms (Bryant-Stephens et al., 2019; Martin et al., 2016). Interventionists appreciated being able to help their communities, valued the relationships they developed through their work, and enjoyed seeing client improvements.

### Challenges and Barriers

While the program helped families in many ways, caregivers discussed several challenges they continued to face. These challenges included persistent difficulties encountering asthma triggers in public places (including school), experiencing depression, anxiety, and increased stress due to ongoing caregiving and societal demands, and difficulties advocating for their children's needs. Research shows that caregivers of children with asthma report more anxiety and depressive symptoms compared to caregivers of healthy children (Easter, Sharpe and Hunt, 2015), and caregiver depressive symptoms has been associated with worse pediatric asthma outcomes (Margolis, Shelaf et al, 2022; Morillo-Vanegas, Sanchez-Salcedo, and Ariño, 2020).

Knowing that caregiver challenges persisted even after RVA Breathes, future programming should consider continued check-ins with caregivers to address ongoing mental health concerns, advocacy needs, and strategies to avoid asthma triggers in public places.

Interventionists echoed caregiver challenges and added concerns about transportation, accessibility of asthma care in virtual settings, continued caregiver smoking, concerns about violence in family homes, reliance on siblings for childcare needs, and a general lack of finances. It is plausible that some of these challenges are connected. The link between caregiver mental health and negative pediatric asthma outcomes might be partially due to caregivers utilizing maladaptive coping skills, such as smoking, that exacerbate asthma symptoms (Jasal et al., 2020). It is also likely that a lack of finances has a cascading negative impact on all aspects of a family's life. Decades of research on social determinants of health shows that children living in poverty have negative health outcomes across the lifespan (Council on Community Pediatrics, 2016). While home interventionists cannot change every family's financial status, they can work to address the social determinants of health (e.g., safe housing, transportation, education and employment, food/clothing/furniture needs) impacting families they work with through targeted community referrals in hopes of creating lasting, positive change.

# Impact of COVID-19

According to caregivers and interventionists, families experienced worsened mental health symptoms, increased social isolation, job loss, lack of childcare, and decreased finances when COVID-19 began. Caregiver reports aligned with published research indicating a notable increase in mental health concerns and increased social isolation during the pandemic (Adams et al., 2021; Cluver et al., 2020; Russell et al., 2020). Nevertheless, an article just published by the primary researcher using a subset of participants in RVA Breathes that completed sessions

before and after the start of COVID-19 (n=125) examined the impact of COVID-19 on caregiver mental health. Our study found that caregivers of children with asthma who received home interventionist support during COVID-19 actually reported lower perceived stress and depressive symptoms compared to before COVID-19 began, whereas caregivers in the control condition saw no significant improvements in mental health scores (Lohr et al., 2023). Findings suggest that support from home interventionists may have alleviated caregiver stress and depressive symptoms during COVID-19, even though caregivers were reporting more stress in focus groups discussions. It is possible that caregiver mental health during COVID-19 is not well captured by questionnaires used before COVID-19 began. Further examination into caregiver well-being during the pandemic is warranted.

While caregivers reported an array of negative impacts due to COVID-19, they also noticed an improvement in their child's asthma symptoms and less need for rescue medication while attending school virtually (March 2020 through September 2021). Caregiver perceptions align with recent research identifying a decrease in ED use and an improvement in asthma control among children with asthma since COVID-19 began (Kenyon et al., 2020; Lohr et al., 2023). This improvement may be due to children having limited contact with respiratory viruses carried by their peers and environmental asthma triggers in school buildings during virtual learning (Oreskovic et al., 2020).

RVA Breathes interventionists had to make several changes as they continued to work with families remotely during COVID-19. Interventionists reported different community referral needs for families and a need to regularly update their resource lists when COVID-19 began. Families began requesting more food assistance, mental health services, technology education, and assistance with virtual access to appointments. Furthermore, interventionists needed to

continually update the community referrals they provided families based on organizations shutting down, some taking longer to respond, and others running out of funds and resources. It is likely that COVID-19 introduced additional barriers to families of children with asthma and challenges for home interventionists that persist today. With this understanding, it is important to categorize barriers to asthma care, interventionist-provided resources, and client engagement in resources as intervention efforts continue to make positive changes in the context of the COVID-19 pandemic.

Future Improvements and Areas of Growth

While both caregivers and interventionists reported positive feedback about the program, they had several suggestions for future improvements. Caregivers discussed the possibility of conducting interventions and holding support groups for teenagers with asthma. This was logical since focus group discussions occurred after the intervention phase was complete, and the children enrolled were now pre-teens (11-12 years old) or teenagers (13-14 years old) instead of school aged children (5-11 years old at enrollment). They also mentioned that intervention efforts should focus on environmental remediation efforts in schools where children spend the majority of their time. Research such as the School-based Asthma Management Program (SAMPRO) coordinates asthma care for children between clinicians, families, and school nurses (Kakumanu et al., 2017) just like RVA Breathes. Dissimilar to RVA Breathes, SAMPRO addresses environmental triggers at school and not in family homes. RVA Breathes decided to focus environmental trigger remediation efforts in participant homes based on a community needs assessment (Everhart et al., 2020). Nevertheless, SAMPRO, or a similar school-based asthma program, may be a good fit for families hoping to address environmental asthma triggers in schools (e.g., mold, cockroaches, dust). Finally, caregivers reported a desire to receive more

resources, even if they did not report a specific challenge. For instance, they wished to receive an air purifier, clothing vouchers, and lists of holiday supports and food banks, even if they did not report air quality, clothing, holiday, and/or food concerns. During RVA Breathes, interventionists did not provide referrals unless specific challenges were reported to them by families and referrals were deemed necessary by the intervention team.

A desire for more resources was also mentioned in the interventionist focus group, particularly regarding financial aid resources. Interventionists disliked their inability to change a family's financial status, and believed that if families had more money, many of their daily challenges and barriers would be minimized. Furthermore, interventionists discussed several topics that would be beneficial for future programming efforts including interventionist trainings on Medicaid, technology, mental health, documentation, and case management skills. While they felt equipped to work with the families in RVA Breathes, the interventionists reported that more trainings on mental health would allow them to do risk assessments when needed, more understanding of Medicaid would allow them to better help families understand their insurance coverage, and more technology trainings would assist them in documenting their work in a post-COVID-19 world. COVID-19 forced home interventionists to use technology for sessions and documentation, whereas they did not necessarily need those skills prior to the pandemic.

Interventionists reported several factors that they disliked about being a home interventionist, including having difficulties with supervisors and lack of perceived support from them, an inability to improve family finances, and losing contact with some clients. They also reported a desire to obtain an asthma certification to help keep up to date on pertinent information and to be useful for promotions and job applications. Overall, caregivers and interventionists perceived a positive relationship with one another that was mutually beneficial,

and with possible enhancements, future programming can continue to improve the lives of children with asthma and their families.

### **Barriers to Care, Resources, and Engagement**

Coding procedures used with CHW session notes identified asthma-specific and social-specific barriers to care that RVA Breathes families reported to their interventionists. Barriers to care were coded as asthma-specific if directly related to a child's asthma care as outlined in guidelines by the CDC, American Lung Association, and American Academy of Allergy, Asthma, and Immunology (e.g., access to providers, environmental triggers, insurance coverage) or socially-specific if they impacted a child's broader systems and may have downstream negative asthma implications (e.g., caregiver mental health, lack of food/clothing/housing/furniture/finances, neighborhood safety). Findings highlighted an array of continued challenges that families reported, many of which interventionists were able to address through providing targeted referrals. CHW resources to address identified barriers to care were gathered from IPHI's internal records and client engagement categories were assigned to each given referral. *Barriers to Care* 

Session notes mentioned 32 unique barriers to care across 152 families that caregivers reported to their interventionist teams during the RVA Breathes intervention program. Through rigorous coding, researchers categorized those unique barriers into three groups: asthma-specific (12), socially-specific (14) and both (6). Asthma-specific barriers to care included seasonal/ weather changes, lack of asthma knowledge, poor public housing living conditions, smoking in the home, lack of finances for asthma care and medications, medical mistrust, asthma triggers in school and public places, no asthma action plan (AAP), cleaning with bleach, lack of insurance coverage, other family members with asthma, and expired medications. These barriers to care

align with published research examining why asthma morbidity remains high for children living in urban areas and reporting an income below the poverty threshold (Butz, Kub, Bellin, & Frick, 2013; Gill et al., 2022; Mansour, Lanphear, and DeWitt, 2000). Nevertheless, reported family, school, and societal challenges cannot be ignored as such barriers impact a child's broader systems and have downstream negative impacts on their health.

Socially-specific barriers to care included caregiver mental health, caregiver physical health concerns, neighborhood safety, safety in the home, home needing repairs, custody disputes, problems with neighbors, caregivers needing insurance and medical providers, and lack of employment, housing, childcare, food, furniture, caregiver education. While these barriers to care are not directly linked to a child's asthma symptoms or management routines, they still impact a child's daily life. For instance, living in an unsafe neighborhood and worrying about food and shelter needs take precedence for families over addressing a child's asthma symptoms. Social determinants of health, categorized as socially-specific barriers, are just as important to address as asthma-specific barriers in hopes of addressing disparities in asthma outcomes (Federico et al., 2020). In fact, a recent review examining social determinants of health for children with asthma created a revised Maslow's hierarchy of needs to be used in healthcare settings to address disparities in pediatric asthma (Federico et al., 2020). The revised hierarchy emphasizes that physiologic (e.g., sleep, shelter, food, and drink), safety (e.g., safe home, safe neighborhood, employment, access to healthcare), and belonging (e.g., social and community support, loving relationships) needs must be addressed before a child can hope to achieve esteem (e.g., confidence, independence, self-efficacy, understand their disease and treatment) and reach their asthma health potential. In essence, socially-specific barriers to care must be addressed

before asthma-specific barriers, and all barriers to care must be addressed in order for a child to reach their health potential.

Some barriers to care outlined in session notes were categorized as both asthma-specific and socially-specific since they could either be directly or indirectly related to a child's asthma depending on specific family circumstances. Barriers categorized as both included child stress and temper, child weight gain, lack of clothing for cold weather, child illness and food allergies, transportation difficulties, and lack of finances. The determination to categorize these barriers as both was made considering the impact of the barrier on a child's asthma symptoms and management routines. For example, a child's stress and weight gain may cause asthma exacerbations, or it may be an additional challenge the child has to face on a daily basis. Without further knowledge of the impact of these barriers on a child's asthma symptoms, it cannot be determined if they are asthma-specific or socially-specific.

#### Interventionist-Provided Resources

Based on available data, interventionists provided targeted referrals for food, mental health, employment, home repairs, adult education, medical needs, furniture, housing, holiday needs, childcare, legal assistance, safety, transportation, clothing, and finances during the RVA Breathes program. CHW session notes mentioned referrals for 50 families; however, IPHI internal records outlined community referrals for 91 out of 152 (59.8%) families enrolled in the intervention groups of RVA Breathes. The majority of interventionist-provided referrals indicated a focus on socially-specific barriers. Since the RVA Breathes intervention provided all families with asthma education, home environmental trigger remediation, and coordination of care with health providers and school nurses, those efforts were not documented in community referrals as they were considered a routine part of the intervention efforts. It is possible that

families received varying asthma-specific resources as part of the RVA Breathes program; however, those efforts were not documented in IPHI's internal records of community referrals or in CHW session notes.

# Engagement in Provided Resources

Based on IPHI's internal records, a little over a third (36.5%) of those families engaged in the resources they were provided; however, we do not have referral engagement information for about half (46.5%) of the referrals listed. Thus, it is possible that engagement information is missing from available data. Future research should specifically inquire about participant engagement in provided referrals during intervention efforts. Even if participants were provided referrals by interventionists to address their specific barriers to care, not engaging in the community referrals they were given would leave families continuing to encounter the challenges they reported. Participant engagement in resources is of vital importance and should be considered in future research investigating how engagement in referrals impacts child and family health.

# **Strengths and Limitations**

Several limitations of this study should be noted. First, while it is a strength of the study to hear from both caregivers and interventionists, participation was voluntary. It is important to acknowledge that caregiver and interventionist perspectives from those whom did not participate in focus groups is also needed to understand the successes and challenges of the home interventionist model of care. Furthermore, while the primary researcher was embedded in the RVA Breathes program since its inception, she identifies as an outsider of the community she was studying. It may be beneficial to have community partners present during focus group discussions in the future to ensure conversation topics were analyzed correctly and probes were

brought up when necessary. Nevertheless, rigorous coding procedures were utilized in an attempt to remove biases and ensure accurate coding of focus group discussions. Unfortunately, the Spanish-speaking "focus group" only recruited two caregivers from the 17 remaining in RVA Breathes at the time of the focus group. More feedback from Spanish-speaking caregivers that interacted with home interventionists is warranted to understand their experience in the RVA Breathes program.

Moreover, interventionists had difficulties with documentation efforts. Prior to COVID-19, interventionists had the option to complete notes and questionnaires on paper or electronically. However, when COVID-19 began, they had to document all interactions electronically as remote procedures were put in place. Several interventionists lacked literacy in the required technology for comprehensive documentation. Furthermore, many factors examined in this study were not explicitly documented during intervention efforts. Future research should consider providing electronic documentation training for interventionists, as well as ensuring documentation of all factors of interest. For this study, it would have also been beneficial to have measurements of participant/interventionist rapport, caregiver thoughts about interactions with interventionists, and family engagement in interventionist-provided referrals (yes/no). This study utilizes some secondary data analysis, and therefore, was limited to the data collected in RVA Breathes addressing main study aims. While there are several limitations to the research presented, findings serve as additional support for the home interventionist model of care for families of children with asthma.

#### **Clinical Implications and Future Directions**

Both caregivers and interventionists voiced thoughts for future asthma interventions.

Based on their feedback, future interventions may want to engage in environmental trigger

remediation efforts in schools, provide an array of general community referrals to all families (including tangible materials, clothing vouchers, holiday baskets/gifts/food, and a list of food banks), and include programming for teenagers. Interventionists voiced a desire for more trainings. It would be useful for home interventionists to receive trainings in Medicaid, technology, mental health, case management, and documentation prior to working with families. Of note, RVA Breathes did address interventionist concerns throughout the duration of RVA Breathes; however, COVID-19 introduced additional barriers for interventionists that were difficult to address part-way through intervention efforts (e.g., need for technology literacy, greater family mental health needs, need to address additional and new barriers to care). Furthermore, supervisory support is important for interventionists and should be a top priority of institutions. Interventionists also reported wanting an asthma certification to aid in job promotions. Future efforts should examine available asthma certification options or generate a new training program, if necessary.

#### **Conclusions**

Home interventionists in RVA Breathes understood the lived experiences of the families they worked with, addressed any reported challenges and barriers to care that they could, and saw positive physical and mental health outcomes in families of children with asthma. They recognized the importance of addressing systemic barriers to care that have negative impacts on children's health and wellbeing. Interventionists also provided families with necessary support during the COVID-19 pandemic, without disruption in care, by quickly moving to a virtual format. Findings indicate that families of children with asthma enrolled in the RVA Breathes intervention program encountered an array of barriers (asthma-specific and socially-specific), and their interventionists were able to address many of their challenges through targeted

community referrals. Caregivers and interventionists had positive thoughts about the program and provided suggestions for future intervention efforts to make the home interventionist model of care for pediatric asthma even more effective. This study can serve as support for the home interventionist model in future intervention programs, and possibly provide support for insurance companies to fund a home interventionist model of care.

# **Dissertation Part Two: Quantitative**

#### Part 2

Part 2 of the dissertation focused on the quantitative methods, results, and discussions from dissertation aims one and two. This section summarized numbers of reported barriers to care, community referrals, and participant engagement in referrals, as well as looked at differences by specific demographic variables. Moreover, this section examined associations of caregiver stress, depressive symptoms, stressful life events, and barriers to care with asthma control over time by group. Data were examined using correlations, chi-square, and ANOVA analyses, as well as multilevel modeling.

#### Methods: Part 2

#### **RVA Breathes Measures**

Covariates. At baseline, caregivers reported on caregiver and child race/ethnicity, caregiver and child age, child sex, yearly household income, and caregiver relationship to child. Yearly household income was also reported at post-intervention.

Stress. Caregivers completed the 14-item Perceived Stress Scale (PSS-14), a well-validated measure of global stress appraisal and an individual's ability to cope with stress (Cohen et al.,1983), at baseline, post intervention, 3-, 6-, and 9-month follow-up. On the PSS-14, participants indicate on a scale of 0 (never) to 4 (very often) if they experienced a particular emotion or had a certain thought in the past month (e.g., "how often have you been angered because of things that happened that were outside of your control?"). Responses to the 14 items are summed and higher scores indicate greater stress. The PSS-14 has demonstrated good reliability, test-retest validity (Cohen et al., 1983), and a two-factor structure (Lee, 2012). Available scores from the 5 research sessions were used in multilevel models. Cronbach's  $\alpha$ =.73 for BL,  $\alpha$ =.77 for PI,  $\alpha$ =.72 for 3M,  $\alpha$ =.70 for 6M, and  $\alpha$ =.69 for 9M.

**Depressive Symptoms.** The Center for Epidemiologic Studies Depression scale (CES-D) (Radloff et al., 1977) is a 20-item measure completed by caregivers at baseline, post intervention, 3-, 6-, and 9-month follow-up. Using four response options, caregivers indicated how often over the past week they felt or behaved in certain ways (e.g., "I did not feel like eating; my appetite was poor," and "I had trouble keeping my mind on what I was doing."). The four response options included: "rarely or none of the time (less than 1 day)," "some or little of the time (1-2 days)," "occasionally or a moderate amount of time (3-4 days)," "most or all of the time (5-7 days)." Responses to the 20 items were summed to create a depressive symptoms score. Positive items such as "I was happy" and "I felt hopeful about the future" were reverse scored. Higher scores indicated more depressive symptoms. The CES-D measure was found to have high internal consistency and adequate test-retest validity (Radloff et al., 1977). Available scores from these 5 visits were used in multilevel models. Cronbach's α=.89 for BL, α=.89 for PI, α=.88 for 3M,  $\alpha$ =.89 for 6M, and  $\alpha$ =.90 for 9M.

Stressful Life Events. The Stressful Life Events and Circumstances Checklist (SLECC) is a 32-item measure asking caregivers if any of the following events has happened in their family in the past 6 months completed by caregivers (Caserta et al., 2008; Kilmer et al., 1998). The SLECC collects information on five sub domains: family turmoil, family separation, poverty, neighborhood violence, and family illness/injury. It was collected at baseline, post intervention, and 6-month follow up. Caregivers respond "yes" or "no" as to whether the event has occurred in their family. Item events include but are not limited to: "Our child saw someone get badly hurt," "Close family member was arrested or in jail," and "Sometimes our family had little food to eat." The term "close family member" was defined as a parent, grandparent, or relative living in the respondent's household. The term "our child" referred to the child enrolled

in the study. The number of "yes" responses were counted to create an overall stressful life events score (0-32). The original measure was validated using a sample of low-income, urban, African American, Latinx, and White families (Kilmer et al., 1998). Available count scores were included in multilevel models. Cronbach's  $\alpha$ =.82 for BL,  $\alpha$ =.84 for PI, and  $\alpha$ =.74 for 6M.

Asthma Control. Children and caregivers completed the Childhood Asthma Control Test (cACT) at every study session, which measures the frequency of daytime and nighttime asthma symptoms, activity limitations, and perception of disease control (Lui et al., 2007). Children aged 5-11 completed four items and their caregivers completed the remaining 3 items of this measure. Answers to all 7-items were summed to create an asthma control score ranging from 0 to 27. Scores  $\leq$ 19 were classified as poorly controlled asthma, whereas scores >19 were classified as controlled asthma. The cACT has shown high internal consistency (>.70) and good test-retest reliability (>.70) (Bime et al., 2016). Scores from each assessment period (baseline, sessions 1-4, post-intervention, 3-, 6-, and 9-month follow up) were modeled in longitudinal analyses. Cronbach's  $\alpha$ =.70 for BL,  $\alpha$ =.74 for S1,  $\alpha$ =.83 for S2,  $\alpha$ =.82 for S3,  $\alpha$ =.82 for S4,  $\alpha$ =.76 for PI,  $\alpha$ =.84 for 3M,  $\alpha$ =.70 for 6M, and  $\alpha$ =.74 for 9M; these alphas are consistent with prior studies (Koinis-Mitchell et al., 2015).

CHW Session Notes (Barriers to Care). Notes were coded for barriers to care, relevant resources, and client engagement in those resources. Details of coding procedures can be found in Measures: Part 1. Due to a lack of information in CHW session notes regarding interventionist-provided resources and client engagement, only barriers to care scores were utilized in multilevel modelling. Coding procedures resulted in overall, asthma-specific, and socially-specific codes for each participant. Barriers across the intervention period were summed

for each participant to create three count variables: overall number of barriers, number of asthma-specific barriers, and number of socially-specific barriers.

Interventionist-Provided Community Referrals. A list of community referrals and family engagement in referrals by ID number was generated using IPHI's internal records.

Community referrals were then counted to generate an overall referral score per family. For instance, a family given a housing, job, and 2 clothing referrals would be given a referral score of 4. Scores were not used in multilevel models since each participant was only given one overall referral score for their intervention period.

Participant Engagement in Community Referrals. Using IPHI's internal records, a participant engagement category was assigned to each community referral. Categories included "yes"- the family engaged in the referral, "no"- the family did not engage in the referral, "partial"- the family reached out to the referral, but may not have been eligible or may not have utilized it, or "unknown"-the family's engagement efforts are unknown. For ANOVA analyses, "yes" was given a score of 2, "partial" was given a score of 1, and "no" or "unknown" were given a score of 0. An average engagement score was generated per participant by summing engagement scores across referrals and dividing by the number of referrals a participant was given. Scores were not used in multilevel models since each participant was only given one overall engagement score for their intervention period.

#### **Data Analyses: Part 2**

Barriers to care coded from CHW session notes and interventionist-provided resources collected through IPHI internal records were compiled and the number of barriers and resources were summarized. Average engagement in community referrals was calculated per participant.

<u>Software Packages</u>: All preliminary analyses and Repeated Measures ANOVAs utilized SPSS version 28. Multilevel modelling was conducted in R version 4.2.3.

Preliminary Analyses: Scores for barriers to care (overall, asthma-specific, socially-specific), number of interventionist-provided resources, average engagement in resources, perceived stress, depressive symptoms, stressful life events, and asthma control were calculated and score trajectories over the study duration were examined. Barriers to care resulted in three count scores for each participant (overall barriers, asthma-specific barriers, and socially-specific barriers), while number of community referrals and average engagement in referrals resulted in one score per participant. Prior to running main analyses, descriptive statistics were run for missing data and outliers. The data were checked for normality, collinearity, and homoscedasticity, and corrected when necessary.

Covariate Testing: Correlation, t-test, and ANOVA analyses were used to test for associations between caregiver and child race/ethnicity, caregiver and child age, child sex, caregiver relationship to the child, and family income at baseline and post-intervention with child asthma control. Significant covariates were controlled in subsequent analyses. Chi-square analysis examined differences in participant income from baseline to post-intervention.

Demographic Differences: Chi-square and ANOVA analyses examined differences in demographic variables by intervention group assignment. Results are discussed to give a depiction of the demographic breakdown of each intervention group. ANOVA analyses were run to examine demographic differences in community referrals and average engagement scores. Analyses provided an initial look into possible demographic differences in resources and engagement and provided a starting point for future research.

Preliminary Analyses with Variable of Interest: Correlation analyses examined associations among caregiver stress, caregiver depressive symptoms, and stressful life events with child asthma control at baseline, PI, and 6-month follow-up, as well as 3-month and 9-month for stress and depressive symptoms. Independent samples t-tests were used to examine changes in caregiver stress, depressive symptoms, stressful life events, and child asthma control (controlled/not-controlled) at baseline, post-intervention, and 6-month follow-up. Changes in caregiver stress, depressive symptoms, and asthma control were also examined at 3-month and 9-month follow-up.

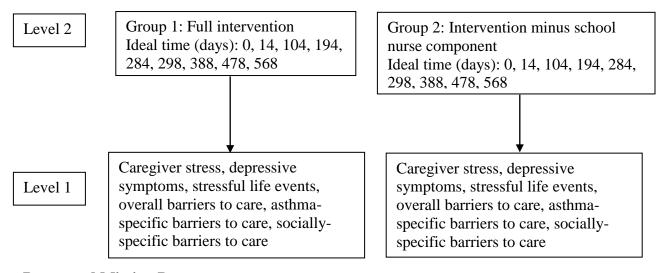
Repeated Measures ANOVAs: Repeated measures ANOVA analyses with a Greenhouse-Geisser correction were conducted to assess differences in variables of interest (PSS, CES-D, SLECC, overall barriers to care, asthma-specific barriers to care, socially-specific barriers to care) across time. Post hoc analyses with a Bonferroni adjustment allowed for examination of when significant changes over time occurred.

MLM Model Structure: A 2 level multi-level model (Figure 4) structure allowed us to assess associations of person-level factors with trajectories in child asthma control over time among individuals nested in asthma intervention groups clustered at the school level. Since group assignment only contained two groups, it was included at level 2 as a between person factor and not as its own level. To be its own level of influence in MLM, we would need at least 5-6 groups for comparison (Raudenbush & Bryk, 2002).

• <u>Level 1</u>: Person-level factors (caregiver stress, depressive symptoms, and stressful life events) and barriers to care (asthma-specific, socially-specific, overall). Each participant has five continuous caregiver stress scores (collected at BL, PI, 3M, 6M, 9M), five continuous depressive symptoms scores (BL, PI, 3M, 6M, 9M), three count stressful life

- events scores (BL, PI, 6M), and four count scores of overall, asthma-specific, and socially-specific barriers to care (S1, S2, S3, S4).
- Level 2: Group assignment and ideal time in the study. Every participant in analyses was assigned to group 1 or 2 of the RVA Breathes intervention and was assigned an ideal number of days in the study at each assessment timepoint (0, 14, 104, 194, 284, 298, 388, 478, 568).

Figure 4. Two Level Longitudinal Model



#### **Power and Missing Data**

Power: Based on a power analysis using G\*Power (Faul, Erdfelder, Buchner, & Lang, 2009), the minimum sample size for hierarchical regression analyses using two predictor variables and three control variables was 107 participants (Aim 2). With 95% power (1-β), the sample of 152 enrolled families was sufficient to detect small, medium, and large effects, despite potentially missing datapoints.

Missing Data: Across all study variables, the number of missing variables was calculated.

Little's Missing at Random (MCAR) test was run to assess for systematic differences in missing data (Little, 1988). Missing data are common in longitudinal research. Multilevel modelling

accounted for missing data and allowed variables to be included that had missing data; therefore, multiple imputation was not necessary for main analyses.

#### **Results: Part 2**

# Sample Characteristics

Participants' demographic information is summarized in Table 7. This study included 152 of the 187 intervention families that completed at least one intervention session (children aged  $7.12 \pm 1.71$ , 41.4% female; caregivers aged  $35.12 \pm 7.89$  years). The majority of caregivers (81.6%) and children (76.3%) identified as Black or African American. Most caregivers identified as biological mothers (87.5%) to the children enrolled in RVA Breathes, and about half of the sample reported residing in public or government subsidized housing (53.3%).

**Table 7**. Sample demographics at baseline

Variable	N=152
Caregiver Race/Ethnicity	
Black/African American	124 (81.6)
Latinx	15 (9.9)
Mixed/Multiracial	5 (3.3)
White	6 (3.9)
Other	2 (1.3)
Child Race/Ethnicity	
Black/African American	116 (76.3)
Latinx	14 (9.2)
Mixed/Multiracial	17 (11.2)
White	3 (2.0)
Other	2 (1.3)
Caregiver Age	
Mean Years $\pm$ SD	$35.12 \pm 7.89$
Min-Max	23-62
Child Age	
Mean Years $\pm$ SD	$7.12 \pm 1.71$
Min-Max	5-11
Child Sex	
Female	63 (41.4)
Male	89 (58.6)
Relationship to Child	
Biological Mother	133 (87.5)
Grandmother	8 (5.3)
Biological Father	4 (2.6)

Step, Adoptive, or Foster Mother	3 (2.0)
Step, Adoptive, or Foster Father	1 (0.7)
Other	2 (1.3)
Household Assistance	
Public or subsidized	81 (53.3)
Private/none	63 (41.4)
Not reported	8 (5.3)

Preliminary Analyses: Tests for normality, homoscedasticity, collinearity, and covariates

Shapiro Wilk analyses assessed the normality of variables in the full sample. Perceived stress variables were normally distributed (W=.981, p=.085); however, depressive symptoms (W=.920, p<.001) and stressful life events (W=.931, p<.001) were positively skewed (skewness=.920±.222; skewness=.819±.222), meaning depressive symptoms and stressful life events were clustered toward fewer depressive symptoms and stressful events, and asthma control (W=.942, p<.001) was negatively skewed (skewness=-1.004±.222) meaning scores were clustered toward better asthma control. Outliers were not eliminated for analyses. It was determined all data responses should be included in analyses as they capture true participant experiences. Instead, skewed data were log10 transformed to be used in Repeated ANOVAs and regression analyses.

A scatterplot of the data (standardized predicted values on x-axis and standardized residuals on y-axis) was generated for each set of analyses to examine homoscedasticity of the data. Based on an inspection of the scatter plots using the Loess fit line for visual examination, it was determined that data did not violate the assumption of homoscedasticity.

To assess for collinearity of predictor variables, tolerance and Variance Inflation Factors (VIF) were assessed. As expected, overall barriers to care was colinear with its sub-scores of asthma-specific barriers to care and socially-specific barriers to care. To address the collinearity, barriers to care scores were included in separate models. All other variables of interest were determined to be independent from one another.

When considering covariates, caregiver and child race/ethnicity, caregiver and child age, child sex, relationship between caregiver and child, reported family income at baseline and post-intervention, and housing assistance were not associated with cACT scores across the post-intervention phase. Therefore, no demographic variables were included in multilevel modeling analyses as covariates.

Number of Barriers to Care, Referrals, and Engagement Over Time

To examine the number of reported barriers to care at each intervention session based on CHW session notes, means and standard deviations were calculated. At session 1, participants averaged 2.27±1.82 overall barriers to care, 1.59±1.33 asthma-specific barriers to care, and .67±.98 socially-specific barriers to care. At session 2, participants averaged 1.48±1.59 overall barriers to care, .90±1.11 asthma-specific barriers to care, and .58±.96 socially-specific barriers to care. At session 3, participants averaged 1.18±1.44 overall barriers to care, .65±.93 asthma-specific barriers to care, and .54±.96 socially-specific barriers to care. At session 4, participants averaged 1.08±1.52 overall barriers to care, .70±1.23 asthma-specific barriers to care, and .36±.74 socially-specific barriers to care. Furthermore, the mean number of community referrals given to participants according to IPHI internal records was 2.90±4.32 and the average engagement in community referrals was determined to be .66±.66, indicating less than partial engagement in referrals on average.

Correlations between Variables of Interest Across Time

Correlations between caregiver stress, depressive symptoms, stressful life events, barriers to care, community referrals and participant engagement scores with childhood asthma control were examined across time. At baseline, depressive symptoms (r=-.191, p=.020) and stressful

life events (r=-.230, p=.004) were negatively correlated with asthma control while perceived stress was not, but was trending toward significance (r=-.156, p=.055).

At session 1, no barriers to care scores were associated with asthma control. However, at sessions 2, 3 and 4, overall barriers to care (r=-.265, p=.002; r=-.204, p=.029; r=-.208, p=.048) and asthma-specific barriers to care (r=-.298, p<.001; r=-.272, p=.003; r=-.281, p=.007) were negatively associated with asthma control. Socially-specific barriers to care were not associated with asthma control at any time point in the intervention phase. Average participant engagement in community referrals was negatively associated with asthma control at session 1 (r=-.257, p=.022), but was not associated with asthma control at any other intervention session. Number of community referrals was not associated with asthma control across the intervention phase. Interestingly, the number of community referrals given to a family was only positively correlated with overall barriers to care at session 1 (r=.217, p=.007), socially-specific barriers to care at session 1 (r=.239, p=.003), and socially-specific barriers to care at session 4 (r=.243, p=.020). All other barriers to care scores across the intervention phase were not associated with the number of community referrals given. Moreover, no barriers to care scores across the intervention phase were associated with a participant's average engagement in community referrals.

At post-intervention, perceived stress (r=-.265, p=.005), depressive symptoms (r=-.239, p=.012), and stressful life events (r=-.304, p=.002) were all negatively correlated with asthma control. At 3-month follow-up, neither perceived stress (r=-.108, p=.313) nor depressive symptoms (r=-.114, p=.286) were associated with asthma control. At 6-month follow-up, perceived stress (r=-.103, p=.345), depressive symptoms (r=-.078, p=.477), and stressful life events (r=-.182, p=.106) were not associated with asthma control. Finally, at 9-month follow-up,

neither perceived stress (r=-.158, p=.128) nor depressive symptoms (r=-.074, p=.483) were associated with asthma control. In essence, caregiver stress and depressive symptoms, as well as stressful life events were only correlated with asthma control at the post-intervention session. *Preliminary Analyses with Demographic Variables: Chi-square and ANOVA analyses* 

Chi-square analyses examined the difference in reported income from baseline to post-intervention (Table 8) and determined there was a significant difference in reported household income. Participants at baseline reported a greater percentage of incomes between \$0-\$11,999 (40.1%) than at post-intervention sessions (23.0%). Importantly, in this sample, only 19 of 152 (12.5%) baseline sessions occurred after the onset of COVID-19 (March 13, 2020), while 84 of the 118 (71.2%) post-intervention sessions occurred after the onset of COVID-19. It is possible that COVID-19 had an impact on household income or family's willingness to report that information.

**Table 8**. Sample income at baseline and post-intervention.

Variable	Baseline	Post-Intervention	chi-square <sup>a</sup>	<i>p</i> -value
	n=152	n=118		
Annual Household Income				_
\$0-11,999	61 (40.1)	35 (23.0)	$34.488^{a}$	<.001
\$12,000-24,999	26 (17.1)	20 (13.2)		
\$25,000-44,999	21 (13.8)	16 (10.5)		
\$45,000+	9 (5.9)	6 (3.9)		
Refused/Don't Know	35 (23.0)	41 (40.6)		

*Note.* <sup>a</sup>likelihood ratio reported when expected count assumption is violated in chi-square analyses. Italicized "*Refused/Don't Know*" category was not included in chi-square analyses.

To assess possible differences in demographic variables by group assignment, a series of ANOVA and chi-square analyses were conducted (Table 9). Household income was the only demographic variable that differed by group. Post-hoc LSD tests revealed that participants in the full intervention, on average, reported a lower household income than participants in the intervention without the school nurse component. At post-intervention, participants in both

groups (48.4% and 50.9%, respectively) had higher rates of refusing to report their income, or not knowing their household income.

 Table 9. Demographics by group

Variable		Intervention	$F(\mathrm{df_1},\mathrm{df_2})$ or	<i>p</i> -value
	Group 1 <sup>a</sup>	Group 2 <sup>b</sup>	chi-square <sup>c</sup>	
	n=95	n=57		
Caregiver Race/Ethnicity				
Black/African American	77 (81.1)	47 (82.5)	$1.987^{c}$	.738
Latinx	9 (9.5)	6 (10.5)		
Mixed/Multiracial	3 (3.2)	2 (3.5)		
White	4 (4.2)	2 (3.5)		
Other	2 (2.1)	-		
Child Race/Ethnicity				
Black/African American	72 (75.8)	44 (77.2)	$2.988^{c}$	.560
Latinx	9 (9.5)	5 (8.8)		
Mixed/Multiracial	11 (11.6)	6 (10.5)		
White	1 (1.1)	2 (3.5)		
Other	2 (2.1)	_		
Caregiver Age				
Mean Years ± SD	35.28±8.01	34.86±7.74	F(2,144)=.041	.378
Min-Max	23-62	24-59		
Child Age				
Mean Years ± SD	7.20±1.81	6.98±1.53	F(2,150)=3.640	.225
Min-Max	5-11	5-10	, ,	
Child Sex				
Female	37 (38.9)	26 (45.6)	0.652	.419
Male	58 (61.1)	31 (54.4)		
Relationship to Child		- (- ,		
Biological Mother	83 (87.4)	50 (87.7)	$4.678^{c}$	.456
Grandmother	4 (4.2)	4 (7.0)		
Biological Father	3 (3.2)	1 (1.8)		
Step, Adoptive, or	3 (3.2)	-		
Foster Mother	- (- ' )			
Step, Adoptive, or	1 (1.1)	_		
Foster Mother				
Other	1 (1.1)	1 (1.8)		
Baseline Annual Household	- ()	- ()		
Income				
\$0-11,999	43 (45.3)	18 (31.6)	10.279	.016*
\$12,000-24,999	17 (17.9)	9 (15.8)		
\$25,000-44,999	7 (7.4)	14 (24.6)		
\$45,000+	4 (4.2)	5 (8.8)		
Refused/Don't Know	24 (25.3)	11 (19.3)		
Post Intervention Annual	(==)	( /		
Household Income				
\$0-11,999	28 (29.5)	7 (12.3)	9.370	.025*

\$25,000-44,999	6 (6.3)	10 (17.5)		
\$45,000+	3 (3.2)	3 (5.3)		
Refused/Don't Know	46 (48.4)	29 (50.9)		
Household Assistance				
Public or subsidized	52 (54.7)	29 (50.9)	0.228	.633
Private/none	38 (40.0)	25 (43.9)		
Not reported	5 (5.3)	3 (5.3)		

*Note.* \**p*-value<.05, \*\**p*-value<.01. <sup>a</sup>Group 1=full intervention, <sup>b</sup>Group 2=intervention group without school nurse component, <sup>c</sup>likelihood ratio reported when expected count assumption is violated in chi-square analyses. Italicized "*Refused/Don't Know*" category was not included in chi-square analyses.

Differences in Barriers to Care, Resources, and Engagement Scores by Demographic Variables.

For one-way ANOVA analyses (Table 10) considering differences across caregiver race/ethnicity, three categories were used, Black or African American, Latinx, and Mixed/Multiracial. Due to small sample sizes, White and Other race/ethnicity categories were excluded from analyses. Interventionist provided community referrals and average engagement in referrals differed by caregiver race/ethnicity (F=18.257, p<.001; F=4.667, p=.012). Post hoc LSD analyses indicated that Latinx caregivers received 6.44±1.07 more community referrals than Black or African American caregivers (p<.001) and 6.93±2.03 more community referrals than Mixed/Multiracial caregivers. Furthermore, Latinx caregivers had families with higher average resource engagement scores (1.09±.49) compared to Black or African American caregivers (.54±.65, p=.005).

According to ANOVA analyses, overall barriers to care and socially-specific barriers to care scores differed by household reported income at baseline (F=2.729, p=.032; F=3.150, p=.016). Post hoc LSD analyses indicated that households whom reported an income between \$0-\$11,999 a year at baseline had  $2.35\pm.94$  more barriers to care than households who reported an income between \$25,000-\$44,999 and  $2.70\pm1.33$  more barriers than households who reported an income of \$45,000 and above. Furthermore, households who reported a yearly income between \$12,000-\$24,999 had  $2.23\pm1.09$  more barriers than households who reported a yearly

income between \$25,000-\$44,999. For socially-specific barriers to care, post hoc LSD analyses indicated that households who reported an income between \$0-\$11,999 had 1.31±.51 more socially-specific barriers to care than households who reported an income between \$25,000-\$44,999 and 1.85±.72 more barriers than households who reported a yearly income of \$45,000 and above. Finally, according to ANOVA analyses, average engagement in community referrals differed by household assistance. Those residing in public or government subsidized housing engaged less in community referrals compared to families residing in private housing. Post hoc analyses were not necessary as housing assistance only contained two categories.

**Table 10**. ANOVA analyses examining differences in barriers to care, resources, and engagement with selected demographic variables.

Outcome(s)	$df_{Num}$	$df_{Dem}$	$SS_{Num}$	$SS_{Num}$	F	p		
Predictor(s)								
Overall Barriers to Care								
Caregiver race/ethnicity	2	141	8.33	2057.68	.285	.752		
<b>Household Income</b>	4	131	151.49	1817.85	2.729	.032*		
Household Assistance	1	142	34.57	2037.65	2.409	.123		
Asthma-Specific Barriers to Ca	Asthma-Specific Barriers to Care							
Caregiver race/ethnicity	2	141	19.33	1023.97	1.331	.267		
BL Income	4	131	42.08	955.30	1.443	.224		
Household Assistance	1	142	20.10	979.06	2.915	.090		
Socially-Specific Barriers to C	are							
Caregiver race/ethnicity	2	141	3.35	615.98	.383	.682		
<b>Household Income</b>	4	131	50.58	525.82	3.150	.016*		
Household Assistance	1	142	1.75	602.89	.412	.522		
Community Referrals								
Caregiver race/ethnicity	2	141	562.27	2171.28	18.257	<.001**		
Household Income	4	131	108.41	1867.59	1.901	.114		
Household Assistance	1	142	23.02	2741.97	1.192	.277		
Average Engagement in Refere	Average Engagement in Referrals							
Caregiver race/ethnicity	2	74	3.62	28.66	4.667	.012**		
Household Income	4	62	.726	28.224	.399	.809		
Household Assistance	1	76	2.02	30.95	4.954	.029*		

*Note.* \**p*-value<.05, \*\**p*-value<.01. **Bold** items are significant at *p*-value<.05.

# Independent Samples T-Tests

Independent samples t-tests were used to examine differences in sample means of caregiver level factors (PSS, CES-D, and SLECC) between individuals reporting well-controlled

asthma (>19) and poorly controlled asthma ( $\leq$ 19) at each study time point pre and post intervention (BL, PI, 3M, 6M, and 9M) (Table 11). At baseline, participants reporting cACT scores  $\leq$ 19 had greater average perceived stress ( $M\pm SD=26.21\pm7.81$ ), depressive symptoms ( $M\pm SD=19.84\pm11.31$ ), and stressful life events scores ( $M\pm SD=6.97\pm4.58$ ) compared to participants reporting cACT scores >19 (PSS:  $M\pm SD=22.92\pm8.34$ ; CES-D:  $M\pm SD=15.04\pm11.22$ ; SLECC:  $M\pm SD=4.15\pm3.96$ ). Similar to baseline, at post intervention, participants reporting cACT scores  $\leq$ 19 had greater average perceived stress ( $M\pm SD=24.06\pm8.19$ ), depressive symptoms ( $M\pm SD=18.23\pm12.59$ ), and stressful life events scores ( $M\pm SD=7.08\pm4.28$ ) compared to participants reporting cACT scores >19 (PSS:  $M\pm SD=20.04\pm9.09$ ; CES-D:  $M\pm SD=10.56\pm8.65$ ; SLECC:  $M\pm SD=3.95\pm.44$ ). There were no significant differences in perceived stress, depressive symptoms, or stressful life events scores between participants indicating well-controlled versus poorly controlled asthma at 3-month, 6-month or 9-month follow-up.

**Table 11**. Differences in caregiver level factors by asthma control (well-controlled, not-well-controlled) at each time point.

	Baseline	Post-	3M	6M	9M
		Intervention			
	t(df),	t(df),	t(df),	t(df),	t(df),
Variable of Interest	<i>p</i> -value	<i>p</i> -value	<i>p</i> -value	<i>p</i> -value	<i>p</i> -value
Perceived Stress	t(149) = 2.502,	t(110) = 2.153,	t(87) = .350,	t(84) =252,	t(92) = .885,
Scale (PSS)	<i>p</i> =.007**	<i>p</i> =.017*	p=.364	p = .401	p=.189
Center for Epidemiologic Studies Depression (CES-D)	t(147) = 2.598, p=.005**	t(107) = 3.625, $p < .001**$	t(87) = 1.068, p=.114	t(83) = .698, p=.244	t(91) =503, p=.308
Stressful Life Events Checklist (SLECC)	t(149) = 4.055, p < .001**	t(102) = 3.741, p < .001**	-	t(78) = 1.079, p=.142	-

*Note.* \*p-value<.05, \*\*p-value<.01. **Bold** values are statistically significant.

#### **Repeated Measures ANOVAs**

Within-subjects repeated measures ANOVAs for caregiver level factors (pre to post intervention)

Repeated measures ANOVA analyses with a Greenhouse-Geisser correction were conducted to examine differences in stress, depressive symptoms, stressful life events, and asthma control scores over time (Table 12). According to ANOVA analyses, the mean scores for perceived stress were significantly different (F(3.721, 230.684) = 10.615, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that perceived stress scores were significantly decreased from baseline to all follow-up visits: post-intervention (p=.002, 95% CI [1.307 to 8.852]), 3-month follow-up (p<.001, 95% CI [1.846 to 8.599]), 6-month follow-up (p<.001, 95% CI [3.301 to 10.604]), and 9-month follow-up (p<.001, 95% CI [2.745 to 9.191]). There were no statistical differences between perceived stress follow-up scores.

Similar to perceived stress, the mean scores for depressive symptoms were significantly different using repeated measures ANOVAs (F(3.519, 214.682) = 6.478, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that depressive symptom scores were significantly decreased from baseline to 3-month follow-up (p<.001, 95% CI [1.969 to 10.741]), 6-month follow-up (p=.018, 95% CI [0.519 to 9.126]), and 9-month follow-up (p<.001, 95% CI [1.921 to 9.789]); however, scores were not statistically different from baseline to post-intervention (p=.092, 95% CI [-.371 to 9.339]). There were no statistical differences between depressive symptom follow-up scores.

When using an ANOVA with repeated measures with a Greenhouse-Geisser correction, the mean scores for stressful life events were significantly different (F(1.777, 119.055) = 9.454, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that stressful life event scores

were significantly decreased from baseline to 6-month follow-up (p<.001, 95% CI [.785 to 3.156]), but not from baseline to post-intervention (p=.460, 95% CI [-.515 to 1.986]). There was also a decrease in stressful life events from post intervention to 6-month follow-up (p=.004, 95% CI [.326 to 2.144]).

Lastly, repeated measures ANOVA analyses examining childhood asthma control pre and post intervention were significantly different (F(3.781, 268.470) = 12.527, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that asthma control scores were significantly increased (improved) from baseline to all follow-up visits: post-intervention (p < .001, 95% CI [-4.335 to -1.360]), 3-month follow-up (p < .001, 95% CI [-4.853 to -1.425]), 6-month follow-up (p < .001, 95% CI [-5.280 to -1.831]), and 9-month follow-up (p < .001, 95% CI [-4.134 to -.977]). There were no statistical differences between asthma control follow-up scores.

**Table 12.** Differences in caregiver level factors and asthma control from baseline through the post-intervention phase

	Baseline	Post- Intervention	3M	6M	9M	Repeated M ANO	
	n=152	n=118	n=92	n=88	n=99	Within s	
Variable of Interest	Mean±SD Min-Max	Mean±SD Min-Max	Mean±SD Min-Max	Mean±SD Min-Max	Mean±SD Min-Max	$F(\mathrm{df}_1,\mathrm{df}_2)$	<i>p</i> -value
Perceived Stress	24.57±8.22	21.15±9.00	20.37±8.22	18.03±7.74	20.12±8.00	<i>F</i> (3.721,	<.001**
Scale (PSS)	1-50	1-39	0-40	2-40	5-39	230.684) = 10.615	
Center for	17.42±11.5	12.67±10.41	11.09±9.81	11.92±10.47	12.02±11.11	F(3.519,	<.001**
Epidemiologic Studies Depression (CES-D)	0-51	0-52	0-47	0-52	0-53	214.682) = 6.478	
Stressful Life	$5.57 \pm 4.50$	$4.45\pm4.28$	-	3.16±3.10	-	F(1.777,	<.001**
Events Checklist (SLECC)	0-19	0-22		0-14		119.055) = 9.454	
Childhood Asthma	18.51±4.58	20.91±4.62	21.17±4.34	21.87±3.97	21.11±4.87	<i>F</i> (3.781,	<.001**
Control Test (cACT)	4-27	4-27	6-27	12-27	6-27	268.470) = 12.527	

*Note.* \**p*-value<.05, \*\**p*-value<.01.

Within-subjects repeated measures ANOVAs during intervention phase.

Repeated measures ANOVA analyses with a Greenhouse-Geisser correction were also used to assess differences in barriers to care and asthma control scores across the intervention phase (Table 13). According to ANOVA analyses, the mean number of barriers to care were significantly different across time (F(2.564, 230.733) = 6.072, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that number of reported barriers to care significantly decreased from session 1 to session 3 (p=.036, 95% CI [0.27 to 1.314]) and session 4 (p=.003, 95% CI [0.212 to 1.436]); however, there was no statistical difference in the number of barriers reported from session 1 to session 2 (p=.425, 95% CI [-.204 to 1.061]). There were no statistical differences between sessions 2 through 4.

When assessing barriers to care sub-scores, the number of reported asthma-specific barriers to care was significantly different across time (F(2.440, 219.629) = 8.212, p < .001); however, the mean number of socially-specific barriers to care was not significantly different (F(2.629, 236.602) = 1.920, p = .135). Post hoc analysis with a Bonferroni adjustment revealed that asthma-specific barriers to care were significantly decreased from session 1 to all other intervention sessions: session 2 (p=.017, 95% CI [0.054 to 0.847]), session 3 (p<.001, 95% CI [0.219 to 1.100]), and session 4 (p=.008, 95% CI [0.107 to 1.058]). There were no differences between asthma-specific barriers to care from session 2 through session 4.

Finally, the mean scores for childhood asthma control were significantly different across the intervention phase (F(2.786, 295.325) = 11.926, p < .001). Post hoc analysis with a Bonferroni adjustment revealed that asthma control scores were significantly increased (improved) from session 1 to session 3 (p < .001, 95% CI [-4.412 to -1.214]), and session 4 (p < .001, 95% CI [-4.878 to -1.309]), but there was no difference from session 1 to session 2

(p=.104, 95% CI [-2.902 to 0.155]). There was also a significant improvement in asthma control scores from session 2 to session 3 (p=.033, 95% CI [-2.806 to -0.072]) and session 4 (p=.041, 95% CI [-3.397 to -0.042]).

Community referrals and average participant engagement in referrals generated one score per participant, and therefore, did not vary over time. Table 11 included the demographic breakdown of those measures at session 4.

**Table 13**. Differences in barriers to care and asthma control across the intervention phase.

	S1	<b>S2</b>	S3	<b>S4</b>		
	n=151	n=133	n=116	n=113		
	Mean±SD	Mean±SD	Mean±SD	Mean±SD		
Variable of Interest	Min-Max	Min-Max	Min-Max	Min-Max	$F(df_1, df_2)$	<i>p</i> -value
Overall Barriers to	$2.27 \pm 1.82$	$1.48 \pm 1.56$	1.18±1.44	$1.08\pm1.52$	F(2.564,	<.001**
Care	0-8	0-9	0-8	0-8	230.733) = 6.072	
Asthma-Specific	1.59±1.33	$0.90\pm1.11$	$0.65 \pm 0.93$	$0.70\pm1.23$	F(2.440,	<.001**
Barriers to Care	0-5	0-7	0-4	0-7	219.629) = 8.212	
Socially-Specific	$0.67 \pm 0.98$	$0.58\pm0.97$	$0.54 \pm 0.96$	$0.36 \pm 0.74$	F(2.629,	.135
Barriers to Care	0-5	0-5	0-6	0-3	236.602) = 1.920	
Overall	-	-	-	$2.90\pm4.32$	-	-
Community Referrals				0-21		
Average	-	-	-	$0.66 \pm 0.66$	-	-
Engagement				0-2		
Childhood Asthma	$18.24 \pm 5.34$	19.72±5.39	21.28±4.40	21.35±4.88	F(2.786,	<.001**
Control Test (cACT)	4-27	0-27	4-27	6-27	295.325) = 11.926	

*Note.* \**p*-value<.05, \*\**p*-value<.01.

# **Multilevel Models**

Multilevel modelling examined trajectories of caregiver level factors and asthma control over time in two level models (outlined in Figure 5). Analyses were run using R version 4.3.2, specifically the "lmer" package. The first level modelled within-subject differences outlining trajectories of stress, depressive symptoms, stressful life events, and barriers to care with asthma

control over time. The second level modelled intervention group assignment and its impact on trajectories in level one over time. Two multilevel models were run based on when variables of interest were collected. The first model examined trajectories of stress, depressive symptoms, and stressful life events with asthma control over time by group. The second model examined trajectories of overall, asthma-specific, and socially-specific barriers to care with asthma control over time by group.

**Figure 5**. Simplistic depiction of models created.

<u>Level-1 Model</u>: within person (added PSS, CES-D, SLECC, and BC scores)

 $\beta_0 = cACT$  at Baseline

 $\beta_1$  = coefficient that describes relation between time and cACT

$$cACT_{ij} = \beta_{0j} + \beta_{1j}*(Time_{ij}) + r_{ij}$$

<u>Level-2 Model</u>: between person (added group)

 $\beta_{0j} = \gamma_{00} + u_{0j}$ 

 $\beta_{1j} = \gamma_{10} + u_{1j}$ 

#### Mixed Model:

$$cACT_{ii} = \gamma_{00} + \gamma_{10} *Time_{ii} + u_{0i} + u_{1i} *Time_{ii} + r_{ii}$$

The "mixed model" is the actual model that is fit.

 $\gamma_{00} + \gamma_{10}$ \*Time<sub>ii</sub> is the intercept and time coefficient (Fixed Effects)

 $u_{0i} + u_{1i}$ \*Time<sub>ii</sub> + r<sub>ii</sub> is the complex error term (Random Effects)

In the first set of analyses, we examined the main effects of perceived stress, depressive symptoms, and stressful life events on asthma control over time by group (Table 14). Results demonstrated a significant stress and stressful life events effect (Est. = -.069, p = .021; Est. = -.224, p < .001) on asthma control over time. As stress and stressful life events decreased, asthma control improved. However, there was no effect of caregiver depressive symptoms on asthma control over time (Est. = .007, p = .591). Furthermore, in level two, intervention group

assignment had no influence on associations of stress, depressive symptoms, or stressful life events on asthma control (Est. = .106, p = .587).

**Table 14**. Multilevel model examining associations of PSS, CES-D, and SLECC with asthma control over time by group

Coefficient	Std error	<i>t</i> -ratio	Approx.  df	<i>p</i> -value
22.973	1.262	18.205	151	<.001**
069	.034	-2.050	151	.021*
.007	.029	.230	151	.591
224	.063	-3.533	151	<.001**
.106	.479	.221	151	.587
Variance	Std error			
2.141	1.463			
16.752	4.093			
	22.973 069 .007 224 .106 <b>Variance</b> 2.141	22.973 1.262069 .034 .007 .029224 .063 .106 .479  Variance Std error 2.141 1.463	22.973 1.262 18.205069 .034 -2.050 .007 .029 .230224 .063 -3.533 .106 .479 .221  Variance Std error 2.141 1.463	22.973     1.262     18.205     151      069     .034     -2.050     151       .007     .029     .230     151      224     .063     -3.533     151       .106     .479     .221     151       Variance     Std error       2.141     1.463

*Note.* \**p*-value<.05, \*\**p*-value<.01.

In the second set of analyses, we examined the main effects of overall, asthma-specific, and socially-specific barriers to care on asthma control over time by group (Table 15). None of the barriers to care scores were associated with asthma control over time (Est. = -.342, p = .372; Est. = -.599, p = .286; Est. = .372, p = .639). Furthermore, group assignment had no influence on trajectories (Est. = -.065, p = .445).

**Table 15**. Multilevel model examining associations of overall, asthma-specific, and socially-specific barriers to care with asthma control over time by group

Fixed Effects	Coefficient	Std error	<i>t</i> -ratio	Approx.  df	<i>p</i> -value
(Intercept)	21.141	0.895	23.620	151	<.001**
Overall BC	342	1.040	329	151	.372
Asthma BC	599	1.067	562	151	.286
Social BC	.372	1.051	.0354	151	.639
Group	065	.475	138	151	.445
Random Effects	Variance	Std error			
Time (Intercept)	1.131	1.064			
Residual	24.668	4.967			

*Note.* \**p*-value<.05, \*\**p*-value<.01.

#### **Discussion: Part 2**

Pediatric asthma interventions utilizing home interventionists have been shown to improve asthma symptoms, decrease emergency and urgent care use, decrease environmental triggers, and address barriers to asthma care for families of children with asthma (Bryant-Stephens et al., 2019; Katigbak et al., 2015; Marshall et al., 2020; Postma, Karr, & Keikhefer, 2009). Although many studies have highlighted the positive impacts of asthma intervention programs on pediatric asthma outcomes (Marshall et al., 2020; Postma, Karr, & Keikhefer, 2009), very few have examined the impact of home interventionists on caregiver level factors such as stress, depressive symptoms (Parker et al., 2008), and stressful life events. One CHW pediatric asthma intervention program from 2008 reported a decrease in reports of caregiver depressive symptoms from pre to post intervention among those in the pediatric asthma intervention group (Parker et al., 2008). Although published findings are limited, it is possible that working with a pediatric asthma home interventionist might have positive influences on a family above and beyond improvements in asthma management (Peretz et al., 2012). Furthermore, it is important to examine the barriers to care that families report and the community referrals that home interventionists provide families in order to better understand how the home interventionist model of care instigates positive health changes for families of children with asthma.

This study examined differences in caregiver level factors (stress, depressive symptoms, and stressful life events) and family-reported barriers to care over time with participants enrolled in a pediatric asthma intervention program, RVA Breathes. We also explored differences in caregiver mental health over time by asthma control score (≤19 compared to >19) and differences in barriers to care, community referrals, and participant engagement in referrals over

time and by demographic variables. Results provide a better understanding of how the home interventionist model of care in the RVA Breathes program positively impacted families of children with asthma. Findings can be used to provide additional support for policy changes that integrate home interventionist support for pediatric asthma care.

#### **Demographic Differences**

First, we examined demographic information to better understand the sample included in analyses. All demographic information was gathered at baseline, and income was gathered again at post-intervention. Chi-square analyses found a statistical difference in income from baseline to post-intervention, in that more participants reported incomes between \$0-11,999 at baseline compared to post-intervention. It is important to note that COVID-19 began in mid-March, 2020. At that time, most families were completing the intervention phase of RVA Breathes. In this sample, 12.5% of families completed their baseline session and 71.2% of families completed their post-intervention session after COVID-19 began. Research has documented that the pandemic had substantial impacts on family finances, and disproportionately impacted lowerincome families, families identifying as an ethnic minority, and women (Andrade et al., 2022). The sample of caregivers used for these analyses predominantly reported a household income below \$25,000 a year (57.2% at baseline), identified as Black and/or African American (81.6%), and identified as a woman (95.4%). Therefore, participants in our sample may have had negative impacts on their family finances during the pandemic. More research is needed to understand the financial impacts of COVID-19 on families of children with asthma, and how pandemic-related financial changes impacted family well-being.

To further understand the participants included in analyses, differences in demographic variables by group were examined. Household income was lower at both baseline and post-

intervention in the full intervention group compared to the intervention group without the school nurse component. Randomization occurred at the school level, and took steps to account for average school income during randomization; nevertheless, participants that enrolled in RVA Breathes reported a lower income in the full intervention compared to those in the intervention without the school nurse component. No other demographic differences were found between the intervention groups. While this information is important to consider when understanding the sample, group demographic differences did not impact subsequent analyses.

The last set of analyses examining demographic differences determined if there were demographic differences in barriers to care, interventionist-provided community referrals, and participant engagement in those referrals. Findings show that caregivers residing in public or government subsidized housing had lower average engagement in referrals compared to participants in private housing. It is possible that caregivers in private housing received fewer, more targeted referrals, and therefore, engaged in most referrals they were provided. Although analyses looked at average engagement, it must be considered a possibility that families residing in public housing received more overall and more generalized referrals than those living in private housing, meaning they may not have engaged in all referrals they were given. Since there are income requirements for public and government subsidized housing, examination of differences in variables by income was warranted.

There were income differences in both overall and socially-specific barriers to care, but not with asthma-specific barriers to care, number of community referrals, or average engagement in referrals. Findings show that households reporting an income in the lowest income bracket (\$0-\$11,999) reported about 2.4 more overall barriers to care and 1.3 more socially-specific barriers to care than households reporting an income between \$25,000-\$44,999, and 2.7 more

overall barriers to care and 1.9 more socially-specific barriers to care than households reporting an income \$45,000 and above. Interestingly, there were no income differences in asthma-specific barriers to care. It is possible that families enrolled in RVA Breathes reported an array of barriers to care directly addressing their child's asthma symptoms regardless of reported income. Since RVA Breathes was a pediatric asthma intervention program and caregivers chose to enroll, it is logical that all families enrolled had difficulties with their child's asthma regardless of their demographic background. The association of lower reported household income and greater barriers to care is well documented (Fung et al., 2014; Lazer & Davenport, 2018), and is further supported by our findings.

Although no other demographic differences were found with barriers to care scores, differences in caregiver race/ethnicity were found in analyses examining number of community referrals and participant engagement in referrals. Caregivers that identified as Latinx received 6-7 more community referrals than participants that identified as Black and/or African American or Mixed/Multiracial. Moreover, caregivers that identified as Latinx had higher average community referral engagement scores compared to those who identified as Black and/or African American or Mixed/Multiracial. This difference by race/ethnicity highlights the importance of knowing specific home interventionist referral and follow-up habits.

The CHW in RVA Breathes who identified as Latina and spoke Spanish was promoted to Lead CHW during the program. She was the only Spanish-speaking interventionist, and worked with all families who spoke Spanish; Spanish-speaking families in RVA Breathes identified as Latinx. Knowing that all the Latinx families worked with the Lead CHW, it is logical that they may have received more community referrals and had more follow-up with their interventionist about those referrals than other families. All home interventionists in RVA Breathes worked hard

for their families, and attempted to provide targeted referrals when needed; however, it is possible they differed in their approach with families and had differences in documentation (see Discussion: Part 1). It is unknown whether this difference by race/ethnicity is due to an interventionist effect or differences in documentation between interventionists. Future research is needed to examine differences in referrals by home interventionist, interventionist documentation efforts, and to determine the target population of each available community referral.

#### **Cross-Sectional Associations with Asthma Control**

Examining demographic differences provided a general overview of the sample included in analyses. The next step was to examine associations between the variables of interest, as well as differences in caregiver level factors between families with a child with poorly controlled asthma (cACT≤19) and families with a child with well-controlled asthma (cACT>19) at each time point in RVA Breathes. As expected, at baseline and post-intervention sessions, worse (higher) stress, depressive symptoms, and stressful life events scores were associated with worse (lower) asthma control scores. Furthermore, at baseline and post-intervention sessions, families that indicated poor asthma control reported more perceived stress, depressive symptoms, and stressful life events scores compared to families that indicated well-controlled asthma. Findings support prior research that caregiver mental health can have negative impacts on their children's asthma (Morillo-Vanegas, Sanchez-Salcedo, and Ariño, 2020), possibly due to less engagement in daily care behaviors, such as picking up necessary asthma prescriptions (Margolis, Bellin et al., 2022), or by using maladaptive coping skills that exacerbate asthma symptoms, such as smoking (Jasal et al., 2020).

Unexpectedly, at intervention session one, average engagement in referrals was negatively correlated with asthma control, indicating that higher engagement in referrals was associated with lower (worse) asthma control. This is an unanticipated finding, but only seen at one time point. It is possible that this correlation is unidirectional, meaning that participants who reported worse child asthma control engaged in referrals more than participants who reported better child asthma control scores. It is logical that families who reported the worst asthma control scores engaged in the majority of provided community referrals in hopes of improving their child's asthma symptoms. Nevertheless, no associations were seen between number of community referrals and asthma control at any time point. It is possible that the number of referrals is not as important to asthma symptoms as the content of the referrals. Interestingly, number of community referrals was only associated with overall barriers to care at session one and socially-specific barriers to care at sessions 1 and 4. These results provide further evidence that content of referrals may be more important than number of referrals. It is possible that specific referrals (e.g., Sacred Heart Center, St. Paul Episcopal Church, Mercy Mall, Waymakers Foundation) were able to address an array of reported barriers, which would lead to fewer referrals given to a family even in the face of many barriers to care.

From sessions 2 through 4, overall barriers to care and asthma-specific barriers to care were negatively associated with asthma control, meaning more barriers were associated with worse (lower) asthma control. It is well documented that barriers to care are associated with poor asthma symptoms (Espaillat et al., 2023; Rodriguez et al., 2022). However, no associations were found between socially-specific barriers to care and asthma control scores. Research highlights the negative impacts of structural racism, poverty, adverse childhood experiences, and exposure to violence on asthma outcomes (Espaillat et al., 2023), which would be considered socially-

specific barriers to care in this study. However, interventionists in RVA Breathes could not overcome the systemic and ingrained social determinants of health for their families during their 9-month asthma intervention. Home asthma interventionists serve as one promising approach to address social determinants of health for specific families through targeted referrals; nevertheless, larger systems issues must be addressed at the state and federal level in hopes of attaining the level of asthma health that families deserve (Espaillat et al., 2023).

## **Improvements Over Time**

After cross-sectional analyses examined associations at each time point in the study, a series of analyses were conducted to examine differences in perceived stress, depressive symptoms, stressful life events, barriers to care, and asthma control over time. Results indicated an improvement in stress, depressive symptoms, stressful life events, overall barriers to care, asthma-specific barriers to care, and asthma control over time. Specifically, improvements in stress scores were seen as soon as two weeks after the intervention phase (at post-intervention), while improvements in depressive symptoms and stressful life events were seen later at 3- and 6month follow-up sessions. Reported overall barriers to care decreased from session 1 to session 3 (a six-month time difference), while a decrease in reported asthma-specific barriers to care were seen from session 1 to session 2 (a 3-month time difference). Asthma control scores improved from baseline to all follow-up sessions as well as session 1 to session 3 (6-months of intervention). Results suggest that RVA Breathes was effective at improving asthma control scores, decreasing barriers to care (specifically asthma barriers to care), improving caregiver mental health, and reducing stressful life events. In fact, findings suggest a reduction in asthmarelated barriers to care with 3-months of intervention, an overall reduction in all barriers to care

after 6-months of intervention, and improvements in asthma control after 6-months of intervention.

Given that caregiver mental health and stressful life events were not measured during the intervention phase, it is difficult to determine how long it takes to see improvements in caregiver level factors. Nevertheless, findings show an immediate improvement in stress after the intervention is complete, and a delayed improvement in depressive symptoms (3-months) and stressful life events (6-months). Since stressful life events is measured at 6-month intervals, it can be assumed that the number of stressful life events decreased on average for families in the post-intervention phase. Results highlight that RVA Breathes had a profoundly positive impact on the families who worked with a home interventionist team. Although findings are in line with prior research suggesting home interventionist programs are associated with improved asthma control (Marshall et al., 2020; Postma, Karr, & Keikhefer, 2009), we also found that home interventionist asthma programs are associated with improvements in caregiver mental health and a reduction in stressful life events and barriers to care.

Based on multilevel modelling, an association between stress and stressful life events with asthma control was seen over time. Results suggest that as stress increased (worsened) and stressful life events increased (worsened), asthma control decreased (worsened). In reverse, as stress improved and number of stressful life events decreased, asthma control improved. Depressive symptoms did not change statistically over time in relation to asthma control. Furthermore, changes in barriers to care scores over time were not associated with changes in asthma control over time. Group assignment had no influence on change trajectories, therefore there was no difference in rates of change between those in the full intervention group with those in the intervention group without the school nurse component. Results suggest that as caregiver

stress improved and families reported less stressful life events, children's asthma control scores improved. RVA Breathes aimed to improve asthma symptoms for families of children with asthma by providing home remediation efforts, asthma education, and coordination of care. However, MLM results suggest that improvements in caregiver stress and decreases in the number of reported stressful life events, possibly through providing targeted referrals, were associated with improved asthma control in children. It is possible that targeting caregiver mental health in future interventions may show improvements in children's asthma control over time.

## **Strengths and Limitations**

While analyses show promising results, findings must be interpreted with a consideration of study limitations. First, interventionists may have differing approaches when working with families. They may provide different community referrals and amount of follow-up with families about each provided referral. Future research should examine specific community referrals and their associations with caregiver mental health and child asthma outcomes. It is possible that specific referrals, and not the number of referrals given, are associated with better health outcomes. Gathering detailed information about the community referrals provided to families may help to better understand the association between referrals, caregiver mental health, and pediatric asthma control.

Another limitation of analyses is that COVID-19 occurred partway through the RVA Breathes intervention. By looking at associations over time, it is impossible to remove the influence of COVID-19. Therefore, all findings were discussed with an understanding that COVID-19 had prominent and pervasive impacts on families and interventionists alike. A study recently published by the primary researcher using a sub-sample of RVA Breathes participants examined differences in stress and depressive symptoms with asthma control from pre-COVID-

19 to after the onset of COVID-19. That study found improvements in stress, depressive symptoms, and asthma control scores from pre-COVID-19 to after the onset of COVID-19 among families in the intervention groups, but saw no improvements in mental health among caregivers in the control condition (Lohr et al., 2023). It is plausible that the participants included in this set of analyses, whom were all enrolled in the intervention groups, also saw improvement in caregiver mental health and asthma control scores after COVID-19 began. Nevertheless, it is possible that measures of caregiver mental health symptoms did not accurately capture caregiver challenges after the pandemic began. Future research should determine if measures of stress and depressive symptoms accurately captured caregiver's well-being after the onset of the pandemic.

Possibly due in part to the pandemic, there were a lot of missing data in RVA Breathes during the post-intervention phase. Although rigorous retention efforts were utilized, about 22% of participants were lost to follow-up by post-intervention, and another 12% were lost to follow-up by the 9-month follow-up session. Retention is difficult in all longitudinal studies, nevertheless, COVID-19 introduced additional barriers and a tremendous strain on longitudinal research that impacted study retention (Tuttle, 2020). However, MLM analyses were able to examine individual trajectories of change over the study duration even when data was not collected.

#### **Conclusions**

Findings suggest that interventionist support for at least 6-months may lead to positive changes in pediatric asthma control and number of reported barriers to care. Furthermore, engagement in home interventionist asthma interventions may be associated with improved caregiver stress and depressive symptoms, as well as child asthma control. In fact, if interventions target caregiver stress and barriers to care, it is possible that it may lead to

improvements in child asthma control over time. Results suggest that working with a home interventionist team in RVA Breathes may have had a positive impact on child asthma control, caregiver mental health, and barriers to care. Findings can be used to support policy changes and funding decisions in support of the home interventionist model of care for families of children with asthma.

# **Combined Conclusions: Main Takeaway Messages**

This dissertation examined caregiver and interventionist experiences with the RVA

Breathes asthma intervention program through both qualitative and quantitative analysis of
caregiver mental health, stressful life events, barriers to care, interventionist-provided resources,
and child asthma symptoms. Caregivers and interventionists discussed enjoying RVA Breathes
and appreciating the targeted referrals and tangible resources. Caregivers also reported some
ongoing difficulties with mental health and encountering asthma triggers in public places.

However, quantitative analyses found improvements in caregiver stress, depressive symptoms,
stressful life events, overall barriers to care, asthma-specific barriers to care, and child asthma
control over time, indicating that interventionist support was associated with positive health
outcomes for families. During focus groups, caregivers and interventionists discussed families
continuing to encounter barriers associated with living in poverty. We did not find differences in
socially-specific barriers to care over time, indicating that families continued to encounter
systemic social determinants of health even with interventionist support.

When COVID-19 began, caregivers voiced appreciation for the ongoing support they received from their interventionists and mentioned that their children's asthma symptoms improved. Quantitative results support this by showing an improvement in asthma control over time. Barriers to care reported in CHW session notes outlined barriers directly and indirectly related to children's asthma. Barriers to care outlined from the CDC, American Lung Association, and American Academic of Allergy, Asthma, and Immunology were used to identify asthma-specific barriers while other social determinants of health were captured as socially-specific barriers. Analyses found negative associations of asthma-specific barriers to care with asthma control at sessions 2-4, meaning greater numbers of asthma-specific barriers to

care were associated with worse asthma control. By addressing asthma-specific barriers to care through targeted referrals, it is possible that interventionists improved children's asthma control. However, community referrals given to families mostly targeted socially-specific barriers to care. It is possible asthma-specific barriers were targeted, but efforts were not mentioned in internal records. Asthma control improvements may also be due to main study efforts including environmental trigger remediation, asthma education, and coordination of care that were not captured in dissertation analyses. About a third of participants reported engaging in the referrals they were provided; however, it is possible that all engagement efforts were not captured in the data gathered. Quantitative analyses did not see associations of number of community referrals or average engagement in referrals with asthma control either cross-sectionally or over time.

To build upon qualitative findings, multilevel models examined associations of trajectories of change in caregiver levels factors and barriers to care with asthma control over time accounting for group assignment. Findings suggested that improvements in caregiver stress and decreases in reported stressful life events were associated with improvements in asthma control over time regardless of group assignment. Caregiver mental health and stressful life events may be valid intervention targets when addressing child asthma control. Overall, findings show how beneficial the home interventionist model of care is for families of children with asthma, even in the face of COVID-19. Findings may be used to provide support for insurance companies to fund the home interventionist mode of care for families of children with asthma.

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