Optimizing Post-Stroke Functioning: Using Mixed Methods to Understand the Role of Built and Social Environments for Physical Activity, Quality of Life, and Lived Experience

by

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Dedication

This dissertation is dedicated to Grant, my husband and best friend, who has provided unwavering love and support through all of the peaks and valleys of this journey.

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Abstract

An estimated 6.6 million Americans over age 20 have experienced a stroke, making it a leading cause of serious long-term disability in the United States. Medical advances in treatment of acute stroke and an aging population have increased stroke prevalence. Many stroke survivors return directly home with changes in neurological functioning. Although a greater number of people are living independently in community-based settings post-stroke, little is known about the role of built and social environments on post-stroke experience. This dissertation used a mixed-methods approach to examine relationships between features of built and social environments and post-stroke functioning.

The first dissertation aim examined macroscale environmental features (e.g. nearby destinations) and their association with post-stroke physical activity. In a sample of stroke survivors with wide geographic variability, the project used objectively measured community characteristics, data on outdoor climate, and objectively measured physical activity to overcome limitations of previous research. Extreme cold weather was associated with lower post-stroke physical activity, whereas, higher neighborhood socioeconomic status and more destinations for intellectual stimulation were associated with higher post-stroke physical activity. However, many environmental destinations were not associated with post-stroke physical activity. Examination of microscale features in the built environment is needed to understand why some destinations were associated with physical activity and others were not.

The second aim examined microscale features of the built environment and their interaction with stroke severity to shape trajectories of physical quality of life post-stroke.

Longitudinal data on a national sample of stroke survivors were linked with microscale audits of pedestrian streetscapes using Google Street View images. The majority of participants lived in environments with few walkable features promoting outdoor mobility. Features at nearby crossings (e.g. curb cuts) were associated with higher physical quality of life post-stroke, but not with changes in physical quality of life over time. Environmental features along the segment (e.g. sidewalk quality) and route (e.g. destinations) were not associated with physical quality of life post-stroke. Crossings lacking pedestrian friendly features may cut off a primary conduit between the individual and society. Interventions to improve built environment accessibility are needed for the growing post-stroke population, and priority should be placed on features at pedestrian crossings.

The third aim of this dissertation uses rich qualitative data to understand how stroke survivors' lived experience is shaped by their outdoor environment. Semi-structured interviews were conducted with community-dwelling stroke survivors. Using interpretative phenomenological analysis, themes pertaining to the lived post-stroke experience traversing the outdoor environment were identified. Findings highlight that post-stroke lived experience navigating the outdoor environment included vigilance, adaptation, and management of dynamic relations. In order to reduce post-stroke feelings of apprehension and hypervigilance while walking in the outdoor environment, investments in the public outdoor infrastructure should be made to remove barriers (e.g. uneven sidewalks) and install facilitators (e.g. benches).

Collectively these findings reveal that features of the outdoor environment are important for post-stroke mobility and quality of life. Although new construction must adopt accessibility standards, the majority of participants lived in environments lacking infrastructure to support post-stroke mobility and quality of life. Creative solutions are needed to bridge old development

into new development. Flexible design strategies (e.g. sidewalks flush with the street) are one approach to support diverse users, such as stroke survivors, who have variation in functioning. Stroke survivors can thrive in outdoor environments if given proper support.

Chapter 1 Background

The background section of this dissertation begins by introducing theoretical perspectives of disability. This is followed by a summary of our current understanding on the role of the built environment on disability and health. The sections that follow focus on stroke specifically, starting with the significance of the post-stroke population for public health. Provided next is a summary of literature examining the association between built and social environments for post-stroke functioning. The chapter concludes by describing the current gaps in our understanding and specific aims this dissertation addresses.

1.1 Theoretical Perspectives of Disability

Disability is a dynamic process that can be acute or chronic and experienced at a variety of times throughout the life course.[1] Currently one in four adults in the United States (61.4 million persons) report some type of disability, and the prevalence of disability in our population is projected to rise due to our aging population.[2, 3] Given the complexity and growth of the disabled population, addressing the needs of this group is one of the most pressing public health priorities of our time. Historically, theoretical perspectives about disability creation has been a point of tension among scholars. This resulted in two polarizing schools of thought. In the medical model of disability, people were viewed as disabled due to their impairments or differences. Alternatively, the social model of disability identifies the way society is organized and structured to be the cause of disability. Conflict between the medicalization of disability and the socialization of disability has served as a major barrier for collaboration between fields and inhibited progress in our understanding of disability as a whole. In an effort to bring these fields together and provide common language for discussion, there has been substantial theoretical development to facilitate partnership between perspectives with a joint goal of improving the lives of disabled people.

Major advancements in our thinking about disability and health occurred in 1991 when two publications were released, *The Disability Creation Process* and *Disability in America*.[4, 5] Both publications merged the social model of disability with the medical model of disability, ultimately providing a more holistic framework to think about the disablement process. *The Disability Creation Process* explicitly incorporated environmental factors and organ systems/impairments as key determinants of disability.[4] In addition, this model included positive (e.g. abilities) and negative (e.g. disabilities) aspects of an individual as contributing factors to disability.[4] In the same year, Nagi expanded his conceptual framework within a chapter of *Disability in America*, defining disability as a "limitation in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment."[5] The chapter explains that disability is a relational process between capacity/limitations, role/task expectations, and the environment. Nagi makes clear that the environment is a critical component of disability.[5] Despite major advancements in conceptual thinking of disability and health, a visual depiction of the complex interaction between an individual and environment was lacking.

To fill this gap in knowledge, Verbrugge and Jette expanded on Nagi's model to develop, what they term "the disablement process."[6] The disablement process maintains Nagi's original pathway of pathology, but it expands upon the model to include intra-individual factors and extra-individual factors. Extra-individual factors included health care factors (e.g. medical care, rehabilitation, and medications) and socio-environmental factors (e.g. social services, built environment, and social support). This model enhanced our view on disability by diagraming the process as well as being the first model to include personal factors as a contributing component of disability.[6] However, the disablement process maintained unidirectional arrows from Nagi's original theory, indicating a causal relationship between pathology, impairments, functional limitations, and disability. A major shortcoming of this model of disability is that the causal relationships depict a progressive decline from pathology towards disability and indicate that disability is inevitable with time.

Shortly following Verbrugge and Jette's publication, Brant and Pope released an Institute of Medicine report entitled "Enabling America."[7] Within this report, the authors provided an illustration of the Nagi model and explicitly stated that disability results from an interaction between person and environment.[7] In addition, the authors recognized the critical need to better understand the environmental role in the disablement process. Within this text, the following recommendation was made:

> *"In accordance with the current understanding of the importance of the environment in causing disability, more research is needed to elucidate and clarify that relationship. Such clarification will facilitate the development of more and improved intervention strategies, both preventive and rehabilitative. More specifically, research is needed to explicitly determine the relationships between the environment and disability where environmental factors are the independent variables and disability is the dependent variable." (Brandt & Pope, 1997, p. 168)*

This report was a call to action, encouraging the development of research that captures the nature of the relationship between environment and disability. This report not only mobilized researchers to publish on this topic, it also preceded the launch of revisions to the World Health Organizations' conception of the biopsychosocial model of health.

The biopsychosocial model of health was developed in 2001, and this model is well known as the International Classification of Functioning, Disability, and Health (ICF). The ICF states that disability includes activity limitations or participation restrictions that result from an interaction between an individual and their surrounding environment.[8] Historically, models of disease have focused on a health condition with a specific etiology. With the launch of the biopsychosocial model of health, an international movement was initiated shifting focus on functioning beyond diagnosis. The biopsychosocial model of health defines health holistically and takes into consideration both contextual and individual characteristics. As shown in Figure 1.1, the ICF has six components that encompass health and health-related domains.[8] At the top of Figure 1.1, health conditions are diseases, disorders, injuries, or related states, which can be classified using the International Classification of Diseases.[9] At the bottom of Figure 1.1, environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. The functioning of an individual is represented in the middle of Figure 1.1 and encompasses three components: body functions and structures, activities, and participation. Functioning reflects an interaction between the health condition and the contextual factors.[8] Using this framework, many people with disabilities can lead healthy lives when they can access enabling environments that support their ongoing functioning needs.

--- Figure 1.1 ---

Environments, and more specifically built environments, have physical attributes that can affect human health through various mechanisms. Built environments range from buildings to parks and have been defined as "the human-made space in which people live, work, and recreate on a day-to-day basis."[10] Features of the built environment include land-use patterns, access to destinations/resources, street connectivity, transportation systems, and features of urban design.[11] Features of the built environment listed above have been shown to be associated with health behaviors, such as physical activity[12, 13] and diet.[14] In addition, built environments are predictive of long-term chronic health conditions, such as obesity[14, 15] and diabetes.[16] The extent to which chronic health conditions interact with built environments to modify activities and participation in society is of great interest to the field of disability and health.

1.2 Measurement of the Built Environment

Six in ten adults in the United States have a chronic health condition and four in ten adults have two or more chronic health conditions.[17] Chronic health conditions are broadly defined by the Center for Disease Control as a condition that lasts one or more years requiring medical attention.[17] People with established chronic health conditions may be more vulnerable to built environment conditions (e.g. uneven sidewalks, absence of curb-cuts) in comparison to peers without chronic health conditions. Research investigating the interaction between built environments and physical functioning explicitly examines this vulnerability.

High quality measurement of the built environment is essential to understand vulnerability to different environments. Built environments are most commonly measured using participant reported information, archival data sources, or direct observation.[18] Participant reported information provides valuable insight to individual perceptions of the surrounding environment and identification of perceived barriers or facilitators within the environment.[18] Strengths to this measurement technique include the ability to capture more detailed information about the surrounding environment and identify how environmental features are perceived to influence the disablement process. A limitation of participant reported information is that it is subject to same-source bias, where people who have greater functioning impairment may be more likely to report environmental barriers and facilitators.

Alternatively, researchers have measured the built environment using archival data. Archival data sources typically make use of geographic information systems and harness the historical nature of these data to examine exposures prior to outcome ascertainment. Strengths to this measurement technique include the ability to quantify environmental features for policy intervention and temporality between exposure and outcome. Archival data are limited in the types of information present (e.g. quality of environmental features is often not present within archival data), years these data are available, and cost.[18]

Lastly, direct in-person observation of the built environment utilizes audit instruments to record features of the environment through in-person or virtual audits. Direct in-person observations of the built environment add great value, especially when quantifying features not commonly collected in archival data (e.g. quality of environment, width of sidewalk). However, direct in-person observation of the built environment is often time and resource intensive. Direct in-person observation requires training of auditors and travel time to destinations when completing the audit in person. In addition, because there are a number of audit tools available and these tools have great variability in features measured, it can be difficult to compare results across different research projects.[18] As summarized above, all three measurement techniques provide valuable information that complement one another.

1.3 Built Environments and Functioning

Participant reported information provides first-hand accounts of critical factors within the built environment that shape physical functioning from the participants' perspective. Qualitative interviews with participants experiencing chronic health conditions have illuminated domains of the built environment important for scientific inquiry.[19, 20] Domains that consistently emerge from participant interviews across study populations were accessibility of the physical environment, accessible transportation, and access to assistive technology.[19, 20] Findings also indicate that environmental factors interacted with one another and had cumulative effects on functioning.[20] For example, natural environmental conditions such as snow interact with environmental policy for snow removal to determine the accessibility of sidewalks within an outdoor space. In addition, participants noted different built environment features necessary for different functioning domains. For example, the absence of curb cuts to enter the street served as an environmental barrier for those with mobility impairment, but had little impact on those with cognitive impairment. These interviews provided supporting evidence to previously theorized interactions between individual and environment.[20] In addition to open-ended qualitative interviews, structured survey questions have also been utilized to examine the relationship between environment and functioning. For example, participants reporting problems with excessive noise, inadequate lighting, and heavy traffic had increased risk of reporting severe difficulty with physical tasks (e.g. climbing stairs, walking a quarter mile).[21] In addition, participants who reported more community mobility barriers and less transportation facilitators were more likely to report limitation in their daily activities.[22] However, self-reported information is subject to same-source bias and can be difficult to utilize for making policy recommendations because it is based on individual perception rather than objective environmental conditions. Therefore, researchers have sought out archival data to create more objective measures of built environments.

Findings from archival data sources demonstrate that street connectivity and parks are associated with positive functioning outcomes (e.g. activities of daily living), however the association between land-use mix and functioning are inconsistent. Connectivity of the built environment is defined as how well streets connect to one another (e.g. streets leading to other streets rather than ending in a cul-de-sac). Street connectivity is associated with instrumental activities of daily living, with higher connectivity associated with reduced restrictions among men.[23] In addition, living in neighborhoods with open space or presence of a park was positively associated with improved self-care and participation.[24, 25] However, current evidence surrounding the association between land-use mix and functioning is inconclusive. The U.S. Department of Transportation defines land-use mix as neighborhood-level heterogeneity in development (e.g. office, retail, industrial, education, health care, residential) at the neighborhood level.[26] Previous research found that among adults with a greater number of functioning impairments, increased land-use mix was associated with reduced restrictions in instrumental activities of daily living.[27] Living in a neighborhood that had more mixed-use areas was associated with better wheelchair mobility and greater fine motor scores.[24] Contradictory to above evidence, other research has found that communities with greater land-use mix and greater destination density were associated with decreased likelihood of physical independence and social integration among participants with spinal cord injury.[25] The disagreement discussed above may be due to differences in study populations. In other words, the relationship between the environment and participation might be modified by the level of individual impairment. This may point to further evidence of potential interactions between individual and environment. Although archival data sources are a powerful tool for assessing macrolevel environmental factors, the archival data often lacks key features of the microscale built environment that are directly relevant to individuals with mobility disabilities (e.g. quality of sidewalk, accessibility of crossing).[28, 29]

Therefore, we cannot rely on secondary data sources alone to capture built environment features relevant to physical functioning.

Previous work using neighborhood audit methods have found that quality of the street and sidewalk, volume of traffic on the street, and street signage to be significant predictors of functioning. Neighborhood audits of the built environment allow for systematic observation of surroundings, where study researchers collect information on the presence and quality of features.[18] Findings from the Chicago Community Adult Health Study found that sidewalk quality was associated with mobility difficulty, but only among adults with severe physical impairment.[28] This study highlights another example of empirical evidence suggesting an interaction between individual impairment and environment. Within the same study sample, poor street conditions, heavy traffic volume, and minimal residential security signs were negatively associated with social interaction, obtaining preventive health care, and voting in the most recent government elections.[30] The above evidence demonstrates that both the presence of features within the environment and the quality of neighborhood infrastructure are important components of individual functioning.

There is great variability in exposure and outcome ascertainment across the studies summarized above. A total of ten environmental domains and twelve functioning domains were represented across these studies which makes it challenging to articulate conclusions. Among studies examining the association between neighborhood-built environment and functioning for those with chronic health conditions, the most common exposure of interest was the accessibility of the built environment. Accessibility was raised as an important component within studies capturing the built environment through qualitative interviews, self-report surveys, and environmental audits. Methodologic approaches using qualitative, self-report, and environmental audit measurement found that the accessibility of the built environment shaped mobility, activities of daily living, and mobility difficulty, respectively. This research provides evidence that the built environment does have an important role in the disablement process. However, the studies had limited variability in individual impairment to further explore interactions between individual and environment. Vulnerability to the built environment might be greater among health conditions that result in neurological impairment, such as those that result from a stroke.

1.4 Stroke Significance

Every year, 795,000 people in the United States experience a stroke.[31] Stroke is a health condition that is disproportionately distributed within the United States. There are observed racial differences within the United States. Adults 45 to 54 years of age self-identifying as Black have a 4.02 greater risk of stroke in comparison to adults 45 to 54 years of age self-identifying as White.[32] There are also differences based on geography. Adults 35 years or older living in the South-Eastern portion of the United States having the highest age-adjusted rate of stroke mortality than any other region of the United States.[31] Stroke is of great public health concern due to the impact on individual functioning and on the health care system. Stroke is a health condition that accounts for $33 billion in direct and indirect health care costs annually.[31] Of these costs, institutionalization in a nursing home facility is the most costly and results in the greatest loss to independence.[33-35] Therefore, interventions to delay or prevent the transition to institutional care are of great social and economic importance.[36, 37] While accessible and safe indoor environments have received significant attention, little research has focused on the outdoor environment. Research investigating the outdoor environment is critically important because an individual's ability to independently navigate public space can have widespread impact on functioning. Previous research has found that navigating the environment by foot or motorized transit allows for individual choice, access to surrounding resources, and facilitates engagement in valued life activities.[38-40] Using the International Classification of Functioning, Disability and Health (ICF) framework, independent mobility is the result of a complex interaction between an individual and the surrounding environment.[8]

After a stroke, neurologic changes can impact static and dynamic balance. This leads to challenges in maintaining independent community mobility post stroke. Functional assessments have shown that static and dynamic balance change drastically through stages of stroke recovery (e.g. acute, subacute, and chronic phase of stroke).[41] Static and dynamic balance are necessary components while walking in the outdoor environment. For example, pedestrians need to have postural control to stand still (static balance) and also turn to look in multiple directions (dynamic balance) while assessing the safety of crossing a street. Postural control includes both maintaining a posture (e.g. standing without support) as well as changing a posture (e.g. standing while picking something up from the floor).[42] This requires static and dynamic balance which might be impacted by neurologic damage following a stroke.[43] Given that stability and balance are requirements for independent walking, post-stroke interventions targeting stability and balance have shown to improve post-stroke gait.[43-46] However, the ICF framework states that disability results from an interaction between individual functioning (e.g. stability, balance) and contextual factors (e.g. environmental factors).[8] Therefore, identifying components within the environment that interact with individual functioning to restrict or support mobility is critical for improving health and rehabilitation outcomes of stroke survivors.

Despite the fact that international organizations have emphasized the importance of environmental features for understanding disability, little is known about which environmental attributes are required for safe and independent mobility.[40, 47] Mobility is dynamic and is a result of the interaction between individual body function/structure and environmental context.[8, 48, 49] While environmental characteristics have received increased attention because of the breadth of their impact on population health,[11, 50] there are limited studies examining the effects of built environment features on stroke survivors' mobility.[47] Additionally, only a handful of studies have examined the built environments' influence on mobility among sample populations with functional impairments.[21, 28, 51, 52] These studies found that environmental features were associated with outdoor mobility, physical functioning, and reports of mobility disability.[21, 28, 51, 52] After a stroke, individuals may be more susceptible to environmental barriers due to changes in neurological function.[53-55] Thus, identifying the salient factors and ultimately changing the environment to be more accessible has the potential to increase independent mobility, participation in the community, and encourage health behaviors to prevent recurrent strokes.[50, 56] Additionally, building neighborhoods that facilitate independent mobility has the potential to reduce health disparities, not only within stroke survivors, but also among people with disabilities more generally.[57, 58] Lastly, environments that are supportive of lifelong mobility have the potential to relieve the burden placed on formal and informal caregiver support and increase physical activity which reduces risk of secondary stroke occurrence.[59]

The large number of stroke survivors returning home underscores the importance of identifying environmental factors that affect independent mobility.[60-63] Among Medicare patients discharged from the hospital after suffering a stroke, approximately 56 percent of patients return directly home (44% discharge to inpatient rehabilitation or skilled nursing facility).[60, 64] It is of critical public health importance that stroke survivors feel supported to move within their home community. Without an environment that supports independent mobility and long-term functioning, additional assisted living care or institutional care may be needed. With these care systems already strained by the aging population, it is necessary to understand what components of the environment are most important for mobility and functioning to support independent aging in place among stroke survivors.

1.5 Built Environment and Post-Stroke Functioning

Stroke is a sudden, and often dramatic health condition with a range of consequences for functioning in a number of domains. After a stroke, people are often left with impairments in mobility, speech, and spatial perception that can make it difficult to engage in community mobility and participation.[31, 65, 66] The resulting individual functioning impairments can potentially lead to a disability, depending on the environmental surroundings the individual is in. The environment plays a role in independent community mobility, a key outcome of post-stroke rehabilitation programs.[67] Independent community mobility allows for choice, independence, maintenance of social relationships, and access to community resources. Community mobility requires advanced motor skills such as ability to adapt to variation in terrain, unexpected disturbances, or external stimuli.[68, 69] In addition, community mobility requires overall planning of path selection, navigation, visual scanning, perturbations from moving obstacles, and gait adaptation to meet environmental demands.[68] After a stroke, there may be increased difficulty completing these tasks due to changes in individual body function. Previous studies suggest that environmental conditions play an important role on post-stroke community mobility and participation.[8]

Mobility limitations after a stroke result from an interaction between an individual's physical capacity and their environment. After a stroke, people often report dissatisfaction with their ability to ambulate outdoors and access their communities.[70] Findings from qualitative research have identified features of the built environment that contribute to this dissatisfaction.[70-

[75] Features within the physical streetscape (e.g. time available to cross the street, traffic speed) have been identified as contributing factors for community mobility post stroke.[70-73] In addition, walking long distances is a challenge for community mobility post stroke.[73, 74] Stroke survivors have reported that walking long distances to a bus stop served as a major barrier to using public transportation systems.[73] Furthermore, some participants reported that they had not even considered taking public transportation because of their acquired mobility limitations.[74] However, individual accounts of mobility experiences in the built environment are unable to capture real-time movement strategies and adaptations in the outdoor setting. To fill this gap, one study empirically examined how environmental settings change gait post-stroke. Within this study, post-stroke ambulation (i.e. gait speed, step length and cadence) was measured across three settings: clinical setting, shopping mall, and urban street environment.[47] The study concluded that there was a lack of substantial difference in gait performance within these different environments.[47] However, the authors treated performance within each setting as homogeneous despite the great intra-setting environmental variability. For example, within the urban street environment, participants were exposed to both a street crossing and a footpath on a suburban street. The participant's performance was averaged across the entire environmental setting (i.e. urban street environment), despite the fact that the environmental demands of walking on a street crossing with cars approaching and walking on a footpath where there is a barrier between the participant and cars, likely results in differential gait performance.[47] There is a need to determine which features of the neighborhood environment are most important for mobility and functioning status post-stroke and the resulting impact environmental features have on participation.

Environmental conditions may determine the magnitude of participation restrictions after a stroke. Meaningful travel destinations, accessible environments, and adequate transportation have all been identified as features of the built environment positively associated with participation post-stroke.[76-78] Meaningful travel destinations can include libraries, senior centers, or recreational facilitates. For example, one study found that 57 percent of stroke survivors were not aware of any fitness center in their neighborhood where they could exercise.[77] In addition, the accessibility of physical environments has been identified as an important component to continued engagement in valued life activities.[79, 80] Using self-reported Measure of the Quality of the Environment and Assessment of Life Habits, Rochette et al. found that barriers of the physical environment contribute to accessing public buildings within the community, maneuvering slippery or uneven surfaces, and maintaining residence in the home.[79] However, within this analysis, physical accessibility was summarized across a variety of spatial scales. Spatial scales ranged from physical accessibility of the participant's home to physical accessibility of community businesses, place of employment, or a friend's home.[79] Therefore, it is difficult to determine if the features of the neighborhood are contributing to post-stroke participation and which features serve as barriers or facilitators. Lastly, transportation has been identified as an important feature of the built environment contributing to participation post stroke.[81] Specifically, the availability and accessibility of public transit systems has been noted as a contributing factor to post-stroke participation.[81] However, it is still unclear if environmental factors are summative in nature (e.g. the more facilitators the greater likelihood of reengagement in valued life activities) or if one environmental factor triggers future trajectories of functioning post stroke (e.g. access to a motorized wheelchair providing access throughout the community).

The environment in which rehabilitation takes place has little resemblance to the outdoor environment surrounding a home in which a patient will return to post-stroke.[82] There are often demands within the outdoor environment surrounding the home, such as inadequate lighting, uneven surfaces, or narrow paths for passage, that are very different from the environment within a clinical setting.[82] Stroke survivors have expressed fear of returning to their neighborhood environment, because it was no longer comfortable and welcoming given their acquired functional impairments.[82] It is still largely unknown the specific role of the neighborhood-built environment for functioning, mobility, and participation post- stroke. In addition, we still do not know what can be done to optimize environments to promote post-stroke functioning and participation.

1.6 Conceptual Model

The guiding conceptual framework for this project is based on the International Classification of Functioning, Disability and Health.[8] As shown in Figure 1.2, Aim 1 of this dissertation examined the relationship between density of neighborhood resources with objectively measured light physical activity and moderate to vigorous physical activity post-stroke; Aim 2 examined features of the microscale physical environment and interactions with individual impairment to shape trajectories of physical quality of life following a stroke; and Aim 3 investigated lived post-stroke experience in the outdoor environment as it pertains to independent mobility.

--- Figure 1.2 ---

1.7 Specific Aims

Stroke is a leading cause of serious long-term disability within the United States, affecting an estimated 6.6 million Americans over age 20.[83] Medical advancement in treatment of acute stroke has resulted in a greater percentage of the United States population living with residual functional impairments of a stroke rather than immediately dying from a stroke.[31, 61] Stroke has sudden and often dramatic effects on an individual's function, resulting in less independence in activities of daily living, declines in ambulation, and increased visual impairments.[31, 63, 83, 84] Due to medical advancements, as well as an aging population, it is estimated that from 2012 to 2030, there will be a 21 percent increase in stroke survivors,[31, 85] and approximately 56 percent of stroke survivors will return directly home.[60] To successfully transition home after a stroke, survivors need to have outdoor environments that support their independent mobility and quality of life. Mobility is particularly important, as it is one of the key pathways by which stroke survivors can maintain social engagement, community involvement, and access to health care resources.[75, 86, 87] Features such as accessible sidewalks have been shown to facilitate mobility among older adults.[51, 88] However, it is not well understood how built environment features shape stroke survivors' mobility and quality of life.

Using a sequential explanatory mixed methods study design, the overarching objective of this research was to determine which features of the outdoor environment (i.e. built, social, natural, and policy environment) are most important for mobility and quality of life post-stroke.[89, 90] The first two aims of this study involved a secondary data analysis of existing data from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study. REGARDS is a cohort of 30,163 participants and was formed to identify the causes of stroke and stroke disparities. This dissertation capitalizes on data collected in three ancillary studies to REGARDS and examines the role of the macroscale and microscale built environments on physical activity and quality of life post-stroke. The three ancillary studies have collected data on built environments, objectively measured physical activity, and longitudinal quality of life post-stroke. To date, no studies have combined these rich data sources to evaluate this question. While these data sources allow us to examine associations between environments and functioning, we lack understanding of the reasons how and why stroke survivors' mobility and quality of life might be differential in diverse environments. Therefore, this dissertation includes a qualitative component. Semi-structured interviews were conducted with a separate sample of stroke survivors (N=20). The qualitative methods were used to identify the meanings and mechanisms through which environmental features shape mobility and quality of life. Specifically, the aims of this dissertation are to:

Aim 1: Examine the relationship between density of neighborhood resources with objectively measured light physical activity and moderate to vigorous physical activity post-stroke.

> <u>*Hypothesis:*</u> *Living in an area with greater density of neighborhood resources will be associated with greater light physical activity and greater moderate to vigorous physical activity.*

Aim 2: Examine features of the microscale physical environment and their interaction with individual impairment to shape trajectories of physical quality of life post stroke.

> <u>*Hypothesis 2.1:*</u> *Living in an area with more positive built environment features (e.g. curb cuts) will be associated with more rapid improvement in physical quality of life.*
>
> <u>*Hypothesis 2.2:*</u> Magnitude of association between features of the microscale physical environment and physical quality of life will be greater among those with moderate/severe stroke impairment in comparison to those with mild stroke impairment.

Aim 3: Identify the most salient neighborhood environmental features for functional status and mobility as reported by stroke survivors using qualitative interviews.

Hypothesis: *The lived experience in the outdoor built environment post-stroke will be shaped by the presence of facilitators and barriers in the microscale pedestrian streetscape. We expect these features will be perceived by stroke survivors as the most salient for mobility and quality of life post-stroke.*

1.8 Figures

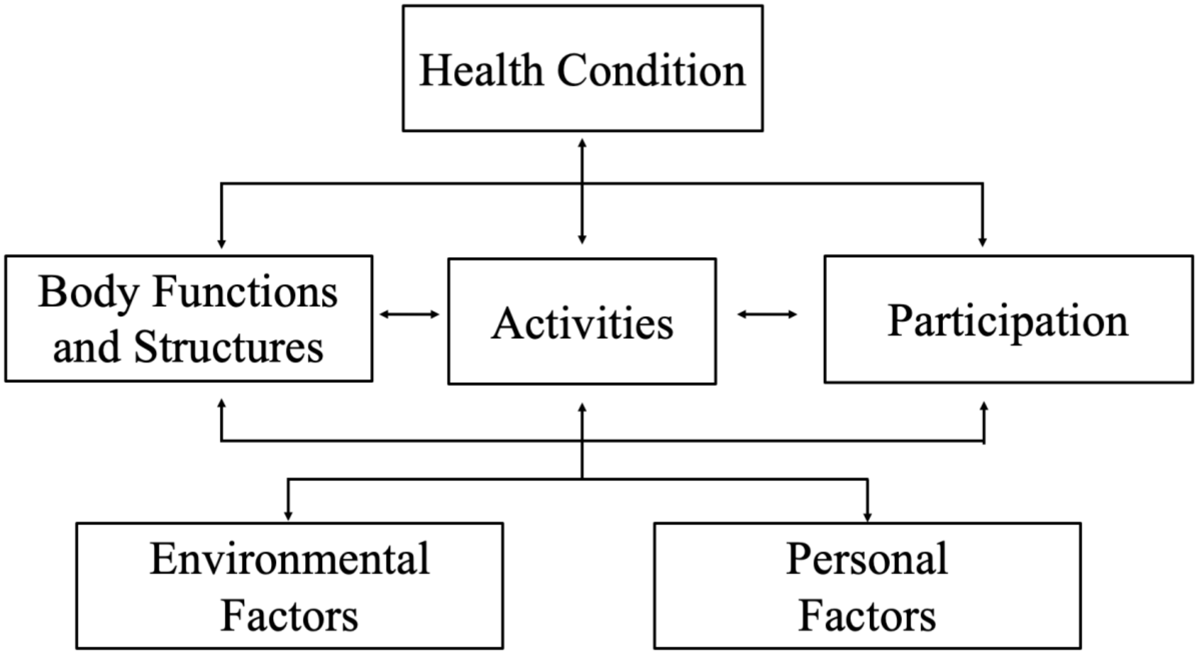

Figure 1.1 The International Classification of Functioning, Disability, and Health Framework (World Health Organization, 2001)

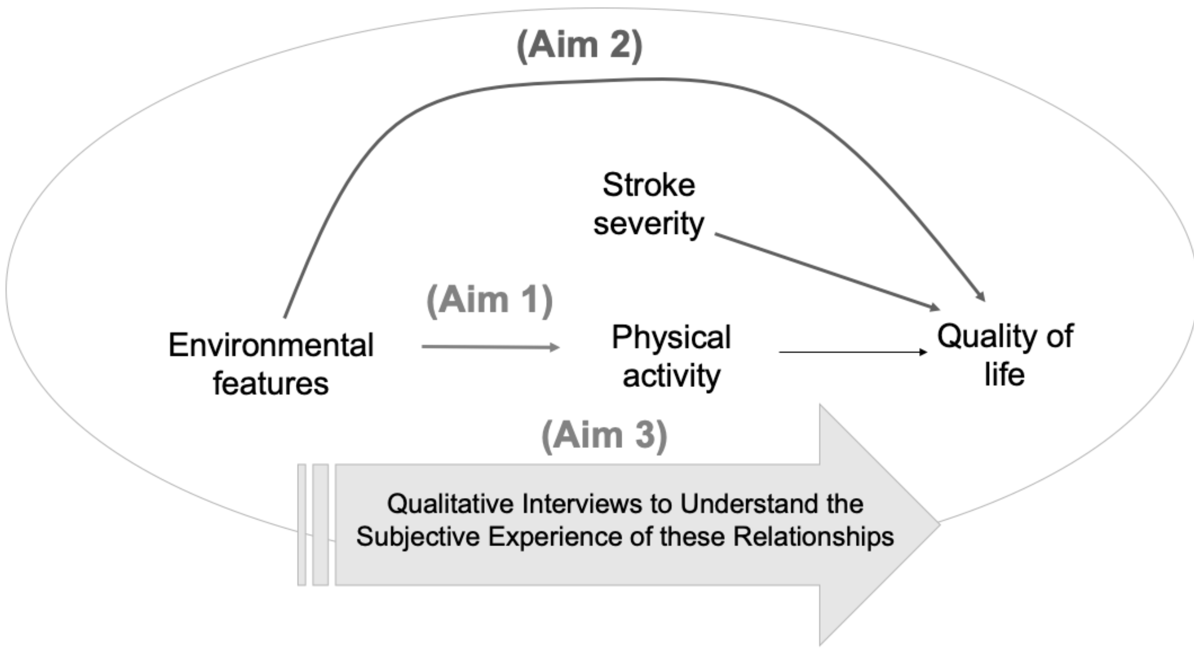

Figure 1.2 Guiding Conceptual Framework

Chapter 2 The Role of Environmental Exposures for Post-Stroke Physical Activity

2.1 Abstract

Introduction: Physical activity (PA) is an important component of post-stroke rehabilitation due to widespread physical, cognitive, and emotional health benefits. Environmental exposures may shape PA behavior following stroke. This study investigates the relationship between environmental exposures and post-stroke physical activity (PA).

Methods: Stroke survivors (N=374) from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study, a bi-racial cohort of black and white adults, with post-stroke accelerometer data were eligible for the current study. Participants' home addresses were linked with secondary data sources to capture surrounding natural and built environment characteristics. Environmental exposures included density of neighborhood resources (i.e. parks, public transportation, food stores, restaurants, physical activity facilities, department stores, mass merchandise, and intellectual stimulation destinations), neighborhood socioeconomic status (nSES, a composite index of neighborhood income, education, and wealth), neighborhood crime, and extreme cold days (temperatures below the 5th percentile over the past year). Post-stroke light PA (LPA) and moderate to vigorous PA (MVPA) were captured using hip-worn Actical accelerometers over a 7-day period. Linear regression and two-part/hurdle models were used to estimate the relationship between density of neighborhood resources and LPA and MVPA, respectively.

Results: A one-day increase in the number of extreme cold days was associated with 0.63 fewer minutes of daily LPA (95% CI:-1.13, -0.13). A one-standard deviation increase in nSES was

associated with greater odds (OR=1.10; 95% CI:1.02, 1.20) of doing any MVPA in the past week. Among participants obtaining any MVPA during the week, a one-unit (count/km^2) increase of destinations for intellectual stimulation was associated with 0.99 (95% CI:0.02, 1.97) more minutes of daily MVPA. All other environmental exposures were not associated with post-stroke LPA or MVPA.

Conclusions: Environmental exposures may facilitate PA participation among stroke survivors. Findings show that weather, nSES, and proximity to destinations for intellectual stimulation are associated with PA over and above individual factors.

2.2 Introduction

Low levels of participation in physical activity (PA) have been observed following a stroke.[91-93] Post-stroke PA levels are lower than healthy age-matched peers[91] and older adults with musculoskeletal or cardiovascular chronic health conditions.[92] Additionally, PA levels post-stroke are well below the recommended PA level[93] despite the fact that stroke survivors can safely improve physical fitness through exercise and PA.[94-96] PA is an important component of rehabilitation after stroke due to the widespread benefits including physical,[97-100] cognitive,[101] and emotional health.[102-104] Previous research suggests that exercise and PA post-stroke is protective of bone health,[97] walking ability,[98] fatigue,[99] and muscle strength.[100] Furthermore, low levels of PA post-stroke are associated with risk for recurrent stroke and cardiovascular disease.[105-107] Known benefits of PA for cognitive health include improvements in executive function and memory.[101] In relation to emotional health, there is evidence that PA after stroke is an independent predictor of life satisfaction.[102] Furthermore PA has been associated with reduction in depressive symptoms post-stroke.[103, 104] For these reasons, the American Heart Association has issued a call for new interventions that "break the relentless post-stroke cycle of reduced PA leading to further reductions in functional capacity and heightened risk of secondary complications."[108]

Stroke survivors have previously indicated that neighborhood resources are important for PA post-stroke.[109-111] Recreational facilities offer buildings and spaces for PA engagement among community members, and recreational facility access is associated with a greater number of steps taken post-stroke.[111] Traveling far distances to PA facilities has been listed as a primary barrier to exercise post-stroke.[109] Additionally, retail and service destinations within the neighborhood environment can serve as motivating factors for active transportation (e.g. walking or biking).[112-114] Limited walkable destinations contribute to post-stroke dissatisfaction with the outdoor built environment. Walking long distances, including to public transportation, has been reported as a challenge for community mobility post-stroke.[70-75] Thus, access to affordable, quality, reliable transportation is an important feature to encourage mobility and participation post-stroke.[110, 115]

The availability and sophistication of linking neighborhood characteristics to population health has seen exponential growth in the past decades.[116] Using archival data sources and geographic information systems, measurement of environmental exposures is possible among studies with variability in time and geography.[18] Granularity in both time and place adds strength to observational studies examining associations between context and health outcomes. The application of advanced geographic methods within stroke research has primarily focused on stroke prevention[117] and acute-stroke health care access.[118] Very little is known of the role of environmental exposures for chronic stroke survivors living in their home community, a group making up an estimated 7.0 million Americans over the age of 20.[31] One recent study capitalized on publicly available data to examine the association between neighborhood walkability (composite index of distance to amenities) and objectively measured post-stroke stepping.[119] The authors found that neighborhood walkability was not associated with post-stroke daily stepping.[119] However, this project was limited in geographic variability (four study site locations) and did not account for the role of climate and weather, important predictors of PA participation.[119] In addition, it was unclear from the study methodology which year neighborhood walkability was assessed and if the assessment of neighborhood walkability preceded measurement of post-stroke walking activity. Additional research is needed to further examine the role of physical and social resources on objectively measured post-stroke PA behavior after controlling for natural environmental conditions.

The goal of this research project is to understand the role of environmental exposures for PA post-stroke. To accomplish this goal, we examine the relationship between density of neighborhood resources with PA. In a sample of stroke survivors with wide geographic variability, this project overcomes many limitations of previous research through the use of objectively measured community characteristics, data on outdoor climate, and objectively measured PA behavior using accelerometry.

2.3 Methods

2.3.1 Study Population

The REasons for Geographic and Racial Differences in Stroke (REGARDS) study began in January 2003 and is a prospective cohort of 30,163 black and white participants who continue to be followed for incident stroke.[120] Retrospectively, participants self-reported previous stroke events at baseline interview. Prospectively, suspected stroke events were obtained through self-report or proxy report during six-month, follow-up phone calls. Suspected stroke events were centrally adjudicated by physicians through medical record review. A total of 3,047 stroke survivors (1,921 self-reported stroke events, 1,126 physician adjudicated stroke events) were within the study cohort at the time of accelerometer data collection.

2.3.2 Accelerometer Data Collection

From May 2009 to January 2013, REGARDS participants were screened for eligibility in an ancillary study to objectively capture PA using accelerometers. Participants were eligible for the ancillary study if they were currently enrolled in REGARDS and answered 'yes' to the question 'on a typical day, are you physically able to go outside where you live and walk, whether or not you actually do?' After accounting for device issues (lost, defective, or non-worn) and excluding participants with missing or insufficient data (device errors, missing log sheets, or non-compliant wear time), 407 post-stroke participants had usable accelerometer data collected after their stroke event (Figure 2.1). Additional details on study design, sampling strategy, recruitment, and study procedures have been previously described.[121, 122]

Objective light physical activity (LPA) and moderate to vigorous physical activity (MVPA) were captured using Actical accelerometers. Participants wore the accelerometer over their right hip and completed a daily wear log over a seven-day period. Actical devices were initialized to collect data in 60s epochs. Activity counts of 50-1,064 counts per minute (cpm) and >1,065 cpm distinguished LPA and MVPA, respectively. Daily minutes of LPA and MVPA were summed across valid wear days (≥four days with accelerometer wear ≥ten waking hours) and divided by the number of valid days to calculate the average daily minutes of LPA and MVPA.[123, 124]

2.3.3 Individual Characteristics

Information collected on individual participant characteristics was obtained from the REGARDS baseline data collection. A computer-assisted telephone interview was completed by trained telephone interviewers to obtain demographic (i.e. age, sex, race, region) and socioeconomic characteristics (i.e. education, income) of participants. Time since stroke was calculated from self-reported year of stroke at baseline (n=274) or from the date of observed stroke within the REGARDS study (n=133).

2.3.4 Geospatial Procedures

Participants' home addresses were identified during initial enrollment, follow-up phone calls, and/or annual mailings. Addresses were updated through regular mailings, a public record database (i.e. LexisNexis)[125, 126], and ancillary study contacts. Participants' home addresses were geocoded using Environmental Systems Research Institute (Esri) ArcGIS® Business Analyst Desktop 10.5.1 with Esri 2016 Business Analyst Data. Point addresses and street addresses were matched with 90 percent or higher probability. Unmatched records were investigated using manual searches (e.g. Google Maps, internal notes, and LexisNexis), and new addresses were processed using the procedure described above. The address at the time of accelerometer wear was utilized, and participants missing a geocoded address were excluded (n=3; Figure 2.1).

2.3.5 Environmental Characteristics

Population Density

Using block-level 2010 Decennial Census population data and block geographies from the US Census Bureau, a weighted population count was generated within a 1 km radial buffer surrounding each participant's home address.[127] Population density was estimated using areal weighting interpolation to assign population data to geographies.[128] Using block geographies, the population in proportion to the land area was calculated within the buffer.

Park Area

The availability of local, state, and national parks within a participant's neighborhood was determined by triangulating three sources of data: Esri StreetMap Premium, Esri Living Atlas, and ParkServe®. After excluding water, each park layer was dissolved into one combined layer to account for overlapping parks. Proportion of park area in 2016 was calculated within a 1 km radial buffer.

Neighborhood Retail Environments

The annual number of neighborhood retail establishments was obtained from the National Establishment Time Series (NETS) database. In order to capture nearby buildings set back from the street, research staff calculated a 1 km sausage buffer using a 0.85 km network distance with a 150 m radius from the street centerline.[129] Counts of NETS establishments geocoded at the address point or street address range level were included in our exposure calculation. The year of NETS exposures was determined by the year of participant accelerometry data collection.

Previous research has defined categories of NETS retail establishments that potentially impact PA behavior.[130] Using Standard Industrial Classification (SIC) codes and name-based algorithms, NETS retail establishments theorized to impact PA behavior were combined into six categories of environmental exposures, and are briefly described below.[130] Food stores include all food retail establishments where the primary purpose is for off-premise consumption including grocers, gas stations, and farmers markets. Restaurants and eating places include a wide variety of establishments including coffee shops, pizza, and fast food restaurants. PA facilities offer a wide range of activities including multi-use facilities, gyms/fitness centers, or recreation centers. Department stores are retail establishments that carry apparel and either major household appliances or furnishings. General mass merchandisers are high volume mass merchandisers carrying everyday goods, and are typically between 10,000 and 40,000 selling square feet in size. Cognitive enrichment establishments, or destinations for intellectual stimulation, are places that include coursework, seminars, games, and other intellectual endeavors (e.g. libraries or social clubs). Additional details on classification, integration, and quality control of NETS based data have been previously described.[130]

Public Rail

Subway, light rail, and commuter rail station information was obtained from the Center for Transit-Oriented Development database. Information from municipal transit agencies was used to code the year of station service.[131] Counts of public rail stations within a 1 km sausage buffer in 2010 were included. No information was available for bus service.

Rural-Urban Commuting Area (RUCA) Codes

RUCA codes capture measures of population density, urbanization, and daily commuting to code census tracts into levels of urbanicity.[132] Using 2010 RUCA 4, primary and secondary RUCA codes are aggregated into four categories (i.e. urban, large, rural, small rural, isolated).[132] In our study, due to small population numbers, “small rural” and “isolated” categories were collapsed into one category.

Neighborhood Socioeconomic Status (nSES)

nSES was measured using previously defined methods.[133] Briefly, the nSES index variable is the sum of six census variables representing income, occupation, and education from the 2010 American Communities Survey.[133] Higher values of this index indicate higher nSES within the census tract.

Crime

Using 2010 Esri CrimeRisk Indexes data, crime was separated into personal crime (i.e. murder, rape, robbery, and assault) and property crime (i.e. burglary, larceny, and motor vehicle theft). An index of 100 is considered the national average, with higher index scores representing greater amounts of crime. Using a 1 km modified sausage buffer, crime risk was estimated using areal weighting interpolation to assign CrimeRisk Indexes to geographies.[128] The modified sausage buffer differs from the sausage buffer, in that all space fully enclosed by the buffered area is filled in.[129]

Extreme Cold Days

Weather can change motivation and feelings of safety to participate in PA. Data on extreme cold days were derived from the Global Historical Climatology Network-Daily dataset integrating daily climate observations from multiple sources.[134] Weather station geocodes were downloaded and spatially joined to 2010 US County shapefiles. Extreme cold temperatures were defined as county temperatures below the 5^{th} percentile of all days over the past year within the county. The variable of "extreme cold days" captures the percentage of days, during the accelerometer wear days, with extremely cold temperatures.

2.3.6 Statistical Analysis

Minutes per day spent in LPA was approximately normally distributed within our study sample. Therefore, LPA was treated as a continuous outcome within a linear regression model. MVPA was right skewed within our study population with a large proportion (20.1%) obtaining 0 minutes of MVPA. Therefore, a two-part/hurdle model was used to examine the association (1) between individual and environmental characteristics with obtaining any MVPA using logistic regression and (2) between individual and environmental characteristics with the number of minutes of MVPA using linear regression among participants accumulating any MVPA.

Using a sequential model building strategy, we examined the association of individual characteristics, environmental characteristics, and individual and environmental characteristics combined. All models controlled for participant wear time in order to estimate relationships above and beyond the amount of time the accelerometer was worn. To estimate the severity of multicollinearity of independent variables, variance inflation factor was calculated and reported for all models. All analyses were conducted using Stata 16.1. Participants provided written informed consent to be a part of REGARDS, and this study was approved by all participating Institutional Review Boards.

2.4 Results

As shown in Figure 2.1, a total of 374 participants met our inclusion criteria. Table 2.4 displays socio-demographic and environmental summary statistics for stroke survivors: included in our study sample, excluded from our study sample, the difference between included and excluded sample, and the test statistic to assess if difference in mean or proportion was significantly different. We found that the included sample was overall younger, healthier, and had greater socioeconomic status in comparison to participants who were excluded. Participants included and excluded from the study sample had similar density of destinations surrounding their home address, but those included in the sample had much higher nSES than those who were excluded from the sample (Table 2.4). On average, participants accumulated 142.02 minutes of LPA per day and 5.75 minutes of MVPA per day. Participants were on average 73 years (Standard deviation: 8.2) of age, with 52% male and 37% self-identified as Black. PA measurement was on average 10 years (SD: 8.99) after a participant experienced a stroke. Participants were distributed across socioeconomic measures of education and income. Environmental characteristics were highly variable across our study sample, with 82% of participants living within urban areas. Additional detail on descriptive statistics of individual and environmental characteristics can be found in Table 2.1.

--- Figure 2.1 & Table 2.1 ---

Within the individual characteristics model, a one-unit increase in age was associated with 3.94 (95% CI:-4.82, -3.05) fewer minutes of LPA per day (Table 2.2). Black race was associated with 18.58 (95% CI:-33.51, -3.65) fewer minutes of LPA in comparison to white race. Within the environmental characteristics model, a one-unit increase in the percentage of extreme cold days was associated with 0.82 (95% CI:-1.37, -0.26) fewer minutes of LPA per day. Lastly, within the joint individual and environmental characteristics model, age (β=-3.83; 95% CI:-4.73, -2.93), race (β=-21.27; 95% CI:-39.50, -3.04), and extreme cold weather (β=-0.63; 95% CI:-1.13, -0.13) were all significantly associated with lower minutes of LPA. None of the other environmental exposures examined were significantly associated with post-stroke LPA behavior.

--- Table 2.2 ---

Table 2.3 displays results of the two-step/hurdle model estimating associations with MVPA. Within the individual and environmental characteristics model, a one-unit increase in age (OR=0.90; 95% CI: 0.87, 0.94) and nSES (OR=1.10; 95% CI: 1.02, 1.20) were associated with the likelihood of accumulating any minutes of MVPA. In addition, the odds of males accumulating any minutes of MVPA were 2.37 (95% CI: 1.27, 4.42) times the odds of any MVPA among women. None of the other environmental exposures examined were significantly associated with the likelihood of participating in post-stroke MVPA. Among participants accumulating any amount of MVPA, older age (β=-0.52; 95% CI: -0.70, -0.34) and self-reported black race in comparison to white race (β=-4.06; 95% CI: -7.59, -0.53) was associated with fewer minutes of MVPA per day. Also, annual income categories of less than $20,000 (β=-6.46; 95% CI: -12.07, -0.85) and Refused (β=-7.70; 95% CI: -13.96, -1.44) were associated with fewer minutes of MVPA per day in comparison to those earning >$75,000 a year. A one-unit increase in cognitive enrichment destinations (β=0.99; 95% CI: 0.02, 1.97) was associated with more minutes of MVPA, conditional on participating in any MVPA. All other environmental exposure examined were not significantly associated with minutes of post-stroke MVPA.

--- Table 2.3 ---

2.5 Discussion

In this geographically diverse, bi-racial cohort, we found that environmental characteristics were significantly associated with PA participation post-stroke. Age, race, and extreme cold weather were all significantly associated with minutes of LPA post-stroke. The likelihood of participating in any MVPA changed significantly depending on age, sex, and nSES. Among participants who accumulated any MVPA, age, race, income, and greater density of destinations for intellectual stimulation (i.e. cognitive enrichment) were significantly associated with more minutes of MVPA. To date, few studies have had the available data to comprehensively examine the role of the individual characteristics and environmental exposures on post-stroke PA participation.

Of the environmental characteristics examined, we found that extreme cold weather, nSES and destinations for intellectual stimulation were associated with PA. Extreme cold weather can influence PA by changing individual motivation to participate and also elicit concerns of safety in the outdoor environment.[135] Stroke survivors might have greater awareness of the effect cold weather has on neuromuscular function (e.g. spasticity),[136] lived experience in the built environment (e.g. icy surfaces), and the combined effects on safe mobility (e.g. loss of balance). We also found that nSES was associated with the likelihood of participating in any MVPA. It is possible that nSES is capturing the underlying quality/investment in infrastructure of the built environment (e.g. sidewalk maintenance), providing greater accessibility of the neighborhood environment for PA participation. In a recent study, researchers reviewed Americans with Disabilities Act (ADA) transition plans within cities and counties.[137] Among those reviewed, only 13% had an ADA transition plan in place, and an average of 65% of curb cuts and 48% of sidewalks were not accessible.[137] Accessible sidewalks are critical for independent mobility and might allow for post-stroke active travel benefits. Lastly, a one-unit increase in destinations for intellectual stimulation was significantly associated with 0.99 (95% CI: 0.02, 1.97) more daily minutes of MVPA. This sample of older stroke survivors might have high motivation to travel to these destinations (e.g. libraries, museum, colleges, and other recreational clubs) for social interaction, community integration, and lifelong learning.[138] Close proximity to these engaging destinations may motivate active transit trips and provide greater autonomy in transportation options.

We did not observe an association between many neighborhood destinations and post-stroke PA. Among the destinations examined in this project, many were privately owned businesses and establishments (e.g. restaurants, food stores, physical activity facilities), while few were publicly owned (e.g. designations for intellectual stimulation, public transit). One potential explanation might be the physical accessibility of these destinations. After traveling to an establishment, upon arrival, stroke survivors may find the physical building/infrastructure to be inaccessible for their participation, thereby discouraging future travel to the destination. While both private and public destinations have federal regulations for accessible infrastructure, the laws were put into place at different times.[139, 140] Destinations which receive federal funding were required to be accessible under Section 504 of the Rehabilitation Act, a law passed in 1973.[139] Accessibility standards expanded to private businesses under the Americans with Disabilities Act (ADA), a law passed in 1990.[140] Although any newly constructed facilities should meet or exceed the minimum requirements for accessible building design, during data collection, these buildings may have been inaccessible given the time needed to implement accessibility standards set by the ADA. Unfortunately, we were unable to locate data measuring the extent to which establishments comply with ADA standards. Nevertheless, this distinction could explain why we observed a positive relationship between destinations for intellectual stimulation and PA, but not private retail establishments and PA.

2.5.1 Future Research and Practical Recommendations

Findings from this study have implications for rehabilitation practice. We found that extreme cold weather was associated with less LPA. Practitioners can discuss the role that cold weather has on PA behavior, and develop a tailored plan with patients to minimize the impact of inclement climates. In addition, destinations for intellectual stimulation were significantly associated with more minutes of MVPA per day. Identifying destinations within the neighborhood environment, where patients would have the capacity and motivation to travel to using active transit, might be a useful strategy for increasing post-stroke PA. Overall, the findings of this study suggest that conversations with post-stroke patients about environmental exposures might provide fruitful information for post-stroke PA.

Additional research is needed to understand the potential role that quality of built environment infrastructure has on post-stroke PA participation. Many environmental destinations (e.g. parks, PA facilities) examined in this study were not associated with post-stroke PA as hypothesized. Future research should evaluate if the quality of the built environment moderates the association between neighborhood destinations and PA, or if these destinations are not associated with PA participation post-stroke regardless of quality of the built environment.

2.5.2 Strengths and Limitations

This study has many strengths. The REGARDS study is a national cohort, and post-stroke participants had geographic variability across the US to allow for comparisons across heterogeneous environments. Our measurement of destinations utilized comprehensive, longitudinal data sources which allowed for linking of the year of environmental characteristics with the year that PA measures were obtained. PA was objectively measured using accelerometers, which are less prone to measurement bias compared to self-reported PA.[141] Actigraph has been shown to be a reliable measurement tool to capture physical activity post stroke.[142] However, emerging literature examining real-world upper extremity movement suggests that bilateral accelerometer placement in needed among stroke survivors to capture hemiparetic movement.[143] Additional research on the number of accelerometers needed to capture post-stroke lower-limb functioning, specifically real-world physical activity, is needed. Lastly, information about weather data during the week of accelerometer data collection was integrated into the analysis, an important predictor of PA participation.

This study is not without limitations. Information on individual functioning was not available within our full study sample, limiting our ability to test for interactions between individual functioning and environmental characteristics. Furthermore, we did not have information about mobility aid use in the outdoor environment. Mobility aids may interact with the outdoor environment to shape physical activity behavior among those with greater physical impairment. There was large variability in the time from stroke to the date of accelerometer data collection within our study sample, limiting our ability to make specific recommendations for specific post-stroke patients. Within Table 2.4, we observed that REGARDS participants who experienced a stroke had different probabilities of inclusion into the study, potentially subjecting our study to selection bias. A number of stroke survivors within REGARDS did not participate in the accelerometer data collection, and the reason for non-participation is unknown. Post-stroke participants who were included in our study sample were generally healthier than those who were excluded from the study and lived in environments with fewer destinations, higher nSES, and less crime (Table 2.4). As shown in Figure 2.2, advantaged neighborhoods (i.e.

“Neighborhood SES”) was positively associated with selection (i.e. “Selection into Study"). In addition, participants who survived and were thereby available for observation (i.e. “Survival”) were able to be selected into the study. Furthermore, participants who survived to the time of observation (i.e. “Survival”) are overall healthier and would be more likely to participate in physical activity (i.e. “PA Behavior”). As shown in the graph, conditioning on the collider of selection (i.e. “Selection into Study”) opens a backdoor path, which could lead to biased effect estimates.

--- Table 2.4 ---

2.5.3 Conclusions

This study examined the relationship between environmental exposures with PA in stroke survivors. Both individual and environmental characteristics were significantly associated with PA participation post-stroke. Important environmental characteristics for post-stroke PA included extreme cold weather, nSES, and destinations for intellectual stimulation. Future research is needed to understand if the quality and accessibility of outdoor spaces are modifying the relationship between neighborhood establishments and PA post-stroke.

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2.6 Figures and Tables

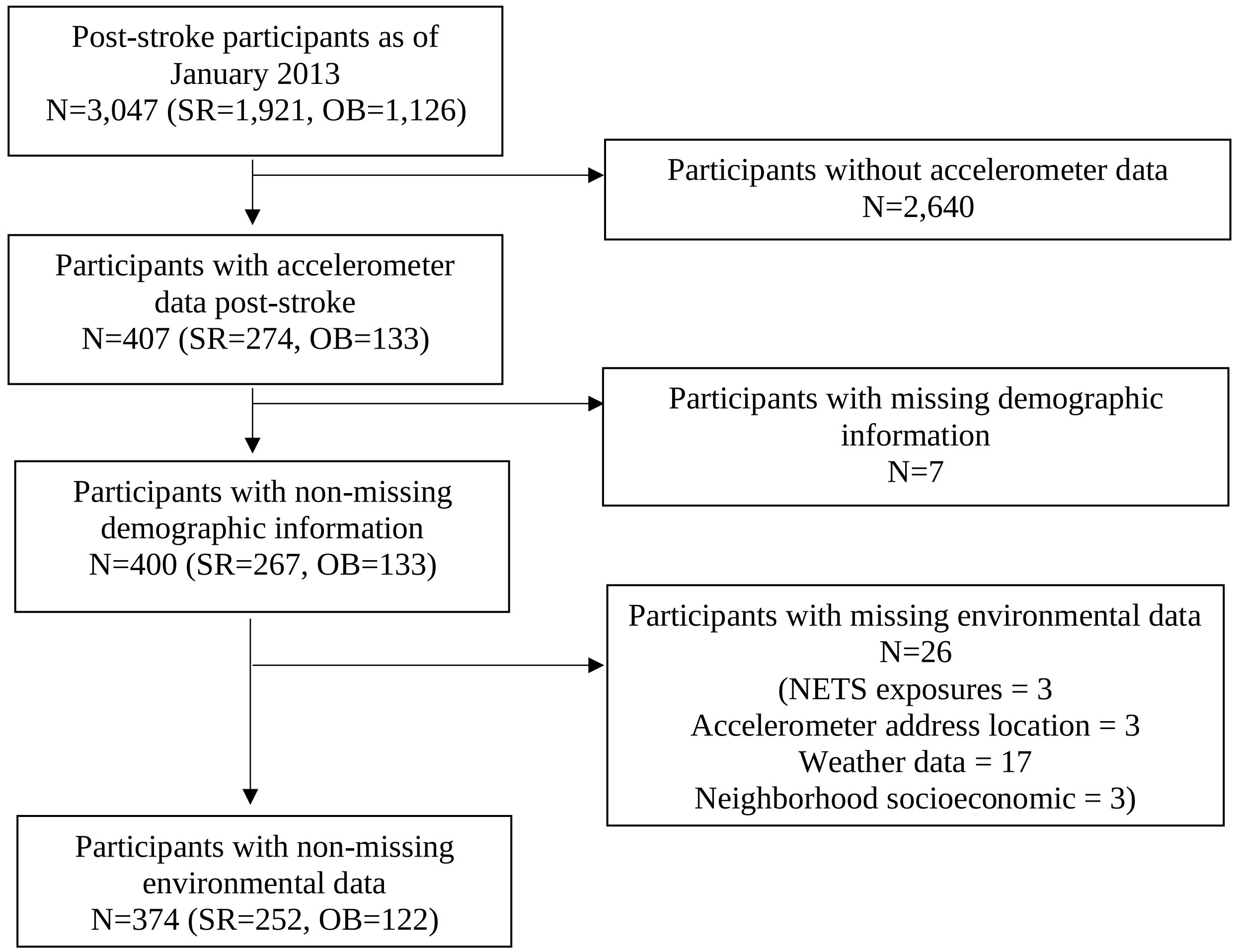

Figure 2.1 Study flowchart using the REGARDS study (REasons for Geographic and Racial Differences in Stroke), United States, May 2009 to January 2013. SR = Self-reported a stroke at baseline REGARDS; OB = Stroke was observed during the REGARDS study period prior to accelerometer data collection.

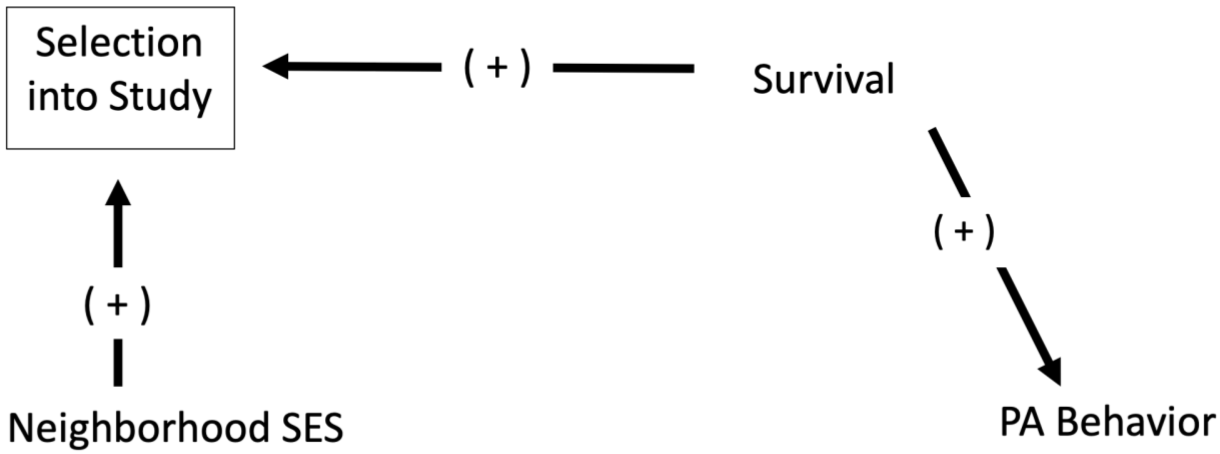

Figure 2.2 Causal Directed Acyclic Graph (DAG) representing the potential backdoor path through which conditioning on the collider “Selection into Study” could lead to biased effect estimates due to survivorship, where those observed in the study sample are a healthier sample than would otherwise be observed if all participants survived to observation.

Table 2.1 Post-stroke participants from the REasons for Geographic and Racial Differences in Stroke (REGARDS) cohort, who have valid accelerometry data and no missing covariate data. Sample characteristics are reported for the analytic sample (n=374).

	Analytic Sample (n = 374)	
Sample characteristics	Mean	SD
Light physical activity (minutes/day)	142.02	74.74
Moderate to vigorous physical activity (minutes/day)	5.75	11.62
Individual characteristics		
Wear Time	868.54	120.27
Age	72.63	8.16
Gender (n, % Male participants)	195	52.14%
Race (n, % Black participants)	139	37.17%
Time since stroke (years)	10.04	8.99
Education (n, %)		
College graduate or more	125	33.42%
Some college	120	32.09%
High school graduate	90	24.06%
Less than high school	39	10.43%
Income		
> $75,000	47	12.57%
$35,000 - $74,999	118	31.55%
$20,000 - $34,999	112	29.95%
< $20,000	65	17.38%
Refused	32	8.56%
Environmental characteristics		
Population density (n/km^2)	1239.72	1641.69
Park area (proportion)	0.04	0.08
Food stores (count/km^2)	2.61	4.28
Restaurants and eating places (count/km^2)	2.56	5.29
Physical activity facilities (count/km^2)	0.28	0.68
Department stores (count/km^2)	0.04	0.19
General mass merchandise (count/km^2)	0.01	0.07
Cognitive enrichment (count/km^2)	0.93	1.94
Public rail (count/km^2)	0.09	0.76
RUCA codes (n, %)		
Urban	306	81.82%
Large rural	42	11.23%
Small rural & isolated	26	6.95%
Region (n, %)		
Non-stroke belt/buckle	185	49.47%
Stroke belt	116	31.02%
Stroke buckle	73	19.52%
Neighborhood socioeconomic status	-0.74	4.97
Personal crime	183.85	155.16
Property crime	159.84	123.59
Extreme cold days	3.56	14.01

Note. SD=standard deviation; km=kilometer; RUCA=rural-urban community area

Table 2.2 Associations between individual and environmental characteristics with post-stroke light physical activity (n=374).

	Individual characteristics		**Environmental characteristics**		**Individual + Environmental Characteristics**	
	β	95% CI	β	95% CI	β	95% CI
Individual characteristics						
Wear Time	0.06	(0.005, 0.12)			0.06	(0.003, 0.12)
Age	-3.94	(-4.82, -3.05)			-3.83	(-4.73, -2.93)
Gender (Male participants)	-1.11	(-15.19, 12.98)			-1.10	(-15.62, 13.42)
Race (Black participants)	-18.58	(-33.51, -3.65)			-21.27	(-39.50, -3.04)
Time since stroke (years)	0.20	(-0.57, 0.98)			0.22	(-0.58, 1.01)
Education						
College graduate or more	-	-			-	-
Some college	15.65	(-1.90, 33.19)			15.96	(-2.41, 34.33)
High school graduate	14.05	(-5.37, 33.48)			17.07	(-3.49, 37.63)
Less than high School	3.90	(-21.68, 29.48)			8.22	(-18.41, 34.85)
Income						
>$75,000	-	-			-	-
$35,000 - $74,999	5.65	(-17.96, 29.25)			9.57	(-14.62, 33.77)
$20,000 - $34,999	-4.13	(-28.82, 20.55)			4.67	(-21.58, 30.93)
< $20,000	-17.67	(-45.33, 10.00)			-10.34	(-39.18, 18.49)
Refused	-3.10	(-35.34, 29.14)			2.18	(-30.69, 35.06)
Environmental characteristics						
Population density (n/km^2)			0.01	(-0.002, 0.02)	0.003	(-0.005, 0.01)
Park area (proportion)			-26.84	(-129.31, 75.64)	-10.21	(-105.25, 84.84)
Public rail (count/km^2)			-1.42	(-12.41, 9.56)	0.06	(-10.05, 10.16)
Food stores (count/km^2)			-3.02	(-6.61, 0.58)	-1.04	(-4.37, 2.29)
Restaurants and eating places (count/km^2)			-0.89	(-3.51, 1.74)	-1.58	(-3.98, 0.83)
Physical activity facilities (count/km^2)			-2.78	(-15.96, 10.41)	-0.91	(-13.03, 11.21)
Department stores (count/km^2)			-1.27	(-46.72, 44.18)	-0.72	(-42.57, 41.13)
General mass merchandise (count/km^2)			-36.23	(-150.00, 77.54)	26.22	(-78.77, 131.20)
Cognitive enrichment (count/km^2)			1.70	(-3.91, 7.32)	3.47	(-1.71, 8.66)
Rural-urban commuting area (RUCA) codes						
Urban			-	-	-	-
Large rural			11.80	(-13.23, 36.84)	8.96	(-13.99, 31.92)
Small rural & isolated			-13.56	(-45.46, 18.34)	-18.51	(-47.78, 10.77)
Region						
Non-stroke belt/buckle			-	-	-	-
Stroke belt			15.92	(-4.29, 36.13)	7.71	(-11.07, 26.48)

Stroke buckle		9.27	(-13.61, 32.14)	8.95	(-12.78, 30.68)
Neighborhood socioeconomic status		1.41	(-0.37, 3.20)	1.16	(-0.67, 2.98)
Personal crime		-0.02	(-0.09, 0.06)	0.02	(-0.05, 0.09)
Property crime		0.00	(-0.09, 0.10)	-0.01	(-0.10, 0.07)
Extreme cold days		-0.82	(-1.37, -0.29)	-0.63	(-1.13, -0.13)
Mean Variance Inflation Factor	1.60	1.88		1.90	
R-squared	0.22	0.07		0.26	

Note. CI=confidence interval; km=kilometer; RUCA=rural-urban community area

Table 2.3 Associations between individual and environmental characteristics with post-stroke moderate to vigorous physical activity.

	Individual characteristics				**Environmental characteristics**				**Individual + Environmental Characteristics**			
	Logit Model (n = 374)		Linear Model (n = 299)		Logit Model (n = 374)		Linear Model (n = 299)		Logit Model (n = 374)		Linear Model (n = 299)	
	OR	95% CI	β	95% CI	OR	95% CI	β	95% CI	OR	95% CI	β	95% CI
Individual characteristics												
Wear Time	1.00	(1.00, 1.00)	0.004	(-0.01, 0.01)					1.00	(1.00, 1.00)	0.004	(-0.01, 0.02)
Age	0.90	(0.87, 0.94)	-0.50	(-0.68, -0.33)					0.90	(0.87, 0.94)	-0.52	(-0.70, -0.34)
Gender (Male participants)	2.49	(1.40, 4.44)	1.60	(-1.13, 4.33)					2.37	(1.27, 4.42)	1.83	(-1.00, 4.67)
Race (Black participants)	0.70	(0.39, 1.26)	-3.40	(-6.31, -0.49)					0.93	(0.44, 1.93)	-4.06	(-7.59, -0.53)
Time since stroke (years)	1.00	(0.97, 1.03)	-0.02	(-0.17, 0.13)					0.99	(0.96, 1.03)	-0.02	(-0.18, 0.13)
Education												
College graduate or more	1.0		ref						1.0		ref	
Some college	0.80	(0.39, 1.63)	0.51	(-2.88, 3.90)					0.77	(0.36, 1.68)	0.67	(-2.96, 4.30)
High school graduate	0.72	(0.33, 1.56)	-3.19	(-6.99, 0.62)					0.87	(0.37, 2.03)	-2.15	(-6.17, 1.87)
Less than high School	0.94	(0.35, 2.50)	-3.26	(-8.30, 1.78)					1.17	(0.40, 3.46)	-2.95	(-8.25, 2.35)
Income												
>$75,000	1.0		ref						1.0		ref	
$35,000 - $74,999	1.46	(0.53, 4.06)	-4.48	(-8.92, -0.04)					2.21	(0.75, 6.53)	-4.39	(-8.99, 0.22)
$20,000 - $34,999	1.07	(0.38, 2.97)	-4.08	(-8.80, 0.64)					1.60	(0.53, 4.86)	-3.78	(-8.85, 1.29)
< $20,000	1.54	(0.48, 4.89)	-6.02	(-11.37, -0.66)					2.58	(0.73, 9.13)	-6.46	(-12.07, -0.85)

Refused	2.15	(0.55, 8.42)	-7.76	(-13.81, -1.72)					3.04	(0.71, 13.07)	-7.70	(-13.96, -1.44)
Environmental characteristics												
Population density (n/km^2)					1.00	(1.00, 1.00)	0.001	(-0.001, 0.002)	1.00	(1.00, 1.00)	0.001	(-0.001, 0.002)
Park area (proportion)					0.34	(0.01, 13.98)	-2.19	(-21.38, 17.00)	0.45	(0.01, 33.02)	5.29	(-13.01, 23.59)
Public rail (count/km^2)					7.66	(0.41, 144.93)	0.06	(-1.85, 1.97)	4.79	(0.33, 70.03)	0.21	(-1.58, 2.00)
Food stores (count/km^2)					0.91	(0.79, 1.05)	-0.02	(-0.73, 0.69)	0.93	(0.80, 1.08)	0.14	(-0.53, 0.81)
Restaurants and eating places (count/km^2)					0.97	(0.88, 1.07)	-0.55	(-1.28, 0.17)	0.95	(0.87, 1.04)	-0.43	(-1.11, 0.26)
Physical activity facilities (count/km^2)					1.03	(0.60, 1.78)	-0.47	(-2.93, 2.00)	0.95	(0.56, 1.62)	-1.02	(-3.32, 1.29)
Department stores (count/km^2)					1.24	(0.22, 6.95)	0.49	(-8.02, 9.00)	2.22	(0.31, 16.04)	0.72	(-7.22, 8.67)
General mass merchandise (count/km^2)					1.28	(0.02, 87.18)	15.92	(-5.38, 37.22)	2.43	(0.03, 225.69)	19.26	(-0.71, 39.23)
Cognitive enrichment (count/km^2)					0.99	(0.82, 1.21)	0.84	(-0.19, 1.87)	1.05	(0.86, 1.29)	0.99	(0.02, 1.97)
Rural-urban commuting area (RUCA) codes												
Urban					1.0		ref		1.0		ref	
Large rural					1.69	(0.65, 4.39)	-0.92	(-5.66, 3.82)	1.43	(0.52, 3.94)	-2.20	(-6.62, 2.22)
Small rural & isolated					3.22	(0.86, 12.01)	-1.85	(-7.75, 4.05)	2.81	(0.70, 11.28)	-2.93	(-8.43, 2.57)
Region												
Non-stroke belt/buckle					1.0		ref		1.0		ref	
Stroke belt					0.61	(0.30, 1.25)	0.98	(-2.92, 4.88)	0.52	(0.24, 1.15)	0.97	(-2.75, 4.69)
Stroke buckle					0.74	(0.33, 1.69)	1.05	(-3.33, 5.43)	0.70	(0.27, 1.79)	1.00	(-3.29, 5.30)
Neighborhood socioeconomic status					1.09	(1.02, 1.17)	0.27	(-0.06, 0.61)	1.10	(1.02, 1.20)	0.03	(-0.31, 0.38)

Personal crime			1.00	(1.00, 1.00)	-0.01	(-0.02, 0.01)	1.00	(1.00, 1.00)	-0.01	(-0.02, 0.01)
Property crime			1.00	(1.00, 1.01)	0.004	(-0.01, 0.02)	1.00	(1.00, 1.01)	0.001	(-0.02, 0.02)
Extreme cold days			0.98	(0.97, 0.997)	-0.08	(-0.20, 0.04)	0.99	(0.97, 1.004)	-0.06	(-0.17, 0.06)
Mean Variance Inflation Factor	8.70	1.57	2.54		1.89		5.63		1.91	
Pseudo R-squared	0.12		0.08				0.18			
R-squared		0.19			0.05				0.23	

Note. OR=odds ratio; CI=confidence interval; km=kilometer; RUCA=rural-urban community area

Table 2.4 Summary statistics of post-stroke participants included (n = 2,682) and excluded (n = 374) from the study sample, along with test statistics to assess if the mean difference between the participants included and excluded from the study sample.

	Included Sample (n = 374)		Excluded Sample (n = 2,682)		Mean or % difference (Included - Excluded)	Test statistic[a]	p-value
	n	Mean (± sd) or percentage	n	Mean (+/- sd) or percentage			
Individual baseline characteristics							
Age	374	65.89 (7.96)	2,682	69.16 (9.18)	-3.28	6.56	< 0.001
Gender (% Male participants)	374	52%	2,682	50%	2%	-0.92	0.3558
Race (% Black participants)	374	37%	2,682	51%	-13%	4.86	< 0.001
Education						46.81	< 0.001
College graduate or more	125	33%	625	23%	10%		
Some college	120	32%	668	25%	7%		
High school graduate	90	24%	780	29%	-5%		
Less than high school	39	10%	600	22%	-12%		
Missing	0	0%	9	<1%			
Income						59.07	< 0.001
> $75,000	47	13%	172	6%	7%		
$35,000 - $74,999	118	32%	572	21%	11%		
$20,000 - $34,999	112	30%	753	28%	2%		
< $20,000	65	17%	774	29%	-12%		
Refused	32	9%	411	15%	-6%		
Cognition Score	290	5.61 (.72)	1,984	5.35 (.93)	0.25	-4.47	< 0.001
CESD	371	1.19 (2.01)	2,668	1.66 (2.48)	-0.48	3.53	0.0004
PSS	374	3.23 (3.00)	2,680	3.92 (3.23)	-0.69	3.90	0.0001
PCS	360	44.07 (10.87)	2,472	40.82 (11.42)	3.25	-5.08	< 0.001
MCS	360	53.95 (8.53)	2,472	52.33 (10.19)	1.62	-2.88	0.0040
BMI	371	28.99 (5.58)	2,654	29.13 (6.21)	-0.14	0.40	0.6880
Self-reported stroke	374	.7 (.46)	2,679	.62 (.48)	0.07	-2.82	0.0049
Self-report exercise frequency						30.11	< 0.001
None	116	31%	1,190	44%	-13%		
1-3 times per week	129	34%	770	29%	5%		
4+ times per week	125	33%	658	25%	8%		

Missing	4	1%	64	2%			
Self-report fall in past year						9.54	0.0080
Yes	75	20%	740	28%	-8%		
No	298	80%	1,935	72%	8%		
Missing	1	<1%	7	<1%			
Self-report general health						29.25	< 0.001
Excellent	48	13%	213	8%	5%		
Very good	97	26%	528	20%	6%		
Good	134	36%	953	36%	0%		
Fair	75	20%	715	27%	-7%		
Poor	19	5%	266	10%	-5%		
Missing	1	<1%	7	<1%			
Environmental characteristics							
Population density (n/km^2)	374	1236.31 (1640.34)	2,655	1496.13 (2717.23)	-259.82	1.80	0.0714
Park area (proportion)	374	.13 (.27)	2,655	.13 (.29)	-0.01	0.32	0.7492
Public rail (count/km^2)	374	2.35 (4.04)	2,655	2.93 (5.6)	-0.58	1.95	0.0518
Food stores (count/km^2)	374	2.41 (4.85)	2,655	2.69 (4.92)	-0.27	1.01	0.3146
Restaurants and eating places (count/km^2)	374	.23 (.6)	2,655	.23 (.59)	-0.003	0.08	0.9337
Physical activity facilities (count/km^2)	374	.04 (.18)	2,655	.06 (.25)	-0.03	1.89	0.0590
Department stores (count/km^2)	374	.01 (.07)	2,655	.02 (.11)	-0.01	1.32	0.1881
General mass merchandise (count/km^2)	374	.7 (1.45)	2,655	.9 (2.28)	-0.19	1.60	0.1092
Cognitive enrichment (count/km^2)	374	.09 (.76)	2,655	.07 (.56)	0.01	-0.37	0.7089
RUCA codes						5.32	0.256
Urban	306	82%	2,203	82%	0%		
Large rural	42	11%	278	10%	1%		
Small rural	18	5%	136	5%	0%		
Isolated	8	2%	38	1%	1%		
Missing	0	0%	27	1%			
nSES	374	-1.16 (4.86)	2,639	-2.38 (4.25)	1.23	-5.13	< 0.001
Personal crime	374	183.58 (154.74)	2,655	197.21 (153.64)	-13.63	1.60	0.1087
Property crime	374	159.75 (123.59)	2,655	174.78 (141.74)	-15.02	1.95	0.0515

Note: sd = standard deviation; RUCA = Rural-urban commuting area

[a]Test statistic represents a two-sample t-test for difference in means and a Pearson chi-square test statistic for differences in categorical variables between those included versus those excluded from the study sample.

Chapter 3 Features of the Microscale Physical Environment and Trajectories of Physical Quality of Life Post-Stroke

3.1 Abstract

Background: Features of the microscale physical environment are important predictors of mobility disability, participation, and outdoor falls among older adults. However, little is known about the association between these features and post-stroke recovery. Features of the microscale physical environment may be particularly important for people after experiencing a stroke given the sudden, and often dramatic, changes in neurological function. This study examines the association between features of the microscale physical environment and trajectories of physical quality of life (PH-QOL) post stroke.

Methods: A subset of stroke survivors from the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study also enrolled in the ancillary Caring for Adults Recovering from the Effects of Stroke (CARES) project. CARES participants who had an adjudicated stroke event prior to follow-up observations and who did not self-report a stroke at baseline were eligible for the current study. Features of the microscale physical environment surrounding participants' home addresses were audited using Google Earth along three spatial scales: crossing (e.g. curb cuts), segment (e.g. sidewalks), and route (e.g. nearby destinations). PH-QOL was captured using the SF-12 around 6 to 12, 18, 27, and 36 months post stroke. Linear mixed models were used to predict trajectories of PH-QOL over time, controlling for individual characteristics. Chained multiple imputation was used to account for missing predictor variables.

Results: A total of 267 participants were eligible for the current study, among whom 204 had non-missing data. The majority of participants lived in neighborhoods with few features to promote outdoor mobility at crossings, segments, and routes. Average PH-QOL at first contact was 40.1 (standard deviation = 0.7), ten units below the population average. Average PH-QOL was consistent over time. Participants living in environments with some crossing features had a 4.99 (95% CI: 2.50, 7.47) higher PH-QOL score in comparison to participants living in environments with few crossing features, after controlling for socio-demographic characteristics, urbanicity, pre-stroke PH-QOL, and stroke severity. Built environment features along the segment and route were not associated with PH-QOL post stroke.

Discussion: Crossing features are important outdoor characteristics to promote PH-QOL post stroke, over and above individual characteristics. Features of the microscale physical environment at nearby crossings, such as curb-cuts, may provide opportunities for autonomous mobility post stroke and reduce feelings of isolation within one's home, thereby improving PH-QOL. These findings may extend beyond stroke survivors, and be generalizable to other groups with similar functioning impairments. In conclusion, accessibility and safety features at neighborhood crossings have the potential to improve PH-QOL among stroke survivors living in their home community.

3.2 Introduction

Built environment attributes are associated with health behaviors[144] and health outcomes.[145] However, much of the evidence to date is based on studies of the "macroscale" physical environment such as land use, street connectivity, housing, and proximity to destinations that can be obtained through archival data systems (e.g. Geographic Information Systems).[144, 145] Our understanding of the relationship between features of the "microscale" physical environment (e.g. sidewalk quality and presence, street lighting, and pedestrian infrastructure) and health is limited. This is especially true within heterogeneous environments, given the high cost (e.g. time, money) of measuring features of the microscale physical environment. Features of the microscale physical environment can capture the quality of the built environment and may change pedestrian feelings of comfort and safety. These features are often measured using systematic social observation (SSO), a strategy that systematically rates streets surrounding a participant's address (e.g. sidewalk presence, condition of street, traffic signage) during an observation period. With the increase in availability and quality of Google Earth Street View imagery, previous work has demonstrated the validity and reliability of completing SSO virtually.[146-150] Using virtual environmental audits, previous research has found that poor street conditions are associated with participation outcomes and mobility difficulties.[151-153]

The biopsychosocial model of health states that disability is a result of an interaction between individual capacity and surrounding contextual factors (i.e. personal and environmental factors).[8] Emerging literature that focuses on the surrounding environment has broadened public health's potential to engage and equitably support people living with chronic health conditions, a growing population in the United States. People with long-term chronic health conditions have repeatedly pointed to the built environment as an important element for participation within home and community settings.[20] Built environment domains identified as integral to participation among those with chronic health conditions include accessibility of the physical environment, accessible transportation, and access to assistive technology.[19, 20] Microscale physical environment features such as quality of sidewalks, volume of traffic, and street signage, have been associated with mobility disability and participation among those with chronic health conditions[28, 30, 154, 155] and are responsible for the majority of outdoor falls among older adults.[156] These relationships may be more pronounced within the post-stroke population.

While some chronic health conditions, such as arthritis, have slow developing functional changes overtime, others, such as stroke, occur suddenly. Stroke survivors have sudden and often dramatic changes in functioning that can impact a number of domains. After a stroke, people are often left with impairments in mobility, speech, and spatial perceptions that can make it difficult to participate within the community.[65, 66, 157] Therefore, the accessibility and structure of the built environment may be particularly important for this population. After a stroke, people often report dissatisfaction with their outdoor transportation options and access to their communities.[70] Findings from qualitative research have identified features of the built environment that contribute to this dissatisfaction,[70-75] such as features within the physical streetscape (e.g. time available to cross the street, traffic speed).[70-73] In addition, walking long distances is a challenge for community mobility post stroke.[73, 74] Stroke survivors have previously reported that walking long distances to arrive at a bus stop serve as a major barrier to utilize public transportation systems.[73, 74] Using archival data sources, research has shown that Census Tract measures of income, education, and wealth are important drivers to post-stroke quality of life and participation.[158] This seminal work established that neighborhoods are a component of the post-stroke recovery process; however, there is a need to expand on this knowledge and provide insight into which features of the environment may be driving the observed relationship. Thus, there is a need to determine which features of the neighborhood environment are associated with quality of life post stroke and the resulting impact of environmental features on participation.

Although studies have investigated the role of neighborhood-built environments on physical activity and chronic conditions, to our knowledge no study to date has examined the relationship between features of the microscale physical environment and post-stroke quality of life. The objective of this project is to examine features of the microscale physical environment and their interaction with individual impairment to shape trajectories of physical quality of life (PH-QOL) following a stroke. We hypothesize that living in an area with more positive built environment features will be associated with more rapid improvement in PH-QOL. Furthermore, we hypothesize that the magnitude of effect between features of the microscale physical environment and PH-QOL will be greater among those with moderate/severe stroke impairment in comparison to those with mild stroke impairment.

3.3 Methods

3.3.1 Study Population

This study population is nested within a large national cohort study, the Reasons for Geographic and Racial Differences in Stroke (REGARDS).[159] The REGARDS study was established in January 2003 with a goal to examine variables associated with stroke incidence. Potential participants were randomly selected from a commercially available list of people living within the United States. REGARDS intentionally oversampled participants self-identifying as Black and participants with residence within the "stroke belt" region (states of AL, AR, GA, LA, MS, NC, SC, and TN) of the United States.[159] The REGARDS eligibility criteria included age 45 or older, self-identifying as Black or White, having no previous diagnosis of cancer, ability to communicate in English, and not holding residence in or being on a waiting list for a nursing home.[159] The proportion of known eligible participants who agreed to be interviewed was over 60 percent.[159] The sampling, recruitment, and telephone interviewing procedures for REGARDS have been described in additional detail elsewhere.[159] REGARDS administered a computer-assisted telephone interview after enrollment into the study. The computer-assisted telephone interview asked participants their race, gender, age, education, income, and PH-QOL at baseline. Participants were contacted every six months after the baseline assessment and were asked if they had a stroke and/or stroke symptoms since the last phone call. Self-reported stroke symptoms were adjudicated through medical record review. Two trained adjudicators with expertise in stroke, including one neurologist, reviewed and adjudicated index hospitalization-event medical records. The same two adjudicators used diagnostic data and imaging to confirm stroke and record stroke severity.

Starting in August of 2005, REGARDS participants who reported a stroke were potentially eligible for enrollment in the Caring for Adults Recovering from the Effects of Stroke (CARES) ancillary study.[160-162] Participants were eligible for the CARES study if they were community-dwelling, active participants within REGARDS, experienced a stroke, and had a primary family caregiver who would agree to participate in the ancillary study.[160-162] CARES aimed to enroll participants and complete baseline interviews within 6 to 12 months post stroke. Follow-up assessments were then scheduled around 18, 27, and 36 months after the stroke date, totaling up to four longitudinal data points collected within CARES.[160-162] Participants provided written informed consent to be a part of both CARES and REGARDS, and studies were approved by all participating Institutional Review Boards.

3.3.2 Main Exposures

Features of the microscale physical environment were measured using virtual audits of the participants' environment surrounding their home addresses at the time of CARES assessments. Virtual audits completed using Google Street View have demonstrated validity and reliability with in-person audits.[146-149] Trained auditors completed virtual audits using Google Street View from February 2020 through April 2020. Neighborhood environmental features were measured using the Microscale Audit of Pedestrian Streetscapes (MAPS) abbreviated audit tool.[163] The MAPS abbreviated contains 54 items at 3 spatial scales: crossing, street segment, and route. Three neighborhood environment composite scores were examined as primary predictors of post-stroke quality of life: overall crossing score, overall segment score, and overall route score.[163, 164] Greater values of overall crossing score, overall segment score, and overall route score represent environments with more features to promote outdoor mobility; such as curb cuts, sidewalks, and nearby destinations.

The overall crossing score is an average score of features at the intersections that occur at the two endpoints of a participant's street segment. If only one intersection was available, the score represents only one crossing. In the event that the participant's street segment had no intersecting streets within 400 meters, the overall crossing score is missing. The crossing score is the composition of 10 audit items including crossing aids, marked crossing, high-visibility striping, crossing material, curb extensions, pre-crossing curb cut, post-crossing curb cut, traffic circle, pedestrian walk signals, and push buttons. The overall crossing score ranges from 0 to 4 within our sample, but could theoretically range from 0 to 10. For ease of interpretation, this score was dichotomized into crossings with "few" features (0-0.5), and those with "some" features (1-4).

The overall segment score is generated from auditing the street segment on which the participant lives. Features of the segment were audited on the side of the street where the participant's home was located (participant's side of the street) and on the side of the street where the participant's home was not located (non-participant's side of the street). An overall segment score represents the average of segment scores on the participant's side of the street and the non-participant's side of the street. A segment is defined as the street on which a participant lives. A segment is terminated when it encounters intersecting streets on either side of a participant's home or when the segment reaches a maximum length of 400 meters. The overall segment score is the composition of 12 audit items including building setback and height; presence, width, continuity, and maintenance of a sidewalk; whether a buffer is present between the sidewalk and the street; presence of a bike lane; number, spacing, and proportion of area covered by trees; and road width. Both positive (e.g. buffer present between the sidewalk and street) and negative (e.g. poorly maintained sidewalk) features are represented within this score. The overall segment score ranges from 0 to 17.5 within our sample, but could theoretically range from 0 to 24. For ease of interpretation, this score was categorized into tertiles representing segments with "few" (0-4), "some" (4.5-7.5), and "many" (8-17.5) features.

The overall route score captures the features and characteristics along a 400-meter route outside of a participant's home address and is the composition of 30 audit items. The route is defined as the participant street segment plus an additional distance to reach 400 meters in total length. If a street segment is less than 400 meters, additional distance is added in the direction towards the nearest supermarket destination. The overall score is the summary of destinations, land use, streetscape features (e.g. transit stop, street lights, driveways/alleys, trash bins, benches, bike racks), and aesthetics/social environment (e.g. landscaping, buildings well maintained, graffiti, physical disorder). Both positive (e.g. landscape well maintained) and negative (e.g. buildings not maintained) features are represented within this score. The overall route score ranges from 0 to 27 within our sample but could theoretically range from -2 to 34. This score was categorized into tertiles representing routes with "few" (0-5), "some" (6-9), and "many" (10-27) features.

3.3.3 Main Outcome

PH-QOL was self-reported using the SF-12 around 6-12, 18, 27, and 36 months post stroke.[165] PH-QOL has been shown to be a valid and reliable measure of health-related quality of life.[165] The physical composite score, representing PH-QOL, is calculated using weighted item composites from the SF-12. PH-QOL composite scores are standardized to have a population mean of 50 and a standard deviation (sd) of 10 with higher scores indicating better self-reported functioning. In this study, the time of each PH-QOL observation was calculated by taking the date of observation and subtracting the stroke date resulting in the number of days since the stroke. For ease of interpretation, the number of days was divided by 30 to provide an estimate of time that indicates the months since the stroke date.

3.3.4 Effect Modifier

Stroke severity was captured at the time of stroke and was obtained through medical record review. Stroke severity was captured using the National Institutes of Health Stroke Scale (NIHSS), a tool that has shown to be a reliable, valid, and responsive tool to measure stroke severity.[166] NIHSS scores range from 0 to 42 with higher scores indicating a more severe stroke. In the current study, this variable was categorized into mild (≤5) and moderate/severe (>5) stroke based on rehabilitation potential (e.g. motor strength improvement) and acute rehabilitation destination (e.g. home, rehabilitation facility, nursing home).[167, 168]

3.3.5 Covariates

There are a number of individual-level characteristics that serve as covariates within the statistical analysis. The covariates include age, gender, race, education, income, pre-stroke PH-QOL, relationship status, and Rural-Urban Commuting Area code (RUCA). Age at the time of stroke was calculated using baseline self-reported date of birth and date of stroke through medical record review. Self-reported gender (male, female), race (White, Black), education (less than high school, high school graduate, some college, college graduate or more), income (less than $20,000, $20,00-$34,999, $35,000-$74,999, $75,000 or more), and pre-stroke PH-QOL were obtained through the parent REGARDS during the baseline assessment. RUCA values for participant's home location at time of CARES follow-up is a measure of population density, urbanization, and daily commuting. RUCA categorizes census tracts into levels of urbanicity.[132] Using 2010 RUCA 4, primary and secondary RUCA codes were aggregated into four categories (i.e. urban, large rural, small rural, isolated).[132] Due to few observations in small rural and isolated environments, small rural and isolated were collapsed into one category.

2.3.6. Analytic Strategy

A total of 360 post-stroke participants were enrolled in the CARES ancillary study (Figure 3.1). Individual and neighborhood characteristics were summarized for the eligible response sample, complete case sample, and imputed sample. Participants were excluded from the study if they did not have an adjudicated stroke (n=55), the first observation date was greater than 36 months post-stroke (n=10), or if they self-reported stroke at baseline (n=28). Of the 267 eligible participants, 204 had non-missing exposure, outcome, and covariate data and contributed 581 PH-QOL observations.

---- Figure 3.1 ----

Using a sequential model building approach, we assessed the role of overall crossing score, overall segment score, and overall route score on quality of life trajectories. Linear mixed modeling with maximum likelihood estimation was used to examine post-stroke trajectories of PH-QOL over time. The average trajectory of PH-QOL with time was evaluated to determine the appropriate functional form of time to use throughout the model building process. Age was centered at 75 years of age and PH-QOL was centered at the population mean of 50 to allow for meaningful interpretation of the intercept. Within Model 1, the unadjusted effects of crossing, segment, and route were estimated. Model 2 included adjustment for socio-demographic factors (i.e. age, sex, ethnicity, education, and income). Model 3 additionally adjusted for RUCA code, pre-stroke PH-QOL, stroke severity (i.e. NIHSS), and relationship status. Interactions between features of the microscale physical environment and NIHSS were evaluated to assess the potential effect modification by stroke severity on the three primary exposure-outcome relationships. Throughout the model fitting process, Bayesian Information Criterion (BIC) was assessed to provide evidence for the fit of the model, with lower BIC values indicating a better model fit.

Chained multiple imputation (MI) was used to classify potential missing data in predictor variables to reduce potential biases and improve estimate precision.[169] This approach accounts for missing data by representing multiple sets of plausible values. A total of 77 observations (10.1%) had missing values for overall route score, 110 observations (14.4%) had missing values for overall segment score, 111 observations (14.5%) had missing values for overall crossings score, 78 observations (10.2%) had missing values for participant income, 78 observations (10.2%) had missing values for NIHSS, and 20 observations (2.6%) had missing values for pre-stroke PH-QOL. Variables that perfectly predict the missing data were detected within the imputation process. However, perfect prediction creates issues during estimation because lack of uncertainty in the parameters leads to numerical instability.[170] Therefore, an augmented regression was used. Augmented regression uses a small number of additional observations with small weights added to the data during estimation in order to prevent perfect prediction.[170] One hundred datasets were imputed using the PH-QOL outcome, RUCA, education, months since stroke, race, gender, age, and relationship status to inform plausible values. STATA procedure MI ESTIMATE was used, with additional details of this approach available elsewhere.[171]

Due to potential influence of observations beyond 36-months post stroke and heterogeneity of effect among those living in urban settings versus rural settings, the following sensitivity analyses were conducted: (1) including all observations less than or equal to 36-months post stroke (n_i = 204; n_{it} = 574) and (2) including all observations with RUCA code of urban (n_i = 165; n_{it} = 468). Statistical analyses were completed using STATA Version 16.1 (Stata Corporation, College Station, TX).

3.4 Results

Table 3.1 shows the distribution of environmental, socio-demographic, and functional impairment characteristics of the CARES eligible response sample, complete case sample, and the imputed sample. At the first point of contact (6-12 months) participants had an average PH-QOL score of 40.1 (sd=0.7). It appeared that self-reported PH-QOL stayed constant across follow-up observations, with average PH-QOL scores of 39.9 (sd=0.8), 40.9 (sd=0.9), and 40.5 (sd=0.9) at 18, 27, and 36 months post-stroke. The mean age of participants was 74.5 and approximately half of participants were female (49%). A greater proportion of participants self-identified as white in comparison to black (white: 61%; black: 39%). Thirty-four percent of the sample held a college graduate degree or higher, followed by some college education (27%), high school graduate (25%), and less than high school education (14%). The largest proportion (36%) earned between $20,000 to $34,999 annually, followed by 31% earning between $35,000 to $74,999, 22% earning less than $20,000, and 11% earning greater than $75,000 annually (Table 3.1; Imputed Sample). In terms of stroke severity, measured using NIHSS, many participants experienced a mild stroke (87.3%) and few participants in the study sample had a moderate/severe stroke (12.7%). The majority of participants lived near crossings (71.8%), segments (43.4%), and routes (42.4%) with "few" features to promote outdoor mobility (Table 3.1; Imputed Sample).

---- Table 3.1 ----

Table 3.2 presents the sequentially, adjusted linear mixed models examining the association between features of the microscale physical environment and trajectories of PH-QOL post stroke, after accounting for missing data. The overall average value of PH-QOL at 6-months post stroke was 38.96 (Table 3.2, Model 1). For every one-month increase in time, there was a 0.01 (95% CI: -0.06, 0.03) average decline in PH-QOL (Table 3.2, Model 1). Close proximity to crossings with "some" features had 3.90 (95%: 1.14, 6.66) greater PH-QOL at all timepoints in comparison to those living near crossings with "few" features (Table 3.2, Model 1). Although non-significant, built environment features of the overall route were associated with greater PH-QOL. Routes with "some" and "many" features were associated with 1.07 (95% CI: -1.76, 3.91) and 1.41 (95% CI: -1.72, 4.54) greater PH-QOL in comparison to routes with "few" features, respectively. Although non-significant, more segment features near a participant's home were associated with lower PH-QOL values. Segments with “some” features were associated with 0.10 (95% CI: -3.03, 2.83) lower PH-QOL in comparison to segments with “few” features. Segments with “many” features were associated with 1.93 (95% CI: -5.21, 1.36) lower PH-QOL in comparison to segments with “few” features. Crossing features were not associated with trajectories of PH-QOL. Observed associations between features of the microscale physical environment and PH-QOL intercept persisted throughout the model building process, with the magnitude of association for crossing features (e.g. curb cuts) increasing with the addition of covariates.

---- Table 3.2 ----

Within the fully adjusted model, presence of “some” crossings features were associated with 4.99 (95% CI: 2.50, 7.47) greater PH-QOL in comparison to “few” crossing features (Table 3.2, Model 3). In contrast, neither segment (e.g. sidewalks) nor route (e.g. nearby destinations) features were significantly associated with PH-QOL throughout the model-building process. Living in a small rural/isolated setting was associated with 3.66 (95% CI: -7.27, -0.05) lower PH-QOL in comparison to living in an urban setting. While age of stroke did not significantly change the intercept of PH-QOL post stroke ($\beta = -0.09$; 95% CI: -0.26, 0.08), age did change the trajectory of PH-QOL over time within our study sample. One unit increase in age of stroke was associated with a 0.01 (95% CI: -0.01, -0.002) decline in PH-QOL over time. Self-identifying as female or White was associated with 0.80 (95% CI: -1.63, 3.23) and 0.36 (95% CI: -1.99, 2.70) higher PH-QOL in comparison to self-identifying as male or Black, respectively. Moderate to severe stroke was associated with 6.83 (95% CI: -11.09, -2.58) lower PH-QOL in comparison to mild stroke. Lower socioeconomic status (i.e. education and income) at baseline was associated with lower values of PH-QOL post stroke. A one-unit increase in pre-stroke PH-QOL was associated with 0.41 (95% CI: 0.31, 0.52) greater PH-QOL on average post stroke. Results from complete-case analyses produced similar findings (Table 3.3).

---- Table 3.3 ----

Theorized effect modification of NIHSS on the relationship between features of the microscale physical environment and PH-QOL was assessed with the inclusion of interactions between NIHSS and crossing, segment, and route features within separate models (results not shown). An overall likelihood ratio test showed that the interaction between crossing features and NIHSS (x^2=1.79, df=2, p-value = 0.4084), segment features and NIHSS (x^2=4.05, df=4, p-value = 0.3991), and route features and NIHSS (x^2=2.27, df=4, p-value = 0.6856) did not significantly contribute to the overall model fit. There was no evidence that NIHSS modified the relationship between features of the microscale physical environment and PH-QOL. Sensitivity analyses within sub-sets of our population (i.e. observations within 36 months post-stroke and observations with RUCA code urban) resulted in similar effect estimates and overall conclusions for the exposure-outcome relationship.

3.5 Discussion

This study contributes to a growing body of literature examining the role of environmental factors within the disablement process. This longitudinal, observational study of community-dwelling stroke survivors found that crossing features were associated with significantly greater PH-QOL post stroke, but did not change the trajectory of PH-QOL over time. Surprisingly, we did not find segment (e.g. sidewalks) or route (e.g. nearby destinations) features to be important predictors of post-stroke PH-QOL. There was no evidence of interactions between features of the microscale physical environment and individual functioning measured through the NIHSS, as theorized by the World Health Organization biopsychosocial framework of health.[8]

Crossing features were associated with greater PH-QOL, and the effect estimate (β = 4.99) was similar in magnitude (73%) to the effect estimate of a mild stroke in comparison to a moderate or severe stroke (β = -6.83). Furthermore, crossing features promoting outdoor mobility theoretically could range from 0-10, but only ranged from 0-4 in this population. This relative scarcity of crossing features suggests that even small improvements in features of the physical environment are associated with better post-stroke outcomes. After a stroke, neighborhood crossings may serve as connections to neighborhood engagement. Crossings with accessibility features (e.g. curb cuts) provide access to engagement in the community, and when individual safety is questioned because of inaccessible crossings, this may literally cut off a primary conduit between the individual and community. Crossing features may explain differences observed in PH-QOL by neighborhood socioeconomic status found in previous research,[158] as these features represent investment in neighborhood infrastructure, and are likely to be differential based on the wealth and earning of neighborhood inhabitants. Crossings without features that allow for safe mobility in the outdoor environment may not only restrict the individual themselves, but also restrict opportunities for society to benefit from a stroke survivor's knowledge, experience, and insight.

Regarding the null findings, it is unclear why features of segments were not associated with PH-QOL, given the body of work suggesting that sidewalks are important predictors of mobility[51] and participation.[154] Even post-hoc reduction of segment features to a simple categorical value (Yes or No sidewalks), no association with PH-QOL was detected. Replication of these findings in other study samples are needed, particularly among stroke survivors with greater levels of impairment. In addition, features along the route were not associated with PH-QOL. It is possible that this is driven, in part, by the spatial scale used within this study. Aligning with MAPS methodology, destinations within 400 meters of a participant's home were examined. Whether 400 meters is a meaningful distance for walking post stroke may be differential based on individual functioning. Additional research is needed to understand the appropriate spatial scale among populations with varying functional impairments.

3.5.1 Implications

With the advent of readily available imagery, it is now possible to view features of streets and neighborhoods directly outside patients' doors. Virtual imagery can be used to observe features of the outdoor built environment that are available to post-stroke patients. Post-stroke medical care can maximize patient success by virtually traversing the outdoor environment with their patients and developing a plan to engage in the outdoor environment post stroke. This could include identifying routes that contain accessible outdoor features, especially within nearby crossings. Practitioners and patients can integrate innovative technologies into a post-stroke discharge plan, such as personalized wayfinding applications that include both permanent (e.g. absence of curb cuts) and temporary (e.g. ice, snow) obstructions, and suggestions for alternative, accessible routes.[172] However, in order to generate these platforms at the national level, we need to build capacity and collect information on the current accessibility of our neighborhood environments in an openly-available database.

In the event that there are no accessible crossings within a patient's neighborhood this knowledge can be used to empower stroke survivors to make change in their community. Research investigating the role of citizen science has shown that when older adults are armed with the knowledge, training, and guidance for how to make change in their community, they are empowered to identify high-priority, realistic changes that are needed within their neighborhood environment.[173] This same approach can be taken to encourage stroke survivors, and people with disabilities generally, to make changes within the community to promote accessibility and inclusion. Communities thrive when they incorporate fully inclusive environmental designs. In order to build an accessible world, people with disabilities need to be at the table throughout the developmental process. In the interim, while we are building an accessible world, technological innovations (e.g. wayfinding applications) can be used to minimize the social exclusion and isolation currently felt by people with disabilities.

3.5.2 Strengths and limitations

This study has many strengths. We objectively measured microscale-built environment features using Google Street View to capture exposures surrounding stroke survivors' home addresses. Virtual environmental audits provided information of both presence and quality of environmental features, components that are largely absent from archival data sources. Longitudinal data was utilized allowing for the examination of environmental features and their association with PH-QOL trajectories post stroke. A clinically meaningful measure of function, NIHSS, was extracted from participants' medical records to investigate built environment features over and above individual functioning. This also allowed for exploration of effect modification by NIHSS on the built environment and PH-QOL relationship. We controlled for pre-stroke PH-QOL, a measure that is rarely available in observational studies, and allowed for the examination of the relationship between neighborhoods and post-stroke PH-QOL, independent of pre-stroke PH-QOL. Lastly, within this project we had geographic variability to allow for examination of differential relationships between features of crossings, segments, and routes outside of participants' home addresses. However, this study is not without limitations. This study enrolled community-dwelling participants, a healthier sample of stroke survivors. This limits our generalizability to community-dwelling stroke survivors. This study was also limited in its investigation of interactions between NIHSS and built environment features. Attempts to examine relationships within strata of NIHSS were not possible given the small sample size of stroke survivors with moderate/severe stroke severity (complete case n = 22; imputed sample n = 34). Investigation of interactions between NIHSS and environmental characteristics is needed within a sample of stroke survivors with greater heterogeneity in impairment. In addition, there are unmeasured confounders that were not controlled for within this project. For example, information about participants' use of a mobility aid within their neighborhood environment was not captured within this project. Lastly, measures of income and education were captured during baseline interviews. Socioeconomic status is likely to change over time and might change drastically after a major health event.

3.5.3 Conclusion

Features present at crossings were significantly associated with better PH-QOL post stroke, over and above individual socio-demographic characteristics, individual functioning, and pre-stroke PH-QOL. Crossing features did not change the trajectory of PH-QOL over time, and there was no evidence of effect modification by stroke severity. Both segment and route features were not associated with PH-QOL post stroke within our study sample. Environmental context is an important driver of quality of life following a stroke. Access to the neighborhood may be modified through features of the physical environment present at nearby crossings. Inaccessible crossings may cause stroke survivors to question their personal safety in the outdoor physical environment cutting off a primary conduit between the individual and society. An inaccessible environment may lead to restricted lives and lower quality of life post stroke. Interventions to make communities more accessible are of great public health importance, and priority should be placed on features to improve accessibility of neighborhood crossings.

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3.6 Figures and Tables

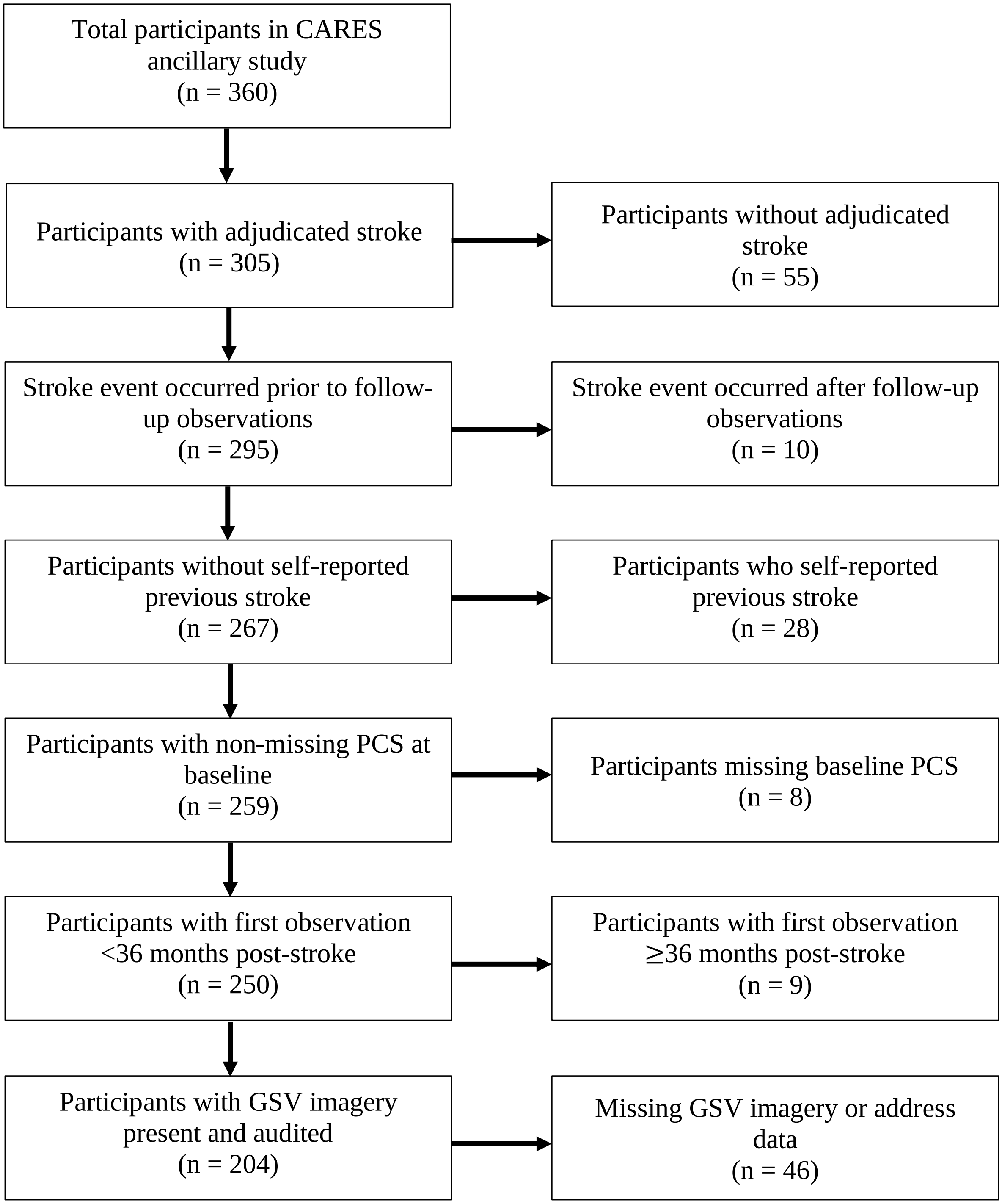

Figure 3.1 Study flowchart of participants from the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study who enrolled in the Caring for Adults Recovering from the Effects of Stroke (CARES) ancillary study and had available environmental data.

Table 3.1 Neighborhood, demographic, and socioeconomic characteristics of response, complete case, and imputed samples.

Sample characteristics	Eligible response sample (n_i = 267; n_{it} = 764)			Complete case sample (n_i = 204; n_{it} = 581)			Imputed sample (n_i = 267; n_{it} = 764)		
	n	Mean/%	SD	n	Mean/%	SD	n	Mean/%	SD
Neighborhood exposures									
Crossings features									
Few	455	70.8%		415	71.4%		548	71.8%	
Some	188	29.2%		166	28.6%		216	28.2%	
Segment features									
Few	272	42.1%		259	44.6%		331	43.4%	
Some	178	27.6%		131	22.6%		187	24.4%	
Many	196	30.3%		191	32.9%		246	32.2%	
Route features									
Few	277	40.9%		235	40.5%		324	42.4%	
Some	217	32.0%		177	30.5%		236	30.9%	
Many	184	27.1%		169	29.1%		205	26.8%	
RUCA code									
Urban	589	77.1%		468	80.6%		589	77.1%	
Large rural	111	14.5%		77	13.3%		111	14.5%	
Small rural/isolated	64	8.4%		36	6.2%		64	8.4%	
Post-stroke PH-QOL									
PH-QOL 6-12 months	267	40.1	10.8	202	39.9	10.5	267	40.1	0.7
PH-QOL 18 months	191	39.9	11.3	150	38.8	11.2	191	39.9	0.8
PH-QOL 27 months	164	40.9	11.2	123	39.7	11.0	164	40.9	0.9
PH-QOL 36 months	142	40.5	10.6	106	40.1	10.8	142	40.5	0.9
Individual exposures									
Age at stroke	267	74.5	7.5	204	74.4	7.6	267	74.5	0.5
Gender (% female)	132	49.4%		99	48.5%		132	49.4%	
Race (% white)	162	60.7%		117	57.4%		162	60.7%	
Education									
<HS	36	13.5%		30	14.7%		36	13.5%	
HS graduate	69	25.1%		48	23.5%		69	25.1%	
Some college	73	27.3%		56	27.5%		73	27.3%	
College graduate+	91	34.1%		70	34.3%		91	34.1%	
Income									
<$20,000	49	18.4%		40	19.6%		58	21.7%	
$20,000-$34,999	86	32.2%		70	34.3%		96	36.0%	
$35,000-$74,999	76	28.5%		58	28.4%		84	31.4%	
$75,000+	26	9.7%		16	7.8%		29	10.9%	
Refused	30	11.2%		20	9.8%				
Pre-stroke PH-QOL	259	46.5	10.2	204	46.6	9.9	267	46.5	0.6
Relationship status									
Divorced	37	13.9%		29	14.2%		37	13.9%	
Widowed	58	21.7%		43	21.1%		58	21.7%	
Other	11	4.1%		10	4.9%		11	4.1%	
Married	161	60.3%		122	59.8%		161	60.3%	
NIHSS									
0-5	199	75.5%		148	72.6%		233	87.3%	
5+	27	10.1%		22	10.8%		34	12.7%	
Missing	41	15.4%		34	16.7%				

Note: n_i = number of total participants; n_{it} = number of total observations; SD = standard deviation; RUCA = rural-urban commuting area; PH-QOL = physical quality of life; HS = high school; NIHSS = National Institutes of Health Stroke Scale

Table 3.2 Associations between neighborhood built environment features, sociodemographic characteristics, and functional impairment with post-stroke physical quality of life, accounting for missing data (n_i = 267; n_{it} = 764).

	Model 1			Model 2			Model 3		
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
Intercept (6 months PS)	38.96	(36.99, 40.92)	<0.01	43.47	(38.82, 48.12)	<0.01	43.61	(39.34, 47.88)	<0.01
Neighborhood exposures									
Crossings features									
Few	ref			ref			ref		
Some	3.90	(1.14, 6.66)	0.01	4.31	(1.6, 7.01)	<0.01	4.99	(2.50, 7.47)	<0.01
Segment features									
Few	ref			ref			ref		
Some	-0.10	(-3.03, 2.83)	0.94	-0.04	(-2.86, 2.79)	0.98	-0.22	(-2.75, 2.30)	0.86
Many	-1.93	(-5.21, 1.36)	0.25	-1.46	(-4.64, 1.72)	0.37	-1.33	(-4.23, 1.57)	0.37
Route features									
Few	ref			ref			ref		
Some	1.07	(-1.76, 3.91)	0.46	1.31	(-1.40, 4.03)	0.34	0.74	(-1.71, 3.19)	0.55
Many	1.41	(-1.72, 4.54)	0.38	1.51	(-1.54, 4.56)	0.33	0.78	(-2.02, 3.57)	0.59
RUCA code									
Urban							ref		
Large rural							0.50	(-2.38, 3.39)	0.73
Small rural/isolated							-3.66	(-7.27, -0.05)	0.05
Individual exposures									
Age at stroke[a]				-0.09	(-0.28, 0.09)	0.32	-0.09	(-0.26, 0.08)	0.30
Gender (female)				-1.59	(-4.02, 0.85)	0.20	0.80	(-1.63, 3.23)	0.52
Race (white)				1.14	(-1.47, 3.75)	0.39	0.36	(-1.99, 2.70)	0.77
NIHSS									
0-5							ref		
5+							-6.83	(-11.09, -2.58)	<0.01
Education									
<HS				-0.72	(-4.78, 3.35)	0.73	-1.20	(-4.76, 2.36)	0.51
HS graduate				-3.53	(-6.7, -0.37)	0.03	-2.37	(-5.14, 0.41)	0.09
Some college				-1.69	(-4.64, 1.26)	0.26	-2.12	(-4.68, 0.44)	0.10
College graduate+				ref			ref		
Income									
<$20,000				-6.25	(-10.98, -1.52)	0.01	-2.82	(-7.11, 1.47)	0.20
$20,000-$34,999				-3.33	(-7.40, 0.73)	0.11	-1.84	(-5.46, 1.77)	0.32
$35,000-$74,999				-3.03	(-6.94, 0.89)	0.13	-1.79	(-5.25, 1.67)	0.31
$75,000+				ref			ref		

Pre-stroke PH-QOL[b]							0.41	(0.31, 0.52)	<0.01
Relationship status									
Divorced							0.31	(-2.92, 3.55)	0.85
Widowed							-1.08	(-4.09, 1.92)	0.48
Other							-0.03	(-5.22, 5.15)	0.99
Married							ref		
Time (months PS)[c]									
Times (months)[c]	-0.01	(-0.06, 0.03)	0.58	-0.01	(-0.05, 0.03)	0.62	-0.01	(-0.05, 0.03)	0.64
Time[c] * Age[a]				-0.01	(-0.01, -0.002)	0.01	-0.01	(-0.01, -0.002)	0.02

Note: CI = confidence interval; PS = post-stroke; RUCA = rural-urban commuting area; HS = high school; NIHSS = National Institutes of Health Stroke Scale

[a]Age centered at age 75

[b]Pre-stroke physical quality of life centered at 50, the population mean value

[c]Time measured as months since stroke occurrence

Table 3.3 Associations between neighborhood built environment features, sociodemographic characteristics, and functional impairment with post-stroke physical quality of life, complete case analysis (n_i = 204; n_{it} = 530).

	Model 1			Model 2			Model 3		
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
Intercept (6 months PS)	38.36	(36.08, 40.64)	<0.01	42.77	(36.80, 48.73)	<0.01	41.94	(36.42, 47.46)	<0.01
Neighborhood exposures									
Crossings features									
Few	ref			ref			ref		
Some	5.42	(2.19, 8.66)	<0.01	5.99	(2.80, 9.19)	<0.01	6.10	(3.23, 8.96)	<0.01
Segment features									
Few	ref			ref			ref		
Some	-0.73	(-4.19, 2.74)	0.68	-0.58	(-3.93, 2.77)	0.73	-0.83	(-3.75, 2.10)	0.58
Many	-4.08	(-7.87, -0.28)	0.04	-3.25	(-6.95, 0.44)	0.08	-2.38	(-5.67, 0.90)	0.15
Route features									
Few	ref			ref			ref		
Some	1.61	(-1.63, 4.86)	0.33	1.25	(-1.9, 4.40)	0.44	0.70	(-2.09, 3.50)	0.62
Many	3.47	(-0.10, 7.05)	0.06	3.23	(-0.27, 6.73)	0.07	2.24	(-0.93, 5.41)	0.17
RUCA code									
Urban							ref		
Large rural							1.05	(-2.40, 4.49)	0.55
Small rural/isolated							-5.08	(-9.46, -0.70)	0.02
Individual exposures									
Age at stroke[a]				-0.08	(-0.28, 0.13)	0.46	-0.07	(-0.26, 0.12)	0.46
Gender (female)				-1.10	(-3.81, 1.61)	0.43	1.13	(-1.66, 3.91)	0.43
Race (white)				1.12	(-1.84, 4.08)	0.46	0.99	(-1.67, 3.64)	0.47
NIHSS									
0-5							ref		
5+							-6.58	(-10.85, -2.30)	<0.01
Missing							0.19	(-2.96, 3.33)	0.91
Education									

<HS				0.78	(-3.56, 5.12)	0.72	0.18	(-3.59, 3.96)	0.92
HS graduate				-2.53	(-6.07, 1.01)	0.16	-2.02	(-5.12, 1.08)	0.20
Some college				-1.32	(-4.59, 1.95)	0.43	-2.23	(-5.08, 0.62)	0.13
College graduate+				ref			ref		
Income									
<$20,000				-8.57	(-14.27, -2.87)	<0.01	-3.80	(-8.96, 1.37)	0.15
$20,000-$34,999				-3.28	(-8.37, 1.81)	0.21	-1.21	(-5.71, 3.29)	0.60
$35,000-$74,999				-3.09	(-8.05, 1.88)	0.22	-1.14	(-5.46, 3.18)	0.60
$75,000+				ref			ref		
Refused				-3.30	(-9.62, 3.02)	0.31	0.20	(-5.33, 5.72)	0.94
Pre-stroke PCS[b]							0.43	(0.31, 0.55)	<0.01
Relationship status									
Divorced							-0.23	(-3.86, 3.41)	0.90
Widowed							-0.63	(-4.06, 2.80)	0.72
Other							1.10	(-4.34, 6.54)	0.69
Married							ref		
Time (months PS)[c]									
Times (months)[c]	-0.04	(-0.10, 0.01)	0.14	-0.05	(-0.10, 0.01)	0.08	-0.05	(-0.11, 0.003)	0.07
Time[c] * Age[a]				-0.01	(-0.02, -0.002)	0.01	-0.01	(-0.02, -0.0003)	0.04

Note: CI = confidence interval; PS = post-stroke; RUCA = rural-urban commuting area; HS = high school; NIHSS = National Institutes of Health Stroke Scale

[a]Age centered at age 75

[b]Pre-stroke physical quality of life centered at 50, the population mean value

[c]Time measured as months since stroke occurrence

Chapter 4 Stroke Survivors' Lived Experience in the Outdoor Environment

4.1 Abstract

Background: Stroke survivors face unique challenges in the outdoor environment when returning to their home community following a stroke. Challenges include navigating uneven terrain, social stigma, and adapting to changes in functioning. Outdoor environments may serve as potential points of intervention to promote independence and participation post stroke. This study aimed to understand lived post-stroke experience in the outdoor environment as it pertains to independent mobility.

Methods: Participants were eligible if they were over the age of 45, could communicate in English, live outside a nursing home, able to walk safely outdoors, were a minimum of six-months post stroke, and had no severe cognitive impairment. Twenty stroke survivors were interviewed (8 males, 12 females; mean age 64.2 years: range 45 years – 90 years). Audio files were transcribed, codes were generated and applied to transcripts, and themes were generated using interpretative phenomenological analysis and interpretation.

Results: Post-stroke experiences in the outdoor environment were multidimensional. Three themes emerged from the stroke survivors' description of personal experiences in the outdoor environment. These themes included feelings of vigilance, employing adaptation strategies, and management of dynamic relations between the self and context.

Discussion: The findings highlight the post-stroke experience traversing the outdoor environment. Investing in the public outdoor environment to remove barriers and install facilitators could reduce feelings of apprehension and hypervigilance while walking in the

outdoor environment. Future research is needed to evaluate the role of environmental interventions on hypervigilance in the outdoor environment post stroke.

4.2 Introduction

Seven million people in the United States have experienced a stroke.[174] It is anticipated that an additional 3.4 million new stroke cases will occur by 2030, making stroke survivors 3.9 percent of the United States population.[174] Advancements in acute care and an aging population are driving observed growth in stroke prevalence, and innovative strategies are needed to optimize life after stroke. The growth of the post-stroke population, along with the lasting effects of stroke on long-term functioning, make stroke one of the leading causes of disability in the United States.[174] Strategies to support safe, independent community living are of great social and economic importance.[33-35] Safe and independent community living is dependent on a number of individual and contextual factors. While previous research has investigated the role of contextual factors within the indoor environment for post-stroke independent living, the role of contextual factors within the outdoor environment on post-stroke experience is largely unknown. Components of the social, built, and natural outdoor environment may contribute to successful home transitions post stroke. Due to stroke's sudden onset, the outdoor settings may have met functioning needs pre-stroke, but could result in unanticipated challenges when returning home post stroke. Previous work has shown that ability to independently navigate the neighborhood environment by foot or motorized transit allows for individual choice, access to surrounding resources, and facilitates engagement in valued life activities among older adults.[38, 39] These findings may extend to stroke survivors, making the outdoor environment of a home an important component of community living and independence. The need to focus on the outdoor environment is underscored by the fact that over half of stroke survivors (56%) return directly to their home community following a stroke.[174]

After a stroke, individuals may be more susceptible to environmental barriers due to changes in neurological function.[53-55] For example, people often have difficulty dorsiflexing their ankle, leading to foot drop post stroke. This physical impairment can lead to greater risk of falls or injuries depending on the sidewalk quality in the outdoor environment. The interaction between an impairment in dorsiflexion with an uneven or cracked sidewalk may lead to an inability to safely walk in the outdoor environment, resulting in mobility disability. However, if the sidewalk was smooth and flat, the individual could interact with an enabling environment to result in the maintenance of balance and ability to walk in the outdoor environment. Thus, identifying the salient factors and ultimately changing the environment to be more accessible has the potential to increase independent mobility, community living, and encourage health behaviors to prevent recurrent strokes.[50, 56]

The large number of stroke survivors returning home underscores the importance of identifying environmental factors that affect independent mobility.[60, 61, 63] Among Medicare patients discharged from the hospital after suffering a stroke, approximately 56 percent of patients return directly home, as opposed to 19 percent discharged to an inpatient rehabilitation facility and 25 percent discharged to a skilled nursing facility.[60, 64] It is of critical public health importance that stroke survivors feel supported to move within their home community. An environment lacking features that support independent mobility and long-term functioning may lead to additional assisted living or institutional care needs. To reduce reliance on these care systems and optimize independence, it is necessary to understand what components of the environment are important to support stroke survivors aging in place. Using the International Classification of Functioning, Disability and Health (ICF) framework, disability results from an interaction between individual functioning and environmental factors.[8] Greater understanding of interactions between outdoor environments and individual functioning is critical for improving health and rehabilitative outcomes among stroke survivors.

Despite the fact that international organizations have emphasized the importance of environmental factors for understanding disability, little is known about which environmental attributes are required for safe and independent living post stroke.[40, 47, 175] Current systematic reviews of the literature found that environmental factors were rarely investigated in relation to post-stroke participation.[175, 176] Recent advances in stroke research have identified environmental factors relevant for stroke survivors including domains of the built, natural, social, political, and socioeconomic outdoor environments.[177] While existing research has investigated barriers and facilitators of post-stroke participation more generally,[178-180] additional research is needed to understand meanings and mechanisms through which environments shape post-stroke experience. Meanings and mechanisms are difficult to capture using a quantitative approach.[181] While quantitative research methods have advantages (e.g. having consistent, precise and reliable data), these methods often have to reduce the complexity of experiences.[181] Therefore, quantitative methods alone are not robust enough to fully describe post-stroke lived experiences in the outdoor environment.

Inquiry into how environments shape post stroke experiences in outdoor environments can be revealed using qualitative approaches. How and why stroke survivors engage with the outdoor environment directly outside of their home is largely understudied. Qualitative research provides rich understanding of stroke survivors' perspectives of and experiences within the outdoor environment. This scientific approach can answer questions about meanings and mechanisms, contextualize the lived experience, and generate new hypotheses to be tested in subsequent research.[182, 183] To fill this gap in knowledge, we aim to understand lived post-stroke experience in the outdoor environment as it pertains to independent mobility. Specifically, we seek to understand how stroke survivors' lived experience is shaped by the outdoor environment around their home.

4.3 Methods

This qualitative study used the method of Interpretative Phenomenological Analysis (IPA).[184] Using semi-structured interviews, the goal of this project was to describe post-stroke mobility in the outdoor built environment. The IPA approach draws on participants lived experiences, perceptions, thoughts, and feelings, and is suggested to be particularly useful when exploring how participants make sense of the world.[184] This study was approved by the participating Institutional Review Board.

4.3.1 Sample Population

Participants were recruited through an existing registry of potential research subjects at a large academic medical center. Potential participants were eligible to participate if they were over the age of 45, able to communicate in English, have residence outside of a nursing home, self-report ability to walk safely outdoors, at least six months post-stroke event, and have less than three errors on the six-item cognitive impairment screener.[185] Screening for eligibility took place over the phone using a standardized screening instrument with questions about the six eligibility criteria. In the event that a potential participant was eligible to participate in the study, informed consent was obtained and a self-report questionnaire was completed. Written or verbal informed consent was obtained prior to data collection. A global pandemic began during data collection, therefore, the first three participants provided written informed consent, completed the self-report questionnaire in writing, and were interviewed in person; while the remaining 17 participants provided verbal informed consent over the phone, completed an online self-report questionnaire, and were interviewed over the phone or using Zoom Video Communications (Zoom, San Jose, California).

4.3.2 Data collection procedures

Participants who provided informed consent completed a self-report questionnaire one to two weeks prior to the semi-structured interview. Self-reported sociodemographic information included gender (male, female), age, race (American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, Black/African American, White), ethnicity (Hispanic/Latino, Non-Hispanic/Latino), education (less than high school, high school diploma/GED, some college, college degree, higher than college degree), annual income (<$15,000, $15,000-$39,999, $40,000-$59,999, $60,000+), occupation (working for pay, student, retired from a paid job, looking for work/unemployed, unable to work because of health problems, keeping house), and relationship status (never married, married, common law marriage, divorced, separated, widowed). Quality of life was captured using the SF-12 questionnaire, a measure that has been shown to be a valid and reliable assessment of health-related quality of life.[165] The physical and mental composite scores were calculated using weighted item composites from the SF-12. Composite scores are standardized to have a population mean of 50 and a standard deviation of 10, with higher scores indicating better self-reported functioning. Participants reported the amount of difficulty with activities of daily living and instrumental activities of daily living. Activities of daily living included the following tasks: getting out of bed or chair, eating, dressing, bathing, and toileting. Instrumental activities of daily living included the following tasks: doing household chores, purchasing items at the store, planning and preparing meals, managing money, using a telephone/cell phone, taking medications on time, and traveling by vehicle places beyond walking distance.[186] Mobility device use, type, and frequency of use was also captured using self-report.

Participants who completed the self-report survey were contacted and an appointment was arranged for face-to-face, telephone, or video communications interview. The semi-structured interview guide was developed by the first author (ET) with guidance from all members of the research team and was informed by theorized interactions articulated in the ICF framework.[8] Topics covered in the interviews included typical encounters and responses while navigating the outdoor environment, priorities when choosing a neighborhood to live in, and successful strategies applied while navigating the outdoor environment post stroke. Interviews were kept as open-ended as possible, and participants were asked to expand on their thoughts using additional prompts and probing to gain a deeper understanding of the participants' experience within the outdoor environment post stroke. In some cases, this included guiding participants to reflect on their previous experiences (e.g. prior to stroke, prior to the pandemic) and identify changes in their experiences in the outdoor environment. Prompts and probing allowed for deeper exploration of how and why lived experiences in the outdoor environment changed over time. As the study progressed, topics arising from previous interviews were explored with subsequent interviewees. This allowed for discovery and refinement of categories and themes that emerged from the interviews. Interviews lasted between 51 and 147 minutes, all interviews were audio-taped and transcribed verbatim.

4.3.3 Data analysis

A thematic approach to IPA was applied for data analysis. This multi-stage analytic coding strategy was used to identify codes and themes within these data; all analyses were carried out by the first author (ET).[187] Analysis of these data followed the six steps outlined by

Smith and Shinbourne.[184] (1) Transcripts were read and reread to become familiar with the data. (2) All transcripts were imported into nVivo qualitative analysis software (QSR International, Melbourne, Australia), a qualitative data management software package. Within nVivo, coding was used to identify sentences or phrases and organize sentences or phrases into initial common themes. (3) Clustering was used to identify emergent themes from common themes and subthemes. Abstraction and compression of common themes and subthemes allowed for the identification of patterns that lead to overarching themes.[184] (4) Iteration was used to refine each overarching theme and its components. The iterative process included several revisions, including checking themes, subthemes, and quotes. (5) The research theme developed a narrative that is grounded in the findings. The narration process includes describing and illustrating themes using data and quotes. (6) The final step in the analysis was the contextualization of the findings. Within this step, study findings were interpreted in relation to what is already known in the current body of literature.

IPA thematic analysis transitions from descriptive to interpretive during the analytic process. In accordance with the IPA approach, the data analysis describes the subjective human experience. The first author (ET) used repeated, reflective engagement while conducting participant interviews and throughout data analysis.[188] The practice of reflexivity (i.e. examination of one's own beliefs, judgements, and practices) permits the researcher to consider how their subjective worldview may shape the research process. Reflexivity during data collection and analysis acknowledges the individual biases and perspectives that impact the research findings.[189]

4.4 Results

Twenty participants, 8 men and 12 women, completed the semi-structured interviews. Table 1 presents the sociodemographic information of participants. Participants were between the ages of 45 and 90, with an average age of 64 years. The majority of participants identified as Non-Hispanic White (89.5%), followed by Non-Hispanic Black (10.5%) and Hispanic White (5.6%). Participants within the study sample were highly educated, with half of participants earning a college degree or more. Participants provided diverse perspectives in terms of annual income earnings, occupation, and relationship status. Twenty-five percent of participants reported foot pain that their limited walking in the past year, 30% of participants reported a serious fall in the past year, and physical quality of life composite score (x = 34.7) and mental quality of life composite score (x = 47.7) were well below the population average of 50.[190] Lastly, 30% of participants reported difficulties with activities of daily living and 50% of participants reported difficulties with instrumental activities of daily living.

4.2. Interview findings

Three main themes emerged in the qualitative data that captured the lived post-stroke experience in the outdoor environment as it pertains to independent mobility. As voiced by the participants here, experiences moving in the outdoor environment included vigilance, adaptation, and managing dynamic relations.

4.4.1 Vigilance

I always try and think about what could possibly go wrong. Thinking that, 'if it could possibly go wrong, it will.' (male, age 70)

Vigilance, keeping careful watch for possible danger or difficulties, in the outdoor environment shaped post-stroke experience in the surrounding neighborhood. Heightened awareness in the outdoor environment is required to maintain safety. Participants described the need to prepare mentally and emotionally prior to walking in the outdoor environment. Take, for example, this participant describing her anticipation of the seasonal changes to the outdoor environment:

> *When you start talking about the fall and the winter months, it becomes very scary, humbling, and often embarrassing. Because the trip hazards are different, and there, it's that little patch of ice that someone didn't put any salt down on, that my vision might not catch, but my leg will. And so, you know, it becomes this, this issue that you have to really learn how to be very vigilant and how to look around.* (female, age 45)

She describes that trip hazards in the outdoor environment can call into question her individual safety and societal views of her functioning. An environmental trip hazard can be "scary" because of the potential loss of balance, subsequent fall, and resulting injuries. Mental preparation for these encounters is needed to employ successful strategies used in the past to navigate a trip hazard. These features can also be "humbling" because of the biographical work being done to understand their body's physical functioning within the outdoor environment. Post-stroke and pre-stroke functioning differ, and subsequent interactions of her new self with the outdoor environment can be psychologically demanding. Lastly, performance in the outdoor environment can be "embarrassing" because failed attempts call into question individual capacity and societal roles. Emotional preparation for difficult encounters is needed in order for stroke survivors to reject the embodiment of a restricted self. Increased vigilance protects the individual from environmental risks.

Acts of vigilance in the outdoor environment are on a spectrum. On the low end of the vigilance spectrum, individuals experience thoughtless, inattentive movement while navigating the outdoor environment. Moderate levels of vigilance in the outdoor environment allow individuals to safely maneuver environmental risks. On the high end of the vigilance spectrum, environmental risks induce fear and stagnation restricting individual participation. This is illustrated in the following participant description of her reasoning for not walking in the neighborhood:

> *Well in in this neighborhood I have walked, not at all. And that would be, because the pavement and the sidewalks are in desperate need of being repaired, and I do not feel safe terrain-wise. The furthest I have walked is in the empty lot next door to talk with new neighbors a couple months ago. I would not feel safe walking in this neighborhood.* (female, age 56)

Throughout the interview, the persistent role of the outdoor environment restricting participation is striking. The participant frequently describes the restrictions she feels in her current environment as "feeling stuck." The deteriorating physical environment has heightened the participant's vigilance and taken away her independent movement throughout the neighborhood. Similar to the above passage, vigilance was often described in relation to fears of falling in built environments lacking accessible infrastructure. Vigilance was grounded in potential injury from a fall and if help would be available in the outdoor environment. These accounts were repeatedly reported in outdoor environments with uneven surfaces and steps.

Environmental triggers that increased vigilance leading to restricted participation took on both physical and social forms. After a stroke, participants described being much more perceptive to environmental conditions such as crowds, traffic, and other pedestrians. Social environmental conditions led to feelings of overwhelm and hypervigilance due to numerous environmental inputs. One participant describes an encounter with their outdoor environment as:

> *I never realized I'd be afraid to walk, you know, and so when I, when I, when I mean everything's nice and quiet, and I know where everything is, and there's not a lot of changes or lot of different input, I'm good. But like I said, when I get closer to that, that busy street and even though we have, I like it because there's more to see as opposed to the same everything else. Yeah, I can feel that I can get my level of nervousness increases, and even like the leaves when they're wet, I'm always afraid I'm going to fall into the street. It's, it's not, fortunately it's not happened, but I think because of the busyness of it, and you could still get hit on a side street, I know that. But I think, psychologically, I start getting a little more apprehensive when there's, when there's, the threat level increases. When there's more cars, more kids on their bicycles and everything else. I see, I feel like the threat to my stability is increased.* (female, age 57)

This narrative illuminates the interaction of social and physical environments which lead to a heightened state of vigilance. Beyond perceived threats to stability, participants also recounted that heightened vigilance in response to social environmental conditions was driven by decreased capacity to get away if there was danger (e.g. assailant). Lack of confidence in ability to flee from danger can lead to restricted participation in the outdoor environment. Participants described how accompaniment increased willingness to engage in outdoor travel. While there were numerous accounts of environmental conditions increasing vigilance in the outdoor environment, there were also components of the outdoor environment that reduced vigilance post-stroke.

Characteristics of the physical environment can decrease vigilance in the outdoor environment. Encounters with environmental barriers can be mentally surmounted in the presence of other environmental supports. When asked how he would feel entering a building with a ramp compared to entering a building with stairs, one participant shared:

> *I mean the qualifier, the qualifier to both of those is, where there's a handrail. You know, if there's a handrail I can handle the stairs. And, I would prefer stairs with a handrail to ramp, a ramp without a handrail. (male, 68)*

Handrails were a qualifying component of the environment needed to feel safe while navigating stairs. The participant language provides emphasis to the important role of handrails in his outdoor environmental experience. By stating "the qualifier to both of those is, where there's a handrail," the implication is that without the handrail present, he would not attempt to navigate stairs. By saying "I can handle the stairs," the participant describes heightened sense of vigilance in the presence of stairs. However, the participant is able to overcome the heightened vigilance when a handrail is present in the environment.

Participants who had greater familiarity with the outdoor environment described feelings of vigilance with less intensity. Familiarity with the outdoor environment brought confidence that they could navigate the outdoor space safely and anticipate or visualize beforehand what types of barriers they would encounter in the outdoor environment. For example, one participant described being vigilant during her recovery period, but with increased familiarity she was able to decrease the sense of vigilance to bring about confidence while navigating the outdoor environment:

> *The more often I did it [went into my neighborhood] after my stroke, the better it got. Familiarity, I think probably just like the same thing if you're, if a child*

is walking for the first time, that the more often they do it, the. Success, to me, breeds success. The more time, the more time, so I was able to do it and actually get home and, you know, I get around, I think I walked probably about the same, and I, I think actually, to be honest, I think I probably walk more because I wanted to make sure I got to the point where I was familiar with it and that I didn't feel those same horrible feelings like there was just a huge open space, so I think I forced myself to walk more than I probably would have under most circumstances, so you know that's in that I say, I'd say I walked more. (female, age 57)

The participant explicitly said that her walking behavior increased after experiencing a stroke. This behavior change was motivated by the desire to become more familiar with her surroundings. When she described becoming familiar enough "to not feel the same horrible feelings," she articulated feelings of vigilance when first encountering the outdoor environment after her stroke.

Vigilance is a powerful driver of outdoor environmental experiences post-stroke. The trajectory of recovery post-stroke is shaped, in part, by feelings of safety in the outdoor environment. Vigilance can be a useful protective mechanism for safety in the outdoor environment. However, chronically high levels of vigilance can hamper post-stroke recovery and lead to persistent restricted participation.

4.4.2 Adaptation

Be patient, things are not gonna happen as quickly as they used to, but be persistent. (male, age 66)

Adaptation, the act of modifying or making an adjustment when faced with challenges in the outdoor environment, is crucial for independent outdoor mobility post-stroke. This included adapting the outdoor environment to meet individual needs. Participants described traveling to another location to walk because the environment directly outside of the home did not support independent mobility. For example, one participant describes why he and his wife do not walk in his neighborhood:

> *That does stop us, you know, walking around the neighborhoods, not my feeling confident in um, the surfaces or the ability to take a rest.*

The participant shared his preference for traveling to a nearby park to walk:

> *There are a lot of benches you can sit on. And, you know, after a while, I'm able to pace myself, I know, yeah, so I'm better able to uh, to walk because I'm confident I can stop and rest.* (male, age 68)

The park provided available seating, and the participant modified his outdoor environment to meet his functioning needs. His previously expressed concern of "not feeling confident" in his "ability to take a rest" was modified by the availability of seating at the park. Features at the park allowed this participant to adapt his walking pace and safely navigate from one bench to another. Seating was an environmental feature which provided necessary support for the participant when he was fatigued and if muscle spasticity were to increase while walking in the outdoor environment.

Experimentation is integral to identify adaptation strategies for independent mobility. Variability in individual functioning requires diverse strategies to achieve independent outdoor mobility. Successful strategies were developed over time with continuous modification. Take this participant's advice for how to overcome difficulty walking in the neighborhood post-stroke:

I would say, it, when you start, start doing short, a short, for a short interval. Try it out. And if it works, then, in, in, you know, increase your capacity by going a little farther. But, but don't take risks, but do try to expand your horizons by trying new things by doing a little bit more each time and then just praise yourself when you, when you accomplish something because it's really a good thing. (female, age 90)

Adapting to meet the demands of the outdoor environment does not follow a standardized approach, and people experimented to identify strategies that worked well for them. Modification is needed in order to meet the needs of a changing body and changing environmental conditions. The participant suggests to "try and expand your horizons"; in other words, experimentation is critical for the formation of and modification to independent mobility in the outdoor environment. He also underscores celebrating successful adaptation to "praise yourself when you accomplish something." Celebration of successful adaptation can support recall for future situations and motivates attempts to engage in outdoor walking behavior.

Participants who viewed barriers as opportunities to improve individual function embraced adaptations. Finding the challenge or opportunity in approaching barriers required capacity to overcome the barriers. As one participant described, successful performance in challenging outdoor environments was perceived as a form of physical therapy to improve her mobility and balance:

I think what might be called kind of challenges, like not having a sidewalk and walking on uneven ground and having to take the stairs, I think actually have been partially instrumental in me recovering. You know, it's forced me to be able to do that, walk on uneven ground and take the stairs every day and, I

> *think it would have been easy, just living in a one-story house to just not do those kind of challenges. So, I thought of it as my physical therapy.* (female, age 67)

Within this excerpt, the participant describes significant barriers in her environment but is able to adapt to overcome the barriers. She attributes barriers as "instrumental in me recovering" and "my physical therapy." Successful adaptations to meet the needs of a challenging environment resulted in maintaining participation and supported reconstruction of the pre-stroke self.

Post-stroke adaptation in the outdoor environment is bidirectional. Individual strategies can be adapted to meet the demands of an outdoor environment. Additionally, outdoor environments can be adapted to meet individual needs (e.g. traveling to a safe-walking destination, improving sidewalk quality). Adaptation supports continued post-stroke participation in the outdoor environment due to frequent changes in individual function and the surrounding context.

4.4.3 Management of dynamic relations

> *In any context, when you have to transition it can be difficult.* (male, age 68)

When navigating the outdoor environment post-stroke, participants described having to manage changes occurring within their body as well as the world around them. This required rapid integration of information to make decisions about movement. Stroke survivors manage changes in functioning between their pre-stroke self and post-stroke self. Perceptions of the environment resulted from the dynamic relationship between participant functioning and the outdoor environment. Changes in individual functioning shaped the way in which participants perceived their neighborhood. When asked if her feelings about the neighborhood environment changed overtime, one participant shared:

> *I think many people in the first six months do recover, you know, some ability, and for me, that definitely happened. Where the things that were really limiting I was able to work through, so my, I think if you looked at, like if you were to chart out a graph of my neighborhood. And the way I felt about it, it would be like pre-stroke: Fantastic, great! Immediately after stroke: Oh my gosh, what am I in? And then later, being able to reflect, then you know it would drop drastically on that graph. And then later, it goes back up, maybe not to the full amount that I used to think it was, it is not, it still has some accessibility concerns for me.* (female, age 45)

The participant offers a visual description of her dynamic perception of the environment while her functioning changed. She shared that pre-stroke her feelings about the environment were "fantastic," driven by a lack of perceived barriers. Immediately after stroke, the participant asks the rhetorical question "what am I in?" suggesting her search for anchors of predictability in her environment.[191] With time the participant achieves a redefined self where her perception of the outdoor environment is "not to the full amount" of her pre-stroke self, but that "it goes back up" from the perception of an inaccessible outdoor environment felt immediately following her stroke.

Moreover, daily functioning within the post-stroke self is also dynamic. With one participant reporting that "normal changes for me from day to day." Take, for example, this participant describing her performance walking in the outdoor environment:

> *I guess I'm being more careful, probably, than I ever have been in that I know if I'm like fatigued, that I have to raise that level of care that I have to be, be a little more exacting in my motion.* (female, age 57)

The participant compared her post-stroke performance with her pre-stroke self. Her statement suggests that she performed at a different level of functioning post-stroke, which demanded "more careful" motion than ever before. She also indicated the level of functioning within her current post-stroke self is dynamic. Observing changes in her functioning, such as fatigue, she integrated this information and changed her performance to be "more exacting in my motion."

The outdoor environment is dynamic and changes the experience of a stroke survivor. The environment can change rapidly (e.g. rain changing the outdoor surface instantly) or slowly over time (e.g. seasonal changes) due to interactions with natural environmental conditions. Furthermore, changes in built environment construction can occur during an outdoor experience. This is exemplified by a participant account of managing multiple changes in the built environment during an outdoor walking experience:

> *Our street is very level, but there's just a few little places where we don't have sidewalks and there are a few places where you have to really watch what you're doing because it's easy for me to trip. I need to remember to pick my left foot up high enough. So, I didn't fall but you know I don't feel as confident as I used to feel walking, I used to love to walk.* (female, age 66)

The participant shared that the majority of her surrounding neighborhood environment is conducive to outdoor walking. Although only "few little places" were absent of sidewalks, this barrier had substantial impact on her outdoor experience. The need to manage the changing environment evoked uncertainty in her walking. The participant mentioned "I used to love to walk" implying the current environmental situation and her uncertainty within it had decreased the fondness she had once felt walking in the outdoor environment.

Components of the environment, including personal items, can interact to change outdoor environmental experiences. When personal items are introduced in the outdoor scene, these items can interact with the outdoor environment to shape experiences. Participants described interactions between personal items (e.g. mobility devices, footwear) and the outdoor environmental experience. As is clear in the following excerpt, a shopping cart can be all that is needed to manage a dynamic environment:

> *With a shopping cart, it was much easier because I could hold on to it and it held my balance. And all the curbs at corners of streets where they intersect, had the sloping ramp. So, that was easy for me to manage crossing streets with a cart, and going up a curve 'cause it was more of a slant. Um, and if I was just walking without a cart, I just had to be extremely careful. Um, carrying bags is not as easy to see down to the sidewalk and, or the road.* (female, age 70)

The participant described walking her groceries home while borrowing a shopping cart and contrasted this experience with walking her groceries home without a shopping cart. The participant characterized the former experience as "easy for me to manage" because the shopping cart supported mobility. This experience was facilitated by the built environment. Using the shopping cart to navigate the route home from the grocery store was possible due to the "sloping ramp" present, allowing the cart to traverse an intersection. Without the sloping ramp (i.e. outdoor environment) the cart (i.e. personal item) would have been an ineffective tool. Without the presence of the shopping cart, the participant "had to be extremely careful" because the shopping cart no longer "held my balance." The interactions between the sidewalk, curb cut, and mobility aid made for a dynamic outdoor experience.

Housing displacement after stroke disrupted recovery and intensified challenges navigating the outdoor environment. Participants described how housing displacement was a consequence of inaccessibility, cost, or maintenance within their pre-stroke homes. Relocation post-stroke brought both anticipated and unanticipated challenges. One participant was displaced due to cost and maintenance of her pre-stroke home; she relocated to a home where she was confronted with unanticipated environmental challenges which restricted participation both inside and outside of her home:

> *I'm just more used to living where its nature. I will never* [with emphasis], *I vow to this day, I will never live where there is a busy road again, even just a two lane road that's busy. Never again. Because when someone says, 'oh, you'll get used to the noise.' No, you don't. Especially if you have a brain problem.* (female, age 56)

Traffic volume in her new neighborhood was an inescapable environmental challenge. The noise impacted her sleep by permeating the walls of her home and created feelings of instability while walking outdoors. Foundational to displacement post-stroke is underlying socioeconomic status. Housing displacement after stroke is disruptive, and removes agency, choice, and autonomy. Underpinning the participant statement "I vow to this day, I will never live where there is a busy road again" is the initial lack of agency in her post-stroke relocation and the persistent lack of agency in feeling stuck in her current housing situation. The above example shows how dynamics of the environment and the individual can compound to result in restriction.

The individual and environment have dynamic relations, both between and within, that are inherent to the post-stroke experience in the outdoor environment. Interactions with the outdoor environment can provide opportunities to either restrict, maintain, or expand participation post-stroke. Experimentation was used to discover strategies to manage dynamic relations between the post-stroke self and the environment.

4.5 Discussion

This study aimed to gain a deeper understanding as to how stroke survivors' lived experience and independent mobility are shaped by the outdoor environment around their home. Emergent themes capturing post-stroke experience in the outdoor environment as it pertains to independent mobility included vigilance, adaptation, and managing dynamic relations. Vigilance manifested in the presence of barriers during the outdoor environmental experience. While vigilance was described as a protective mechanism for safety in the outdoor environment, it also restricted participation when chronically high levels of vigilance were experienced. Trajectories of recovery post-stroke might be shaped, in part, by feelings of vigilance in the outdoor environment. Adaptation was used to maintain independent mobility in the outdoor environment and was bidirectional. Participants described both adapting individual strategies to meet the demands of an outdoor environment and adapting an outdoor environment to meet individual needs. Successful adaptation strategies supported continued post-stroke mobility in the outdoor environment. Lastly, management of dynamic relations, both between and within, the individual and outdoor environment is inherent to the post-stroke experience. Experimentation was applied to identify successful strategies for managing dynamic relations between the post-stroke self and outdoor environment. In the paragraphs that follow we situate each theme within current stroke research.

Within this project, participants described acts of vigilance as a central theme to protect themselves from danger while traversing the outdoor environment. Descriptions of vigilance while traversing the outdoor environment included reference to active and conscious decision making. As it pertains to walking more generally, there is a body of evidence studying the role of vigilance during outdoor walking. Assessments of sensory vigilance capture active and conscious awareness in visual and auditory fields.[192, 193] This body of evidence views vigilance, or increased perception of the outdoor environment, as a protective mechanism against potential falls. Additionally, vigilance in the outdoor environment relates to previous stroke research on biographical work and restoration of a sense of self and identity after stroke.[191, 194, 195] Previous research found that after a stroke it was necessary to actively and consciously make choices about behavior that had previously been assumed.[194] Participant descriptions while navigating the outdoor environment included assessment and re-assessment of themselves and the outdoor environment to maintain safety and security while walking outdoors. Lastly, participants described familiarity as a way to decrease sense of vigilance in the outdoor environment. This aligns with previous accounts of familiarity with environments being a facilitator of participation post-stroke.[178]

Although there are many ways vigilance may be protecting stroke survivors outdoors, it is possible that hypervigilance, or chronic preparation to encounter hardships, in the outdoor environment may lead to unwanted outcomes. Participants in this study described restricting their participation due to high levels of vigilance in the outdoor environment. Furthermore, hypervigilance may have biological consequences beyond participation restrictions. Research on racism-related vigilance has found that anticipatory stress of racism is associated with arterial stiffening, waist circumference, sleep difficulty, and hypertension.[196-199] People with disabilities consistently report higher rates of obesity, low levels of physical activity, high rates of smoking behavior, and are at greater risk of secondary health conditions.[200-202] Higher levels of unhealthy behaviors and secondary health conditions among people with disabilities in comparison to their non-disabled counterparts might be driven, in part, by experiences felt in an environment built to meet the needs of the majority and not the needs of the whole population. High levels of vigilance in the outdoor environment may lead to manifestation of secondary health conditions unrelated to prior stroke. Investigation into associations between vigilance and development of secondary health conditions post-stroke is needed.

Another central theme to mobility in the outdoor environment was adaptation. Previous research has identified adaptation as an important component for the resumption of valued activities post-stroke.[178] Descriptions of adaptation are examples of what has previously been defined as biographical accomodation.[203] Biographical accommodation is done after a chronic illness through biographical work, which includes the biographical time, body, and conceptions of self (i.e. BBC chain).[203] Adaptation is a way in which stroke survivors can define and redefine their self to reconstruct the BBC chain. Previous research found that refamiliarization is one way in which defining and redefining of the self occurs after a chronic illness.[203] Refamiliarization with the body occurs with limitations-testing, where testing and retesting performance is an iterative process.[203] While participants described refamiliarization through experimentation, we also found that refamiliarization occurs not only within the body, but also between the body and the environment. Environmental conditions in which limitation-testing is taking place frames how the performance is integrated into biographical work. Performances constructed in a context may have transferability into similar contexts or into contexts with fewer environmental demands. Further investigation of the transferability of performances between clinic, home, and outdoor environments is needed.

Management of dynamic relations was the third central theme to mobility in the outdoor environment post-stroke. It is theorized that life reorganization after a stroke includes efforts to create continuity in the face of permanent change.[194] This includes searching for anchors of predictability and searching for links between the old and new self.[194] Participants described these anchors of predictability when orienting their thoughts and feelings about the surrounding environmental context. Original thoughts and feelings about the environmental context were shaped and subsequently altered with changes in functioning. Furthermore, participants' experience with dynamic relations is ideally situated within the biopsychosocial model of health.[8] The biopsychosocial model of health, well known as the ICF, provides a common language for understanding functioning in society.[8] Within this framework, disability is the result of an interaction between personal and contextual factors. As described by stroke survivors in this study, mobility in the outdoor environment was related to the dynamic interactions, both between and within, the environment and self. Time was a component of dynamic relations described by participants within this study. However, time is not currently captured within the ICF framework. As has been demonstrated in previous literature, time is a theme that persists within stroke research and consideration of integrating time into the internationally adopted framework of disability and health is warranted.[75, 204, 205]

4.5.1 Implications

This study highlighted the experience of frequent challenges while navigating the outdoor environment post-stroke. Stroke survivors should know that encountering challenges in the outdoor environment was commonly reported as part of the post-stroke lived experience. To reduce the negative impact of environmental challenges, stroke survivors initially travelled the environment with support (e.g. mobility aid, accompanied by someone) in order to re-familiarize themselves with the world outside their home. Being familiar with the outdoor environment can provide additional walking confidence and opportunity to develop adaptation strategies if barriers are encountered. In addition, developing strategies to navigate the outdoor environment was iterative and filled with experimentation. Learning the best adaptations that work for individuals in their environment are likely unique, and personalized strategies can be developed in order to minimize mobility restrictions in the outdoor environment.

There are also a number of important implications for health care professionals arising from this study. Most importantly, health care providers working with the post-stroke population should be aware of individual vigilance while navigating the outdoor environment. As such, health care providers attempting to engage their patients in outdoor walking behavior should consider an individualized approach to minimize post-stroke vigilance in the outdoor environment. Vigilance can be decreased through familiarization with the outdoor environment. The role that vigilance in the outdoor environment has on the effectiveness of post-stroke walking interventions is an area in need of further investigation.[206] Home visits to both assess the accessibility of the outdoor environment and develop tailored strategies may be considered to optimize functioning post-stroke. Increasing access and utilization of occupational therapy could facilitate the development of post-stroke adaptation strategies in the outdoor environment.[207] Furthermore, management of dynamic relationships outside the home likely involves experimentation to maximize mobility in the outdoor environment. Health professionals should consider the role they themselves play in influencing the development of beliefs about outdoor walking among stroke survivors. Inquiry into features of the surrounding environmental context can guide patients to attribute performances to an interaction between their capacity and the outdoor environmental setting. These conversations can minimize the mis-attribution of failed performances solely to individual impairment.

Lastly, these findings have implications for public health and public health research. Features of the outdoor environment that are inaccessible are perceived as a threat to stroke survivors' health and safety. These threats can create stress and hypervigilance when considering participating in their environment. Investing in the public outdoor environment to remove barriers (e.g. curbs without curb-cuts) could reduce feelings of apprehension and hypervigilance. Furthermore, adding facilitating environmental features (e.g. railings, benches) can cultivate confidence while traversing the outdoor environment post-stroke. Reducing hypervigilance in the outdoor environment post-stroke may have a large impact on recovery and rehabilitation post-stroke, especially as it pertains to outdoor mobility. Not only would these improvements be supportive of stroke survivors mobility in the outdoor environment, accessible outdoor environments also align with the World Health Organization goal for developing *Global age-friendly cities*.[208] Support for accessible communities is desperately needed for the growing number of stroke survivors and the preservation of outdoor mobility after stroke.

4.5.2 Strengths and limitations

This study provided rich insight into the experience of traversing the outdoor environment post-stroke. The descriptions shared by stroke survivors provided detailed information to explain the complex relationship between the individual and the environment. Furthermore, this study provided flexibility in the mode of data collection (i.e. telephone call, or video communications). This allowed the participant to choose which mode they preferred to share their story in and minimized selection bias due to barriers of entry (e.g. laptop ownership). A number of participants enjoyed sharing their story, with many recalling that their story has never been previously shared. One participant shared "I could talk hours just because it's, it's been a voice that I've had to keep inside, except for telling my poor husband, so it's nice to have somebody listen to me out there." The qualitative approach taken in this study provided new insights into the subjective experience of community dwelling stroke survivors and the multi-dimensional nature of navigating the outdoor environment.

Despite the strengths of this study, there are some limitations. This study was carried out within a convenience sample of twenty community dwelling stroke survivors. Although we did not enroll participants until data saturation, the final three interviews yielded no new categories or themes. This suggests that additional interviews would have had limited impact on the findings presented and theoretical saturation of coding schemes was achieved.[209] Participants were recruited from an existing registry of potential research subjects at a large academic medical center with limited geographic diversity. This sample of stroke survivors did not represent stroke survivors living in different environmental contexts (e.g. rural areas). Future research in this area should have greater representation of stroke survivors living in varying levels of urbanicity and geographic diversity.

4.5.3 Conclusions

Experiences in the outdoor environment are dynamic and shaped by both personal and environmental factors. Integration of information about individual functioning and environmental factors lead to shifts in perception of safety and vigilance while walking outdoors. Furthermore, the above findings highlight the complexity of managing multiple transitions and the use of adaptations to meet the needs of individual functioning and the demands of outdoor environments. The study findings have implications at the individual, interpersonal, and community levels. At the individual level, familiarity with the outdoor environment can provide additional walking confidence and opportunity to develop adaptation strategies. At the interpersonal level, healthcare professionals can support a patient's mobility by developing strategies to minimize post-stroke vigilance in the outdoor environment. At the community level, investment in the public outdoor environment should be made to remove barriers (e.g. curbs without curb-cuts) and add facilitators (e.g. railings, benches) to improve confidence while navigating the outdoor environment post stroke. Future research is needed among a more sociodemographic and geographic diverse sample for a more holistic understanding of the role of environmental factors on lived experiences in the outdoor environment post stroke.

4.6 Acknowledgements

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4.7 Tables

Table 4.1 Demographic, socioeconomic, and functioning characteristics of participants completing semi-structured interviews (n = 20)

	Frequency (%) or Mean (Range)
Gender	
Male	8 (40%)
Female	12 (60%)
Age (years)	64.2 (45 – 90)
Race/Ethnicity	
Non-Hispanic Black	2 (10.5%)
Non-Hispanic White	17 (89.5%)
Hispanic White	1 (5.6%)
Education	
College degree +	4 (20%)
College degree	6 (30%)
Some college	7 (35%)
Missing	3 (15%)
Annual income	
<$15,000	2 (10%)
$15,000 - $39,999	2 (10%)
$40,000 - $59,999	8 (40%)
$60,000 +	5 (25%)
Missing	3 (15%)
Occupation	
Working for pay	6 (30%)
Retired from paid job	8 (40%)
Unable to work due to health	6 (30%)
Relationship status	
Married	12 (60%)
Divorced/separated	4 (20%)
Never married	3 (15%)
Widowed	1 (5%)
Foot pain has limited walking over past year	
Yes	5 (25%)
No	15 (75%)
Serious fall over past year	
Yes	6 (30%)
No	14 (70%)
Mobility device use[a]	
None	13 (65%)
Sometimes	4 (20%)
Often	2 (10%)
Always	1 (5%)
Quality of life	
Physical composite score	34.7 (21.3 – 47.2)
Mental composite score	47.7 (22.0 – 59.0)
Activities of daily living	
Any difficulties	6 (30%)
No difficulties	14 (70%)
Instrumental activities of daily living	
Any difficulties	10 (50%)
No difficulties	10 (50%)

[a]Participants used a variety of mobility devices, some used multiple devices and their device use was dependent on the environment; 1 participant used a manual wheel chair, 1 participant used a scooter, 3 participants used a walker, 7 participants used a cane, no participants used crutches or a powered wheel chair

Chapter 5 Discussion

5.1 Overview

Through a series of three research studies, my dissertation adds to an emergent body of literature examining the role of social and built environments for stroke survivors functioning.[47, 70-82] This dissertation was motivated by the growing number of stroke survivors with changes in individual functioning returning to their home communities.[31] There is anticipation that the observed growth over the last decade will not subside in the future, with 3.4 million additional stroke cases expected by 2030.[31] Advancements in acute stroke care and an aging population are driving observed growth and there is need for creative strategies to optimize functioning after stroke. Through my work, I have come to understand that functioning impairment is part of our shared human experience, but restricted participation does not have to be. The environments in which we live play a critical role in functioning post stroke. I funded this research by applying for and receiving a F31 training grant from the National Center for Medical Rehabilitation Research within the Eunice Kennedy Shriver National Institute of Child Health & Human Development. During my doctoral studies, the dynamic relationship between the built environment and mobility served as a focal area I will continue to pursue in the coming years. This chapter summarizes dissertation findings, triangulates results from the quantitative and qualitative studies, and discusses the implications of this dissertation research.

5.2 Summary of findings

This dissertation contributes new knowledge to our understanding of the built environment for post-stroke functioning and how features of the outdoor built environment can shape post-stroke physical activity, quality of life, and experiences in outdoor space. Taken together, the results of this dissertation suggest that built and social environmental characteristics have implications for mobility and quality of life among stroke survivors residing within them. In Aim 1, we found that living in a neighborhood with more destinations for intellectual stimulation was associated with greater moderate to vigorous physical activity behavior. Among participants obtaining any moderate to vigorous physical activity behavior during the week, a one-unit (count/km^2) increase of destinations for intellectual stimulation was associated with 0.99 (95% CI:0.02, 1.97) more minutes of daily moderate to vigorous physical activity behavior. Other important environmental predictors of post-stroke physical activity included weather and neighborhood socioeconomic status. Extreme cold weather was associated with 0.63 fewer minutes of daily light physical activity (95% CI: -1.13, -0.13). Lastly, neighborhood socioeconomic status was associated with greater odds (OR=1.10; 95% CI:1.02, 1.20) of doing any MVPA in the past week. Neighborhood socioeconomic status may indicate investment in local infrastructure, and informed our next research question where we investigated the role that the microscale built environment had for post-stroke functioning.

In Aim 2, we found that features of nearby crossings were an important driver of post-stroke PH-QOL. Participants living in environments with "some" crossing features had 4.99 (95% CI: 2.50, 7.47) higher PH-QOL scores in comparison to participants living in environments with "few" crossing features after controlling for socio-demographic characteristics, urbanicity, pre-stroke PH-QOL, and stroke severity. Relative to the magnitude of association of a mild stroke in comparison to a moderate or severe stroke ($\beta = -6.83$), crossing features had almost as large (73%) of an association. Features along segments and routes were not associated with post-stroke PH-QOL. Interventions to improve outdoor crossings features have the potential to play a large role in post-stroke quality of life. Furthermore, the scarcity of crossing features observed within this study suggests that even small improvements in crossing features are associated with better outcomes. The lack of association between features along the segment and route with post-stroke PH-QOL was surprising. These null findings may be explained, in part, by our high-functioning population sample. Replication of these findings in a group of more severely impaired stroke survivors may reveal different findings.

Lastly, in Aim 3 we found that the lived post-stroke experience in the outdoor environment as it pertains to independent mobility was multidimensional. Three themes emerged from the semi-structured interviews with stroke survivors. These themes included feelings of vigilance, employing adaptation strategies, and managing dynamic relations between the self and context. Traversing the outdoor environment post-stroke could be stressful to participants, and lead to feelings of hypervigilance and decreased likelihood of going into the outdoor environment. Investing in the public outdoor environment to remove barriers and install facilitators could reduce feelings of apprehension and hypervigilance while navigating the outdoor environment post stroke.

5.3 Triangulation of quantitative and qualitative findings

Triangulation is the integration of information to provide a more complete understanding than any one piece of information alone.[210] Triangulation is most often achieved in mixed methods research by combining statistical results with personal experiences of participants. The intent of utilizing sequential explanatory mixed methods in this dissertation was to develop results that expand our understanding of built and social environments for post-stroke functioning and validate the results obtained from each method.[89, 90, 210] Below the results of the three aims are merged together to allow for comparisons across research aims.

Estimates of the association between features of the macroscale built environment and post-stroke physical activity were obtained from Aim 1 and combining these findings with descriptions of the lived experience in the outdoor environment in Aim 3 provides a more holistic understanding of the built environment for post-stroke physical activity. The theorized mechanism through which destinations are positively associated with post-stroke physical activity is through walking to get to a destination. In other words, stroke survivors would use active transport (e.g. walking) to obtain goods and services nearby. Described in the vigilance section of Aim 3 within this dissertation, we highlight a participant's description of her walking experience in the outdoor environment. The participant described that greater destinations in the outdoor environment are enjoyable because there is "more to see as opposed to the same everything else." This aligns with the theorized mechanism described above, where more destinations and a rich outdoor environment would be associated with increased physical activity behavior. However, an important component missing from this mechanism is the potential damage inflicted to the brain following a stroke.

Brain damage may induce sensory challenges when navigating a rich, distraction dense, built environment. This may, in part, explain the absence of relationship observed for many destinations of the built environment with post-stroke physical activity behavior. Expanding on her experience above, the participant further articulated ways that environmental triggers could increase a sense of vigilance in the outdoor space, especially within the context of her individual functioning. She shared that "I think because of the busyness of it… psychologically, I start getting a little more apprehensive when there's, when there's, the threat level increases." She ties her feelings of apprehension to the busyness of the street. This might explain why many of the environmental characteristics examined in Aim 1 were not associated with physical activity. It is possible that the increased destinations cause greater traffic and distractions within the outdoor environment, thereby deterring stroke survivors from engaging in physical activity behavior when they perceive the environment to be of greater threat. Some stroke survivors experience changes in sensory systems that can make destination-rich outdoor environments chaotic and disorienting.[21] Relating back to the ICF framework, we know that body function and structure (e.g. sensory systems) can interact with the built environment (e.g. nearby destinations) to result in differential activity and participation (e.g. physical activity) outcomes (Figure 5.1).

--- Figure 5.1 ---

Some findings from Aim 3 are concordant with the absence of associations found for many environmental destinations within Aim 1. Therefore, a greater understanding of underlying sensory systems and the interaction with the outdoor macroscale built environment may elucidate interactions described by participants in the qualitative project within future quantitative inquiry.

Taken together, Aims 2 and 3 play complementary roles in our understanding of the microscale built environment for post-stroke quality of life. Within Aim 2 of this dissertation, we find that features at nearby crossings were associated with greater physical quality of life post stroke. This relates to the dynamic relationships that participants described while navigating a walking trip in Aim 3. The participant described her walking trip getting groceries, and shared that "all the curbs at corners of streets where they intersect, had the sloping ramp. So, that was easy for me to manage crossing streets." The curb cuts, a primary crossing feature captured within Aim 2, made it easy for this participant to manage crossing the street to travel to a nearby food store. These findings nicely complement one another and provide further evidence for the important role of crossings for post-stroke physical quality of life.

The second aim of this dissertation found that features along the neighborhood segment and neighborhood route were not associated with post-stroke physical quality of life. Within Aim 3, participants had diverse perceptions of environmental barriers. While one participant described her reasoning for not walking in the neighborhood being driven by the poor condition of her outdoor environment and stated “well in in this neighborhood I have walked, not at all. And that would be, because the pavement and the sidewalks are in desperate need of being repaired, and I do not feel safe terrain-wise.” This contradicts other descriptions of environmental barriers being perceived as challenges or opportunities for improvement. One participant shared “I thought of it as my physical therapy” when reflecting on challenges such as absence of sidewalks or uneven ground in her built environment. We may not have observed an association between features of the microscale built environment on segments and routes with post-stroke physical quality of life because we did not distinguish between the perspectives of these two types of stroke survivors. It could be that we are averaging associations across two distinct groups where (1) participation is restricted by outdoor barriers and (2) outdoor barriers are observed as challenges. Further investigation is needed to identify personal characteristics that determine whether someone views environmental features as challenges or as opportunities.

This study used both quantitative and qualitative methods to elucidate meaning and mechanisms behind relationships. Quantitative methods were first applied within a national sample of stroke survivors in order to understand the association between (1) the macroscale built environment and post-stroke physical activity (n = 374), and (2) the microscale built environment and post-stroke quality of life (n = 267). This was followed by a qualitative component with a separate sample of stroke survivors (n = 20), which sought to better explain the underlying reasons for observed associations. The purpose of the qualitative study was not to simply restate the patterns and observations of the quantitative study, but rather to explain underlying associations observed and reveal new insights and mechanisms that structure these relationships. Convergence of findings from this dissertation provide an enhanced understanding of the built environment role in post-stroke mobility and quality of life.[210] Triangulation of findings can also increase confidence in conclusions from each aim of the project when consistency of conclusions are reached.[211] Using a sequential explanatory mixed methods approach and triangulating findings from the qualitative and quantitative data enhanced the validity of the findings.[89, 90] In conclusion, this sequential explanatory mixed methods research strategy provided a more holistic understanding of the role that the built environment plays for mobility and quality of life post stroke than either method could have uncovered in isolation.[89, 90, 212]

5.4 Dissertation implications

The results of this dissertation have implications for future research and interventions to shape population health and reduce disparities in people with functioning impairments. Using the International Classification of Functioning, Disability, and Health to frame our investigation, this dissertation examined how the macroscale environment, microscale environment, and individual perception of these spaces contributes to post-stroke functioning.[8] The extent to which outdoor built environment conditions contribute to post-stroke disability has received limited attention within the current body of literature. This dissertation begins to fill this gap in the literature and uncover the role of the outdoor built environment for post-stroke functioning.

5.4.1 Stroke survivors

Taken collectively, the findings of this dissertation have important implications for community dwelling stroke survivors. Study findings highlight that environmental conditions can shape mobility and quality of life post stroke. Living in communities with access to destinations for intellectual stimulation and attributes to encourage safety at nearby crossings (e.g. curb cuts) was associated with greater physical activity and quality of life post stroke. While moving to a new location after a stroke may not be beneficial because of decreased familiarity and loss of social relationships, there are ways in which stroke survivors described adapting to an environment unfit for their needs. Identification of spaces further from the home that are safe to walk might be an initial step toward rebuilding sense of self and walking confidence post stroke. Finding a location with smooth, flat surfaces and opportunities to rest (e.g. benches) were described as top priorities by stroke survivors within this project. New developments (e.g. wayfinding applications) can be used to minimize the restrictions in mobility and resulting isolation felt after a stroke. If barriers accessing a supportive built environment persist, stroke survivors may consider advocating for greater investment in built environment infrastructure within their community. When armed with the knowledge, training, and guidance for how to make change in their community, previous research shows that older adults are empowered to identify high-priority, realistic changes that are needed within their neighborhood environment.[173] Stroke survivors should be encouraged to make changes within the community to promote fully inclusive environmental designs.

5.4.2 Health professionals

Within this project we identified built environment features important for mobility and quality of life among stroke survivors living in their home community. Health professionals can use this knowledge to work with patients and determine ways to maximize participation within the built environment. A way in which health professionals can maximize patient success is by virtually traversing the outdoor environment with their patients using Google Earth Street View imagery. In the event that built environment barriers are encountered near the patient's home, this would provide an opportunity for stroke survivors to work with an occupational therapist and develop a plan to adapt and safely engage in the outdoor environment. Practitioners and patients can incorporate innovative technologies into a post-stroke discharge plan, such as personalized wayfinding applications that include both permanent (e.g. absence of curb cuts) and temporary (e.g. ice, snow) obstructions, and suggestions for alternative, accessible routes.[172] Identifying safe walking routes could prioritize walking towards areas with destinations for intellectual stimulation and walkways that include accessible pedestrian crossings along the route. Furthermore, information on neighborhood environments can be integrated into health care systems to allow for tailored discharge planning for stroke survivors. This could ultimately lead to improved patient care and health outcomes.

5.4.3 Public policy

Within the United States, we have adopted national policies to address built environment barriers. Accomplished as a result of activism and advocacy from the disability community, large pieces of legislation have been passed which impact the structure of the built environment around us. Within this section I highlight two laws, their current regulation over the outdoor built environment, and what additional contributions are needed to build an accessible future.

At the national level, Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA) are two large pieces of legislation that have required new construction to abide by accessibility standards. In 1973 Section 504 of the Rehabilitation Act was passed, the first disability civil rights law to be enacted in the United States.[139] This law prohibits discrimination against people with disabilities in programs/activities that receive federal funding. Reasonable accommodations must be made in order to allow someone with a disability to fully participate in a program, utilize a service, or perform a job. Within this piece of legislation, it is stated that "no otherwise qualified individual with a disability… shall be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." This law was later expanded on with the passing of the ADA in 1990. The law "declares that no qualified individual with a disability shall be excluded from the participation in, denied the benefits of, or subjected to discrimination by a public entity" and "prohibits discrimination on the basis of disability in the enjoyment of any place of public accommodation."[140] In other words, stroke survivors have protection under the ADA to have equal access to our public spaces and places. This includes accessibility to buildings, streets, crosswalks, public transportation, parks, city halls, schools, libraries, and much more. The ADA, along with Section 504 of the Rehabilitation Act, established a precedent for disability protections which included, but was not limited to, accessibility in the built environment. Since 1990, accessible design has been established as a standard for alterations and new construction of facilities. However, application of accessibility standards to only new construction can result in segmented built environment infrastructure. For example, a stroke survivor could navigate off a curb and into the street using a curb cut, and then after crossing the street this person may find that there is no curb cut present. This could result in a dangerous predicament where the stroke survivor would need to mount the curb or remain in the street with motor vehicle traffic.

A major gap in our knowledge about the adoption of ADA accessibility guidelines is due to the lack of information captured about the accessibility of the built enviornment.[137, 213] This area of research could be greatly advanced through the curation of a national database to capture ADA transition plans at the local level. This could include reporting standards of local ADA transitions plans, accomplishments over the past year, and plans and priorities for the year to come. Public health has a history of curating and cultivating rich population level data. Furthermore, an essential public health service listed by the Centers for Disease Control and Prevention is to “enable equitable access.” Given that our built environment has been driven by the needs of the majority, we observe differential access for minority groups in our population, including the post-stroke population. Further investment in urban development and planning is needed to build environments which support stroke survivors’ mobility and quality of life.

5.5 Population health: What an accessible built environment can do

Population health deals with the patterns of health in groups of people, rather than in individuals. While the International Classification of Functioning, Disability, and Health (ICF) was a groundbreaking publication, its application is best suited at the individual level. The ICF uses codes to classify and categorize individual functioning within a specific context.[8] The ICF framework has grounded many of my ideas about functioning and validates the role that both health conditions and contextual factors play in the disablement process. However, a different framework is needed to think about population health and patterns of functioning of the population in context. I have taken this as an opportunity to explore the role of built environment factors on functioning at the population level. Such a framework could be used to guide future research questions investigating the role of the built environment for population health. Further inquiry in this area is needed to provide evidence for communities’ return on investment when building accessible infrastructure to enhance public good. Figure 5.2a displays the theoretical population distribution of impairment. On the y-axis is the proportion of people within the population ranging from 0 to 1, while on the x-axis is a theoretical distribution of impairment ranging from 0 to 10.

--- Figure 5.2. ---

The Washington Group's short set of disability questions asks about difficulty in executing an act or task along six dimensions including vision, hearing, mobility, cognition, self-care, and communication.[214] This is an effective standardized set of questions to capture functioning in terms of activity, as defined by the ICF. Using the Washington Group's short set of disability questions, we know that one in four noninstitutionalized United States adults report any disability.[2] Represented by the dotted black line in Figure 5.2a is the proportion of the population that reports some level of difficulty in executing activities, 25% of the population. Historically, public health has approached reducing restrictions within the population by preventing impairment all together. Prevention of impairment shifts the population distribution, thereby reducing the proportion of the population reporting restrictions in activities or participation (Figure 5.2b). For example, a public health intervention to reduce injury and impairment from car crashes is the adoption of national rules and regulations requiring seat belt use in motor vehicles.[215] Seat belts have been an effective public health measure to decrease impairment in the population by shifting the population distribution of impairment towards the y-axis. This intervention reduced the proportion of the population experiencing restrictions in activities and participation. However, an added foundational lever can be manipulated in tandem with approaches preventing impairment in order to alter the proportion of the population experiencing restrictions in activities and participation. Informed by the ICF framework, the additional lever that public health can draw on is changing the context to be more inclusive and lift restrictions in participation. By investing in public infrastructure to make built environments accessible and inclusive to the whole population, I theorize that the proportion of the population reporting restrictions would decline (Figure 5.2c). Alternatively, with greater barriers present in the environment, I theorize that the proportion of the population reporting restrictions would rise (Figure 5.2d). Through my work, I have come to understand that functioning impairment is part of our shared human experience, but restricted participation does not have to be. The environments in which we live are critical for engagement in activities and participation. Optimizing post-stroke functioning at a population level requires a multipronged approach and should include investment in community infrastructure.

5.6 Strengths and limitations

5.6.1 Strengths

Key strengths of this dissertation include the sequential explanatory mixed methods approach and rich multi-level measurement of the built environment. First, using a sequential explanatory mixed method approach, we were able to draw upon the strengths of both quantitative and qualitative research methods to capture a more complete understanding of the outdoor built environment for post-stroke experience. The sequential explanatory mixed methods approach allowed for the grounding of research findings from Aim 1 and Aim 2 within the words of stroke survivors in Aim 3. Triangulating the findings from the quantitative studies with the qualitative study contextualized the results within the post-stroke experience. Furthermore, results that were consistent across research methods (e.g. accessible crossings playing an important role post stroke) provided greater validity to these research findings. Using a sequential explanatory mixed methods approach provided a more holistic understanding of the role that the built environment plays for mobility and quality of life post stroke than either method could have uncovered in isolation.[212]

Second, rich measurement at the macroscale and microscale environmental levels allowed for rigorous investigation of the role that built and social environments play for post-stroke mobility and quality of life. Within the first aim of this dissertation, measurement of destinations utilized comprehensive, longitudinal data sources which allowed for linking of the year of environmental characteristics with the year that physical activity measures were obtained. Within the second aim of this dissertation, we measured microscale built environment features using Google Street View to capture exposures surrounding stroke survivors' home addresses. Virtual environmental audits provided information of both presence and quality of environmental features, components that are largely absent from archival data sources. Within the third aim of this dissertation, we captured the subjective experience of the environment post stroke and the impact it has on independent community mobility. The strength in measurement and variety of built environment measures facilitated greater understanding of the role of both the macroscale and microscale built environment on post-stroke functioning.

5.6.2 Limitations

Key limitations of this dissertation include the generalizability of findings and limited detail on individual impairment. First, all three studies included in this dissertation enrolled community-dwelling stroke survivors. Investigation into differences between selected sample of stroke survivors within Aim 1 and Aim 2 compared to the overall post-stroke population in the REasons for Geographic and Racial Differences in Stroke (REGARDS) study revealed that our selected sample had more mild impairment. The sub-sample of stroke survivors with mild stroke severity limited our ability to empirically test interactions between individual impairment and environmental factors on post-stroke functioning. It also limited the generalizability of these findings to community-dwelling stroke survivors with more mild impairments.

Second, there was limited information on individual impairment within this dissertation. Because this dissertation relied in part on secondary data, rich measurement of individual impairment was lacking from our analyses. Within Aim 1 of this dissertation, we did not have information on individual impairment to inform the relationship between the macroscale built environment and post-stroke physical activity. Within Aim 2 of this dissertation, we did have information available on stroke severity. This was a measure that was abstracted from medical records, however functioning can change dramatically over the course of our observation period (i.e. stroke date to 3 years post-stroke). Further investigation of relationships examined in this dissertation is needed using data with rich information on impairment, environment, and post-stroke functioning.

5.7 Conclusion

Motivated by the growing number of stroke survivors returning to their home communities, this dissertation responds to the pressing need to support independent community living post stroke.[31] Advancements in acute stroke care and an aging population are driving the increased prevalence of stroke survivors within the United States. Features of the outdoor built environment are a potential point of intervention to support functioning, independence, and aging in place after stroke. Although functioning impairment is part of our shared human experience, restricted participation does not have to be. The results from my dissertation can be utilized to advance built environment research while helping to identify the underlying mechanisms and structural processes of the built environment on post-stroke functioning. It is my hope that by identifying these features, we can create more inclusive communities that lead to improved health, mobility, and overall quality of life, especially among community dwelling stroke survivors.

5.8 Figures

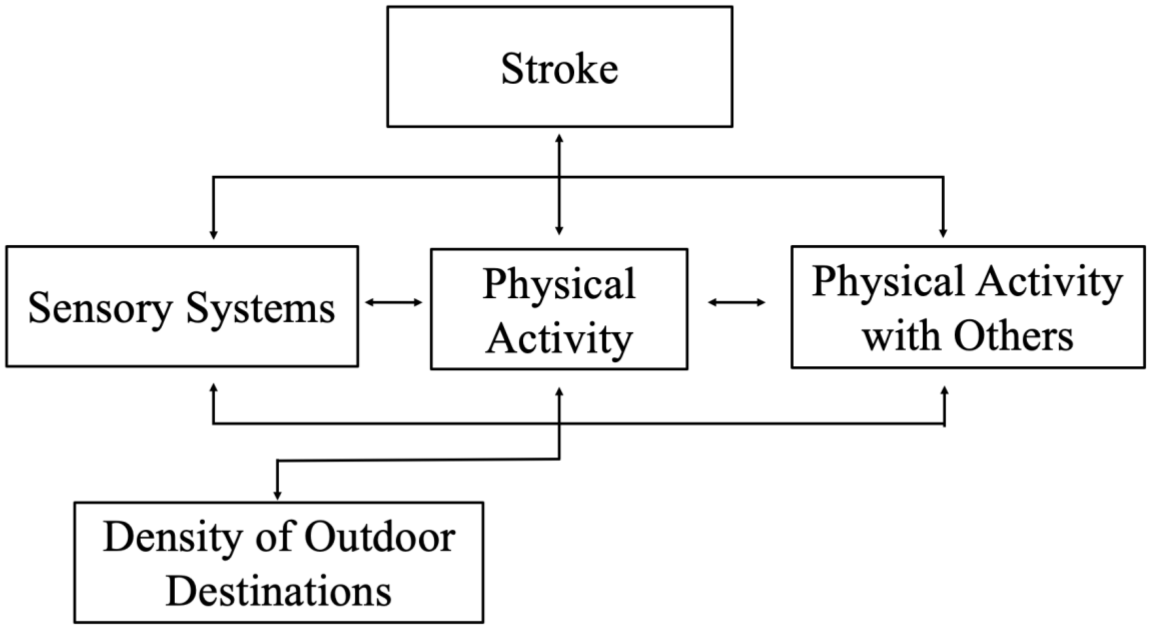

Figure 5.1 Situating effect modification of sensory systems on the true association between density of outdoor destinations and physical activity behavior within the International Classification of Functioning, Disability, and Health framework (World Health Organization, 2001).

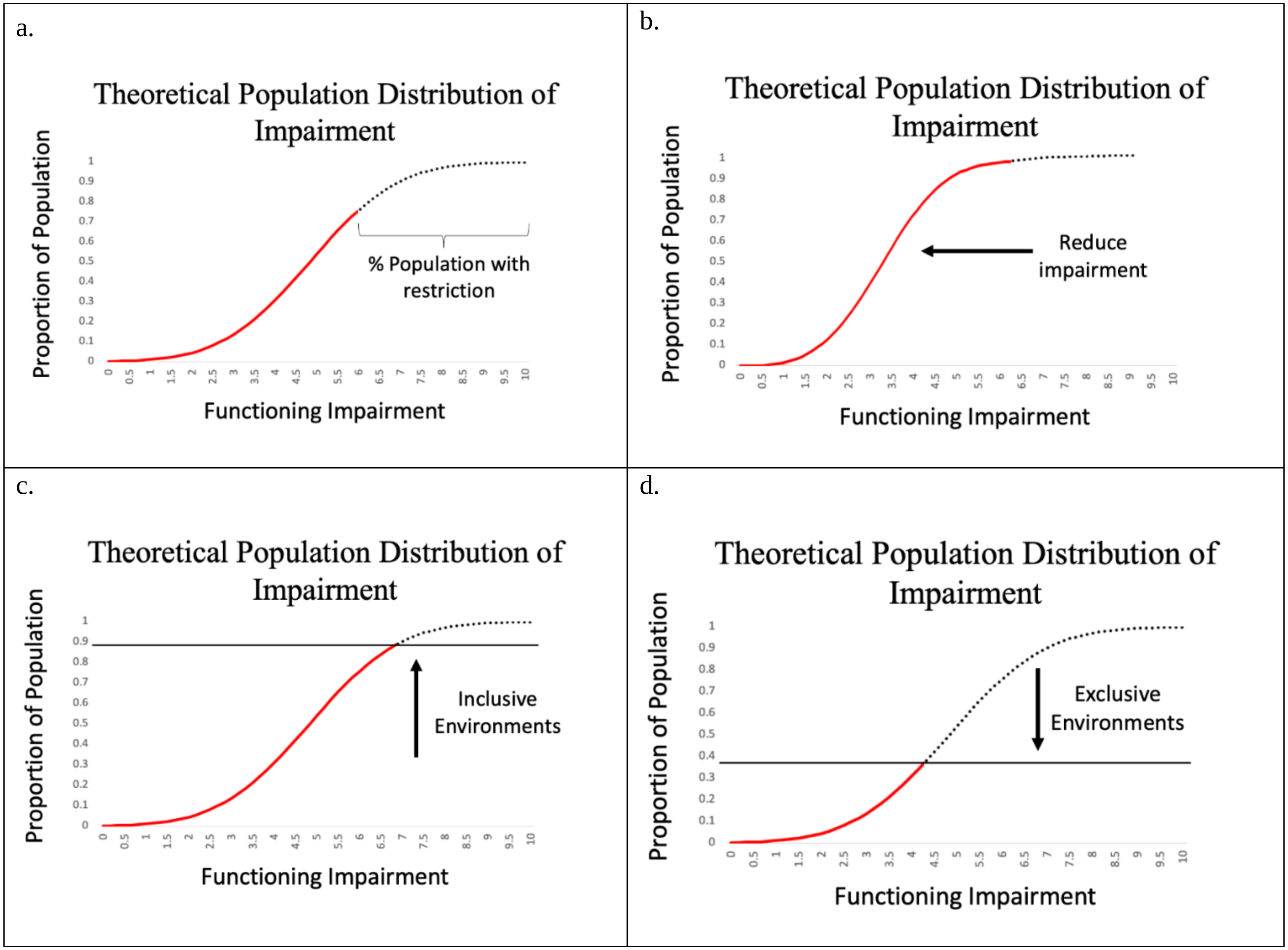

Figure 5.2 Proportion of population reporting restricted activities and participation depends on distribution of impairment within the population and the accessibility of environments.

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