

**Urban Planning Solutions for a Public Health Crisis: COVID-19 Related Sociodemographic
Factors and Stressors Impacting Pediatric Oncology Patients and Their Families**

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Abstract

This thesis uses a case study approach to evaluate the COVID-19 related sociodemographic factors and stressors that impact households with a pediatric hematology oncology patient and analyzes how the urban environment and built environment interact with and exacerbates these factors and stressors. Discussion focuses on ways New York City can leverage existing programs to maximize reach to cover medically or otherwise vulnerable households, as well as offer longer-term policy solutions to increase the resilience of New York and New Yorkers. This thesis concludes that urban planning tools can meaningfully address a public health crisis and makes the case that it is more important than ever to study, work, and develop interventions across disciplines to advance common goals.

Table of Contents

Abstract	ii
Introduction	1
The COVID-19 Crisis in Context	2
The COVID-19 Crisis: Research Context	3
Scope and Focus of Thesis	4
Literature Review	6
Children and COVID-19	6
Children with Cancer and COVID-19	7
Why Study This?	9
Methodology	11
Study Population	11
Survey Instrument	12
Findings	14
Density: Household Composition and Housing	14
Transportation and Access to Institutions and Community Assets	16
Unemployment and Financial Burden	17
Food Insecurity	19
Other Findings	20
Findings in Context	22
Density and Disease Transmission	22
Defining Densities	23
Contextualizing Questions of Financial Security	28
Impacts of Economic Crises and Income Loss	29
Financial Toxicity and Food Insecurity	31
Discussion and Recommendations	34
Density and Crowding	34
Limiting Viral Transmission	38
Proposing a Healthy Housing Consortium	40
Addressing Income Loss, Unemployment, and Unemployment	44
A More Resilient Food Supply Chain	46
A Stronger Food Assistance Network	50
Conclusion	56
Appendix	58
Bibliography	63

Introduction

Disasters are as old as time. Equally as long, various societies have attempted to explain them, find meaning in them, and cope with their consequences. The word 'disaster' derives from the ancient Greek words for "bad star," attributing disasters to the position of the planets (Solnit 2010). Even today we tend to try to explain disasters in terms far greater than us. We call them acts of god, or perfect storms; we even call them natural. Disaster scholars argue that there is no such thing as a natural disaster, but rather only natural hazards and socially constructed vulnerabilities which interact with events to create disasters (Mora 2009, Gould 2016, Chmutina 2019). Geographer Neil Smith, in 2006, declared that "there is no such thing as a natural disaster. In every phase and aspect of a disaster – causes, vulnerability, preparedness, results and response, and reconstruction," the impacts are mediated by social and socially-constructed conditions. There has been an increasing movement to remove the word 'natural' from disaster, so that we might finally and fully accept responsibility for outcomes of natural hazards and other events (Bell 2017 & Emanuel 2017).

Disasters do not affect all elements within a society or community equally, and are often mediated by issues of wealth, race, ethnicity, class, and other demographic categories. For example, "racial and ethnic communities ... are more vulnerable to natural disasters, due to factors such as language, housing patterns, building construction, community isolation and cultural insensitivities" (Fothergill et. al. 1999). These vulnerabilities are by no means naturally occurring. While much disaster literature focuses on extreme weather and geologic events, the scope and scale of public health disasters like pandemics can be as devastating as climate or geologic

disasters. The ongoing COVID-19 pandemic demonstrates that the same trends observed during other types of disasters are also observed during public health disasters.

By the end of March 2020, New York City was firmly established as the United States' epicenter of the COVID-19 crisis. Some sought to ascribe meaning to the situation by using it to foster a sense of community. For example, on March 31, New York Governor Andrew Cuomo tweeted that the “[t]his virus is the great equalizer” (Cuomo 2020). In fact, it can more accurately be considered the great *revealer* of inequality.

COVID-19 disproportionately impacts communities of color. Senior economist at the Center for American Progress Olugbenga Ajilore said that “[t]he toll of the pandemic shows just how pervasive structural racism is” (Flagg et al. 2020). The toll he refers to is the outsize portion of hospitalizations and deaths among Black, Hispanic and Native Americans due to the coronavirus as compared to white Americans.

The COVID-19 Crisis in Context

Chronically ill people and their families face unique stressors during disasters and public health crises and require special considerations in planning for such events. Likewise, COVID-19 is a respiratory disease which disproportionately impacts socially and medically vulnerable communities. The virus is most physically harmful to those with pre-existing medical conditions. Pediatric hematology and oncology patients are immunocompromised. The US Centers for Disease Control (CDC) stated immunocompromised people “are at higher risk of getting severely sick from SARS-

CoV-2, the virus that causes COVID-19” (Centers for Disease Control and Prevention 2020). Again, the unique stressors faced by chronically ill people and their families require special considerations during disasters and crises. These stressors include (but are not limited to) resources and activities related to the management of the chronic conditions, and may include accessing medications, health providers, or other items, institutions, or professionals related to their care (Suneja 2018). Further, these stressors are often compounded by other vulnerabilities faced by these families, and often interact with the built environment and other aspects of urban environments. This, in turn, may compound or otherwise exacerbate existing vulnerabilities.

The COVID-19 Crisis: Research Context

Researchers at Columbia University Irving Medical Center’s Division of Pediatric Hematology, Oncology, and Stem Cell Transplantation developed a retrospective and prospective review of their patients in the Tri-State Area to analyze a number of indicators with respect to COVID-19. A broad objective of this review is to build a comprehensive database of all these patients in the study area to learn how COVID-19 affects them. Other objectives include analyzing the effects of COVID-19 on various patient indicators related to patient nutrition, nutritional status, and their microbiome, oncology outcomes and protocols, mental health of patients and their families, and more. One study arm of this broad investigative inquiry seeks to understand COVID-19 related sociodemographic factors and stressors on this study population. This is the study which I have participated in and serves as the case study for this thesis.

Survey data for this thesis has been collected, and continues to be collected, under the direction of Dr. Manuela Orjuela, the lead investigator for the study COVID Related Sociodemographic Factors and Stressors Impacting Pediatric Oncology and Hematology Care Delivery. Dr. Orjuela is a molecular epidemiologist at the Mailman School of Public Health's Department of Epidemiology and a practicing pediatric oncologist at Columbia University Irving Medical Center (CUIMC) in the Division of Pediatric Hematology, Oncology, and Stem Cell Transplantation.

Scope and Focus of Thesis

This thesis is guided by the following research questions: what are the COVID-19 related sociodemographic factors and stressors that impact families with a pediatric hematology oncology patient? How does the urban environment and built environment interact with and/or exacerbate these factors and stressors? How can cities impact, impede, interact, with additional burdens of COVID on cancer patients and their families?

This thesis contributes to a growing body of knowledge of the COVID-19 crisis with respect to children with blood cancer and other diseases and their families. It also more broadly aims to better understand, in order to better serve, vulnerable communities during protracted public health crises. Bringing an urban planning perspective and set of tools will aid in gaining a more comprehensive understanding of the experiences of families with a chronically ill child than either a strictly public health or strictly urban planning approach would. Built environment effects on families with children with blood cancer and diseases, particularly with respect to COVID-19, is a

research area that, while important, receives less attention than most others. This project can help fill this research gap and can help bridge the gap between planning and health.

This thesis also intends to help bridge the gap between theory and practice. Gaining a more comprehensive understanding of families' experiences and needs during a pandemic increases health practitioners' ability to better serve families now *and* helps practitioners better prepare for future catastrophes. Lessons learned from the COVID-19 pandemic will inform how communities must prepare for and learn to withstand future pandemics, disasters, and crises.

Literature Review

Children and COVID-19

The National Center for Disaster Preparedness (NCDP) recently issued a report on the extent of avoidable COVID-19 deaths in the United States as of October 16th, 2020, entitled “130,000-210,000 Avoidable COVID-19 Deaths – and Counting – in the U.S.” The report reviews the disproportionate fatalities attributable to COVID-19 in the United States as compared to other high-income nations, as well as low- and middle-income countries. The report finds that upwards of 130,000 deaths nationwide could have been avoided if not for poor leadership decisions, insufficient federal coordination, and delayed policy intervention. This is exemplified by the nation’s insufficient testing capacity; long-term inadequate testing efforts have hindered the nation’s ability to identify and contain COVID-19 outbreaks, as has the failure to aggregate and streamline data from the state level to the federal level (Redlener 2020). Another reason cited for the disproportionate deaths in the U.S. is the Trump administration’s demonstrated “hostility to much of the critical guidance and recommendations put forth by its own health agencies,” (Redlener 2020) which precluded the widespread adoption of protective behaviors aimed at minimizing the spread of the virus.

Concluding their report, researchers at the NCDP introduce the notion of collateral grief and the broader implications of the lives lost to COVID-19. Each death represents a person who played meaningful roles in the lives of others, and each death implicates broader loss, burden, grief, economic instability, and other struggles for those left behind. Included in those collaterally grieving are children. Children are “the least susceptible to the physical effects of COVID-19” as a broad demographic, but even

those who are healthy are indeed impacted by COVID-19. The report offers sobering numbers on some ways children in New York State are burdened by the ongoing pandemic:

In New York State alone, it's estimated that 325,000 children have been pushed into or near poverty as a result of the economic impacts of the pandemic. Other reports estimate that at least 4,200 children in New York have lost a parent to the disease, leaving thousands at risk of foster care placement that had been under the care of a single parent (Redlener 2020).

Describing the ways in which families with children are impacted and challenged by COVID-19 is key to begin to learn how to make the pandemic more bearable. Likewise, identifying what areas of home life are changing significantly and in what ways is imperative in order to grapple with recovery.

Children with Cancer and COVID

Children undergoing treatment for hematologic cancers and other blood diseases are immunocompromised. Dr. Bradley Gampel, a resident physician at CUIMC and a member of the broader study's research team writes "it is well established that viral respiratory infections in chronically ill and immunocompromised children are associated with increased morbidity and mortality compared to the general population" (2020). Therefore, one might expect children undergoing treatment for blood cancer and disease to be more likely to experience poorer outcomes with respect to COVID-19,

which is a viral respiratory disease. However, the evidence thus far is inconclusive and additional research is needed.

There is relatively little data on how this patient population fares clinically with respect to COVID-19, but there is still promising preliminary data available. In May of 2020, pediatric cancer expert Dr. Farid Boulad et. al. (2020) of Memorial Sloan Kettering Cancer Center wrote a report which “suggests that pediatric patients with cancer may not be more vulnerable than other children to infection or morbidity resulting from SARS-CoV-2” (2020). This study is fairly limited but does examine outcomes across various medical institutions in New York City, which together “care for a sizable portion of the city’s pediatric hematology, oncology, and HCT community” (Gampel 2020). The current literature on whether these children are more vulnerable to COVID-19 infection is inconclusive, which can contribute to fear of the virus in pediatric patients themselves, in their families, and throughout communities.

Dr. Gampel posits that this fact may be reinforced by or be a function of protective measures that this immunocompromised patient population already undertakes, writing that “social distancing to prevent infections is a well-established behavior in pediatric hematology, oncology, and HCT patients, [so] this may not be reflective of the general pediatric population” (2020). In other words, it appears that this particular pediatric population does not experience worse medical outcomes due to COVID-19 as a function of their underlying disease or immunocompromised status, likely or at least in part because of effective personal protective precautions this population already undertakes.

This is a promising, albeit perhaps somewhat unexpected, outcome. However, it would be premature to consider that this population need not be concerned about COVID-19 infection. It remains a dangerous and largely unknown disease, with inequitable burdens for an indeterminate amount of time. Just because this patient population does not experience significantly worse outcomes than other children does not mean that contracting the virus is of no risk to them – immunocompromised people can still have worse outcomes even if *overall* as a group they have presented thus far as having not. Further, children carrying the virus can still contribute to household and community spread. The virus's novel status renders it anxiety-inducing, especially for families already burdened with anxiety related to their child's cancer diagnosis, which can have implications for a person's confidence and ability to access care and other things needed for daily living.

Why Study This?

The COVID-19 pandemic introduced the world to a new disease and revealed and exacerbated many preexisting vulnerabilities. Likewise, in many ways, in exposing existing stressors, it reflects patterns typical with other protracted crises. Therefore, it is imperative to work towards increasing our understanding of how the novel virus affects people, including this study population of families with a child with blood cancer or other blood disease. Understanding how the current pandemic affects the pediatric hematologic oncology and related diseases patient population and their families will be vitally important in understanding their prospects for recovery with respect to COVID-19 and will help identify key areas for intervention. Additionally, this course of study may help practitioners identify possible interventions; increase sensitivity in approach in the

clinical setting; may help better connect patients and their families to available resources; and provide lessons that can be applied to this population and populations facing similar medical and sociodemographic vulnerabilities during future protracted crises.

Methodology

I took a case study approach to the “COVID Related Sociodemographic Factors and Stressors Impacting Pediatric Oncology and Hematology Care Delivery” study. The research team and I used a semi-structured survey instrument to ask participating households about a range of stressors and factors affecting them due to the pandemic.

Study Population

The study population is pediatric patients being followed for hematologic oncologic diseases or other blood diseases and their families. While the study is inter-institutional across several major medical centers in the Tri-State Area, the findings presented in this thesis are all from families of patients being treated at Columbia University Irving Medical Center in New York City, and all participants live in New York.

Interviews are conducted in English and in Spanish, and our participant population is limited to those who can speak these languages. That said, the participant population is a diverse one. Two communities highly represented in the study are immigrant communities from Latin America and Hasidic Jewish communities, neither of which are monolithic communities nor cultures.

The survey instrument is designed to be answered by a head of household, or someone who could answer questions about the household at large. By design, the patients themselves are not eligible to be interviewed themselves. Some patients continue to be followed after their eighteenth birthdays. They are still not eligible for participation, as the study’s survey instrument is geared towards the heads of

household. In these cases, a parent or other primary caretaker would still be interested; it is the informed consent of the parent or caretaker that is obtained.

Survey Instrument

The survey instrument is a semi-structured survey of 124 questions which asks about how the COVID-19 crisis has affected participants with respect to socioeconomic and sociodemographic stressors, impact in getting care for their child, and their own and their child's anxiety during the pandemic.

The intersection of COVID-19 and cancer poses a unique set of burdens on families, and as such, an interview whose goal is to understand these burdens can be particularly demanding. Care is given to minimize excessively burdening participants.

The order of questions was purposive; particularly sensitive questions were spaced out throughout the survey to avoid emotionally fatiguing participants. Every effort is made to ensure the comfort and safety of participants. They are made aware at multiple points that they may pause or stop the interview at any point, may ask for clarification or explanation at any point, and may decline to answer some questions or respond that they do not know the answer. They are also made aware that participation is optional.

Lastly, interviews end with an open question, asking about any positive traditions, habits, or other activities shared by the household that may have emerged as a result of COVID. This is done in an effort to end the interview on a more positive note.

Areas of inquiry in the survey instrument can be categorized within the following groups: Employment; Financial Toxicity; Household Composition; Built Environment;

Potential Exposures to COVID-19; Attitudes regarding COVID-19; Food Security; and Demographics

It must be noted that the study is ongoing; researchers continue to recruit participants and collect data. As such, the findings shared and disseminated in this thesis are preliminary and not meant to draw definitive conclusions about how COVID-19 has affected populations beyond those studied. That said, this thesis includes rich data from 18 in-depth semi-structured interviews conducted between July 15, 2020 and September 14, 2020 (and one from November 12, 2020). Much can be learned from these interviews, and preliminary prevalent themes impacting this study population can tentatively be identified. From there, meaningful discussion and recommendations for intervention and future study can be made. Recommendations will focus on ways New York City can leverage existing programs to maximize reach, as well as offer longer-term policy solutions to increase the resilience of the city for more New Yorkers.

Findings

Density: Household Composition and Housing

Participants live in a range of housing types. The majority of participating households live in apartments, although some households live in single-family homes. A large portion of families from our study sample of 18 families live in upper Manhattan, particularly in the Washington Heights neighborhood, close to Columbia University Irving Medical Center.

Several participants also reported living in a home in which multiple households reside. Multiple households in one home were reported by participants residing in both apartments and houses. Several participants described this housing decision as one based on financial necessity. In these homes, there tends to be at least one person who leaves the home regularly to work. Further, some in these households reported doing work in which they were likely to be in contact with multiple people, for example “doing deliveries.” These households also tend to be multigenerational, with three generations residing in the home.

Some participating families live in crowded homes. While the interviewers did not ask participants about the measurements of their homes, interviewers did ask about the number of rooms in homes and how many bedrooms are shared. Families living in crowded homes tend to live in communities with high rates of household crowding – in particular, Washington Heights in Manhattan and parts of Brooklyn, including Borough Park. Most patients do not sleep in a bedroom by themselves. However, a few participants reported that the patient did sleep in his or her own bedroom – but that a

caregiver (most often a parent, sometimes a sibling) would sleep in the room when the patient was most sick.

Most bathrooms are used by multiple members of the household, with only one participant in our sample reporting that the patient was the only person who used his or her own bathroom.

The survey also asks if someone, apart from the participating respondent and the patient/child, has been infected with COVID-19. About one third of participants did report that at least one person in the household had COVID-19. Further, of those participants responding yes, many said that everyone in the household had been infected with COVID-19; “we all got it,” one shared. In another instance, the participant said that the patient tested positive (without experiencing symptoms) during a routine screen, and subsequently “everyone in the family had mild symptoms” and all (save for one child) tested positive for antibodies to the virus. In another, the participant reported that some members of the household tested positive for COVID-19, and the rest were presumed to have been infected because every member of the household exhibited symptoms. In yet another household, the participant was a mother to three children. She shared that two of her sons (the patient and his brother) were both hospitalized with severe cases of COVID-19, and her husband (the children’s father) died from COVID-19.

This study does not try to draw community level conclusions about the likelihood of contracting the virus, rather just identify different pathways in which it may occur amongst the study population. The survey does not ask about the COVID-19 status of the patient (child with a blood disease or cancer), just about anxiety relating to it and

other household changes. All patients have been tested for COVID-19 in the course of their treatment and clinical visits. Some participants disclose COVID-19 status independently.

Transportation and Access to Institutions and Community Assets

COVID-19 has changed the way that participants navigate their communities. Some participants reported changes in how they get to and from the hospital or clinic where the patient receives treatment, as well as how they feel about getting to and from these institutions. Some expressed fear or anxiety about leaving their homes. While some are not necessarily scared of becoming sick with COVID-19 themselves, they do fear “bringing it home” and exposing their immunocompromised children.

One woman living in Brooklyn expressed trepidation in accessing things she would typically access before the pandemic. Regarding grocery shopping, she said she’ll “send the kids out” because she believes they are “not at as high a risk” of contracting the novel coronavirus. Another woman says that in order to avoid long lines and heavy crowds at the grocery stores, she will wake up early in the morning to go buy food. One participant said she tried to buy more food than she normally would have in one trip so that she can go out to the grocery store less frequently. She said she feels less safe, and at a greater risk of coming into contact with the coronavirus, when she goes out for food. This feeling was prevalent throughout the sample, but most participants felt they had no choice but to go out anyway.

This is not without exception. One mother said that she has her groceries, and most other goods, delivered to her home. However, she understood her position to be atypical, frequently reflecting on her good fortune and privilege.

Unemployment and Financial Burden

The COVID-19 pandemic has had profound economic impacts with pronounced felt effects at the household level. Contributing to the financial burdens already faced by families with a child with chronic illness are unemployment and underemployment experienced by many participants. Some have had to reduce or stop working in order to care for their ill child, while others have experienced job loss or reduced hours due to the pandemic. Likewise, many participants noted that their typical incomes were disrupted because of less frequent work – both because of COVID-19 and as a consequence of their child's illness.

Some participants reported being unable to work because of the patient's illness. These participants are primarily the mothers of sick children. When asked if she worked in order to earn money for the household, one mother joked that "caring for my child is a full-time job," referring specifically to the additional activities involved in caring for her child who was home with a chronic illness. Another mother shared that while she might like to work, she cannot because she is at the hospital with her son, who must be at the hospital as an inpatient for an extended period of time.

A third mother shared that she considers herself to be facing a difficult decision. Prior to the pandemic, she worked as a home healthcare aide seven days a week, a job she still has. She did receive four weeks off in order to care for her daughter, which she

should have been paid for. However, at the time of the interview she had not yet been paid and was considering working less. Some people were furloughed or had their hours reduced at work due to COVID-19. One woman said she was “waiting for the boss to call” her to tell her to return to work.

Participants reported coping with limited continued income in a number of ways. Many participants collected government unemployment benefits. Other participants cited a need for collecting unemployment benefits, or that they would be entitled to receive them, but have faced significant logistical barriers to collecting them, including an application process that is difficult to navigate. For example, one participant described having tried to apply but the process is “so complex,” and the status of her application was pending at the time of the interview. Someone else, when asked whether she receives government unemployment benefits, answered, “[i]t It is very difficult to apply.” The respondent had called a benefits office the day prior to the interview and waited on the phone for hours. At the time of the interview, she was still waiting for someone at the benefits office to return their call.

Some participants were not collecting government unemployment benefits, but it was something they considered. For example, one mother answered “no [to receiving unemployment], but I should be.” Another participant responded that she does not qualify for unemployment benefits but has applied for disability benefits. Interviewed in the summer of 2020, she noted that her household had used all their savings in April and struggled with paying the rent. Unable to afford it on her own, she received assistance from family members the month prior to the interview and was receiving rent assistance from social services at CUIMC the month she was interviewed.

Food Insecurity

While participating families represent a range of food security outcomes, nearly everyone in the sample did report changes in how they acquire food. Many participants in the study experienced food insecurity, citing changes in their ability to afford the foods they usually ate before the pandemic, changes in the composition of their meals, and changes in how they procure food.

Specifically, many answered that even when they do have enough to eat, it's not always the types of food they want to eat. They said this was both because of affordability and availability in food stores. Many families reported that food has become increasingly harder for them to afford. Additionally, one participant said that "some products are not available," an experience echoed by many. Specifically, many report eating fewer fresh vegetables, fruits, meat, and fish, citing the increased costs of these food items. For example, one participant shared that "because meat is more expensive" they buy and eat less of it.

Some families had used free meals provided in schools prior to the pandemic. The children of some of our participating families might not have been in school regardless of the pandemic, as one mother described that "we've been in the hospital for a few weeks." Similarly, another shared that "we have been in the hospital all this time." A third mother shared that her daughter, the patient, "got pulled out of school when she was diagnosed" although she was not an inpatient at the time of the interview. For these households, school closures have not meant a disruption in that means of

meal procurement, despite the fact that they may have benefited from school meals even if COVID-19 was not what kept them from accessing this aid.

However, for others, school closures due to COVID-19 does mean a disruption in a previously reliable source of free meals. One family, when asked whether they receive free school meals, replied “well, school meals, but before,” meaning before the onset of the pandemic. One participant did say that her child’s school continued to provide “grab and go” meals.

Other Findings

Some participants have spoken about the impact of limited social and physical support since the onset of the COVID-19 pandemic. For some, restrictive visitor policies in the hospital setting due to COVID-19 has been a source of additional isolation and stress. A few participants from two-parent households noted that while their child was an inpatient in the hospital, only one parent could be at the hospital with the child at a time. One participant shared this experience, noting a brief exception:

‘Realmente no hemos tenido tiempo juntos. Llevamos 24 días en el hospital con nuestro hijo, y solo yo puede entrar, no permite a mi esposo visitar. La pandemia nos ha afectado mucho. Ayer fue el cumple de nuestro hijo, y fue el único día que permitieron a mi esposo entrar y pudimos pasar tiempo juntos. Él sólo pudo visitar por 4 horas.’

‘We haven’t really had any time together during the pandemic. We’ve been at the hospital for the past 24 days and my husband isn’t allowed to enter. Only I can be inside with our son. Yesterday was his birthday, and that was the only day they let

my husband visit and spend some time together. He was allowed to visit just for 4 hours.'

Some have described this experience as challenging and isolating, particularly given the shock of the sudden change in 'togetherness.' Another woman described the opposite, and that the pandemic has offered an opportunity to increase their ability to be together in a positive way. She described being very unified with her family; "every activity we do we do it together. We eat and play together. The only thing that has separated us is whenever I take my son to the hospital or clinic."

Faith and religion are two other recurring themes brought up by participants in this study group. One participating mother described the pandemic as a message from god. Another offered thanks to god throughout the interview when describing her good fortune, and shared that her household gives money to their church on a weekly basis. "Before everyone did their own thing, the virus united families on the one hand but on the other hand a lot of people died. Now we remain more united, we cooked, spent time together, prayed together."

Findings in Context

Density and Disease Transmission

Politicians and laypeople alike broadly ascribe an inordinate amount of blame on the spread of COVID-19 to ‘density,’ which will be defined later in this section. While spatial conditions can certainly promote or hinder the spread of a respiratory virus, it is a complicated matter which merits nuanced consideration.

New York State Governor Andrew Cuomo largely attributed New York’s initial establishment as the country’s epicenter of the pandemic to density, saying, “[i]t’s very simple. It’s about density. It’s about the number of people in a small geographic location allowing that virus to spread . . . Dense environments are its feeding grounds” (Hamidi 2020). So powerful was this notion that dense cities promote the spread of COVID-19 that many with the means to move away from New York City, and in particular the city’s most dense borough, Manhattan, did so (Haag 2020).

The Citizens Housing and Planning Council (CHPC) investigated this issue as far back as May of 2020. The CHPC contests the use of the term “density” as a so-called “catchall term that encapsulates many aspects of urban life,” instead considering it to be oversimplification that “is not helpful to the creation of virus mitigation strategies” (CHPC 2020). The CHPC asserts that there are other elements of the urban environment that contribute to the spread of COVID-19 but that blaming density alone is an incomplete and unsubstantiated observation. For example, they write that across the city, “population density and COVID-19 case rates are not only misaligned, but in many places appear almost opposite one another,” meaning, some of the densest communities (with respect to residential density) have had some of the lowest rates of infection, while less dense areas have experienced relatively higher rates of infection

(2020). Failing to examine the nuances of different types of density (which will be described in the following section) and of other elements of the urban environment preclude meaningful understanding of the role the built environment plays in mediating viral transmission and can lead to ineffective prevention and recovery strategies.

In fact, there is a long tradition of misusing terms of density. Jane Jacobs, the journalist and activist, lamented the impacts on cities of the systemic and chronic failure of planners to distinguish between city density and housing overcrowding. She traces the confusion between high city density and overcrowding to the era of Garden City planning, which considered both to be urban ills; “they hated both equally, in any case, and coupled them like ham and eggs, so that to this day housers and planners pop out the phrase as if it were one word, “highdensityandovercrowding” (Jacobs 1961).

This way of considering dense urban areas has endured, and its use remains fraught with inconsistencies and contradictions. Further, blaming density at face value worsens the ongoing management of the pandemic, makes it harder for individual households to navigate their communities safely and *confidently*, contributes to misplaced fears and anxieties, and overall worsens the path toward economic and other recoveries.

Defining Densities

It is more helpful to consider the various manifestations of density, which each carry different kinds of risks and protections, including different levels of risk to various viral exposures. The CHPC outlines four distinct types of density, which are four of many, which are: Residential Population Density, Internal Residential Density,

Institutional Settings Density, and Public Spaces and Workplace Density. Residential Population Density is most commonly measured as the average number of people living per square mile. Internal Residential Density is the number of people per housing unit, and typically is used in reference to situations in which a unit is housing more than it was designed to accommodate. Institutional Settings Density is where many people are housed in the same living environment and can refer to places like shelters and nursing homes. Public Spaces and Workplace Density refers to large numbers of people gathering in places like supermarkets, places of worship, on public transportation, major offices, and other publicly accessible places.

People tend to move through these different spaces in different ways, and so risk of exposure to viruses including the novel coronavirus is not equal amongst them. Grouping them as one does a disservice to our understanding of transmission and to a public weariness of exposure. Rather, it is a counterproductive exercise in misplacing blame.

The CHPC conducted detailed analysis to identify trends in transmission rates and their relationship to these types of density, finding that “[a]t each level of comparison, between the most impacted counties in the nation, the counties in and around New York City, the five boroughs, and neighborhoods citywide...COVID-19 rates ... diverge significantly from patterns of population density” (CHPC 2020). The report specifically cites that there is *no clear association* between rates of infection and residential population density, or, people living per square mile. The CHPC firmly rejects the notion that residential population density might be a key determinant of the impact of the virus.

On the other hand, while residential density is not a determinant of the impact of the virus, the CHPC found that internal residential density, or overcrowding, may be. Specifically, they write that “[a]cross NYC neighborhoods, overcrowding is somewhat positively correlated with higher rates of COVID-19, meaning that neighborhoods with a greater share of overcrowded households are more likely to have a higher per capita case rate” (CHPC 2020). In neighborhoods with high rates of overcrowding, then, there very well may be higher rates of spread of the virus. Further, neighborhoods with a higher burden of overcrowding tend to experience other burdens at higher rates, too, including amongst children. In fact, children growing up in crowded houses can experience negative effects for the rest of their lives and is one mechanism for the transmission of intergenerational social inequality. In the short-term, crowded housing can “harm children’s school achievement, behavior, and physical health” (Solari 2012). This is important to note because it suggests that neighborhoods with high rates of crowdedness experience more negative outcomes, which may be compounded by COVID-19.

Given the prevalence of these overlapping conditions, it can be difficult to tease out the cause of the higher per capita case rate. Still, this observational data is important, and rightly alerts public health and urban planning practitioners to meaningful influences in the spread of the virus. There is a clear pattern that households experiencing the burden of overcrowding are more likely than those not experiencing overcrowding to be exposed to COVID-19.

The CHPC notes that “internal residential density, or overcrowding in housing, is somewhat positively correlated with higher rates of COVID-19 cases per capita in New

York City” but adds that it is hard to ascribe this correlation to internal residential density itself. Teasing out the effect of density itself is challenging, particularly given the “overlapping issues of racial inequality and social determinants of health” which render certain populations within New York City more vulnerable to contracting, spreading, and experiencing worse outcomes than others (CHPC 2020).

The CHPC listed as a key finding that “more information is needed on how housing conditions have played a role in this crisis” and cannot conclude the extent to which internal residential density is responsible for spreading the virus (2020). Likewise, this thesis offers no conclusive findings about exposure and transmission patterns amongst our population of interest, immunocompromised children. This thesis does not seek to make such conclusions, nor any about their home environments. Rather, its purpose is to gather and disseminate lessons from which can be applied to other scenarios and cases as necessary. Identifying preliminary trends across cities can better contextualize various sub-groups and patient populations, as well as improve understanding of how the study population can better navigate their communities for the remainder of this pandemic.

These findings have been replicated elsewhere. A team based at the London School of Economics conducted a study in which they found that residential density affects the timing and extent of viral transmission, “with denser locations more likely to have an early outbreak,” but ultimately the team has found “no evidence that population density is linked with COVID-19 cases” (Carozzi 2020). The team cites the “higher connectedness of denser location[s]” as why outbreaks are more likely earlier on in these areas (Carozzi 2020). To take this a step further, this high level of connectedness

can positively implicate enduring and recovering from the pandemic and should not only be considered a risk factor for early spread.

In fact, a study published in the *Journal of the American Planning Association* found that while “metropolitan population [is] one of the most significant predictors of infection rates, with larger metropolitan areas experiencing higher infection and high mortality rates,” they also found “that after controlling for metropolitan population, county density is unrelated to the infection rate and negatively related to the mortality rate” (Hamidi 2020). In other words, metropolitan regions are sure to experience higher rates of infection and mortality due to the greater number of people residing within. However, within the metropolitan regions, density is less telling, and there is no association between density and infection rate. Denser communities within an affected region are not worse off in this viral pandemic. Hamidi et. al. (2020) posits that dense counties may actually be at an advantage because they are more likely than less dense regions to have robust networks key to responding to the needs posed by the pandemic. They concluded that connectivity including tourists, businesspeople, and other transient people is an important potential factor of vulnerability, and this fact increases the risk of transmitting infections across borders. It is this high level of connectivity, they conclude, that is more predictive of COVID-19 spread than density (Hamidi 2020). Therefore, planners should not reject dense development, but rather should *advocate* for it.

This finding has been validated in inquiries about the transmission of COVID-19 with respect to people experiencing other health conditions, as well. For example, researchers at Columbia University distinguished between density and crowding in their research “Associations Between Built Environment, Neighborhood Socioeconomic

Status, and SARS-CoV-2 Infection Among Pregnant Women in New York City” (Emeruwa 2020). They found that the highest probability of infection with the novel coronavirus was highest “for those residing in neighborhoods with high household membership,” and that odds of infection were “higher among women residing in neighborhoods with high unemployment rates, large household membership, and greater household crowding.” And, importantly, that there “was no statistically significant association between SARS-CoV-2 infection and population density” (Emeruwa 2020). Intra household crowding, and *not* population density, was statistically correlated with higher odds of infection with the virus that causes COVID-19. By correctly identifying conditions in which the spread of COVID-19 appears more likely, policy development can more effectively and efficiently address true problems.

Contextualizing Questions of Financial Security

Much literature about children in crisis settings and living through disasters describes them as resilient or speaks about their prospects for healthy recovery and recuperation through the lens of resilience. And, while children certainly are resilient in many ways, they are also particularly affected by disasters and pandemics (Masten 2020). And, while children are not among the financial earners of most households, they are indeed affected by household financial activity and strain. The protracted and confounded burdens of their illness, household financial strain (Yoshikawa 2012), and food insecurity (Alaimo 2001) may very well bode poorly for their short-term and longer-term health and well-being of children in households with a sick child.

Medical debt is a complex, contentious issue in American politics. It has long been established that millions of Americans have difficulty paying their medical bills, which leads millions into debt due to unpaid or underpaid bills (Doty 2005). It was reported that among the estimated 530,000 families who filed for bankruptcy in 2019, more than half cited medical costs as the reason for their financial distress (Konish 2019). Another study found that rising healthcare costs associated with the Affordable Care Act have made healthcare harder for many people to afford and led many to defer healthcare. In fact, researchers concluded that “medical debt is greater for those with any type of high deductible (HD) insurance, and among those more vulnerable (lower income, minority, treatable chronic diseases)” (Rabin 2020). Clearly, interacting with the health system is costly. These costs can accumulate and have compounding effects for people with prolonged illnesses, such as cancer. Further, these costs can cross over and strain households’ abilities to pay for other necessities, like housing and food.

This section will discuss various issues related to economic well-being of households with someone with cancer, emphasizing impacts on households with a child with cancer, particularly in light of the COVID-19 pandemic.

Impacts of Economic Crises and Income Loss

Economic crises can amplify pre-existing economic hardship, like financial toxicity and food insecurity. COVID-19 is a pandemic disease, but a major part of the crisis (and unfortunate reason for its politicization and that of proposed solutions) is economic. As cities have entered long periods of quarantine, and owing to other factors beyond the scope of this paper, economic activity and outcomes have stalled. There

have been high rates of unemployment, with uncertain prospects and timelines for recovering these lost jobs. These changes in the economy, unemployment, underemployment, income loss – presents challenges for families and households, adjust budget, inability to afford things typically can afford,

Unfortunately, children of parents who have lost jobs feel the effects of job and income loss, as “[p]arental job and income losses are strongly associated with parents’ depressive symptoms, stress, diminished sense of hope, and negative interactions with children” (Kalil 2020). However, these associations were not found for those who lost their jobs but did *not* lose their income (for a number of reasons). Just the opposite, “job losses without income losses are associated with more positive parent-child interactions” (Kalil 2020). The loss of income is the stronger indicator of negative interactions between parents and children, rather than the loss of the job itself.

Parental job loss is prevalent across the country, and New York City and the surrounding Metropolitan area is no exception. Further, rates of parental job loss appear to be increasing. It was reported that between January and March, 3.4% of children in the New York Metro Area had all parents unemployed (which includes one parent in a one-parent household, and two parents in a two-parent household) and 7.7% had either parent unemployed (in a two-parent household). These rates rose as the duration and scope of the pandemic grew. Between April and August, 13.9% of children in the New York Metro Area had all parents unemployed, and 24.4% had either parent unemployed (Parolin 2020). This report also finds, unsurprisingly, that parental job loss “can quickly translate into elevated rates of hardship” if not relieved by some sort of financial relief (Parolin 2020).

Financial Toxicity and Food Insecurity

Financial Toxicity is a term gaining increasing traction in the discussion of the affordability of cancer treatment and associated costs. It refers to the financial burden and distress associated with cancer, and its potential negative effects on physical, financial, and other types of health. Carrera et. Al. (2020) describe it as “the objective financial burden and subjective financial distress of patients with cancer” due to costs of care. They also describe how “the discussion on mitigation mainly geared toward interventions at the health system level” is important, but it is challenging to effect change at that level, and slow to be felt by patients, their families, or others further downstream. Simply put, it misses a meaningful opportunity to intervene at the individual level, which is equally important because maladaptive coping with financial toxicity can contribute to negative health and other outcomes. For example, some have found financial toxicity to be associated with nonadherence to prescribed protocols, and ultimately worsened outcomes (Knight 2020).

Financial toxicity, particularly as it relates to families with a child with cancer, remains an understudied area. Closing this gap in study is especially urgent in the wake of COVID-19, as broader economic challenges can interact with financial stressors directly related to the child’s cancer treatment. For example, protracted periods of additional financial stress on many families, facing under employment and unemployment, or additional expenses associated with the pandemic, can all interact to produce worse outcomes.

Food Insecurity is defined by the United States Department of Agriculture (USDA) as an assessed “household-level economic and social condition of limited or uncertain access to adequate food” (Coleman 2013) Different from hunger itself, it can certainly manifest as hunger in individuals. While it is fairly well documented that food insecurity can contribute to a range of poor health outcomes, it is not well understood how food insecurity affects cancer outcomes (Patel 2019). That said, food insecurity “remains an underrecognized social determinant of health,” (Patel 2019) and regardless of the clinical manifestations of it in pediatric oncology patients, it certainly has broader negative ramifications.

As with financial toxicity, there is less research on food insecurity with respect to the pediatric oncology population perhaps because, by definition and as outlined in the U.S. Rare Diseases Act of 2002, all pediatric cancers are considered rare (PDQ 2020). About 15,000 children are diagnosed annually in the country with cancer. Or, it may be because food security or insecurity is a burden on the household, and not one primarily or exclusively on the child presenting in the clinical setting

A 2019 commentary in the American Cancer Society Journals referred to screening for food insecurity as “a missing piece in cancer management,” (Patel 2019) and a missed opportunity to identify children in need. These needs are growing as the pandemic looms on. Back in April 2020, early on in the course of the pandemic researchers published a comment in *The Lancet*, describing the confluence of as a “social crisis in the making” (Van Lancker 2020). They describe disrupted access to key institutions like schools as contributing to various social problems, including food insecurity. Further, they write that prolonged school closures “could have detrimental

social and health consequences for children living in poverty, and are likely to exacerbate existing inequalities” (Van Lancker 2020). Understanding how disrupted access to key institutions is crucial to identifying households in need, as well as identifying broader trends in inequality. Identifying needs and trends are important first steps in formulating solutions.

Discussion and Recommendations

Density and Crowding: contending with looming rent and real estate crises with education and advocacy

The urban planning and public health communities have effectively distinguished between density and intra-home crowding as it relates to the spread of COVID-19. The public still lags in understanding this nuance and its implications for disease, as many able to afford it continue to leave the dense borough of Manhattan en masse for the less dense suburbs (Haag 2020). Those left to contend with a rapidly changing real estate market face considerable uncertainty. While average rents decreased city-wide, the decreases have been most dramatic in more affluent neighborhoods as a function of vacancies by those fleeing the dense urban cores for the suburbs. In fact, according to a recent article in the New York Times, in neighborhoods with the highest rates of infection with COVID-19, “rents have actually increased 0.3 percent” from February to July, “and a disproportionate share of Black and Hispanic renters, many in the service industries, have shouldered that burden” (Chen 2020).

At the same time, affordable housing projects are threatened by the broader economic downfall due to the pandemic; The Department of Housing Preservation and Development (HDP) experienced budget cuts this past summer “when the city agreed to decrease its capital funding by 40 percent over two years” (Chen 2020). HDP is the agency responsible for overseeing most of the city’s affordable housing. Although the city eventually agreed to reduce some of the planned cuts in funding to HDP, there are still major concerns. The New York Housing Conference, which calls itself “NY’s affordable housing advocate,” projects that the city’s slashing of capital funding could

mean that 21,000 fewer affordable housing units are built in the next two years, which in turn translates into “22,176 fewer construction jobs, 12,096 fewer jobs in related industries and \$7.98 billion less in total economic spending” (New York Housing Conference 2020). In other words, the budget cut decreases the development of additional needed affordable housing units *and* decreases economic activity in supporting industries.

Additionally, the NYHC warns of longer-term ramifications for development in New York City, writing that nonprofit and for-profit developers may be less willing to work in the city should they feel that the city may not necessarily follow through on development and other deals. Lastly, they warn of other missed opportunities for projects that could translate into more housing options and available affordable units, like “converting hotels into housing” (New York Housing Conference 2020). In sum, budget cuts risk acutely exacerbating affordable housing shortages, and missing opportunities to generate economic activity.

Leading voices in city planning and politics echo this concern. The Regional Plan Association urges the different governing bodies in New York and New York City to make the construction of new dwelling units easier by easing limiting zoning and other restrictions. They argue that adding more housing choices is key to safely and affordably meeting the needs of the housing insecure. Some of their specific recommendations include promoting accessory dwelling units (ADUs), legalizing and facilitating the construction of ADUs and conversions through regional and local zoning changes and ordinances, easing other requirements which in practice preclude the

construction of more affordable units, and other similarly supportive actions (Negret et. al. 2020).

Brooklyn Borough President Eric Adam also advocates for facilitating use conversion, and specifically advocates converting empty offices into housing (Chen 2020). Additionally, the New York City Housing Authority is actively seeking out alternative sources of funding to address gaps in their budget due to cuts (Chen 2020). Creating more affordable housing units, and maintaining existing ones, can in part help reduce unwanted excessive intra-unit crowding (keeping in mind that there are plenty of reasons multiple households might choose to live in one housing unit aside from financial constraints and limited affordable housing stock).

Continuing to educate the public and public leadership will be key to increasing advocacy for continued housing assistance and affordable housing development. The decisions that the City makes which implicate affordable housing in New York is of particular consequence to our study population (especially those overburdened by rent), to families coping with any type of chronic illness, and to households otherwise vulnerable in the area. As this pandemic progresses, it is imperative that the city reconsiders housing policy and capital spending. The city must center affordable housing as it plans and prioritizes economic recovery.

This includes educating public servants and leadership at all levels, because they contribute to the spread of misinformation. They also are in positions to enforce existing policy, and effect future change. Thus far, they have largely been doing it with misinformation, wrongly citing density as a feature of the built environment which allows for rampant unrestrained spread of the coronavirus. Correcting the collective

understanding of density and appropriate housing development and re-use strategies can help improve crowding in the city.

City Council Speaker Corey Johnson is working to address misinformation and outdated planning practice. He introduced legislation, “Planning Together: A New Comprehensive Planning Framework for New York City” on December 17th, 2020, addressing the city’s “piecemeal approach to development and capital spending” that has predominated for over 100 years (Johnson 2020). Johnson’s legislation identifies key issues with the current planning regime, including an “uneven zoning landscape that exacerbates socioeconomic inequality,” among other things (2020). The legislation proposes “a ten-year comprehensive planning cycle designed to encourage equitable, just, and sustainable growth by meaningfully connecting the City’s budget, land use, and strategic planning processes to build a proactive vision for the future” of the City (Johnson 2020). Johnson’s legislation meaningfully acknowledges the impact that housing has on health and other outcomes, which underscores the potential impact such legislation could have on the public, the study population, and other medically vulnerable populations. The City must adopt this legislation and its measures in order to further equitable and affordable housing for more New Yorkers, including medically and otherwise vulnerable. Further, such policy based on comprehensive study should decrease the likelihood that future disasters will increase housing injustice.

These considerations regarding housing security in New York City are important, but equally (if not most urgently) important to minimizing health risks and poor outcomes due to COVID-19 associated with current intra-home crowding. A more immediate

solution to circumventing intra-home crowding is necessary to keep the public safe, and those most vulnerable out of the virus's way.

It is neither feasible nor fair to propose or present an intervention as a personal matter, as if 'if only people lived with fewer people, they'd be at lesser risk.' Addressing intra-home crowding, if and when appropriate and for those who want it, requires broad and comprehensive consideration. In the meantime, given the prevalence of intra-home crowding, there are ways to reduce negative health impacts of the felt effects associated with intra-home crowding, and to specifically and most urgently reduce the risk of transmitting COVID-19.

***Limiting Viral Transmission Within a Household with a Known Infected Person:
Expand existing programs in New York City which allow infected people to self-isolate at no cost***

New York City has a COVID-19 Hotel Program, particularly the Isolation Hotel Program for Those with COVID-19. This is a program which allows people presumed to be infected with COVID-19 and who live or share space with other people the opportunity to self-isolate. On November 10th, 2020, New York City Councilman Mark D. Levine described this program as one that "too few NYers know about" (Levine 2020). While the portion of this program that specifically housed front line responders and other healthcare workers is no longer operating, the City is still offering to house members of the public who meet certain criteria in hotels for two weeks.

While estimates of program usage are not easily available to the public, the Councilman's tweet might indicate that it is an underutilized program. Meaningfully

increasing its availability, expanding eligibility for participation, and improving its logistical execution is one way in which people from crowded households can avoid transmitting the virus to everyone in the household.

According to the program's homepage on the New York City government's website,

"You may qualify to self-isolate in a hotel, free of charge, for up to 14 days if you do not have a safe place to self-isolate. This can mean:

- *Your home does not have space for you to stay six feet away from others*
- *You share rooms or a bathroom*
- *You live with someone who is vulnerable*

Additionally, "[h]otel rooms are also available for New Yorkers without COVID-19 but who live with someone who has COVID-19" (COVID-19 hotel program 2020).

While helpful for those who might have been referred to the problem, there are significant gaps which render this program unsuitable for certain groups. Particularly as rates of infection are rising, it would be wise for the City to increase utilization of this program. Gaps in service preclude its maximum impact. Some gaps include a lack of broad awareness; people with children may need to secure alternative forms of childcare (with limited ability to afford it); capacity of the program and how many hotel rooms are available; the capacity of the staff of hotels; safe transportation to and from the hotel, including public safety; and disruption in work for those who might be staying.

Expanding the program to address these gaps could increase the program's utilization and ultimately help reduce the transmission of the coronavirus within crowded households, and throughout the public at large. The study population, particularly those living in crowded households, could benefit from the Hotel program's expansion. Meeting the special needs of this population might be done with expert input, perhaps by leveraging existing relationships with organizations that already engage with this population or other families with a chronically ill child.

Expanding the Hotel program to include input from these organizations, and to reach and serve even some of these households would be helpful. While considering how members of these households can safely quarantine might be considered better suited as a focus of a medical center or some other organization which already considers this population's needs, that fails to consider how dense urban networks can be more broadly and strongly leveraged, and risks over-burdening foundations which may not have the capacity to do this work.

Proposing a Healthy Housing Consortium

Creating a consortium in which health care systems like CUIMC are partners in community planning could meaningfully address inadequate housing in such a way as to minimize a household's medical vulnerabilities or vulnerabilities exacerbated due to COVID-19. There is a growing movement across the United States in which hospitals increase their extra-institutional commitments to their surrounding communities in order to improve health outcomes. In fact, the Deloitte Center for Health Solutions, of the Deloitte consulting firm, conducted a representative survey of health systems and found that "80 percent of hospital respondents reported that leadership is committed to

establishing and developing processes to systematically address social needs as part of clinical care” (Lee 2017). However, most activity supporting these commitments is not necessarily institutionalized or impacting communities at large; respondents reported a need for expanding their capabilities to screen more broadly in communities and not just for “high-utilizer” populations (those populations most frequently interacting with the health system) (Lee 2017).

The state of Massachusetts requires institutions planning major expansion to invest in communities impacted by these expansions, specifically “5 percent of the cost of a hospital expansion must be reinvested in community health” (Rios 2018). Several hospitals in Boston, Massachusetts undergoing expansions chose to invest in housing and stable housing initiatives. Hospitals have a choice in how they invest in community health. Their choice of housing highlights a growing recognition of the built environment’s tremendous impact on health. Dr. Megan Sandel, one of Boston Medical Center’s (BMC) leaders of their housing initiative said “[o]nly about 10 to 20 percent of health is actually determined by what type of health care you get” and “the social determinants of health -- where you live, what your environment is like” are more significant to health outcomes (Rios 2018).

Boston Medical Center is investing 6.5 million dollars over the span of five years “to support a wide range of affordable housing initiatives” that go beyond simply constructing and operating housing. Instead, BMC “is investing in a diverse group of community partnerships in neighborhoods where many of our patients already live, which will enable them and other residents to access a larger pool of stable, affordable housing” (Boston Medical Center, Media Relations 2017). In fact, a press release from

BMC noted about 15 community partners in these initiatives (Boston Medical Center, Media Relations 2017). While proposing a consortium may sound idealistic, it is not unrealistic. Political will can direct major urban health centers to invest in their communities and can even tie a center's growth and policies to responsible community engagement and investment, as demonstrated in Boston. These health centers can adopt meaningful strategies to improve housing and the built environment, which can have lasting impacts on communities' health.

Columbia University Irving Medical Center ought to engage with New York City as a partner in community planning and spearhead a healthy housing consortium much like the Boston Medical Center. Columbia University is among the largest landowners in New York City. Owning 246 buildings and land parcels, Columbia is second only to the City itself (Warerker 2018). Not without controversy, Columbia University continues to expand its reach. The university's most recent expansion is on its Manhattanville campus (Young 2020). Members of the community expressed concern over business and residential displacement. Built with glass windows instead of walls, the campus's new buildings were designed to invite the community in. However, reporter James S. Russell (2019) wrote for Bloomberg CityLab that although [t]here are no gates at Manhattanville...the aura of institutional ownership and control is unmistakable." Likewise, Columbia University has recently completed a number of capital projects and new development at the medical campus a mere 40 blocks north of the Manhattanville campus (Facilities Management and Campus Services 2020). Columbia ought to complement any capital project or expansion with a meaningful investment in the community, and do so by engaging community partners.

One meaningful way that Columbia might do that would be creating a consortium between the university and key community stakeholders to better protect and increase housing security. Our study's preliminary findings highlight tenuous housing conditions our study population faces, which includes difficulty paying for rent and intra-home crowding. Particularly during a pandemic in which intra-home crowding plays a role in facilitating the transmission of the respiratory virus, CIUMC has a commitment to support healthy and safer housing for its patients experiencing this need. CUIMC should recognize the outsize impact that COVID-19 has had on its patients and its community at large by meaningfully investing in healthy housing initiatives in the Washington Heights and surrounding areas. CIUMC can begin by addressing immediate housing insecurity and crises faced by its patients during the pandemic by leveraging existing resources. For example, CUIMC might repurpose vacant dormitories, or rent apartment or hotel rooms for affected patients and their households.

After, they can adopt BMC's model of large investments in healthy and secure housing initiatives; this would benefit communities that their patients reside in *as well as the broader community*. Health systems must take seriously their potential as a partner in community planning, an endeavor which can also benefit the health system.

CUIMC's Office of Government and Community Affairs may be an appropriate office to spearhead a consortium initiative. GCA liaises between the various professional schools at CUIMC and local, state, and federal governments. Their purpose is twofold; the GCA works to keep "deans, faculty, students and departmental administrators abreast of legislative and regulatory developments impacting their respective fields" and also works to advance the goals and interests of the Medical

Center through legislative advocacy and representation in professional organizations (Office of Government and Community Affairs 2020). This office is situated to leverage existing relationships in the community as well as develop strategic new ones in order to develop a healthy housing consortium. Households in this thesis's case study struggle with housing security, as mentioned in the findings section. This patient population can certainly benefit from such a consortium which centers housing justice. The study's patient population is narrow, but they share experiences and vulnerabilities with other households of medically vulnerable children. Any household interacting with the Columbia health system ought to be housed securely.

Addressing Income Loss, Unemployment, and Underemployment

Mitigating collateral effects of financial burden with income continuity and supplementary income is a key short-term consideration. Given the literature that income loss, more than job loss itself, was the modifying variable for poorer outcomes in relationships, the City must consider meaningful approaches to income continuity. Given the particular confluence of potential risk factors for financial, food, and other vulnerabilities that our study population faces, it would be important to increase screening for such vulnerabilities in the hospital and clinic setting. The City ought to consider liaising with hospitals, all of which have social work offices, to better connect families and services they might need.

That said, steps towards addressing job loss and returning those able and willing, to work, will be invaluable in the City's economic recovery from fallout from COVID-19. This includes ***addressing unemployment and underemployment with a public***

option. While income continuity for those unable to work, whether due to job availability, or as a function of a child's illness, is extremely important, so, too, would be increasing access to employment opportunities. In order to address the dearth of jobs currently found in the private sector, the City should consider a public option for employment. Essentially, it means that the City will have a job available to anyone in need and will work toward creating these jobs and supporting training and related infrastructure to enable this public option. *A public option for employment is one means by which the City can address unemployment and underemployment, as well as generate economic activity in the wake of depressed economic function. One City leader advocating for this option is Elisa Crespo.* Elisa Crespo is the Education Liaison at the Bronx Borough President's Office and is currently running to represent the Bronx's District 15 in City Council. She recently wrote an op-ed in the Gotham Gazette (Crespo 2020) advocating for a citywide Public Option for employment, what she calls a "bold idea" to address historically high unemployment in the City.

It must be acknowledged that these policy recommendations have generally been proposed for vulnerable populations in overcrowded housing. However, the point here is to highlight how existing policy advocacy and movement can serve medically vulnerable communities, or communities whose vulnerabilities are compounded due to a medical condition. In other words, increasing the scope and reach of a policy, and explicitly acknowledging additional beneficiaries (or, perhaps, including and elevating their voices within these practices), can increase the policy's support and engage an oft-overlooked population. It also underscores the notion that one need not reinvent the wheel or create entirely new policies to serve particular communities, in order to

explicitly serve more people. While a simple point, it is potentially powerful and bears reinforcing.

Addressing Food Insecurity with a More Resilient Food Supply Chain

Not only has COVID-19 affected how individuals buy and consume food, it has “brought the greatest shift to modern history’s food supply chain” (Murphy 2020). Murphy and Schlegelmilch attribute this shift to a rapid increase in demand by households coupled with people consuming food at home, rather than in restaurants and schools (2020). Anticipating that this shift in food consumption patterns in the United States will last for months, they propose a series of innovations for the food supply chain to meet the new demands and strains on it brought on by the COVID-19 crisis. On the GetFoodNYC COVID-19 Emergency Food Distribution website’s homepage, which outlines different food resources available during the pandemic, they specifically write that “our supply chain is strong, but it is changing to adapt” (GetFoodNYC: COVID-19 Emergency Food Distribution 2020). The food supply chain in New York City was certainly strained. Noting that “more than half of the city’s meat, fish, and produce comes through the distribution center,” the Hunts Point Food Distribution Center in the Bronx, New York is a key asset. Longtime worker at Hunts Point Ric Galan has described working there during the pandemic as “going to war,” where upwards of 8,500 people work every day “working non-stop in order for the community to be fed” (Riederer 2020). These workers and Hunts Point are increasingly strained by the intense and changing needs of the City and its food infrastructure due to COVID-19.

Galan shared that “[a]ll of us here, we’re used to having five, six, seven family members at home -- it’s a normal thing,” reflecting on the increased risk living with so many people can have on transmitting the virus, and living with the fear that “it’s so much easier for it to impact us a little bit harder when just one person has to, God forbid, be infected and come home, since they’re an essential worker” (Riederer 2020).

Considering the challenges in food access and changes in consumption patterns within our study population, increasing the resiliency of the food supply chain would be a meaningful systems-level step towards addressing these challenges. Increasing the resiliency of the food supply chain can improve continuity of food availability, reduce the likelihood of shortages thereby decreasing price inflation, and decrease supply-side sources of food insecurity.

Grocery stores have long been considered as key anchoring institutions in the wake of disaster (Hinderaker 2020) and are proving themselves to be essential in helping New Yorkers weather the COVID-19 pandemic. The pandemic has demonstrated the fragility of the food supply chain, from the fields to the markets. Responding to reports of COVID-19 outbreaks among workers in animal processing facilities in the United States, the Centers for Disease Control (CDC) sought to characterize the burden of COVID-19 “among workers in food processing, food manufacturing, and agriculture workplaces” (Waltenburg 2020). The CDC writes that many of these workplaces are high-density, and therefore “can cause high risk for transmission” of the virus that causes COVID-19. They found that nearly 9,000 workers across 742 food and agriculture workplaces that responded to their inquiry tested positive for the virus (Waltenburg 2020). This figure only represents a portion of

workplaces in 30 states, but underscores the fact that a COVID-19 outbreak in a major food processing plant is plausible, has happened, and has the potential to disrupt food distribution.

Disruptions at the production level can cause disruption further downstream, which can be compounded by “a sudden surge in demand, driven partially by individuals stockpiling in anticipation of food shortages” and other reactionary behavior due to COVID-19 (Murphy 2020). New York City Emergency Management (NYCEM) issued a press release in May 2020 outlining their efforts, in concert with various governmental and private partners, to identify disruptions in the food supply chain that could impact the city. NYCEM utilizes a variety of tools to gain a comprehensive understanding, including the Federal Emergency Management Agency’s (FEMA) Supply Chain Analysis Network (SCAN) for a national picture, and others used to gain insight into more regional and ultimately localized parts of the supply chain. Analyst at NYCEM Erika Amaya commented that “a decision made by one producer or city or state can have ripple effects that might not be seen immediately” (N.Y.C. Emergency Management 2020) although the felt effects of it might be recognized by individual consumers.

In response to continued scrutiny of the food supply chain, New York State Legislature passed a bill, bill number S8561A entitled “An act to amend the agriculture and markets law, in relation to establishing a New York food supply working group” in order to increase the resiliency of the state’s food supply system (Metzger 2020). The bill’s sponsor, Senator Jen Metzger said, “one of the lessons of this pandemic is the need to strengthen our regional food systems to help reduce our vulnerability to

disruptions in national supply chains while also supporting local farms and food businesses,” and that “we need to re-evaluate state policies in light of what we’ve learned...and bring new ideas to the table” (Metzger 2020). This is a positive step in acknowledging the value and vulnerability of the food supply chain, recognizing that it needs systematic consideration to gain a holistic understanding.

It would be very important in working to increase the food chain system’s resilience to consider the downstream effects on vulnerable communities like our study population and those experiencing similar hardship. Recognizing how sensitive the public is, – as is the study population – it is imperative to increase the resiliency of the food supply chain at multiple points. Specific action points would include innovating relationships with non-traditional partners. Likewise, decentralizing production and reducing dependence on large, major suppliers – in such a way as to promote working with a diversity of sources – could be beneficial. And, leveraging existing workers and local networks and reorienting them to work to these goals could help enact these changes (Murphy 2020).

These changes have the potential to increase resilience of the food supply chain as it impacts food availability and access in New York City. By creating redundancies and reducing dependence on any single source of food or distributor, the felt effects of any one disruption are mitigated. A more resilient food supply chain can alleviate some of the strain experienced by the study population of interest in this thesis. Recall those that described shortages in their local markets and those not eating the kinds of food they want because they were unavailable or more expensive as compared to what they

paid before the onset of the pandemic. A more resilient food supply chain as described above can help alleviate these outcomes by addressing their root causes.

While a systems-level approach to increasing the resiliency of the food supply chain is crucial and can play an important role in stabilizing access to food, it is also important to highlight ways in which the city can increase food support on an individual- and household-level.

Addressing Food Insecurity with a Stronger Food Assistance Network

One important mechanism through which many families rely on as a meal source is school lunches. When schools are closed, accessing this source of meals changes. Recognizing that “[t]he continuation of school provided meals is essential in preventing widespread food insecurity,” (Van Lacker 2020) New York City has been working to maintain distribution of meals to those who would have received them in schools with a range of initiatives. While important, these initiatives can be challenging for some households to access or simply not enough.

New York State introduced the P-EBT, which stands for Pandemic Electronic Benefit Transfer. This program means that every child enrolled in a public school in New York City received \$420 on a card to spend on food (Salazar 2020) but left out children not enrolled in a public school who could still benefit. Further, the cash transfer must still be spent in a store which accepts EBT benefits, which does not resolve hesitancy around navigating public food procurement spaces. Not all children with blood cancer or disease who are part of households at risk for or experiencing food insecurity attend

public schools, and some may not be currently enrolled in school at all (recall that some students cannot attend while ill or were inpatient in the hospital).

Another way New York City has worked to minimize gaps in meal provisions caused by less in person schooling is with the Community Meals programs, in which any New Yorker can visit and acquire a meal at no cost. At the time of writing, the city has made meals available daily at over 200 sites throughout the city (Community Meals 2020), although hours may vary. And, working to expand food aid in the city, food stored in an emergency stockpile warehouse in New Jersey, first created in the spring as an emergency supply reserve of food, has begun end of September, 2020 to distribute food to pantries in the outer boroughs of New York City (Gonen 2020).

This is not meant as an exhaustive list of food resources in New York City. Rather, it highlights some of the most broadly available, as well as any gaps or ways in which it does not necessarily meet the unique needs of households with a child with blood cancer or disease. Some might question whether food provision for a sick child might even be appropriate given the potential for special dietary restrictions or needs, but even if that is the case, the household could still benefit from more secure food access.

A lot of these sites tend to be grab-and-go, which can present logistical challenges for those wishing to avoid navigating these central points in the community. For example, Community Meals “can be picked up [by any member of the general public] from 3:00pm - 5:00 pm, Monday to Friday” which can be a challenging time if it conflicts with a typical workday. Recall that some households avoid groceries due to crowding on long lines. It is not unreasonable to consider that households might

consider this 2-hour window as ripe for a long line or crowd of some sort. Also, a child with an illness might follow a specialized diet or otherwise be restricted in what they can consume. Even if that is not the case, the family might be more conscious about feeding the child with healthier food options than they might otherwise opt for in order to support the child's health and recovery. This is another way in which medical vulnerability renders an available resource inadequate to meet their needs.

The city does operate some food delivery assistance options for those who qualify. For example, the GetFoodNYC Emergency Home Food Delivery assistance program is available for those unable to acquire a free meal at a grab and go, but does have its own limitations. According to their website, it would appear that one is eligible for food delivery to the home via this program if one meets the following criteria:

“You are eligible for the program if you:

- Are unable to go out and get food for yourself, **and**
- Do not have someone else in your household or a neighbor or friend who can get food for you, **and**
- Do not receive enough food from Meals on Wheels, God's Love We Deliver, or a similar service to cover your daily food needs, **and**
- Are unable to afford food delivery from a restaurant or grocery store.”

(GetFoodNYC Emergency Home Food Delivery 2020)

However, upon accessing the online registration portal for NYC Food Delivery Assistance, eligibility seems more restricted than initially advertised as above. Below is a screenshot from the webpage which appears upon accessing the registration portal:

Who is this for?

This website is intended for individuals and families who meet all of the following criteria as a result of the COVID-19 emergency:

- No members of the household can go out and get food because they are at increased medical risk or homebound
- No neighbors or family members can go out and get food for you
- Do not receive meal assistance from other providers (incl. Meals on Wheels or God's Love We Deliver); and
- You are unable to afford meal delivery or grocery delivery

Households that qualify may order two food deliveries per week at a time for up to two weeks.

The first delivery will be delivered within six days of the initial order date.

Visit nyc.gov/GetFood to find the nearest food pantry, soup kitchen, or DOE Grab'n'Go site located in your neighborhood.

source: <https://cv19engagementportal.cityofnewyork.us/#/display/5e7555117ad6750216160409>

An important difference between these two eligibility criteria is the message about receiving meal assistance deliveries through another organization. It is not clear whether one is eligible for participation in the NYC Food Delivery Assistance program if one receives other food delivery assistance. This precludes providing assistance to those who may experience the greatest amount of need and must leverage resources from multiple organizations and agencies in order to meet their households' food needs.

Mixed messages can disincentivize people from trying to access these resources, believing that the challenges of meeting unclear criteria are not worth the benefit. The idea of having to prove one's need can be a challenging barrier to overcome, particularly for those trying to access assistance for the first time. Recall,

some of our participants said that enrolling in government benefits and assistance programs was confusing, time-consuming, and in other ways challenging.

Further, registration for assistance is largely dependent on access to the internet. While one can request food by calling 311 (which is dependent on having access to a working phone line), there is some evidence (Early 2017) demonstrates that additional steps can decrease someone's likelihood of or willingness to follow through. And, only up to two people in a household can receive food delivery with this resource, potentially leaving households with more than two people (or with many more than two people) with incomplete assistance. The city ought to expand the NYC Food Delivery Assistance programs in order to address these gaps.

In considering how to expand this program to meet the needs of a broader audience that could benefit, the city can consider adopting parts of programs modeled by other programs which deliver meals to the medically vulnerable. In New York City, two such organizations which serve this purpose are Meals on Wheels and God's Love We Deliver. Building in some redundancy to the city's network of food resources is advisable, and could potentially stave off food insecurity for a broader range of vulnerable families.

For example, according to Delilah Guzman (2020), "a food pantry fills in where a government fails," and can only do so much with limited resources. She works at the West Side Campaign Against Hunger (WSCAH), which operates a major food pantry in New York City. Based in Manhattan's Upper West Side, it was actually the first supermarket-style pantry in the country, meaning that people using the pantry are able to choose what food products they would like. She also emphasized that WSCAH is an

emergency service; WSCAH is facing increased demand and limited funding in the wake of COVID-19, and can only allow a person to collect a few days' worth of food one time in a given month. The organization simply does not have enough funding to meet the true needs of New Yorkers experiencing this need. She noted that some customers exchange tips about other pantries they visit in order to more fully meet their needs.

Organizations serve an essential role but are obligated to the community in ways different from the City government. The City government should do more to meet the particular needs of the most vulnerable, including households rendered vulnerable in part because of medical needs.

Considering that people, and people from our study population in particular, continue to struggle to access food indicates that currently available assistance has opportunities to improve; there may be a gap in knowledge about these resources, there may be logistical barriers to accessing these resources, or there may be barriers within the resource itself which precludes it from reaching more in need.

Increasing redundancy by expanding the city's program could improve a relatively robust network of food assistance programs in the area, strained by the increased demand brought on by the COVID-19 pandemic. Such an effort would certainly align with the benefits offered by living in dense cities and communities. Beyond increasing redundancy, the city ought to work toward strengthening the existing networks of assistance, and better connecting agencies, those served by agencies, and those who *ought* to be served.

Conclusion

Leveraging Planning Tools During Public Health Crises:

Bridging the gap between Urban Planning and Public Health:

The fields of Urban Planning and Public Health have a rich, shared history of mutual goals and joint interventions. Along the way, the two fields have largely diverged (Corburn 2007), although plenty of Public Health specialists focus on the built environment, as do Urban Planning practitioners work explicitly toward the goal of improving public health. However, these practitioners do not reflect the norm. This study underscores the ways that urban planning tools and interventions can meaningfully intervene on public health problems and improve health outcomes.

One way a unified approach between urban planning and public health could work is by **leveraging universal programs**, or other widespread pre-existing programs or infrastructure. This can allow for the seamless integration of additional support or flexibility in both the **short-term and long-term**.

The aforementioned policy recommendations are not new - **they have already been proposed to address community transmission of COVID-19, affordable housing, and food insecurity**. The point here is to highlight how existing policy advocacy and future implementation of planning related efforts can serve medically vulnerable communities, and communities whose vulnerabilities are compounded due to a medical condition. In other words, increasing the scope and reach of a planning policy, and explicitly acknowledging additional beneficiaries (or, perhaps, including and

elevating their voices within these practices), can increase the policy's support, engage an often-overlooked population, and address a public health crisis.

It also underscores the notion that one need not reinvent the wheel or create entirely new policies to serve particular communities in order to explicitly serve more people. While a simple point, it is potentially powerful and bears reinforcing: we are stronger together, and addressing one area can have a profound impact on another. We should have health in all policies, especially planning.

This thesis will contribute to a growing body of knowledge on the COVID-19 crisis with respect to children with blood cancer and other diseases and their families. It also more broadly aims to better serve vulnerable communities during protracted public health crises. Bringing together urban planning and public health perspectives and tools illustrates the experiences of families with a chronically ill child better than either perspective would alone.

Public health interventions are inconsistently funded and can be difficult to justify. This thesis offers solutions that leverage what is already in place, reducing the need to fund and create new infrastructure, which may be more appealing for those investing in it and revitalizes what is already in place. **This thesis makes the case that it is more important than ever to study, work, and develop interventions across disciplines to advance common goals.**

Appendix

The Survey Instrument:

Areas of inquiry in the survey instrument can be categorized within the following groups: Employment; Financial Toxicity; Household Composition; Built Environment; Potential Exposures to COVID-19; Attitudes regarding COVID-19; Food Security; and Demographics. Below is a list of these categories, each expanded upon to provide an example of some information that is asked. Note: these questions are not verbatim how the participants are asked.

Employment

- Whether the participant is currently employed
- What types of work and/or government benefits the participant receives
- Whether there are additional people who financially support the household
- Whether the participant (or other members of household) experienced job loss due to COVID-19
- Whether the participant needed to work more hours or get an additional job during the pandemic

Finances and Spending, and Changes in Finances and Spending

- Estimated *household* income in the past month
- Whether the household regularly gives money to support other individuals, organizations, or religious groups, and if the amount has changed due to COVID-19

- Changes in ability to afford usual and/or necessary expenses (such as, but not limited to, utilities)
- Whether households use government benefits or public assistance in order to afford certain expenses, and whether this is new since the pandemic or used prior
- Changes in other types of spending, or ways of extending budget compared to pre-pandemic

The home, household composition, and the built environment

- What type of housing does the participant reside in
- How many people and how many households live in the same home, and how many are adults, how many are children

Potential exposures to COVID-19

- How the pediatric patient and participant travel to/from the hospital and clinic, and how they travel to get things needed for daily life/for accessing things to maintain health
- Whether members of the household leave the home and go to/from work, how many days/week, and for what type of work
- Where the pediatric patient spends the majority of their time (in their own home, in institutions like school/daycare, in other homes)
- Whether shared common areas in the home are shared with other households and/or families

- Whether the participant has lost a close friend or family member to COVID-19

Attitudes related to COVID-19

- Whether participants feel safe (with respect to *not* contracting the coronavirus) while engaging in various activities
- How fearful participants are with respect to contracting the coronavirus
- How fearful participants are with respect to the pediatric patient contracting the coronavirus
- If the participants wanted to get tested for COVID-19, whether they would have an easy time doing so
- Whether participants have health insurance

Food, food intake, and food security

- According to the guidelines put forth by the United states department of Agriculture, whether participants and their households experience any indicators of food insecurity
 - Whether the household has experienced changes in accessing food, meal provision, size of meals, frequency of meals, affordability of meals, and other changes
- Whether the household ate more of, less of, or the same amount of various types of food (comprehensive list of most food groups)
- Whether the household uses food related resources, be they government-, school-, or community-based

Additional Information Regarding the Study Methodology

Study population:

Participants are recruited at major medical institutions in the Tri-State Area, including but not limited to Columbia University Medical Center in Washington Heights, Manhattan, and Maimonides Medical Center in Borough Park, Brooklyn. This thesis only included interviews with participants from CUMC, as participants at the other institutions have not yet been interviewed at the time of writing this thesis.

Informed consent is obtained either in the clinical setting, or over the telephone.

Because consent can only be obtained from those who have reached the legal age of consent, which is 18 years in the United States, and our population of interest is families of pediatric patients, a parent or other primary caretaker involved in the care of the pediatric patient is consented. Informed consent is obtained according to the norms and regulations set forth by Columbia University's Institutional Review Board (IRB).

Data Collection:

Data is maintained in a confidential online platform, REDCAP. Access is limited to those approved to be on the research protocol approved by the Institutional Review Board (IRB) of Columbia University.

Interviews are conducted on the telephone, using the Google Voice cell phone application. A primary interviewer from the research team leads the interview, while a second member from the research team listens in, takes detailed notes, and clarifies any answers to questions as necessary. This method reduces the possibility of interviewer subjectivity or the potential for bias.

For example, rather than asking about any and all types of assistance participants might be receiving at one time, questions were organized thematically – a question about food assistance would be included amongst questions more broadly related to food intake and access, while a question about housing assistance would be included amongst questions more broadly related to housing.

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