

Community reintegration among Latino stroke survivors: An ecological framework

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ABSTRACT

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Purpose: In the United States, stroke is the leading cause of disability. The majority of survivors sustain permanent physical and/or cognitive impairments. Stroke survivors with impairments experience depression, loss of functional independence, and poor quality of life (QOL). Stroke disparities exist among different racial and ethnic groups of the US population. Latinos experience a first time stroke at a younger age compared to non-Latino Whites. As a result, Latinos live with impairments for a greater number of years. The vast majority of stroke survivors return to live in their communities. Reintegrating into home and social activities is key to survivors' perceived QOL. This dissertation project sought to understand from an ecological framework the post-stroke community reintegration experiences of Latino older adults in an urban New York City neighborhood. The study also sought to examine the viewpoints of health and social service providers, whose opinions, actions, and programs can support stroke survivors' reintegration into community.

Methods: Qualitative in-depth interviews were conducted with 30 Latino stroke survivors 50 years of age and older who had experienced a disabling stroke within 36 months. In addition, 20 health and social service providers based in a large medical center, and multiple senior centers in the northern Manhattan section of New York City were interviewed. The stroke survivor data was analyzed using a phenomenological approach. A thematic analysis approach was used to analyze the data from the health and social service informants. Data analysis identified physical, psychological, social, and environmental factors pertinent to stroke survivors' community integration experiences. These identified factors were categorized into macro-, exo-, meso-, and

micro-levels to capture the psycho, social, and environmental ecology in which community reintegration takes place for Latino stroke survivors.

Results: Qualitative accounts of survivors revealed several microsystem factors, including a struggle to maintain a positive self-concept and to engage in activities associated with valued identities and roles, while simultaneously suffering chronic pain, fatigue, and functional limitations. Changes in their affect lead survivors to socially isolate themselves. In addition, they relied more on women than men for social support, a salient mesosystem factor. Survivors encountered significant exosystem level barriers in the environment that limited their ability to travel and access activities. For some, these barriers inadvertently left survivors homebound. Survivors also encountered a societal culture, a macrosystem factor, which stigmatized them due to their impairments. Interviews with health and social service professionals revealed various factors that influenced community reintegration of people with stroke. At the macrosystem level, funding for programs and healthcare financing dictated services and eligibility criteria. In the exosystem, a segmented medical model of care postponed the conversation on community integration. Professional practices, organizational level constraints and culture were mesosystem level factors that influenced community reintegration. The confluence of these factors created an ecological system that influenced stroke survivors' opportunities to socially engage in their home and community life.

Conclusion: An ecological approach provides a useful framework to understand the complexity and potential interplay of factors that contribute to community integration post-stroke for Latino older adults in an urban area.

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DEDICATION

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CHAPTER 1: INTRODUCTION AND SPECIFIC AIMS

In the United States, stroke is the fourth cause of death and the leading cause of long-term disability, making it a major public health concern (ASA, 2016). Of the approximately 795,000 stroke cases per year, 82% of people survive their stroke (CDC, 2012). Although more people survive their stroke than die from it, 75% of survivors sustain permanent physical and/or cognitive impairments (CDC, 2012). Stroke survivors with impairments are at an increased risk of developing co-morbidities, loss of functional independence, and reduced quality of life (CDC, 2012).

Stroke differentially affects the US population, with African Americans and Latinos shouldering a greater burden of disease and disability than Whites. Although Latinos and non-Hispanic Whites have comparable rates of stroke history (2.4% and 2.5% respectively), stroke incidence is projected to increase the highest among Latino men by 2030 (AHA, 2017). Moreover, Latinos experience a stroke for the first time at a younger age -- 67 compared with 80 among non-Latino Whites (ASA, 2017).

Current research points to differential effects of stroke risk factors between men and women, with hypertension and metabolic syndrome having a greater effect on stroke risk in women than in men (Reeves MJ, 2008). Compared with men, women have higher stroke mortality; specifically, each year, 60% of deaths from stroke occur among women (Bushnell et al., 2014; Go et al., 2014). In addition, gender disparities in acute stroke treatment have been documented, such that women compared with men experience greater delays in reaching emergency departments and are less likely to receive key treatments to minimize if not prevent impairment (Reeves, 2008). Women also fair worse in post-stroke outcomes. Women experience poorer functional outcomes, more depression, and lower quality of life than do men (Reeves MJ,

2008). In addition, women compared to men are more likely to be institutionalized after experiencing a stroke (Petrea et al., 2009). Poor outcomes across access to emergency care, acute treatment, and functional outcomes are exacerbated by women's increased likelihood of being socially isolated (Petrea et al., 2009).

Stroke morbidity is expected to increase as the US population ages and ethnically diversifies. As the leading cause of long-term disability, the increased incidence of stroke will lead to an increase in prevalence of functional disabilities among adults. With most stroke survivors living with physical impairments residing in the community, the need for medical and social services and neighborhood-based support systems also will grow. Projections concerning national shifts in demography, aging, and health (US Census Bureau, 2010) demand that closer attention be paid to identify the factors that promote or inhibit effective integration into the community after individuals survive a stroke.

This dissertation project sought to understand from an ecological framework the post-stroke community reintegration experiences of Latino older adults living in an urban New York City neighborhood. The study also sought to examine the viewpoints of health and social service providers, whose opinions, actions, and programs can support reintegration into community for stroke survivors.

In the sections below, I provide a detailed discussion of stroke and relevant conceptual models of community integration. I then offer a rationale for utilizing an ecological approach as a framework to understand the complexity of factors that contribute to community integration post-stroke among Latino older adults. Because adults in this study previously resided in their communities prior to experiencing a stroke, this dissertation focuses on their re-entry into the

community. Therefore, in subsequent sections, I use the terms community “integration” and “reintegration” interchangeably.

1.1 Stroke: Definition and Major Types

Stroke is a neurological disease with a sudden onset that damages the brain. A stroke occurs when the brain abruptly stops receiving oxygen due to a clotted vessel or bleeding in or around the brain, which disrupts the blood flow to the brain (NSA, 2018). Without oxygen, the brain tissue surrounding the affected blood vessel dies causing brain damage. Stroke symptoms may include numbness or weakness on one side of the body, slurred speech, difficulty seeing in one or both eyes, or severe headache (NSA, 2018). There are two main types of stroke, hemorrhagic and ischemic.

A hemorrhagic stroke is described as a brain aneurysm burst or a weakened blood vessel leak, both cause blood to spill into or around the brain creating swelling and pressure, which cause damage to cells and tissue in the brain (NSA, 2018). Although hemorrhagic strokes account for 15% of all strokes, they are responsible for about 40% of all stroke deaths (NSA, 2018).

Ischemic strokes occur when blood does not reach the brain because of a blood clot. Ischemic strokes occur most often, making-up over 80% of all strokes (NSA, 2018). A transient ischemic attack (TIA) is an ischemic stroke sub-type. In TIAs blood vessel blockages are temporary, clots dissolve or dislodge on their own, and symptoms pass in no more than five minutes. TIAs do not cause permanent brain injury given the temporality of symptoms. Unlike TIAs, ischemic strokes cause permanent brain injury. The type and severity of impairment post-stroke is related to the location of the stroke in the brain and the extent of the damage to the brain tissue. Ischemic strokes are responsible for the majority of long-term impairment (NSA, 2018).

1.2 Stroke Related Impairment

Stroke survivors can sustain a range of impairments, including physical, sensory, cognitive, speech, and emotional deficits that impact their ability to function independently (NINDS, 2014). Physical impairments, the most common, include weakness, difficulty with motor control, or paralysis, with the face, arm, leg, or an entire side of the body affected. Other forms of physical impairment involve difficulty swallowing when damage occurs to the area of the brain that controls the muscles for swallowing, a condition called dysphagia. Survivors may have difficulty with coordinating body movements, a condition called ataxia, that leads to problems with body posture, walking, and balance. Survivors with physical impairments may have trouble with swallowing, walking, grasping objects, and balance, all key to instrumental activities of daily living that affect the ability to live independently (NINDS, 2014).

Stroke survivors may also incur sensory deficits including the ability to feel touch, pain, temperature, or spatial position (NINDS, 2014). Patients with severe sensory impairments may not recognize their own limbs. Pain, prickling, or numbness can occur, and are symptoms of weak or paralyzed limbs. Survivors are often afflicted by chronic pain resulting from brain damage to the nervous system (Caswell, 2018; NINDS, 2014). Stroke patients with nervous system damage may feel the sensation of pain radiating from their limbs or side of the body with the sensory deficit. Pain is also caused by non-functioning limbs remaining in static positions over prolonged periods causing joints to essentially freeze in place (NINDS, 2014).

A quarter of stroke survivors experience language impediments, involving the ability to speak, write, and understand spoken and written language (NINDS, 2014). Damage to the brain's language areas can result in severe communication impairments that can leave a person unable to express him or herself verbally or in writing, unable to understand spoken or written language

often speaking incoherently, and in the most severe case can lose nearly all of their linguistic ability, unable to understand language or use it to express thought (NINDS, 2014).

1.3 Stroke Course of Care: Implications for Community Reintegration Experiences and Trajectory

The stroke continuum of care consists of acute, postacute, and long-term patient care, with each care stage addressing a different medical recovery phase of the stroke survivor. Although described as a continuum (Norrving & Kissela, 2013; Wisel, Iver, Sunnrhagen, 2013), stroke care is segmented with the medical team focused on addressing the needs of the patient in that stage of recovery in order to “hand-off” the patient to the next level of care (Wisel, Iver, Sunnrhagen, 2013). Why this is relevant to community integration post-stroke, is that the medical team, in particular the social worker, is focused on supporting the patient in the current phase of recovery, for example patients moving on to a nursing care facility would not receive an overview of the available resources in the community should the patient need them in the future. Rather, community integration is left to the last medical provider before the patient is discharged home despite calls for integrating community integration in acute care (Duncan et al., 2005).

For most patients, stroke care begins in the emergency room followed by a stay in the acute stroke unit (Wissel, Olver, Stibrant Sunnerhagen, 2013). The focus of the acute stroke unit is to medically stabilize the patient and prevent greater damage to the brain. Once medically stabilized, and depending on the extent of impairment and the patient’s home situation, the medical team will decide whether the patient is best suited to return home, to be transferred to an inpatient rehabilitation unit, or a nursing care facility. Acute rehabilitation most often takes place within hospitals where patients receive 24-hour medical care along with appropriate rehabilitation therapy (NSA, 2006). The length of stay in an inpatient rehabilitation unit depends

on the patient's condition. This setting provides the greatest intensity of rehabilitation with patients typically receiving rehabilitation five days a week for an hour a day. Sub-acute rehabilitation is for patients with severe impairments who cannot handle the demands of an acute program. Patients appropriate for sub-acute rehabilitation require medical attention from a skilled nursing team and receive rehabilitation over a longer time period in shorter spurts. In acute or sub-acute settings, the patient is discharged home with a referral for either homecare or outpatient care. Homecare involves visiting nurse service and rehabilitation therapy—physical, speech, occupational--as appropriate. Home-based rehabilitation depends on the patient's needs, typically patients should receive three, one-hour therapy sessions per week for up to the medically recommended. Patients able to ambulate may be approved for outpatient rehabilitation services (NSA, 2006).

There are multiple deficiencies in post-discharge care (McKevitt, Redfern, Mold, & Wolfe, 2004; Reed, Wood, Harrington, & Paterson, 2012). In a review by Murray et al. (2003) of twenty-three studies, stroke survivors reported experiencing difficulties with communication regarding post-stroke care, having limited access to or unawareness of services, and lack of advice or guidance for claiming benefits. The American Stroke Association (AHA) clinical practice guidelines (Duncan et al., 2005) for the management of adult stroke rehabilitation care emphasize the importance of engaging the patient and the patient's family, and utilizing community resources to improve post-stroke outcomes. According to the AHA, follow-up care and linkages to community resources should be coordinated by the time the stroke-survivor is discharged. However, there is little evidence on the ways health professionals facilitate access to community resources for stroke survivors and their caregivers (Reed et al., 2012). Even less is known about community support strategies for stroke survivors. Nor is there research on

hospital-community collaborations that assist survivors and caregivers with identifying resources to meet their short and long-term needs, thereby facilitating the transition from discharge to home and from home into community. This dissertation project addresses these two important gaps in knowledge.

1.4 Community Integration Post-Stroke

Community integration (CI) conventionally defined as participation in home, productive activity, and social engagement (Gordon WA, 2006; McColl, 1998), is the ultimate goal for stroke survivors and other people with disabilities. CI is a function of multiple factors, including physical, psychological, social, and environmental contexts (Yasui & Berven, 2009). CI originated in the deinstitutionalization movement of the 1970s, whose basic principle was that all people, including people with developmental disabilities and psychiatric illness, are entitled to full community participation (Gordon WA, 2006; Minnes et al., 2003; Yasui & Berven, 2009). Since then other marginalized groups, including people with physical and cognitive disabilities have advocated for social integration in community life (Cardol et al., 2002; Minnes et al., 2003; Yasui & Berven, 2009). As a result, community integration is a key component of disability-related public policy and legislation in the US (Crossley, 2017; Scotch, 2001). McColl et al. (1998) note that virtually all of the definitions of community integration in the research literature are multidimensional, which reflects the complexity of the underlying construct. Common dimensions across CI definitions are relationships with others, independence in living, and meaningful activities to fill one's time (McColl et al., 1998). However, much of the research examines single domains of CI, mostly participation in activities (Anderson & Whitfield, 2011; Cardol et al., 2002), functional impairment (Baseman, Fisher, Ward, & Bhattacharya, 2010), social support (Pellman, 1992), and quality of life (Clarke, 2005).

Most research on community integration related to stroke is based in Canada and Europe (McKevitt et al., 2004; Reed et al., 2012; Salter et al., 2008). In the US, there is a dearth of research on CI post-stroke. Moreover, there is almost no research on CI among racial/ethnic minorities. Another major goal of this dissertation is to address these gaps in the literature to help advance research on community integration post-stroke among racial and ethnic minorities in the United States.

In spite of the research attention given to CI, a uniform definition of the concept remains elusive. As a result, there is neither a standard measure of CI, nor consensus on how best to conceptualize the construct. Existing CI frameworks emphasize different domains based on the underlying theoretical assumptions of the models. Yasui and Berven (2009) identified four predominant CI models: (1) the functional independence model, (2) the acculturation model, (3) the normalization model, and (4) the subjective experience model.

CI in the functional independence model, as its name implies, is defined as functional independence in environments outside of institutions (Yasui & Berven, 2009). In this framework, CI is conceptualized as the physiological ability to independently perform activities of daily living necessary to live in a community setting. The functional independence model closely identifies with the medical approach to impairment, where the focus is on restoration of physical functioning after the acute crisis phase of illness or injury (Yasui & Berven, 2009). This model reduces community integration to functional ability and places onus on the individual to adapt to the environment.

In the acculturation model, CI is defined by two characteristics: (1) the extent to which the dominant, non-disabled, community values and supports the minority, disabled, community, and (2) the extent of involvement by members of the disabled community in the dominant, non-

disabled, community (Yasui & Berven, 2009). This model holds social support as a key environmental factor in community integration where in addition to the dominant community's broader recognition and support of the minority community, relationships between disabled and abled persons are valued and viewed as an indicator of community integration (Yasui & Berven, 2009). In this model community integration of people with disabilities is dependent on people without disabilities' acceptance and involvement.

Likewise, the normalization model places value in relationships between disabled and non-disabled people in relation to community integration. Wolfensberger and Thomas, pioneers of the normalization principle, defined community integration as the participation in activities and settings by disabled people in culturally meaningful social roles with non-disabled individuals (Wolfensberger and Thomas, 1982 as referenced in Yasui, 2009). However, the normalization model goes further than the acculturation model in how it conceptualizes CI by placing value on relationships with non-disabled people, which are viewed as more socially valued persons (Yasui & Berven, 2009). Moreover, a premise of normalization is the idea that community integration of people with disabilities is dependent on the support of non-disabled people. According to this model, to garner support, services for people with disabilities should promote the incorporation of disabled people in activities with the non-disabled.

A drawback of both the acculturation and the normalization model is that both place an emphasis on non-disabled people facilitating community integration for people with functional impairments. These models disenfranchise people with disabilities by placing them in a passive role in the process of their own integration. In contrast, the subjective experience model gives primacy to the voice of people with disabilities in defining community integration on their own terms. In so doing, people with disabilities are actively engaged in the process of determining

when community integration has been achieved or what they need in order to do so (McColl, 1998). Gordon et al. (2006) assert that research based on empowerment paradigms, such as the subjective experience model, should acknowledge the complexities of life after a disabling event by understanding disability beyond illness. The subjective experience model best supports a study on the understanding of the multidimensionality and complexity of community integration post-stroke. Specifically, a subjective experience approach engages the active participation of survivors to identify the personal, social and environmental barriers and facilitators to their community integration.

Over the last thirty years the concept of disability evolved from a deficit within the individual to an expression of functional limitation influenced by the social environment (Pledger, 2003). This conceptual shift represents a move away from a medical interpretation of disability towards an ecological view that conceives disability as a dynamic process that fluctuates depending on the interaction between biological, psychosocial, and environmental factors. In contrast to the narrow focus of the medical model, the social model of disability centers on a systems approach to understanding the disability process. The philosophical underpinnings of the new disability paradigm lie in Nagi's framework of disability. Nagi (1976) posited that pathology should not be viewed as the singular determinant of individual functioning. Rather functional limitation is an expression of the extent to which the environment restricts or accommodates impairment. However, individually neither model adequately conceptualizing disability. Disability is an individual and social phenomenon. Disability is a complex interaction between individual level factors and the various inter-acting contexts in which the person lives.

Given that CI is dependent on multiple interacting factors, which include physical, psychosocial and environmental (e.g., healthcare system, neighborhood features) contexts, in this dissertation, I argue that an ecological approach provides a useful framework to identify and study factors that promote and present barriers to community integration post-stroke. In the sections that follow, I discuss the ecological approach and expand on the rationale concerning the use of this framework to understand community integration.

1.5 Ecological Approach to Community Reintegration Post-Stroke: A Framework for CI

Bronfenbrenner's ecological model posits that behavior is contingent on multiple interrelated social and biological determinants (see Figure A for model of community integration post-stroke). To effect change at the population level, the social and biological influences of behavior and disease must be understood (Bronfenbrenner, 1977; Glass & McAtee, 2006). Because intrapersonal, interpersonal, and community factors can influence the community integration experiences of stroke survivors, an ecological approach provides a useful framework to understand the complexity of factors that contribute to community integration post-stroke.

Bronfenbrenner (1977) argues that human development outcomes are the results of dynamic and reciprocal interactions between the individual and his or her environments at multiple levels of a system, including micro, meso, exo, and macro. His focus is on how the individual is influenced by and copes with the people, environments, and systems that continuously and reciprocally exert influence in their environmental context.

1.5.1 Microsystem: Intrapersonal Level

According to Bronfenbrenner, the individual resides in the microsystem or intrapersonal level. The intrapersonal level includes attitudes, norms, and internal psychological states and processes, such as self-esteem, identity, and the self-concept, as well as psychological coping

processes. It is well-known that self-esteem and a general sense of mastery are key to maintaining psychological well-being (White et al., 2016). In the context of stroke and recovery from stroke -- as well as other chronic conditions -- these factors are important given that stroke may interfere with or influence psychosocial adjustment.

In coping with stroke, a major task involves managing the emotional distress and the physical and functional limitations that ensue (Vanhook, 2009). The emotional and psychological consequences of stroke, in particular, are unique given the trajectory of recovery immediately after stroke (Visser, Aben, Heijenbrok-Kal, Busschbach, & Ribbers, 2014). More specifically, the major physical gains in recovery from a stroke are typically seen within the first three months post-stroke, with subtle gains observed within the first 12 months. These particular nuances of the recovery process from stroke -- namely, the uncertainty of achieving full recovery -- can be especially challenging for psychosocial well-being.

In particular, stroke can influence feelings on mastery and sense of control. In fact, key theories of adjustment to chronic illness place great emphasis on the importance of gaining a sense of mastery (Taylor, 1983) and maintaining a satisfactory self-image as essential tasks of adapting (Moos, Fenn, & Billings, 1988). In a phenomenological study with stroke survivors in England, participants reported feeling socially stigmatized, viewing themselves as separate from others and self-conscious of other's perceptions of themselves (Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007). These findings suggest that individual behavior is influenced by an individual's self-image, which may be particularly relevant for stroke as survivors faced with adapting to their physical and cognitive impairments may influence their psychological well-being and interest in social interaction.

Social Roles and Identities

Social roles and social identities also are key aspects of the intrapersonal level. Various psychological theories assert that social roles and social identities are critical to psychological well-being, given that they provide a sense of self-affirmation and identity (Cohen & Wills, 1985; Pearlin, 1983; Thoits, 1986). Among stroke survivors, identity processes also involve accepting the “stroke survivor” identity, which may create additional adaptive demands. This process of espousing the identity of “someone who had a stroke” will vary depending on the severity of the stroke and might also involve accepting the identity of “disabled”. Given the sudden nature of stroke, this process of moving from an identity of “abled” to “disabled” can be particularly challenging. Another particularly distressing aspect is the fear of stroke recurrence. This could threaten the identity of having adapted to the stroke, or of being a “stroke survivor” and create intense anxiety of death or permanent disability (Salter, Hellings, Foley & Teasell, 2008).

The setting and social roles in the microsystem are key to understanding adjustment to chronic illness. There is a wide body of research documenting the impact of chronic illness on individuals’ self-concepts and social roles, including some research on Latinos (Abraído-Lanza, 1997). Given that social roles are key components of self-hood and identity, roles disruptions due to chronic illness present major adaptive tasks (Charmaz, 1999). However, individual behavior in terms of self-concept and image are also influenced by relationships with spouses, family, and friends, which constitute an individual’s mesosystem. Indeed, qualitative studies of stroke survivors underscore the importance of support from other people in constructing a valued social identity (Anderson & Whitfield, 2012).

1.5.2 Mesosystem: Interpersonal Level

A mesosystem or interpersonal level comprises the interrelations among a person's individual setting and the relationships with family, friends, social service agencies, and health care providers. A particularly important feature or factor in the mesosystem is the concept of social support. Despite the lack of an agreed upon definition of the concept, social support is broadly defined as resources and interactions provided by others that may help an individual better deal with a situation (Wills and Fegan, 2001). The effects of social support on health are widely documented, with evidence showing a link between social support and better health outcomes (Cohen, 1988; Wills & Ainette, 2012). Large scale epidemiological studies conducted over the last 30 years indicate that individuals who maintain strong ties to family, friends, and community are at a lower risk of dying from all causes compared to individuals who are socially isolated or disconnected (Berkman & Kawachi, 2000).

Social support is predominantly measured by assessing social networks, relationships, and supports. Social network is operationalized by the size, density, intensity, frequency, dispersion, and homogeneity of a person's network (Wills & Filler Fagen, 2001). Social relationship measures assess the existence, number, and type of relationships. Social support measures assess the type, source, frequency, and quality of resources provided by others. These social network, social relationships, and social support measures are characterized as either structural or functional, each has its own theoretical assumptions. Structural social support measures assume that the number of established relationships, the consistency of these relationships, and the range of these relationships are important (Wills & Filler Fagen, 2001). Structural measures focus on such items as the existence of primary relationships, the frequency of interactions with network members, and normative roles. Structural measures do not consider

the quality of relationships or the resources provided by these relationships to the individual. In contrast to structural measures, functional measures of social support value the quality of resources for their functional asset to the recipient (Wills & Filler Fagen, 2001). Functional items include the extent of emotional, esteem, informational, and instrumental forms of support (Wills & Filler Fagen, 2001).

Family and Social Support

Survivors report that the psychosocial consequences of a stroke pose as much of a challenge to their quality of life as do functional impairments. The intrapersonal and interpersonal impacts of a stroke are expressed in survivors' narratives when they describe feeling a loss of self, confidence, independence, control, and weak social relationships (Salter, Hellings, Foley, & Teasell, 2008).

The return home and transition back into community life may further exacerbate these psychosocial consequences, as the physical and social environment may pose considerable obstacles. In a qualitative meta-synthesis of nine studies focused on the experience of living with stroke, Salter et al. (2008) reported that change and transformation were constant backdrops for participants' experiences with identity, functional ability, and adaptation to their physical and social surroundings. Survivors report poor social integration and strains within close family support networks (McKevitt, Redfern, Mold, & Wolfe, 2004; Teasell, Jutai, Bhogal, & Foley, 2003).

Observational studies with caregivers highlight that family and friends may poorly relate to a survivor's functional state, which may weaken social relationships and may contribute to survivors feeling socially isolated (Murray, Ashworth, Forster, & Young, 2003). Similarly,

tension surrounding role changes between caregivers and survivors may also negatively affect social support and social participation (Murray et al., 2003).

1.5.3 Exo- and Macrosystems: Community & Cultural Context

Whereas the micro- and mesosystems exert direct influence, the exo-and macrosystem exert an indirect influence on the individual. The exosystem encompasses neighborhood characteristics and community-level structures, including the health care system, transportation, government services, and the built environment that influence a person's opportunities and related behavior (Diez Roux & Mair, 2010; Satariano, 2006). The relationship between neighborhood characteristics and health outcomes have been the subject of considerable research, which has established a link between community level factors and health behaviors such as physical activity, diet, tobacco exposure, alcohol consumption, and depression, among other topics (Satariano, 2006).

This body of research confirms the importance of considering the physical and social attributes of neighborhoods that can affect the health of residents. A systematic literature review conducted by Jellema et al. (2017) found reengagement in valued roles and activities post-stroke to be related to physical attributes of neighborhoods, including accessible environments, transportation, services, and access to educational opportunities and information. In the same study, social and physical attributes of neighborhoods, such as residents' negative perceptions and attitudes, and the need to travel long distances, were identified as barriers to meaningful engagement by stroke survivors (Jellema et al., 2017).

The healthcare environment represents another exosystem level factor that may exert influence on patient care. The influential report of the National Academy of Sciences, Unequal Treatment, underscores the role of the health care environment in racial and ethnic health

disparities (Smedley, Stith, & Nelson, 2003). The report highlights how aspects of the health system such as its organization, financing, and the availability and delivery of services, differentially affect the care received by racial and ethnic minorities (Smedley, Stith, & Nelson, 2003). For example, for stroke rehabilitation, Burton (2000) raises issue with the short-term nature of services, the focus on functional recovery, and delivery in synthetic clinical environments that do not translate to patients' environmental contexts. This is particularly relevant to stroke survivors whose functional abilities change over time and who may benefit from ongoing rehabilitation (Woodman, Riazi, Pereira, & Jones, 2014). Moreover, community integration poses varying physical, occupational, and speech demands on the survivor depending on his or her involvement in different roles (housekeeping vs. worker), home and community activities, and social involvement. Community integration typically occurs during survivors' recovery trajectory, when rehabilitation services typically decrease (Burton, 2000; Cott, Wiles, & Devitt, 2009). Cott, Wiles, & Devitt (2009) emphasize the need to deliver rehabilitation in the patient's real context. They assert that rehabilitation services should be maintained to "adequately address issues of the role of the environment, the nature of community, the importance of meaning and choice" for the stroke patient (page 1571).

Examples of other macro level factors that affect patient care include health system financing and public policies and laws, as well as broader societal beliefs, values, and customs. Health care financing, such as recent cost-control efforts in Medicare and Medicaid reimbursement policies (Ginsburg, 2014), may impose parameters on the type and amount of health care services patients are eligible to receive. As a consequence, patients may not receive needed medical care and support services, which, in turn, could affect their ability to resume valued activities. In addition to medical care and support services, attributes of neighborhood

social environments, such as social norms, social stressors, and social cohesion, are hypothesized as pathways through which the social environment affects health (Diez Roux & Mair, 2010). In the context of stroke and impairment, social norms and attitudes can support or impede functioning and social participation of people with disabilities (Field & Jette, 2007).

To summarize, an ecological approach provides an excellent framework for studying community reintegration post-stroke. Although the sections above describe the micro, meso, exo- and macro systems as categories, a key assumption of the ecological framework is that these systems fluidly interact to influence behavior, as depicted in Figure A. In other words, the levels do not exist in isolation. Rather, factors across levels affect each other. For example, the quality of public transportation and the accessibility of the built environment can affect social interactions and participation. Similarly, dominant social norms can reinforce a stroke survivor's negative or positive self-concept, leading to the inclusion or marginalization of people with disabilities in society. At the individual level, comorbidities such as chronic pain and depression have been linked to social withdrawal (Arden Harris, 2014). Although from a public health perspective, addressing upstream causes of disease and disability yield the largest impact, health is a function of the interaction between biological, psychological, social, and environmental factors (Frieden, 2010). Therefore, studies on community reintegration post-stroke using an ecological lens will yield more complete descriptions of the complex interplay of factors that influence CI outcomes in regards to independent living, meaningful participation in activities, and social relationships. For all these reasons, this dissertation project employed an ecological perspective to understand the community reintegration experiences of stroke survivors.

1.6 The Research Setting: Washington Heights-Inwood

The research conducted in this dissertation study focused on the community of Washington Heights and Inwood, an ethnically and geographically diverse area in northern Manhattan. Represented in local government and policies by Manhattan Community District 12, Washington Heights and Inwood spans from the northern tip of Manhattan at 218th Street to its southern boundary roughly at 155th Street, and east-west from river to river. In 2013 the total population in the area was 195,302 people of predominantly Latino descent (71%) followed by Whites (17%) and Blacks (7%) (King et al., 2015). The majority of the population is between the ages of 25 and 64 (58%) and an additional 13% are over the age of 65. Foreign-born residents make-up 48% of the population and 39% of the population has limited English proficiency (King et al., 2015).

It is important to note that Washington Heights-Inwood is home to a large Latino population of Dominicans. Numbering approximately 1.5 million, Dominicans comprise the fifth largest population of Latinos in the United States (Brown & Patten, 2013). Moreover, New York is home to almost half (48%) of all Dominicans living in the US. Although research on the health of this population is growing, in general, Dominicans are an understudied population. Relative to Latinos in general, Dominicans have a higher rate of foreign nativity (37% versus 55%), a lower rate of English-language proficiency (65% versus 55%), and slightly higher rates of poverty (26% versus 28%) (Brown & Patten, 2013). Given the lack of research on community integration experiences among Latinos and Dominicans in particular, this study's findings provide needed information to address the needs of Latino stroke survivors.

The socioeconomic profile of Washington Heights-Inwood also should be noted. Social and economic conditions are worse in Washington Heights-Inwood than the New York City

(NYC) average. A high percentage of adults in the area have not completed high school (30%) compared to 20% for NYC (King et al., 2015). Also, the area has a high rate of poverty (27%), unemployment (16%) and rent burden (54%) compared with the average rates for the City of 21%, 11%, and 51% respectively. One third of the population receives some form of public assistance. Similarly, one third of the total population is Medicaid-eligible, whereas in NYC the Medicaid eligibility rate is about 19% (King et al., 2015).

Washington Heights and Inwood is served by two hospitals belonging to the New York Presbyterian Hospital network. The New York Presbyterian Hospital/Columbia University Medical Center in Washington Heights and the Allen Hospital in Inwood serve the northern Manhattan area. The New York Presbyterian Hospital/Columbia University Medical Center is a Joint Commission designated Stroke Center. Patients presumed to be having a stroke are taken to this particular hospital for diagnosis and acute treatment.

Social services provided by a range of community-based organizations are a mainstay for many residents in Washington Heights-Inwood. The area counts on over 35 organizations and programs that service the older adult population, three transportation programs for people age 60 and over (as well as public transportation) and a range of nutritional and exercise resources (WHICOA, 2013). A bilingual stroke support group called Stroke Warriors is one of the support services offered in the area. This support group of peers and health professionals offers survivors and caregivers a resource for discussing various issues related to stroke, including coping strategies and other health-related information.

1.7 Specific Aims and Research Questions

The premise of this study is that community integration is best understood by considering the dynamic relationships between the levels of influence in the ecological framework.

Moreover, given the breadth of the ecological approach, it is essential to include both stroke survivors and social service providers and stakeholders. Therefore, in addition to stroke survivors, this study examined the viewpoints of health and social service providers, whose opinions, actions, and programs serve as important “gatekeepers” that facilitate (or hinder) stroke survivors’ reintegration into community. By taking this approach, the goal is to advance understanding of the complexity and potential interplay of factors that contribute to community integration post-stroke for Latino older adults in an urban area.

This study utilized a qualitative methodological approach. In-depth interviews were conducted with stroke survivors and health and social service providers to formulate an understanding of the ecological context in which community integration post-stroke takes place for Latino older adults in two urban NYC neighborhoods (Washington Heights and Inwood). The study had two broad aims:

1. Using Bronfenbrenner’s ecological model, to qualitatively describe and analyze the community reintegration experiences of Latino elders with stroke; and
2. To examine the supports and services aimed at facilitating community integration by exploring the viewpoints of health and social service stakeholders.

The study sought to answer three central questions:

1. What are the post-stroke community integration experiences of Latino older adults living in Washington Heights-Inwood?
2. What are the perspectives of health and social service professionals as to the barriers and facilitators to community integration post-stroke among Latino clients?

3. What is the interrelationship between the multiple levels of the ecological system that characterizes the post-stroke community integration experiences of Latino older adults in Washington Heights-Inwood?

CHAPTER 2: STROKE SURVIVORS

2.0 Introduction

Aim 1 of this dissertation project sought to describe the post-stroke community reintegration experiences of Latino older adults living in an urban area. Framed by the ecological paradigm and guided by qualitative methods, a phenomenological study was conducted to arrive at the essence of community reintegration from stroke survivors' perspectives that included their experiences at the micro-, meso-, exo-, and macrosystem levels. This chapter presents findings from interviews with thirty older adult Latino stroke survivors from northern Manhattan in New York City. The chapter first provides a review of the research setting. Next, the study's theoretical framework and methodological approach are discussed. Finally, the chapter describes the major themes identified from the findings.

2.1 Research Setting

As of 2013, 71% of the population in northern Manhattan reported being of Latino origin with the majority of residents being foreign-born Dominicans (King et al., 2015). Dominicans comprise the 5th largest Latino group in the United States based on figures from the 2010 Census and Washington Heights-Inwood is home to the largest Dominican community in the US (US Census Bureau, 2011). Yet, Dominicans are under-represented in health research.

Stroke is the fifth cause of death in northern Manhattan (King et al., 2015). Risk factors for stroke such as obesity, diabetes, and hypertension are prevalent in the area. Among adults, 22% are obese and 10% have diabetes. Hypertension is the tenth leading cause of death in the community (King et al., 2015). Yet despite poor health indicators, the life expectancy in

Washington Heights and Inwood is 83.2 years, two years higher than the NYC average of 81.2 years (Li et al., 2015)

The Northern Manhattan Stroke Study (NOMASS), a longitudinal prospective study of 893 ischemic stroke survivors, found that two thirds of patients in Washington Heights-Inwood were discharged home (Sacco et al., 1998). In these cases, primarily family members, including spouse, daughter, or daughter-in-law, provided assistance to the stroke survivor. In NOMASS, over 40% of stroke survivors residing in their homes required assistance to ambulate at 6 months (Sacco et al., 1998).

2.2 Epistemological Assumptions, Research Framework, and Theoretical Perspective

The study's philosophical assumptions were based in social constructivism (Araujo Sadala, 2002). Utilizing a social constructivism approach, knowledge claims about Latino stroke survivors' experience with community integration were generated from the pattern of meaning they gave to the phenomenon in common. Survivors perceived their world from different standpoints depending on their personal situation. As the subjects of their experiences, survivors constructed their realities from the cultural, economic, social and historical context operating in their lives. Given the subjective nature of reality, the meaning of their experience or situation was personal and accordingly varied between survivors. Yet, the structure of the phenomenon of community integration was understood by revealing the fundamental nature or essence of the situation through an inductive process to pattern the meaning stroke survivors gave to their experience.

The theoretical approach for the study was based on phenomenology because of its focus on first-hand descriptions of lived experiences and its consideration of personal context on

perceived experience (Finlay, 2009; Flood, 2010). To inform our understanding of community reintegration post-stroke for Latino older adults, it was key to consider the impact of psychological, social, community, and broader contexts on community integration. This study was designed using a qualitative approach to develop a holistic, largely narrative, first-hand account of the community reintegration experiences of Latino stroke survivors. A qualitative research design allowed for a range of factors, both anticipated and unanticipated, to emerge (Creswell, 2003). Furthermore, it uncovered underlying processes across multiple levels of influence relevant to community integration. The rationale for using this method was to capture the complexity inherent in how survivors experienced participation in home, productive activity, and social engagement after a stroke.

2.3 Sample and Recruitment

A convenience sample of 30 Latino stroke survivors living in Washington Heights-Inwood was recruited for this study. The inclusion and exclusion criteria for the study were informed by research in the areas of stroke rehabilitation and aging, and the ethnic, language, and geographical foci of the study (Burn et al., 1994; Caspersen, Pereira, Curran, 2000; Clarke, 2005; Kim, Warren, Madill, & Hadley, 1999; Kwakke, Kollen, Lindeman, 2004; Power, 2011; Reeves, 2008).

The study eligibility criteria included: (1) having had a stroke between 3 to 36 months prior to the time of the interview; (2) age of 50 to 80 years; (3) self-identify as Latino of any race; (4) speak Spanish and/or English; (5) physical residence in Washington Heights or Inwood based on zip codes 10032, 10033, 10034, and 10040 for at least one year post-stroke, and (6) ability to independently answer interview questions without a proxy. Stroke survivors with any

of the following self-reported criteria were excluded from the study: (1) living in an institution; (2) having other neurodegenerative diseases, for example, Alzheimer's disease; and (3) having severe aphasia or severe cognitive impairment.

Recruitment of study participants occurred through two methods: (1) by self-referral (e.g., from flyers posted throughout various sites in the community), and (2) by direct contact with stroke patients at two Columbia University Medical Center (CUMC) stroke clinics. Thus, the sample consisted of community-dwelling stroke survivors, some of whom (40% of the sample) were drawn from two stroke clinics ($n = 12$).

Initially recruitment centered on generating a neighborhood sample of participants by distributing study flyers at senior centers, community sites with bulletin boards (e.g., local parks and pharmacies), during local health fairs and community events, and at Columbia Community Partnership for Health, a CUMC health and community wellness information resource center in Washington Heights. The study flyer was intentionally distributed at a range of neighborhood locations to avoid largely relying on senior centers for study participants, who, by virtue of participating in a senior center, would likely report greater levels of participation in community activities. The bilingual recruitment flyer described the study in brief and the eligibility criteria with the researcher's contact information printed on tear-off tabs.

Interested volunteers self-referred by contacting the researcher to enroll in the study. To confirm study eligibility, all potential study participants were screened by phone using a short eligibility questionnaire. This method of recruitment using flyers generated 18 eligible participants. Participants reported learning about the study mostly from word-of-mouth ($n = 10$, 55.6%), from the Columbia Community Partnership for Health ($n = 6$, 33.3%), or at community

outreach events, such as a health fair ($n = 2$, 11.1%). None of the participants reported learning about the study from a senior center. Although accrual of participants using these community-based recruitment methods was slow, it achieved the goal to include in the sample survivors who were not necessarily currently receiving medical treatment (or monitoring) for their stroke.

In response to the Dissertation Committee's recommendation to also integrate recruitment of respondents from a clinic sample, recruitment of the remaining 12 participants occurred at the ColumbiaDoctors Neurology clinic and the New York Presbyterian (NYP) Ambulatory Neurology Continuity Clinic with permission of the respective medical directors. Identification of potential participants occurred by reviewing the attending physician's patient roster for that clinic day. Patients who were diagnosed with an ischemic or hemorrhagic stroke, were between 50 and 80 years of age, had a Latino last name, and did not meet exclusion criteria were selected for the study. The researcher introduced herself to the patient and described the study purpose and procedures. Patients that agreed to participate were then administered the eligibility questionnaire in-person to confirm they self-identified as Latino and lived in one of the four qualifying zip codes.

2.4 Data Collection Procedures

Interviews with participants were scheduled at mutually convenient times and at respondents' preferred location. The researcher conducted all interviews mostly at participants' homes with the exception of three that were completed in the researcher's office. The majority (28 out of 30) interviews were conducted in Spanish. Participants were informed that their privacy and confidentiality would be protected and that they could refuse to participate in the study or withdraw at any time without explanation. Also, the researcher affirmed that dropping

out of the study in no way would affect participants' standing at CUMC. Prior to being interviewed all participants provided signed consent and agreed to be audio recorded. Participants received \$20 cash for participating in the study. The duration of interviews ranged from 38 to 99 minutes, with an average duration of 76 minutes. A field notes form was used to record observations of the interview as well as new ideas prompted by the interview data.

To protect participants' identities, participants were assigned a unique and arbitrary identification number used on their respective eligibility screening form, interview guide, field notes form, and dataset entry. The consent forms and incentive receipts, as well as the contact information tracking sheet, were kept separate from the completed eligibility screening forms, interview guides, field notes forms, and Excel dataset to protect participants' identities.

2.4.1 Interview Guide

An ecological framework for community integration (CI) guided the interview for stroke survivors. These interviews explored the CI conceptual domains of participation in home, productive activity, and social engagement. Data was collected using a semi-structured questionnaire to capture the survivors' lived experiences with stroke and elicit their views and experiences at the micro-, meso-, exo-, and macrosystem levels (including intrapersonal, interpersonal, and community factors) that influenced their integration experience, while allowing for unanticipated factors to arise. The interview guide consisted of 20 closed-ended questions on survivors' demographic, socioeconomic, and stroke information (see Table 3 for data). The interview guide also included 14 open-ended questions (see Table 1 for sample questions).

2.5 Data Analysis

The purpose of the data analysis was to systematically identify essential features and relationships about the community integration experiences of Latino stroke survivors. The analysis of the data followed Groenewald's (2004) approach to phenomenological "explication of the data" (p. 49). The term explication in phenomenology is used over the term analysis because explication implies an examination of the parts of the phenomenon while keeping the "context of the whole" (Groenewald, 2004). The process of explaining the data involved three steps:

(1) Bracketing and phenomenological reduction. The audio for every interview was reviewed in its entirety to become familiar with the words of the interviewee in order to develop a holistic sense of the individual's experience with reintegration. By reviewing the audio, phenomenological reduction—the opening of the researcher to the phenomenon as described—was practiced. The process of reduction facilitated bracketing, that is preventing the researcher's personal views or preconceptions to color the participant's experience.

(2) Delineating units of meaning. Survivors' statements that explained the phenomena of community integration post-stroke were extracted from each interview. These statements or units of meaning were carefully analyzed by considering the literal content, the frequency with which a unit was mentioned, and how it was stated. The form in which units of meaning were stated considered both its linguistic and non-verbal cues. Non-verbal cues were noted in the field notes form, the content of which was included in the analysis.

(3) Clustering of units of meaning to form themes. Grouping together units of meaning lead to the development of themes. These themes and sub-themes were then grouped again or clustered

to determine central themes. Lastly, identifying the patterns and deviations across survivors' narratives yielded a general structure of participants' experience with community integration. This last step included the selection of illustrative quotes that reflect the range of experiences and beliefs within themes.

2.6 Validation of Findings

Multiple data verification strategies were employed. First, findings were described in detail and supported by rich quotes to support the approach used to generate and interpret the data. Second, the range of answers found in narratives was reported in the findings. Third, the researcher routinely practiced reflexivity to identify her assumptions and preconceptions, and to examine the impact of these on the wording of interview questions. The researcher's role to the respondent was also examined, and how this dynamic affected responses to questions. For example, to dissuade participants from providing desirable answers, the researcher monitored her body language, facial expressions, and verbal reactions to participants' answers. Moreover, the researcher strived to maintain neutrality throughout the interview while practicing active listening with the participant. These practices provided the opportunity for revising questions and re-framing the data interpretation as the project progressed. Finally, findings were discussed during weekly project meetings with the dissertation sponsor to further validate the researcher's interpretations.

2.7 Researcher's Personal Bias & Knowledge

The discursive nature of qualitative research involved building rapport and maintaining a collegial relationship with the participant. The respondent was viewed as a co-researcher given his/her knowledge, experience and expertise with community integration post-stroke.

Maintaining objectivity involved bracketing personal values, assumptions, and biases throughout the research process. My perceptions of community reintegration post-stroke were formed by a series of experiences with stroke survivors. First, my research background includes work on risk factors and social support among stroke survivors. During qualitative interviews with dyads of stroke survivors and their caregivers a theme that emerged was the negotiation between stroke survivors' desire to resume meaningful activities and the boundaries set by the caregiver whether family, friend, or paraprofessional. Despite caregivers' good intentions to protect their loved ones, their protective behavior inhibited stroke survivors from reintegrating into community. Second, I also worked with the Stroke Warriors support group in northern Manhattan. Support group members expressed varied perceptions of themselves and their experiences post-stroke. Third, the most impressionable experience with a stroke survivor is also my most personal. I am a family member of a stroke survivor. My husband at the age of 39 experienced an ischemic stroke that temporarily paralyzed the left side of his body. This experience exposed me first hand to a stroke survivor's transition to a new normal full of fear of a recurrent stroke. The sudden nature of the stroke and its unexplained cause left us fearing a recurrence. Despite my experience with stroke survivors, to avoid introducing bias into the data analysis, I maintained notes and discussed the data analysis with her dissertation sponsor throughout the process to ensure that its interpretation was faithful to participants' narratives.

2.8 Results

The results reflect both the common themes found across all participants as well as themes that were pertinent to survivors with current impairments, as their disabilities reflected very different experiences. Using the data analysis approach described in section 2.5, the following 13 themes were generated:

1. Fear of Stroke Recurrence
2. Stroke Affect
3. Post-Stroke Identity
4. Limits to Social Participation
5. Poor Health Literacy
6. Shrinking Social Networks Post-Stroke
7. Female Family Members Carry Greater Burden of Responsibility
8. Poor Understanding and Navigation of Social Services System
9. Accessibility to & Perceptions of Senior Centers
10. (In)Accessibility of Public Transportation
11. Built Environment Limits Activity
12. Cultural Ignorance
13. Punitive Public Policies

Each theme is described below within their respective ecological level (see Table 2 for emergent themes by ecological level). The illustrative quotes used to describe each theme are presented in their original Spanish and their English translations in brackets. The quotes were translated from Spanish to English by the researcher who is a native Spanish speaker, and who has had a wealth of experience translating research instruments and findings. The dissertation sponsor (also a native Spanish speaker experienced in conducting research with Spanish-speaking Latinos) reviewed the selected quotes to verify their accuracy. Quotes originally in English were kept in the same language.

Participants

In total 30 Latino residents of northern Manhattan who experienced a stroke within the last three years participated in this study. Table 3 provides summary information and descriptive statistics for the entire study sample.

Participants predominantly identified as Dominican (90%, $n = 27$) and as Latino White (60%, $n = 18$). The average respondent was 65 years old. Most respondents were either separated or divorced (50.0%, $n = 15$). Most lived alone (46.7%, $n = 14$), others lived with a spouse (26.7%, $n = 8$), or with their child (16.7%, $n = 5$). The vast majority (93.3%, $n = 28$) had lived in Washington Heights-Inwood for more than 10 years.

The majority of the sample had low social status. Just over three quarters of participants (76.6%, $n = 23$) reported obtaining a high school education or less. The majority of participants (70%, $n = 21$) reported an annual income of less than \$10,000. With the exception of one participant with private insurance, 96.37% ($n = 29$) of participants were covered by Medicaid (60%, $n = 18$), Medicare (6.7%, $n = 2$), or both (30%, $n = 9$). About one-quarter of the sample, 26.7% ($n=8$), reported having current stroke-related impairments. All respondents, however, experienced some level of impairment after their stroke. Lastly, roughly half of participants (40%, $n = 12$) had their stroke within a year of the interview, while the rest of survivors experienced their stroke within one to three years of the interview (60%, $n = 18$).

Differences between the neighborhood and clinic samples were observed in a few demographic characteristics. More participants in the clinic sample reported being single (33.3%, $n = 4$) or divorced (25%, $n = 3$) compared to the neighborhood sample, of whom 16.7% ($n = 3$) were single and 16.7% ($n = 3$) were divorced. However, more participants in the neighborhood sample reported being separated (33.3%, $n = 6$) compared to the clinic sample (25%, $n = 3$). The two samples also differed in their household composition with more participants in the clinic sample living alone (58.3%, $n = 7$) and fewer living with a spouse (16.7%, $n = 2$) compared to the neighborhood sample that included fewer participants living alone (38.9%, $n = 7$) and more participants living with a spouse (33.3%, $n = 6$). The time passed since participants' stroke and

reported impairment differed between samples. All of the participants in clinic sample had experienced their stroke within a year of the interview (100%, $n = 12$) whereas in the neighborhood sample, more time had elapsed between the stroke and the interview (11 to 24 months= 55.6%, $n = 10$; 25 to 36 months= 44.4%, $n = 8$). A greater proportion of participants in the clinic sample (50%, $n = 6$) compared to the neighborhood sample (11.1%, $n = 2$) reported currently experiencing stroke related impairments, possibly because the clinic sample had experienced a stroke within six months of the interview and were still in recovery.

2.8.1 Microsystem

In the ecological model, the microsystem includes intrapersonal factors such as an individual's self-esteem, identity, and self-concept, as well as psychological coping processes that influence adjustment to illness such as stroke. Within the microsystem, four themes emerged from interviews with stroke survivors: (1) Fear of Stroke Recurrence, (2) Stroke Affect, (3) Post-Stroke Identity, (4) Limits to Social Participation, and (5) Poor Health Literacy. Each theme is described below.

Fear of Stroke Recurrence

Common among all survivors was the fear of stroke recurrence. To be a stroke survivor is to live with the fear of another stroke that could result in impairment, or worse, death. For some survivors, the extent of their fear impacted their behavior outside their home and with family. Fearing a stroke recurrence outside their home, some participants opted to stay home, believing their home was safer than being outdoors, and that they would be less likely to get injured. One survivor feared being left alone and not having help in the event of another stroke. Another survivor spoke of developing a fear of sleeping because her strokes had occurred while asleep.

She coped with the fear by forcing herself to stay awake until her exhaustion and sleep overcame her. The following quotes illustrate survivors' fear with a recurrent stroke:

“¿Si me da uno grande y me mata?” [“What if I get a big one and it kills me?”]

“I am scared. It's scary, very scary. I'm scared because I am always sleepy. All the strokes happened when I was sleeping. It's not easy.”

Stroke Affect

Survivors also spoke of being aware of a change in their affect after the stroke. A change in affect was described as lacking interest or motivation (the Spanish word used was *ánimo*) for their hobbies and usual activities. Others spoke of no longer feeling happy after their stroke. Some survivors attributed this change in mood to fatigue, chronic pain, to their poor physical functioning, and to needing to depend on others to carry out tasks. Survivors' sentiments about their changes in affect are captured in the following quotes:

“I use to hear my music, I don't hear music, I don't do nothing. No me da deseo, no tengo ese ánimo ya. No lo siento, no me da deseo ya de escuchar mi música.” [“I used to hear my music, I don't hear music, I don't do nothing. I don't feel like it, I don't have that interest anymore. I don't feel it, I no longer have desire to listen to my music.”]

“Sé que después de que me dio esto he cambiado, yo estaba más gruesa, más activa, como más alegre, ahora como que no me da deseo de nada, no sé, sera porque no puedo yo misma hacer muchas cosas, salir, levantarme pronto, esperar que me hagan las cosas, eso se me hace más difícil.” [“I know that after I got this I've changed, I used to be heartier, more active, happier, now I don't have a desire for anything, I don't know, maybe because I can't do many things, go out, get up quickly, waiting for everything to be done for me, this makes it difficult for me.”]

“No es lo mismo. Yo era alegre, ya no.” [It's not the same. I used to be happy, not anymore.”]

Post-Stroke Identity

Acute among survivors with impairments was a sense of self-loss about the roles and activities they held prior to their stroke. Participants expressed a loss of purpose from no longer being self-sufficient.

Worker Role

Among survivors who were employed prior to their stroke, their self-concept was negatively impacted by their inability to work after the stroke. They had gone from being financially independent to depending on the assistance of public programs or family and friends, and a few found themselves without recourse and owed several months of back rent. These quotes from survivors exemplify their struggle with their pre- and post-stroke identities:

“A mí se me hace difícil, me da hasta como depresión. Pues según tu sabes yo tenía un motivo pa’ salir, pa’ trabajar, pa’ pagar mi renta, pa’ hacer mis cosas, y ya nada de eso, ¿tú me entiendes? Ya no lo puedo hacer.” [“It’s hard for me, it gets me kind of depressed. I had a reason to go out, to work, to pay my rent, to do my things, I don’t have that anymore, do you understand? I can’t do it anymore.”]

Independence & Self-Sufficiency

Salient in survivors’ narratives was their struggle with maintaining their independence in their activities yet feeling useless from their limited abilities. Some survivors described themselves as “*impotent*” or “*useless*” due to their inability to be fully independent and for having to rely on others.

“Yo ya no puedo ser el hombre que yo era. De ninguna manera. A mí me gustaba ir a los night-clubs y a las discotecas a bailar con dos o tres mujeres, me gustaba ir a restaurantes buenos a comer distintas comidas, restaurantes finos, me gustaba ir a las movies, a mí me gustaba ir a obras de teatro, a Radiocity Music Hall, a Madison Square Garden, a Central Park a los

conciertos en el verano que dan a gratis, Prospect Park en Brooklyn, a distintos sitios, New Jersey, y son muchas cosas que yo dejé de hacer...poco a poco yo dejé de ser yo porque no podía ser el hombre libre y feliz, no podía bailar, no podía correr, no podía nadar como yo quería, como fueron pasando las cosas me fui cohibiendo de todo eso.” [I can’t be the man I use to be, in any form. I use to like going to nightclubs to dance with two or three women, I use to like going to good restaurants to eat different foods, I liked going to the movies, I liked going to plays, to Radiocity Music Hall, to Madison Garden, to Central Park to the free summer concerts, to Prospect Park in Brooklyn, to different places, New Jersey, there are a lot of things I stopped doing...little by little I stopped being me because I could not be a happy and free man, I couldn’t dance, I couldn’t run, I couldn’t swim like I wanted to, as things started to happen I kept keeping myself from all of that.”]

“Yo hacía todos mis oficios, yo cocinaba, yo lavaba, yo venía a cuidar a mis muchachos, los llevaba a la escuela, los recogía, ese era el motivo que yo tenía, tú sabes, para subir y bajar, yo salía a mis compras al día, no me importaba salir pero ahora no lo puedo hacer sin ayuda y con el baston. ¿Vé? Son cosas ya distintas. Imagínate que tú quieras ir, yo me iba antes como a la tienda, me iba hacer cualquiera diligencia, me tocaba ir a pagar la renta yo cogía la guagua y la pagaba, ahora yo ya no puedo hacerlo sola.” [“I would do all of the housekeeping. I cooked, I did laundry, I would take care of my kids, I took them to school, picked them up, that was my motivation, you know, to go up and down, I would go out to do my shopping every day, I use to go to the store, I would do all my errands, when it was time to pay the rent, I would take the bus and pay it, now I can’t do it by myself.”]

Within the context of functional independence, reliance on others was a salient theme.

However, not because survivors perceived overburdening others, rather they expressed concern about how their dependence on others poorly reflected on their self-concept, as one participant said:

“Es bueno cuando tú te puedes defender tú. Que puedes hacer todas tus cosas, tú, sin tener que llamar a nadie, eso es muy bonito, pero después de que tú tengas que depender en otra persona, no es lo mismo. Para nada. No se lo recomiendo a nadie.” [“It’s good when you can defend yourself. When you can do all of your things yourself, without having to ask anyone,

that's beautiful, but after you have to depend on someone, it's not the same, at all. I don't recommend it to anyone.”]

Yet for other survivors their need to avoid feeling useless was motivation to carry out their activities, as stated by one participant: *“Yo puedo hacer todo pero necesito ayuda pero yo lo hago. Yo cocino, me baño...yo limpio, pero el dolor no me deja. Pero yo no quiero volverme inútil”* [*“I can do everything but I need help. I cook, I shower...I clean, but the pain doesn't let me. But I don't want to become useless.”*]. Survivors strived to maintain a sense of control and to feel useful and competent by adapting their activities to their new level of functioning. They did so even if the activities took longer to complete or left them physically drained and in pain. Some survivors feared their condition worsening if they accepted help. Instead survivors adapted how they accomplished routine activities, for example they did not cook or clean as often as they did prior to their stroke, or they split activities into more manageable tasks, as captured by these survivors' quotes:

“Yo no cocino todos los días. Yo cocino una vez para toda la semana porque me da deseo de comer comida casera. Antes del derrame cocinaba every day, ahora una vez por el dolor.” [*“I don't cook every day. I cook once for the entire week because I crave home cooking. Before the stroke I cooked every day, now once because of the pain.”*]

“Tengo que adaptarme, tengo que adaptarme, ya no me queda de otra. Tengo que seguir buscando algo que me ayude, que me arregle este lado, no me puedo quedar tranquila. Yo siempre estoy investigando. Yo me meto con todos los médicos, les digo to'.” [*“I have to adapt myself, I have to adapt, I don't have a choice. I have to keep looking for something that helps me, that fixes this side, I can't stay put. I am always researching. I go to all the doctors, I tell them everything.”*]

“Dejar [el apartamento] regado, dejarlo sucio. Eso me está matando. Yo dije si yo consigo alguien me voy a botar en la cama a esperar que me hagan todo y me voy a poner peor. Eso fue lo que yo pensé.” [“I leave [the apartment] messy, leave it dirty. It’s killing me. I told myself if I get someone to help me I am going to throw myself onto my bed to wait for everything to be done for me and I will get worse. That’s what I thought.”]

Limits to Social Participation

In addition to the fear of recurrence, for some survivors their behavior outside of their home and with others was influenced by a fear of falling, fatigue, and pain. Among survivors with impairments many spoke of limiting their radius outside their home to their immediate block, mostly due to fatigue from walking and chronic pain, as two participants said:

“A no salir a la calle a caminar. Si yo camino un bloque ya estoy cansada, ya no puedo.” [“I don’t take walks outside. If I walk a block I get tired, I can’t anymore.”]

“Yo no puedo salir tan lejos. Todo lo que consigo es aquí cerca. Yo no puedo caminar tan lejos por los dolores.” [“I can’t go out far. Everything I get it’s from nearby. I can’t walk too far because of the pain.”]

A few survivors expressed being afraid to leave their home or go outside unaccompanied due to fears of falling and injuring themselves:

“Me da miedo irme de boca, me caiga, y me dé un golpe peor. Mejor me quedo tranquila [en mi hogar].” [“I am afraid of falling on my face, and injuring myself badly, I rather stay [home].”]

“Ya yo no podía, y si no tenía que salir con alguien acompañándome, no me fuera a caer y darme un golpe que no pudiera pararme. Mi calidad de vida empezó a cambiar dramáticamente. Ahora mismo yo vivo de esta silla de ruedas.” [“I couldn’t anymore, if not I had to go out accompanied by someone, I

didn't want to fall and hit myself so bad that I could not get up. My quality of life began to change dramatically. Currently I live in this wheelchair.”]

Moreover, for many survivors with impairments, chronic pain and functional mobility kept them socially isolated from spouses, family, and friends. A striking finding in their narratives about their social isolation was that survivors chose to isolate themselves from others. The severe chronic pain and fatigue they experience kept them home, preferring solitude to being uncomfortable around others:

“¿Cómo yo voy a estar sentada con dolor? Yo mejor me quedo en mi casa acostada. I've got pain every day, every single day. Not only today, not tomorrow, it's every day. Seven days a week I am in pain.” [“How am I going to be sitting in pain? I rather stay home lying down. I've got pain every day, every single day, every single day. Not only today, not tomorrow, it's every day. Seven days a week I am in pain.”]

“Mi hermana me decía ‘ven pa'ca yo iba corriendo, ‘vamos ahí a una tienda, vamos al mall,’ ahí iba yo y ahora yo no voy a un lado porque si camino un poco retirado ya mi cuerpo no tiene fuerza, para nada.” [“My sister would tell me ‘come over’ and I would go running, ‘let's go to a store, let's go to the mall,’ I would go and now I don't go anywhere because if I walk some distance my body has no strength, at all.”]

One survivor's severe chronic pain influenced the decision to separate from his spouse in order to shield her from his ailments:

“No quiero a mi esposa aquí...yo sufro al verla no poder dormir cuando yo me levanto llorando, gritando, brincando en la cama cuando me da la neuropatía que empiezan las piernas a brincar solas y a temblar que ella se sienta a llorar como una niña y no duerme. Que se levanta y no quiere comer porque esta pensando en mi y no le da apetito, pierde el apetito. No es justo. Mientras que ella allá [en Puerto Rico] vive feliz. Aquí ella lo que estaba era enfermándose.”

Aquí ella se estaba enfermándose de la presión, llegó a padecer de la presión alta y de los nervios. Ojos que no ven, corazón que no siente. Yo no creo que sería justo de mi parte por ella estar aquí cuidándome a mí, se enferme por mi culpa. Eso no es amar, el que ama no quiere ver a nadie sufrir.” [I don’t want my wife here...I suffer seeing her not be able to sleep when I wake up crying, screaming, jumping in bed from the neuropathy in my legs, and I start shaking that she sits up and cries like a little girl and doesn’t sleep. She gets up and doesn’t want to eat because she’s thinking of me and doesn’t get an appetite, she loses her appetite. It’s not fair. While [in Puerto Rico] she lives happy. Here she was getting sick. Here she was getting sick from high blood pressure, she ended up having high blood pressure, and anxiety. Eyes that don’t see, heart that doesn’t feel. I don’t think it would be fair on my part to have her be taking care of me here, that she get sick because of me. That’s not loving someone, he who loves doesn’t want to see anyone suffer.”]

Poor Health Literacy

Although an overwhelming majority of survivors spoke positively about the stroke care they received, instances of poor health literacy emerged in their narratives. With the exception of one participant, no other survivors knew the type of stroke they suffered. Poor health literacy was identified as a significant issue among this sample. Not knowing his or her stroke diagnosis may keep a survivor from properly addressing the underlying cause of their stroke. Poor health literacy was also observed in one participant who challenged her medical diagnosis of depression. In that case, she believed that depression was a severe psychotic condition:

“[Doctor] told me that what I had was depression but I don’t have depression, I don’t know what it is to have depression. What is depression? You tell me. I don’t know what it’s like to have depression, what does depression feel like? I don’t feel bad. For me depression is people screaming, who are crazy, for me, I don’t know.”

2.8.2 Mesosystem

A mesosystem or interpersonal level comprises the interrelations among a person's individual setting and the relationships with family, friends, social service agencies, and health care providers. Within the mesosystem, four themes emerged from interviews with stroke survivors: (1) Shrinking Social Networks Post-Stroke, (2) Female Family Members Carry Greater Burden of Responsibility, (3) Poor Understanding and Navigation of Social Services System, and (4) Accessibility to & Perceptions of Senior Centers. Each theme is described below.

Shrinking Social Networks Post-Stroke

Most respondents described their pre-stroke social networks as a small group of family and friends that for many decreased in size and composition post-stroke. Many survivors spoke of friends initially visiting them at the hospital or upon their immediate return home. Afterwards, however, they experienced an abrupt decrease in social contacts. Survivors attributed the disappearing behavior of their friends to their impairment or to no longer engaging in activities they previously shared in common with friends. One participant believed that her friends had stopped visiting her because she could not engage in conversation given her slurred speech: “*ya no puedo hablar porque el habla tampoco me sale bien, yo empiezo hablar y no sé qué decir, es por la enfermedad que sufrí en el sistema.*” [“*I can't speak anymore because I can't speak well, I start talking but I don't know what to say, it's from the illness that I suffered in my system.*”] Friends of another survivor stopped contacting her after she decided to stop drinking and using drugs, she said: “*No one comes anymore. There's no more music, there's no more beer, there's no more alcohol (laughs). You know that's how it is.*”

These survivors expressed feeling hurt or angry for the loss of friends, many who they considered close friends. An unanticipated outcome of their stroke was learning who their true friends were but also having to consider being devalued by these friends because of their stroke related impairments.

Female Family Members Carry Greater Burden of Responsibility Than Do Males

In response to questions about their sources of help and support, clear gender differences and roles emerged. Compared to the narratives about their sons, participants' daughters provided more frequent, greater amounts, and distinct types of instrumental support. Sons by and large provided only one type of support. For example, one son, a taxi driver, chauffeured his mother as needed while another son covered the monthly electricity bill for his mother. In contrast, daughters provided a variety of forms of support: emotional, informational, and instrumental assistance. Daughters were described as more involved in the care of their stroke surviving parent, frequently calling and visiting, buying groceries, cooking, housekeeping, making doctors' appointments, and financially supporting her parent. As one survivor said:

“Gracias a Dios que por lo menos mi hija para conmigo y me ayuda hacer las cosas, y me dice ‘mami no te preocupes yo voy a estar contigo hasta que tu me necesites, yo voy hacer todo lo que necesitas, estate tranquila’, ...si no fuera por ella yo me la viera fea, quien sabe lo que fuera yo porque no es fácil, no es fácil que tu te quieras bañar, te quieras cambiar, quieras doblar una gaveta y la cosa no la puedas jalar porque no tienes fuerza,...que uno no pueda hacerlo es duro.” [“Thank God my daughter stops by and helps me with things, and she tells me ‘mommy, don’t worry, I am going to be with you until you need me, I am going to do everything you need, relax’ ...if it wasn’t for her I would be in a bad situation, I don’t know what would happen to me because it’s not easy, it’s not easy that you want to shower, that you want to change, that you want to fold a bucket but you can’t pull it because you don’t have strength...not to be able to do things on one’s own is hard.”]

A double standard was observed in how stroke survivors accepted the role adopted by their daughters yet did not expect the same of their sons. Participants rationalized their son's behavior to having their own responsibilities and families even when the same was true for their daughters:

“Si no fuera por mi hija, no fuera nada ahora mismo yo. Ella es la que me hace todo a mi. Todo, todo, Como quien dice mi mano y mi pie es ella...Tengo un [hijo] pero ya tiene 33 años y tiene su esposa, tú me entiendes, tiene sus hijos.”
[“If it wasn't for my daughter, I would be nothing right now. She does everything for me. Everything, everything. She's like my hand and foot...I have a son but he's 33 years old and has a wife, you know, he has his kids.”]

“En todo que necesite, están ahí. Nunca me abandonaron. El varón cuando necesito ir a un sitio, él me lleva. No todo el tiempo está disponible...ella me paga la renta, me paga la luz, runs all my errands”. [“In everything I need, they're there. They never abandoned me. My son when I need to go somewhere, he takes me. He's not available all the time...she pays my rent, pays the electricity, runs all my errands.”]

Survivors who were female and lived alone explicitly preferred receiving help from their daughters over sons. In particular, they cited feeling more comfortable receiving help from their daughters with personal hygiene and toileting, as one participant said: *“Con ella por lo menos, cómo te digo, con él me llevo bien pero con ella más. Porque ella es mujer igual que yo, ¿tú me entiendes? Yo con ella no me da vergüenza quitarme la ropa, que me bañe, lo que sea a mi no me da vergüenza eso, pero con él sí.”* [“With her at least, as I said, I get along with him but more with her. Since she's a woman just like me, do you understand? With her I am not embarrassed to take my clothes off, that she shower me, whatever it is it doesn't embarrass me with her but I am with him.”]

This gender difference was also observed in the roles fulfilled by nieces and daughters. Nieces provided social support in different ways. In one case, the stroke survivor depended on the niece to lend her money to complete her rent. Also, nieces as well as daughters informally filled the role of home attendant. One stroke survivor was in the process of applying to make her daughter her official home attendant. By doing so, the daughter would obtain financial compensation. This represented a form of reciprocity on the part of the survivor and a way to contribute to the household income. The stroke had left the survivor unable to work and financially dependent on her daughter.

Poor Understanding and Navigation of Social Services System

The majority of survivors described their experience with obtaining social services as a self-guided, frustrating, and a lengthy process. Many survivors had learned about entitlement services on their own or from word-of-mouth. Survivors, in particular those unable to resume employment, found themselves in crisis, worrying both about their health and their ability to meet the basic needs of their families, as one participant shared:

“Vivo dándole gracias a Dios por todo, por lo poco, por lo mucho, por lo que me pueda dar. Hay que darle gracias a Dios por un techo que nunca quiero perder, aunque ahora debo cinco meses, mi amor, dime tú, pa’ no estar preocupada, sin poder dormir, dando mente, aunque estoy buscando ayuda y espero en Dios que me lo resuelva, he aplicado para disability, he buscado ayuda en los cupones, welfare.” [“I live giving thanks to God for everything, for the little I have, for everything I have, for whatever he can give me. I thank God for the roof that I never want to lose although right now I owe five months, love, you tell me, to not be worried, unable to sleep, always thinking about it even though I am looking for help and I trust in God that it will get resolved, I’ve applied for disability, I’ve looked for help in coupons, welfare.”]

Those who had worked with social workers described the process as frustrating. Respondents expressed feeling dissatisfied with the limited assistance they had received from the social worker. Some survivors spoke of receiving insufficient direction from social workers to properly navigate the system on their own. With limited or no prior experience navigating the social welfare system, survivors expressed interest in working with a social worker to identify needed social services and process applications on behalf of people in need, as one participant said:

“Incluso que yo dije que cuando yo vaya al hospital les voy a decir que me pongan a una trabajadora social, que yo le pueda llamar, pueda hablar con ella, a cualquiera cosa...por un ejemplo, si yo necesito algo que ella me ayude porque yo no sé mucho de letra no sé, ¿cómo, cómo te digo, cómo que me ayude a buscar algo, qué si yo quiero que me ayude a resolver cualquiera problema, tu me entiendes? Si yo necesito llenar algún papel, me lo llene, ¿tú me entiendes? Si yo necesito ir a una farmacia ó necesito una medicina, que ella me diga cómo es. Que me ayude a resolver cualquiera cosa que yo necesite porque en verdad yo necesito una trabajadora social.” [“Actually I said that when I go to the hospital I am going to tell them that they assign me a social worker, that I can call, talk to her, about anything...for example, if I need anything that she help me because I don't know much about reading, how can I explain, that she help me look for something, that she help me resolve a problem, you know? If I need to fill out a form, that she fill it in, you now? If I need to go to a pharmacy or I need medicine, that she tell me about it. That she help me resolve anything I need because honestly I need a social worker.”]

Those participants whose stroke had occurred within six months at the time of the interview found themselves in a precarious situation. With no means of support, they nervously waited for notification and confirmation that they had been approved for services. During the application period, without funds or access to supplemental benefits such as SNAP, survivors spoke of finding themselves in dire circumstances unable to pay rent or purchase groceries. While conducting one interview, the brother-in-law of the participant arrived with groceries. One

other participant noted disliking Meals-On-Wheels, a food delivery service for homebound adults, because it lacked ethnic food choices.

Accessibility to & Perceptions of Senior Centers

Despite the potential for senior centers to facilitate community integration for stroke survivors, most participants did not speak favorably of these centers. Many survivors believed that senior centers were not for people of their age. Instead, they asserted that the centers were meant to cater to the very old and frail. Moreover, some respondents viewed the centers as unpleasant places. The following quote captures the attitude of some survivors towards senior centers:

“A mí díque me querían meter a un programa de esos que van 25,000 viejos a pasar el día a un centro de esos, y eso es un asco porque ahí los que van son un chorro de viejos babeándose, escupiéndose, hay unos que van y se hacen las necesidades encima y hay una peste por todo el sitio y los limpian cuando quieren, cuando no, no. Las comidas se las tiran en la mesa como un perro...yo estoy hablando de un senior center. Aquí hay senior centers que yo la llevo a usted y a usted le da náusea antes de la hora, es más, antes de la hora usted dice sáqueme de aquí. Hay unos que son limpios, hay otros que no.” [“Supposedly they wanted to enroll me in one of those programs that 25,000 old people go to spend their day at those centers, and to me [those centers] are disgusting because those who go are a lot of old people who slobber, spit, there are others that go and defecate on themselves and the whole place stinks and they’re cleaned when they want to, when they don’t they don’t. The meals are tossed on the table like a dog...I am talking about a senior center. There are senior centers around here that if I took you, you would get nauseous within the hour, in fact before the hour was over you would be asking to get out. There are some that are clean, others are not.”]

Another survivor had been turned away from a senior center because she did not meet the age requirement despite being 59 years old: *“They didn’t let me in...I didn’t have the required*

age. I went with a friend of mine who's from that center, she invited me to eat. I told her they weren't going to let me in. They didn't let me in so my friend said that I was her home attendant. The home attendant with a cane, more sick than the other one....I was interested in going because I had nothing to do."

Others expressed a dislike for the activities available, preferring more "intellectual" pursuits such as book discussions, learning to dance or play an instrument, trips to museums or music venues, as well as classes in which they could learn a new skill. One survivor expressed interest in opportunities to volunteer teaching a class on sewing.

2.8.3 Exosystem

The exosystem in the ecological model contains social structures, including employment opportunities, public services, neighborhood characteristics, mass media, and health services that influence and may determine a person's settings. Within the exosystem, two themes emerged from interviews with stroke survivors: (1) The (In)Accessibility of Public Transportation, and (2) Built Environment Limits Activity. Below, both themes are discussed.

(In)Accessibility of Public Transportation

All modes of available transportation presented challenges to survivors. Public transportation in northern Manhattan consists of subways, buses, and paratransit (i.e., Access-A-Ride), none of which met the needs of survivors with physical impairments. The subway and bus routes in Washington Heights and Inwood run north-south, which create public transportation "deserts" on the west and east side of the neighborhoods. For survivors with limited mobility, "walking distance" to bus stops and subway stations took on a subjective meaning dependent on their walking ability, gait, stamina and endurance, as survivors said:

“If I walk a block I am tired, I can’t anymore.”

“Yo no puedo caminar tan lejos por los dolores. El tren, la guagua, el taxi, se me hace difícil. Tengo que [tomar transporte público] cuando no le hablo a Access-A-Ride y tengo un appointment. Me voy sola. Yo puedo tomar la guagua, yo puedo subir y bajar escalares, no apurada. El tren de aquí, no, porque las escaleras están empinadas entonces se me hace difícil.” [“I can’t walk that far because of the pain. The train, the bus, the cab, it’s all-difficult. I have to take [public transportation] when I don’t call Access-A-Ride and I have an appointment. I go alone. I can take the bus, I can go up and down stairs, without being hurried. The train here, no, because the stairs are steep so it’s hard for me.”]

Although buses have ramps and wheelchair seating, the additional travel times incurred from the number of stops and vehicle traffic made buses unpopular among survivors, as one survivor said: *“Y de aquí a Central Park en un bus, ¿sabe cuánto es? Dos horas de camino y a veces más dependiendo del tráfico. No creo que vale la pena coger dos horas en un bus... Vamos a ser realista con lo que la vida le ha dado.” [“From here to Central Park, do you know how long it takes? Two hours and sometimes more depending on traffic. I don’t think it’s worth taking two hours on the bus...Let’s be real with what life has given you.”]*

The subway system also has significant flaws, only 4 out of the 15 stations in northern Manhattan are wheelchair accessible and 1 of 4 accessible stations is only accessible for southbound travel. Distance to an accessible subway station was a barrier in particular for survivors using wheelchairs, as one participant said: *“Usted dígame, en esta area, ¿dónde hay un tren con elevador para silla de rueda o rampa? Dígame!” [“You tell me in this area where is there a train with an elevator or a ramp for wheelchairs? Tell me!”]*. Survivors mentioned the elevators in wheelchair accessible stations as unreliable, which made travel by subway risky as survivors could find themselves stranded at the station without a working elevator.

The third public transportation option for survivors was paratransit, known as Access-A-Ride, which picks-up passengers at their doorstep. Survivors with mobility impairments considered Access-A-Ride unreliable and susceptible to travel delays that caused them long wait times and to arrive late to their appointments. The following quote captures these sentiments:

“Yo me quité del seguro que daba Medicaid Choice porque la ambulette ésas empezaron a cambiar de compañía y lo que traían era basura que venían, usted le decía que vinieran a las 9 de la mañana a buscarlo y llegaban a las 10-10:30am. Y cuando uno llegaba a la cita, dejan a uno para lo último pa’ después venir a recoger dos tres personas y regar a las personas por todo lado y a veces yo llegaba aquí a las siete de la noche so yo cancelé el servicio.” [“I took off the insurance that Medicaid Choice offered because the ambulette service started to change companies and what they had was trash, you would tell them to arrive at 9am and they would arrive at 10-10:30am. When you would arrive to the appointment, they would leave you until last to then pick-up two or three people and drop off people everywhere and sometimes I would come back home at 7pm so I cancelled the service.”]

Some survivors with mobility impairments resided in buildings without elevators or with exterior steps. They criticized the inability of Access-A-Ride drivers to assist them to and from the building to the vehicle. One survivor who uses a wheelchair recounted with emotion an incident she experienced with an Access-A-Ride driver who was willing to help her navigate four steps to the curb. The driver was overcome by the weight of the survivor in the wheelchair and lost control causing the driver and survivor to fall down the steps. She sustained an injury to her leg but the psychological impact of the incident caused greater damage--she cried at the thought of having to exit her building to attend another doctor’s appointment. The following are the survivor’s words: *“Yo me pongo mala desde que sé que tengo appointment por la maldita silla, no quiero, no quiero bajar los escalones, por la subidera y bajadera. Nos fuimos de cabeza (breathing heavy and begins to cry).” [“I get sick the moment I learn I have an appointment*

because of the damn wheelchair, I don't want to, I don't want to go down those steps, because of having to go up and down [the steps]. We fell head first (breathing heavy and begins to cry)"].

The preferred travel method for survivors with and without impairments were cabs. Survivors with Medicaid were eligible to use cabs for medical appointments with the cost covered by the insurance plan. For those without Medicaid or wanting to travel for other reasons unrelated to medical care, cab rides despite the necessity were expensive luxuries. For survivors with mobility impairments transportation can be overly complicated, exceedingly inconvenient, expensive, and potentially hazardous for those faced with physical barriers.

Built Environment Limits Activity

For a survivor with impairments his or her physical surrounding, once familiar and effortless, after a stroke becomes new and strenuous. The realization that the slope of a sidewalk, the steps in front of businesses and residential buildings, the multiple flights of stairs in walk-up buildings, are now physically taxing if not insurmountable for survivors with limb weakness, fatigue, or paralysis is as sudden as the onset of a stroke. One participant said: *"I go down [the stairs] without a problem, I go up [the stairs] without a problem, but in a lot of pain."* Survivors spoke of limiting their activity in the neighborhood to a few places that were near their apartment and were physically accessible. Survivors with moderate impairments spoke of limiting their activity, for example to business on their block or within a block radius that they could physically access. The nearest recreational park for one wheelchair user was unusable because it contained baseball and basketball fields for abled bodies.

Those survivors that used mobility devices spoke of being restricted to areas in their apartments large enough to accommodate the wheelchair or walker. The apartment doorways and

hallways of a few survivors were too narrow to fit a wheelchair. One participant would leave her wheelchair outside of her bedroom to have her spouse carry her to bed because the door casing was too narrow to fit the wheelchair. Another survivor would forgo a walker to use a cane to slowly and cautiously walk in order to move around her small apartment.

2.8.4 Macrosystem

The macrosystem in the ecological model refers to the broader societal beliefs and values, and institutional cultures that impact the individual. Within the macrosystem, the themes of: (1) Cultural Ignorance; and (2) Punitive Public Policies emerged from interviews with stroke survivors. Both themes are described below.

Cultural Ignorance

Survivors with visible impairments (20%, $n = 6$) spoke of being subjected to disparaging comments about their appearance or mobility from neighbors and strangers:

“Dos veces dos señores me digieron ‘Ay tan bonita y coja!’ me dió como depresión. Después yo le dije ‘eso no fue por mí, es Dios que me lo mandó.’ Eso me dió como depresión. No sé porque lo dijieron.” [“Twice two men told me ‘so beautiful and fucked-up/lame!’ it sort of gave me depression. I told him ‘this wasn’t because of me, God gave this to me.’ It sort of gave me depression. I don’t know why they said that.”]

Another survivor attributed Dominican macho culture for the lack of empathy shown to her by her neighbors:

“Los Dominicanos son muy machistas, los hombres Dominicanos. Ellos dique son amigos míos, conocidos, pero cuando me ven dicen ‘hay mira tu no sirves pa’ nada, ya métete a monja, vete a la cama pa’ que te mueras, ya no sirve pa’ nada.’ No me dicen mira estás caminando mejor, I see you’re walking better; they don’t tell me that. They tell me the opposite. I don’t pay mind to them. I don’t pay mind to them. ‘Ya tú ta vieja, you’re old.’ Gente conocida del bloque que enfrenta uno.” [“Dominicans are very macho, Dominican men. They are

supposedly my friends, acquaintances, but when they see me they say 'oh look you're not good for anything, go be a nun, go to bed to die, your useless.' They don't tell me you're walking better, I see you're walking better, they don't tell me that. They tell me the opposite. I don't pay mind to them. I don't pay mind to them. 'You're old, you're old.' People I am familiar with from the block"]

Another survivor spoke of people's lack of consideration for wheelchair users:

"La silla eléctrica le proviene a uno más libertad pa' ser cosas, salir mas lejos, venir, y la gente cuando ve una silla eléctrica se mueve pa' lado, con esta [silla manual] se quedan parados como estatuas. Si uno no les grita y después le quieren dar a uno también. Se paran en el medio donde es para bajar la silla de ruedas en la alacena a hablar y si uno les dice que se muevan, quieren darle a uno. Es lo que me ha sucedido." ["The wheelchair gives me greater freedom to do things, travel farther, and when people see a power wheelchair they get out of the way, with this one [manual wheelchair] they stay still like statues. If I don't yell at them then they want to hit you too. They stand to talk in the middle of the sidewalk that's meant for the wheelchair and I tell them to move, and they want to hit you. That's what's happen to me."]

The same respondent also spoke of strangers questioning his stroke identity, which may indicate misinformation or misperception of the range of stroke impairments a survivor may incur. Some people may believe or expect to see severe deformity in stroke survivors, as expressed in this quote by a survivor recounting his experience:

"Como dos semanas atrás yo estaba hablando con uno de los conocidos de la bodega sobre lo que me sucedió con el stroke y llegó un individuo y me dijo 'Te viera dado un stroke estuvieras tirado, no pudieras hablar, no estuvieras aquí. Estuvieras en un maldito nursing home.'" ["About two weeks ago I was talking with one of my acquaintances at the bodega about what had happened to me with the stroke and a man came in and told me 'Had you had a stroke you would be on the ground, without the ability to talk, you wouldn't be here. You would be in a nursing home.'"]

Punitive Public Policies

Supplemental Security Income (SSI) is a federal program that pays monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older. One SSI recipient shared that she experienced financial difficulties with the government because she was not informed about the program's financial requirements. Because she and her husband had not visited their home country for over 20 years, they decided to sell a modest property that they had inherited from the spouse's father. They profited about \$6,500 from the transaction, which they deposited into their checking account. SSI found them to be in violation of income requirements by exceeding the \$3000 in assets for a couple. Consequently, his SSI -- their only source of income-- was decreased from about \$700 to about \$450 per month. In addition, they incurred a fine for violating the program's regulations. Although this SSI issue was unique to one participant in the sample, it nonetheless exemplifies how public policies can maintain people of very limited means financial depressed.

2.9 Summary

Findings from the data on the community reintegration experiences of Latino stroke survivors in an urban area indicate that their integration into home and community is dependent on various psychological, physical, social, and environmental factors at the micro-, meso-, exo-, and macrosystem levels as well as is influenced by the interaction between levels. The findings suggest that every level exerts an influence on community reintegration. However, the data also showed that the influence of each level on community reintegration varies by individual context.

Participants voiced the realities of being a stroke survivor: to be a stroke survivor is to live with fear. Fears reflected various anxiety-provoking situations: a recurring stroke that may

leave them impaired, further disabled, or that may even kill them; being alone at home or outside in the event of another stroke; or sustaining an injury from a fall given their poor balance. For many survivors, participation in home, productive activity, and social engagement -- all domains of community integration -- were hampered by chronic pain, fatigue, and functional limitations. Many survivors found themselves grappling with reconciling their old and new identities tied to their participation in home and productive activities. Survivors no longer able to contribute financially or domestically were left feeling useless or powerless.

Changes in their affect, in part from their chronic pain and fatigue, lead survivors to isolate themselves socially. Simultaneously, survivors had to deal with dwindling social circles of friends they attributed to their condition.

Survivors' narratives revealed an over-reliance on women over men for social support. Daughters, nieces, and home attendants, who are mostly women in this profession, were significant sources of social support, including social engagement. Some participants were unaware of opportunities for social engagement and productive activity available at local senior centers. Others held poor opinions of these organizations.

Notwithstanding individual level factors, survivors encountered significant environmental and cultural barriers. The built environment posed a series of obstacles to survivors limiting their activities and, for some, their freedom outside their home. For example, stairs and steps caused some survivors to be homebound. All modes of public transportation proved challenging to survivors with physical impairments. Lastly, survivors encountered a culture that was uninformed, inconsiderate, and ignorant that made for an unwelcoming environment that highlighted survivors' differences. The experiences of Latino stroke survivors at home, in

meaningful activity, and in social engagement reinforce the complexity of community integration as an interaction between individual level factors and the context in which the survivor lives. In the final chapter of this dissertation I provide an in-depth discussion and analysis of how the findings of interviews with stroke survivors contribute to the broader literature within community integration.

CHAPTER 3: HEALTH AND SOCIAL SERVICE PROVIDERS

3.0 Introduction

Investigated through an ecological lens, various interacting systems influence community integration post-stroke. Key among them are the macro-, exo- and meso-systems. The second aim of this dissertation project sought to identify the barriers and facilitators to community integration post-stroke from the viewpoint of health and social service organization representatives in northern Manhattan who either directly serve or whose services could be of use to stroke survivors. These individuals are responsible for implementing policies and practices that affect stroke survivors from bedside to the community. Obtaining their perspectives provided insight into the ways macro-, exo-, and meso-system components exert influence on the behavior of individuals integrating into their community after a stroke. This chapter presents findings from interviews with twenty health and social service providers serving the neighborhoods of Washington Heights and Inwood in New York City. Specifically, respondents consisted of administrators of senior service organizations, a disability advocate, a local community board representative, and health and social work professionals at area medical organizations whose positions qualified them to speak on the topic. The chapter provides a discussion of the methodological approach followed by a description of the major themes identified from the findings.

3.1 Research Methodology

The design for this research project was based on qualitative methods, which allowed for the analysis of participants' narrative viewpoints on the multi-level factors that impact stroke survivors' use of support services provided by local senior centers in Washington Heights and

Inwood. Qualitative research allows for a range of factors, both anticipated and unanticipated, to emerge thereby uncovering underlying processes and beliefs held by health and social service professionals that may influence stroke survivors' experience with community integration (Creswell, 2003).

3.2 Sample and Recruitment

The researcher identified a range of professionals who constituted a diverse set of health and social service providers. The perspectives, opinions, and actions of these key informants represent the meso-, exo-, and macrosystem factors that may influence the process of reintegration into community for Latino stroke-survivors. The health and social service providers were identified using multiple directories, including those from the Washington Heights-Inwood Council on Aging, New York City Department for the Aging, and New York Presbyterian Hospital. The researcher generated a purposive list of 27 senior service administrators, social workers, community advocates, and clinicians working in northern Manhattan to take part in key informant interviews. Once the interviews were underway, key informants suggested two additional individuals to interview for their professional expertise and organizational role. Thus, a total of 29 individuals were contacted to participate in the study.

Key informants were recruited by email and telephone except for the two individuals who were referred to the study by key informants, who provided in-person introductions. The recruitment email introduced the researcher, described the study, explained the selection of key informants and how participant's confidentiality would be ensured, and emphasized that participation was completely voluntary. Key informants were first contacted via email using the recruitment email. Informants unresponsive to the initial email received a follow-up email and/or

telephone call to inquire about their willingness to participate in the study. On average, two contact attempts by email and/or telephone per key informant were made prior to scheduling the interview. In total 29 key informants were contacted for the study, 20 of whom were successfully recruited. One key informant declined to participate citing not being appropriate for the study. Eight individuals were deemed non-responsive after four contact attempts.

The selection of informants from diverse professional backgrounds provided important data on the ecology of Washington Heights-Inwood in which community integration by stroke survivors takes place. All key informants either held leadership positions or key roles within their organizations but varied in experience directly working with stroke survivors. The study sample consisted of administrators of senior service organizations ($n = 15$), a disability advocate ($n = 1$), a local community board representative ($n = 1$), and clinical care providers ($n = 3$). Table 6 provides summary information and descriptive statistics for the entire study sample. At the time of the interview, most informants (85%) had worked in their current positions for more than five years, with 9 (45%) reporting more than ten years and 8 (40%) reporting more than five but less than ten years. Three (15%) informants were in their positions for more than two years but less than five. The sex and racial/ethnic composition of the key informants consisted of all women and more than half identified as non-Hispanic White (55%), followed by Latina (35%), and two identified as Asian (10%).

3.3 Data Collection Procedures

The researcher led all logistical coordination of the key informant interviews, which were scheduled at mutually convenient times and at respondents' preferred location. The researcher conducted all interviews mostly at key informants' offices with the exception of two that were

completed by telephone or in the researcher's office. All key informants provided signed consent and agreed to be audio recorded prior to being interviewed. The duration of interviews ranged from 40 to 214 minutes, with an average duration of 75 minutes. A post-interview form was used to record observations of the interview as well as new ideas prompted by the interview data.

3.3.1 Interview Guides

The interview guides explored concepts associated with ecological theory to capture respondents' views and experiences at the macros-, exo-, meso-, and micro-levels in the following areas: health care delivery for stroke survivors, institutional policies and culture, provider-patient interaction, knowledge of community-based services and practices, and community integration support for stroke survivors.

Two semi-structured interview guides were used, one for each type of key informant: (1) senior service providers and community advocates, and (2) clinical care providers. For senior service providers and community advocates, the interview guide consisted of 14 closed-ended questions on the informants' demographics and home organization (see Table 6 for data). The interview guide also included twenty open-ended questions, eight of which included sub-questions to further probe on specific topics (see Table 4 for sample questions). Similarly, for informants based in clinical care sites the questionnaire consisted of nine closed-ended questions on the participants' demographic information and their home organization (see Table 6 for data). This interview guide included twelve open-ended questions (see Table 4 for sample questions). The data collection instruments were used to guide the interview and prompt respondents to discuss certain topics and probe specific areas. While interviewing participants, their responses served as the guidepost by which subsequent questions and probes were generated. In other

words, the researcher followed the respondent's flow of thoughts, probing as new information was presented while guiding the conversation to stay on topic.

3.4 Data Analysis

Keeping with the qualitative research design of the study, the data underwent a thematic analysis. The purpose of the analysis was to identify, analyze, and report patterns or themes in the data that describe the ecology of northern Manhattan from the perspective of health and social service providers in the area. The data analysis followed Braun and Clarke's (2006) approach to thematic analysis. Thematic analysis involved the following steps: (1) twice reviewing each interview to first obtain an overall impression of the narrative followed by taking notes on specific aspects of the data and ideas for coding, (2) from the initial list of ideas about the data, an initial code list was generated to reflect the key terms, aspects, attitudes, or values expressed by participants, (3) the list of codes was then sorted into potential themes and sub-themes along with sorting the coded data into respective themes and sub-themes, (4) Refinement of themes and sub-themes occurred followed by (re)naming themes based on the analysis. The last step was sorting the themes and illustrative quotes into each level of the ecological model (e.g., macro-, exo-, and meso-level) to identify factor that influence the community reintegration experiences of Latino stroke survivors in Washington Heights-Inwood. Thus, the study findings emerged from an inductive and iterative process with the data.

3.5 Results

The results reflect both the common themes found across all types of participants as well as themes that were pertinent to a sub-set of participants (e.g., health care professionals or senior

center administrators). Using the data analysis approach described above, the following seven themes were generated (see Table 5 for emergent themes by ecological level):

1. Financing, Funding, and Reimbursement Policies
2. “Handing-Off” the Patient to the Next Level of Care
3. Knowledge of Community Based Agencies and Their Services
4. Discordance in Expectations Between Social Workers and Patients
5. Organizational Level Constraints
6. Organizational Culture
7. “Clueless” About the Health Care System

3.5.1 Macrosystem Level Factors

Financing, Funding, and Reimbursement Policies

Funding for programs and healthcare financing, and reimbursement emerged as macrosystem factors. All participants cited policies and other guidelines related to funding, health care financing, and reimbursement as dictating organizational policies for both hospital and community providers.

Federal and state health care financing and reimbursement policies set the guidelines for in-patient hospital stays. Interviews with New York Presbyterian social workers revealed that they engage in a delicate balance between serving the patient and meeting metrics imposed by these policies. Medicaid and Medicare reimbursement is in part subject to criteria such as length of stay, whether patient hospital readmission occurs within a certain time frame, and scoring high in patient satisfaction. These criteria lead New York Presbyterian (NYP) to implement policies to ensure the hospital is paid for rendered medical services. This practice places pressure on health care practitioners to treat and coordinate services efficiently. As one participant stated:

“Once that patient doesn’t meet that criteria [for hospitalization], there’s no more reimbursement and sometimes we tell families you’re gonna get billed for hospitalization.”

“... years ago we use to wait ok let the family visit this facility, that facility, this could go on and on that’s not in the best interest of the patient. Also if the patient is past their meeting criteria for hospitalization no one is getting paid.”

These health care financing and reimbursement policies also put pressure on the patient and his or her family to make care decisions. These situations are captured in the following quote:

“In NY state we apply to a minimum of five [rehabilitation] facilities in the geographic area and wherever a bed becomes available first that’s where the patient is supposed to go so that in addition to acknowledging that patients have a right to choose where they want to go so we try to balance those two aspects of the placement process so sometimes it is challenging for us as well but because length of stay is such a big issue and especially with stroke patients we want them to get their rehab as quickly as possible so there are no further residuals sometimes families are not happy so that combined with we want our satisfaction scores to be up there it it’s very tricky.”

For community-based social service programs, funders -- both public and private -- stipulate in their contracts the eligibility criteria of participants who can be served by the programs they sponsor. One social service informant commented, *“We will often get calls from a social worker that they have a family in need of this or an individual that has a need and we have to see if they’re appropriate for the criteria that foundation requires.”* Senior centers are primarily funded by the New York City Department for the Aging (DFTA), which contractually obligates the centers to provide services to individuals 60 years of age and older. The senior centers interviewed for this research all stated serving seniors 59 years of age or older. DFTA also requires the centers to provide specific services, such as congregate lunches, and programming (e.g. evidence based health programs). A few senior center key informants indicated that they refer individuals under the age of 60 to other community organizations for

services. Multi-service agencies could provide case assistance or case management to adults under 60, however, social opportunities offered through congregate lunch and recreational events and classes are unique to senior centers.

For survivors under 60, this age requirement presents a barrier to engaging in beneficial social activities that are key to community integration. Although many senior center leaders asserted that they do not deny access to services, many encourage these younger patrons to utilize the center accompanied by someone who meets the age criteria. This way, under DFTA rules, both patrons count towards the number of people served by the agency, as one participant said:

“The Department for the Aging will not allow us. Sometimes we fudge it a little bit because people need services and they’re close to the boundary or an aid can come in with an individual for instance if someone can’t have lunch alone and needs help, the aid can be there when they have lunch but by and large if they’re younger than 59 we really can’t serve them in the Center.”

3.5.2 Exosystem Level Factors

“Handing-Off” the Patient to the Next Level of Care

Stroke continuum of care emerged as a significant finding relevant to community integration (see Figure B for stroke continuum of care model). For the vast majority of stroke cases in northern Manhattan, diagnosis and treatment begin in the emergency department at New York Presbyterian Hospital and at the Allen Hospital. For these stroke patients, the emergency department is the point of entry into the health care system. Depending on patients’ stroke outcomes, their treatment may involve several levels of care resulting in prolonged involvement in the health care system. From the emergency room, stroke patients are admitted into the acute stroke unit, which at New York Presbyterian Hospital (NYP) is designated by the Joint

Commission as a stroke center for its commitment to improving outcomes for stroke care.

Depending on the severity of physical and mental impairments resulting from the stroke, patients are discharged from the acute stroke unit to one of five levels of care. The first three care options are specific to in-patients who are deemed to no longer meet the criteria for hospitalization.

These patients may either be discharged home: a) without rehabilitation, b) with a prescription for outpatient rehabilitation, or c) with homecare. The fourth and fifth levels of care, known as sub-acute and acute rehabilitation programs, are reserved for stroke patients with more severe impairments who need continued medical attention along with more intense levels of rehabilitation. Stroke patients with continued medical needs and who can only withstand moderate levels of rehabilitation therapy are discharged to a sub-acute rehabilitation facility. Otherwise, stroke patients needing medical attention and who can withstand more frequent, intense, rehabilitation therapy are discharged to an acute rehabilitation program.

A closer examination of the stroke continuum of care reveals two features that are critical to community reintegration. First, the continuum of care consists of different treatment pathways that offer multiple opportunities for social workers to discuss community supports with patients and their families. Second, the continuum of care is dominated by a “medical treatment” approach. It does not extend beyond allied health professionals to encompass community-based organizations whose services have the potential to facilitate community integration post-stroke. Hospital-based social workers’ description of their clinical units and their role within those units was rooted in a medical model. Consequently, they did not necessarily consider community integration to be a relevant topic for discussion at their level of care. The focus of acute stroke care is to medically stabilize the patient. Then the priority becomes transitioning the patient to the appropriate level of rehabilitation therapy. As such, social workers described their clinical

units and their roles as intermediary stops along the continuum of care. As intermediary stops, they viewed their role as preparing the patient for the next level of care:

“...don’t forget, at the hospital they’re in their acute phase, it’s just a matter of getting through that phase and then on to the next level of care so it’s like a handoff. So I don’t know how much of that talk regarding integration back into the community takes place at the hospital.”

“...social workers are assigned by units so [each unit will] have their own social worker...the social worker will meet with the patient and family, get their choices and get the insurance approval to come over here, and then from here I do the same thing. I get them on to the next level of care either home or to sub-acute but I do not follow patients once they’re in the community like once they’re done here they I mean they can follow-up with outpatient social worker but I only follow patients when they are on my service.”

The acute-care social workers in this study saw themselves as responsible for “handing-off” the patient to the next level of care. In so doing, the discussion about community-based supports was also largely handed off to the next level of care. One respondent shared not knowing whether the conversation about community integration occurs at any level of care: *“I hope it happens somewhere along the continuum, but from acute care setting I don’t know if it happens.”* She also added: *“My assumption is that that conversation takes place at the rehab facility or with the home care agency, if they do I don’t know if that’s being done; that may be at a major stroke center, I don’t know.”*

The general consensus among acute care social workers was that the conversation on community reintegration belongs further out in the continuum of care. Specifically community reintegration becomes an issue once the patient is back home and could be addressed by a community social worker. The following comment illustrates this perspective: *“maybe a*

community social worker going into the home and meeting the patient and the patient's family, you know, once the patient completes their physical therapy and they are where they are going to be to assess their limitations, talk to the patients about what is important to them, what their goals are, and then hook them up with something out in the community and maybe get some programs going that the patient can attend. I don't know what's out in the community, I mean, and I'm in the field so that's got to say something."

3.5.3 Mesosystem Level Factors

The analysis revealed various themes related to the mesosystem level and community integration. These include a relative lack of awareness among hospital-based social workers concerning community-based agencies and services they offer that can facilitate community reintegration post-stroke. Another theme centered on discordance in expectations between social workers and stroke patients. Other key themes involved organizational-level constraints and cultures.

Knowledge of Community Based Agencies and Their Services

When hospital-based social workers were asked how they learn about northern Manhattan community-based organizations and their services, responses centered on the use of on-line search engines, querying colleagues, and from outreach initiated by the non-profit. Hospital-based social workers interviewed for this study do not have access to a current catalogue, printed or web-based, of local services. Instead they spoke of relying on on-line searches and information provided directly by the community-based organizations, the comments of two participants illustrate these issues:

"Sometimes the agencies that are in the community will send us some information, sometime they come here and do in-service for us so we have many

people speak to educate us to the community services most of them will reach out to the hospitals to let us know they're in the community."

"I have to say Google is my best friend. I mean I've found a lot on Google 'cause I find the department doesn't have as much like referral like printed out referral information I feel like a lot of it I'll just know and even for like stroke support groups, financial resources, like I feel like I find a lot of information online and I'll give it to the patients and families."

In general, social workers held the belief that community-based organizations should outreach to NYP without expressing a need or interest in reaching into the community to learn about existing services, this sentiment was captured in a comment made by a participant:

"...maybe send us materials that we could give out...Those agencies reaching out to us so that we know that they're out there."

The senior center administrators interviewed for this study emphasized the robust network of senior service providers within northern Manhattan and in geographic proximity that cross-refer to each other. Respondents repeatedly mentioned the Washington Heights-Inwood Council on Aging (WHICOA) as a well-established and organized coalition of over thirty social service providers. In addition to advocating for local seniors, WHICOA serves as a mechanism for communication and information dissemination between community-based providers. Respondents rely on the existing within neighborhood referral network as well as word of mouth to refer existing and gain new clients.

Many respondents stated not having a need to publicize their services in conventional media outlets such as the local paper as current demand helped them meet their programmatic goals. A few participants did identify the use of flyers and mailers to publicize upcoming

activities but these were sent to individuals registered with the organization's mailing list. One respondent did raise the need to improve communications between local health care providers and organizations in order for patients to obtain information on available community services.

Discordance in Expectations between Social Workers and Patients

Inherent in the ecological model is that behavior is influenced by the interaction between levels. This was observed between the exo- and meso-system in the way social workers' interaction with stroke patients was influenced by social workers' perceived responsibility to hand-off the patient to the next level of care. Social workers have a responsibility to ensure patients' discharge plans are coordinated. On the other hand patients expect to receive care management from their social worker. This discordance between social workers' perceived role and the role patients ascribed to social workers is captured in the following quote: *"I feel like each patient when I meet them they might have their expectation of what they think I'm going to do so I'll say I'm not applying for social security disability for [you but] here's what you do, here's where you go, here's what you collect, you know, and yeah a lot of times they have that expectation coming in of what I [should be] doing for them so I have to educate them as to my role...."*

Patients may be left feeling overwhelmed and may not know how to act on the information provided, especially at a time when they are also adjusting to their illness and impairment. Patients and their social support network, if available, are responsible for simultaneously navigating the social welfare system in addition to the health care system. According to participants, stroke patients express concern over securing basic resources through public assistance, such as income, food stamps, and personal assistance. The most vulnerable

stroke patients are in a financial crisis, unable to return to work they focus on obtaining safety net services. In contrast social workers are concerned with follow-up treatment and services related to their treatment as expressed by one respondent:

“Patients will have concerns, their main concern is social security disability. For my part I need to make sure the patient is going home with their home care services and I feel like for stroke especially support groups, you know, talking to them about support groups but their agenda might be I want my food stamps now, you know, that’s not keying in to my role here so yeah sometimes there is a disconnect... discharge planning can incorporate a lot of different elements but I feel like for me primarily it’s like making sure that the home care services can go in, that’s like my number one priority is setting that up.”

Organizational Level Constraints

Community integration can also be negatively affected by organizational level constraints including large caseloads, small staff, and the language skill set of staff. Whereas senior center social workers spoke Spanish, their hospital counterparts did not. These social workers inability to speak Spanish was a barrier to meaningfully engaging in conversation with patients. Hospital translation services that are meant to overcome language discordance between patients and providers appear at times to complicate communication with patients who will often defer to their English speaking friends and family to interact with the social worker, the following quote illustrates this point: *“I find language is a barrier if they are not English speaking even though you know we offer interpretive services I just feel like it’s an extra layer.”*

Limited staff was another barrier that afflicted both clinical units and senior centers. A small staff of four to seven members typically operates a senior center that serves hundreds of clients per month. In general the organizational structure of senior centers includes an Executive or Program Director, a caseworker, two cooks, a janitor, and a driver. Understaffing keeps senior

centers from expanding their programs, providing more services to clients, and from promoting their services in the community as growth in client pool beyond their capacity will stress the available infrastructure of a senior center.

Similarly, social workers in clinical units discussed being overwhelmed by their patient caseload and lack of additional staff support, which results in limited contact with patients, as illustrated by the following quote: *“I have all the patients on the service and because I’m doing all this other coordination, usually it’s once or twice per week where I’ll be speaking to them or reaching out to them but it’s I wish it could be more but under the circumstances it’s just not but yeah it’s not equal for everyone there’s like some people who I am talking to every day, and then there’s some people where I see them once a week, they don’t really have needs, I’m just checking-in and then they’re off...and I do not have an assistant which many do so...”* These social workers’ primary focus is on discharge planning and all else, including the conversation on community integration and the available supports is secondary.

Organizational Culture

A culture of acceptance is key to stroke survivors integrating into community. Senior centers offer the potential to facilitate a survivors’ reintegration given their social engagement and recreational mission. However, a salient theme in the narratives of senior center administrators was the belief that older adults with impairments would be better served at social adult day programs, rather than at their centers. The general belief was that senior centers were under resourced and not required to meet the needs of clients who needed assistance with toileting and feeding. Despite clarifying that stroke related impairments range where not all

survivors require help ambulating, toileting or feeding, the administrators' responses emphasized the need for an aid such as a family member or home attendant to accompany the survivor.

Clients' attitude emerged as a contributing factor to fostering an environment welcoming to people with disabilities. An administrator spoke of multiple instances where clients pushed other clients using walkers or canes during fire drills because they were considered slow and being in the way. This same respondent strongly felt that the culture fostered by current clients was hostile to those with disabilities as clients despite having health problems consider themselves active and able.

3.5.4 Microsystem Level Factors

“Clueless” About the Health Care System

Patients' knowledge of and experience with the health care system emerged as a factor that can negatively impact community reintegration. For some patients, their stroke serves as their introduction to the health care system. Poor knowledge of and experience with the health care system places patients at a disadvantage as patients do not understand the system or know how to navigate the complex set of policies and care pathways, the following quotes from social workers illustrate survivors' limited experience with the health care system:

“we try educate the families as much as we can as to the deficits that we see may not be lasting deficits but it's the ones we see right now and helping them, educating them, to try to understand why the patient needs another level of care before going home. The difference between acute care, subacute care, rehab, acute rehab many people have no idea what these things mean until they're actually in the system so they'll use terms interchangeably like rehab physical rehab, you know, nobody knows what that is and we start throwing terms out...even people in the field don't know the difference is and we have to

educate...that's very hard for patients' families: "Why can't you do it now, we want the most right away" that's hard for many patients' families to understand."

"I feel like a lot of people when they come in here they are clueless as to the system so you have to tell them what to do and where to go "

"You'll hear a lot of people say I've been working my whole life, I'll get a lot of that, and they're only giving me... especially for the home health aid..."

3.6 Summary

For both hospital and community providers, organizational policies are dictated by public financing stipulations and reimbursement regulations. These macrosystem factors impose parameters on hospital and social service providers. Medicare and Medicaid reimbursement policies, for example, compel NYP Hospital to consider patient length of stay, hospital readmission, and patient satisfaction in their treatment plans. Public and private funding stipulates the types of programming offered at senior centers, and who is eligible for these programs. Senior centers are mandated to serve adults 60 years of age or older. There is very limited availability of community center options for people under the age of 60 who have experienced a stroke and who can no longer engage in paid work. In this study, 5 out of 30 (or 16% of the sample) respondents were below the age of 60. These "younger" stroke survivors are not eligible for services provided by senior centers. In other words, there is a service gap for younger stroke survivors who seek social engagement.

The medical basis of the stroke continuum of care emerged as an exosystem factor that defined the goal of acute care units and the roles of hospital social workers. Although conceived as a continuum (Wissel, Olver, Stibrant Sunnerhagen, 2013), stroke care is segmented into

different levels of care, each with a distinct care goal that delineates the role of social workers in these stroke care units. Social worker informants in this study considered discharge planning their main responsibility. They did not consider community integration relevant at their stage of care. They assumed that the conversation about community integration occurs as the patient returns home. However, the assumption that there will be a community-based social worker to take responsibility for the patient's community integration appears uncertain given the segmentation of the stroke continuum of care and the fact that it excludes links to community based services. This is problematic, given that these services stand to facilitate community integration post-stroke.

Social workers' poor knowledge of existing community services may further reflect the lack of integration of community services as part of medical care. Moreover, social workers' home departments lacked the infrastructure to facilitate the identification and referral of patients to community-based supports. As a result, social workers relied on search engines such as Google, their own professional networks, and infrequent in-services provided by community-based organizations to inform themselves about available services in northern Manhattan.

In contrast, senior center leaders highlighted the robust network of services for seniors that exist in northern Manhattan. The availability of senior centers, recreational opportunities, health programming, transportation, case assistance and social engagement, stand to facilitate community integration for stroke survivors. However, the analyses suggest that two meso- and exo-system factors that interacted to create a significant barrier to community reintegration. Specifically, senior centers do not need to publicize their services, and -- when combined with social workers' poor knowledge of their existence -- this produces a situation in which stroke survivors are left with the responsibility to access information. The onus on the stroke survivor to

find this information occurs at a pivotal time in the illness trajectory – precisely when the survivor is confronted with delicate physical, psychological, social, and socioeconomic adjustments. Moreover, survivors’ limited experience with and poor knowledge of the health and social service systems -- an issue also raised by social workers -- indicates a clear need to better support stroke survivors throughout the process of care, recovery, and integration.

Respondents identified other barriers to discussing community integration with stroke patients. These barriers centered on the organization’s infrastructure and personnel’s skillset. Respondents interviewed from both types of organizations (clinical and community) commented on the constraints imposed by being understaffed. NYP Hospital informants spoke of large patient loads per social worker that limited the time spent with each patient. Similarly, many senior centers operate with minimum staffing of only 5-7 members. Senior centers easily serve the mandated numbers of clients set by funders. Increasing their client membership would tax the centers and compromise their ability to provide their services. Therefore, senior centers are dissuaded from publicizing their services in the community.

The purpose of interviewing senior center administrators was to obtain their viewpoints on how to facilitate the involvement of stroke survivors in their centers. An unexpected finding was that clients and administrators create an unwelcoming environment for people with impairments. In general, administrators considered senior centers to be for “healthy” older adults without significant impairments. Their belief incorrectly casts people with impairments as unhealthy. Administrators considered stroke survivors as better served by social adult day programs that count on trained staff to assist members with eating, toileting, and ambulating. Moreover, administrators were concerned that a noticeable proportion of members with visible impairments (e.g., those using wheelchairs or needing help with activities of daily living) would

create an uncomfortable environment for existing clients. Clients' unfavorable attitudes towards members with mild impairments (e.g., use of walkers and canes) also made for an unwelcoming environment. These attitudes may reflect the broader public discomfort and stigma related to impairment. Furthermore, another striking finding was that senior centers -- through the beliefs and actions of their leaders and members -- perpetuate harmful misconceptions about older adults with impairments. As a result, stroke survivors with impairments face feeling alienated in the unwelcoming environment found at senior centers.

Perspectives of health and social service providers in northern Manhattan furnished insight into the ways that *their own* ecological system exerts influence on their behavior and attitude. Furthermore, their perspectives contributed to understanding how their professional ecological systems can potentially influence the community integration experiences of stroke survivors in Washington Heights-Inwood.

CHAPTER 4: DISCUSSION

In the United States, stroke causes more long-term impairment than any other illness or condition (ASA, 2016). Individuals with functional impairments face great psychological, social, and environmental obstacles to full participation in home and community life. Despite the available research on environmental factors that affect community integration post-stroke (Jellema et al., 2017), research on the interplay between multiple levels of influence is scarce. Moreover, although Latinos constitute 16% of the United States population (U.S. Census, 2011), research on community integration among Latino stroke survivors is scarce. This study takes a first step towards filling these gaps in research.

The findings from this study underscore the importance of considering an ecological approach to understand the community reintegration experiences of Latino stroke survivors. The ecological model considers the complex interaction between the micro-, meso-, exo-, and macro-systems. These levels encompass intrapersonal or individual (e.g., biological and psychological), interpersonal or social (e.g., functional and structural social support), community (e.g., built environment and infrastructure), and societal factors (e.g., cultural beliefs and public policies) (Bronfenbrenner, 1977). Applied to community integration post-stroke, this model reveals the range of factors that facilitate and impede survivors' meaningful participation at home, in community, in productive activity, and the quality of their social engagement. Inherent in the model is the idea that to facilitate community integration, it is essential to address multiple levels of the ecological system.

This study contributed in multiple ways to the limited knowledge base on the community integration experiences of stroke survivors in general, and among Latinos in particular. First, the

study explored community integration from an ecological perspective. Second, the study focused on Latinos with stroke to understand first-hand their perspectives of the micro-, meso-, exo, and macro-systems and their effects on community participation post-stroke. Lastly, the study gathered data from health and social service professionals who play key roles in survivors' community integration experiences. Given the study's use of phenomenological methods, the findings capture from an insider's perspective the ecological context that characterizes community integration for Latino stroke survivors. In the next sections, I describe and discuss some of the most significant findings.

4.1 Discussion of Main Findings

A primary aim of this study was to explore the post-stroke community reintegration experiences of Latino older adults living in Washington Heights-Inwood. This was explored by considering experiences at various levels of the ecological model.

Findings revealed key issues at the intrapersonal level. Specifically, stroke survivors experience many challenges related to identity and psychological well-being, adjustment, and coping. Given the sudden nature of stroke, the process of moving from an identity of "abled" to "disabled" can be particularly challenging for survivors. Another particularly distressing aspect is the fear of stroke recurrence. This could threaten the "adaptive" identity of "stroke survivor" and raise intense fears of death or permanent disability (Salter, Hellings, Foley, & Teasell, 2008). Fear and uncertainty of having future strokes afflicted all survivors in the current study, an emotional response frequently reported by stroke survivors (Boden-Albala, Carman, Moran, Doyle, Paik, 2011). Distressed by the fear of suffering or dying from a recurrent stroke, some survivors' in this study coped by avoiding being alone anywhere. In doing so, they were able to

deal with the intense fear of being alone in the event of another stroke, for which they would need immediate assistance.

Mood disorders, in particular depression, are well-documented conditions among stroke survivors (Paolucci et al., 2005). For example, several studies show that stroke increases the risk of depression; furthermore, depressive symptoms may be a symptom of subclinical cerebrovascular disease that may result in clinical stroke (Glymour et al., 2012; Wendell et al. 2010). In this study, many survivors recognized a change in their mood post-stroke. While some survivors reported no longer feeling happy, others spoke of other changes in psychological well-being that are symptoms of depression. For example, some survivors mentioned a loss of interest in their usual pursuits. In fact, deterioration in social and leisure activities is common post-stroke (Salter, Heelings, Foley, & Teasell, 2008). Furthermore, because positive emotions are associated with greater likelihood of recovery of functional status (Seale, Berges, Ottenbacher, Ostir, 2010), it is critical to address mood and depression among stroke survivors.

Addressing mood and depression is also important for pain management. Respondents in this study reported pain as a limiting factor in their ability to ambulate and engage in activities within and outside of their home. About half of all stroke survivors experience some form of pain from stroke-related injury to the nervous system (Caswell, 2018). Chronic pain may lead to depression in survivors; conversely depression may influence how survivors perceive pain severity (Caswell, 2018). Although treating depression may help reduce pain, pain management can involve pharmacological treatment. Given the current US opioid crisis (NASEM, 2017), non-pharmacological treatment for pain management among stroke survivors merits attention.

The effects of stroke on mood and psychological well-being are due, in part, to the influence of stroke on feelings of mastery and sense of control. Leading theories of adjustment to chronic illness emphasize that maintaining a satisfactory self-image (Moos, Fenn, & Billings, 1988), and gaining a sense of mastery (Taylor, 1983) are major adaptive tasks. Moreover, a sense of mastery and competence are integral to well-being (White, 1987). Moos (1982) proposed that one important adaptive task of chronic illness involves maintaining a sense of competence despite the reliance on others for care and support. Stroke survivors in this study devised a variety of strategies to maintain a valued identity or role. For example, to maintain the homemaker identity and preserve competence in performing various functions related to that role, women reported that they adapted activities such as housekeeping and cooking into smaller, more manageable tasks, in accordance with their functional ability. Findings also indicated that women tended to rely on daughters for support. These results are consistent with other studies of Latinas with disabling conditions, and may reflect cultural norms about appropriate providers of support (Abraído-Lanza, 2004).

Although this study did not explore coping and adjustment in the short (e.g., less than six months) versus long term (e.g., greater than two years), it is likely that survivors differ in their psychological and functional well-being over time. In this study, fear of a recurrent stroke, need for social services and public assistance, as well as severity of functional impairments were more salient in the narratives of survivors who had experienced their stroke within six months of the interview compared with those survivors further removed from their stroke. Therefore, the literature on community reintegration would benefit from an exploration of stroke physical and psychosocial recovery over time.

There is a wide body of research documenting the impact of chronic illness on individuals' self-concepts and social roles (Helgeson & Zajdel, 2017). Given that social roles are key components of self-hood and identity, roles disruptions due to chronic illness present major adaptive tasks (Charmaz, 1999). The ability to fulfill valued role activities may be particularly important among people with chronic diseases and disabilities such as those who suffered a stroke (Anderson & Whitfield, 2012; Haslam et al., 2008; Vanhook, 2009; Woodman, Riazi, Pereira, & Jones, 2014). Because of pain and disability, however, stroke may interfere with the ability to perform various valued activities associated with the different roles (Zahuranec, Skolarus, Feng, Freedman, Burke, 2017). The findings of this study compliment those of other studies of Latinos coping with disability (Abraído-Lanza, 1997), and demonstrate that individuals strive to fulfill activities associated with roles and identities that they value.

Other research on stroke survivors underscores the challenges inherent in having to integrate "stroke survivor" as part of one's identity. For example, in Pathchick et al.'s (2015) qualitative study of stroke survivors, respondents mentioned how their self-identities were intrinsically tied to the cognitive abilities that had been impacted by stroke. Moreover, these impairments lead to "fundamental changes in participant's sense of self" (page 3219).

A further finding of the current study concerned loss of social activities. Survivors experienced a loss of contact with friends and decreased participation in social activities post-stroke. These findings were also reported in a recent systematic review of the impact of stroke on survivors' social support and social networks (Northcott, Moss, Harrison, & Hilari, 2016). Similar to the findings in this review, in the present study respondents cited fatigue, chronic pain, and physical and speech impairments as the causes of their social isolation. Pain and fatigue may also influence mood and psychological well-being that may lead stroke survivors to withdraw

socially (Wallace, Wexler, McDougle, Miser, Haddox, 2014). These findings highlight the importance of considering individual level variables within an ecological model.

The disability literature offers additional explanations for the social withdrawal of friends and extended family. This behavior may result from discomfort that social network members' experience, or their lack of knowledge concerning how they should interact with a family member or friend with impairments (Vanhook, 2009). Alternatively, the withdrawal of friends and family might instead reflect their compassion or consideration for the stroke survivor. Given survivors' acute chronic pain and fatigue, social network members may be trying to avoid "pressuring" stroke survivors into social activities for which they lack interest or are not physically capable of engaging. Survivors, too, demonstrated avoidant behavior. They deliberately isolated themselves from social activities in which they engaged prior to their stroke. Deliberate isolation may be a maladaptive strategy that survivors use to cope with their inability to meet the emotional and physical demands involved in social interactions with friends and family (Anderson & Whitfield, 2012). Isolation might result in lack of needed social support, as well as other negative psychological consequences (e.g., loneliness).

Survivors' spoke to the challenges they face in the social environment that extends beyond their close social circles. Survivors undergo a process of psychological adjustment to their new stroke identity. At times, this identity was challenged by acquaintances and strangers who hold conflicting ideas about how a stroke survivor should appear or behave. For example, survivors were questioned about whether they did, in fact, experience a stroke. This response may point to the public's lack of awareness concerning the range of impairments and functional disabilities incurred after a stroke. Other qualitative studies of stroke survivors also report that

respondents were constantly “fighting stereotypes about what people with stroke could do and a general stigma of stroke disability” (Anderson & Whitfield, 2012).

This lack of awareness also stands to contribute to the public’s lack of consideration for the needs of people with stroke, for example, the failure to keep sidewalk curb cuts clear for people with mobility impairments or those who use a wheelchair. Unfriendly environments may lead stroke survivors to disengage with their surroundings (Jellema, van Hees, Zajec, van der Sande, Nijhuis-van der Sande, & Steultjens, 2017). Because survivors isolate themselves – or because the physical environment makes it so difficult to get out – survivors with impairments are “not seen”. At the same time, “not seeing” people with disabilities makes “able-bodied” individuals less sensitive to the needs of people with disabilities.

Survivors poor knowledge of the health and social service systems emerged both in the interviews with social service providers and survivors. Social workers expressed the need to educate patients on different aspects of the health care system, in particular, health insurance coverage and rehabilitation options while preparing them for discharge. In contrast, survivors spoke of their need for substantial guidance on navigating the social service system and expecting this assistance from the hospital social worker. Yet, social workers explicitly negated that their roles involve facilitating information on community integration. Studies on reengagement in activities by stroke survivors found information access to be important (Jellema, van Hees, Zajec, van der Sande, Nijhuis-van der Sande, & Steultjens, 2017). In the present study, community supports were not integrated with medical treatment or stroke continuum of care. Without patient referrals to community-based supports, survivors are left to navigate the social service system and access information on their own, which may comprise their ability to reintegrate into home and community.

An unexpected finding, which also emerged both in the interviews with social service providers and survivors, concerned specific social climate issues in social service agencies. Ironically, senior centers that are designed to meet the social, physical, emotional, and intellectual needs (as per the mission of many centers) of older adults – including those with physical impairments – are, in fact, hostile to people with disabilities. Attitudes among both clients and administrators that senior centers are for “healthy” adults result in the exclusion of people with stroke for being “unhealthy” from impairment. Culturally, impairments carry stigma and people with impairments are stigmatized. This leads to negative social positioning, where people with impairments are treated as the “other” and are denied social group membership and a sense of belonging (Haslam et al., 2008). An assumption of this dissertation project was that senior centers were ideal places to facilitate social engagement for disabled stroke survivors. A startling finding was discovered in the analysis of interviews with the social service providers -- that senior centers leaders, and their clients, by perpetuating negative stereotypes of people with disabilities, may not be positive sources of social support in this context.

The findings also revealed that the interplay between factors at various levels of the ecological model impact the community reintegration experiences of Latino stroke survivors. Among survivors, fear of stroke recurrence, chronic pain, fatigue, and mood affected their social well-being, involvement outside their home, and ability to travel using local modes of transportation. Respondents’ poor health literacy, coupled with limited assistance from social service professionals, affected survivors’ ability to navigate the health and social service systems. In addition, findings from the social service providers revealed additional evidence of the interaction of ecological factors that contributed to community reintegration experiences. Specifically, results indicated that clinical social workers had poor knowledge of community

support services, and they worked in settings that lacked infrastructure to link patients to local social service providers. Moreover, their perceptions and attitudes indicated that they considered community reintegration as falling outside of their roles and responsibilities. Combined, these multi-level ecological factors interacted to create significant barriers for survivors' ability to access appropriate therapeutic care and community support services, which could improve community reintegration post-stroke. In addition, survivors' poor knowledge and negative perceptions of senior centers, coupled with senior centers' lack of need to promote their resources and services, prevented survivors and their caregivers from accessing these support services. Moreover, ignorance concerning impairment and disability at the organizational and neighborhood level further marginalized the experiences of Latino stroke survivors.

To summarize, the findings of this research confirm that macro-, exo-, meso-, and micro-levels factors influence the bio, psycho, social, and environmental ecology in which community reintegration takes place for Latino stroke survivors. In the next sections, I provide a discussion of the study limitations. Next, I discuss implications for practice that emerged from the findings of this research, and offer concluding comments on community integration among Latino stroke survivors.

4.2 Limitations

Several limitations of this research must be acknowledged. First, stroke diagnosis was assessed via by self-report. This study did not have access to medical records, which would have permitted verification of respondents' type of stroke and other medical conditions. Moreover, the study relied on respondents' reports of time since stroke, which may be subject to recall and other biases. It is important to note also that respondents currently were living in their homes,

and details related to their community reintegration experiences, access to and experiences related to rehabilitation (including physical therapy) may also have been subject to recall and other biases.

Findings were also based on data collected at one time point with survivors at different stages in their recovery. In addition, a wide range of study topics were covered in the interviews. The average interview lasted 76 minutes, about 15 to 30 minutes more than the length advertised in the study flyer. In a very small number of cases, time prevented the researcher from delving further into certain topics.

This study explored the experiences of "Latino" stroke survivors. However, the majority of respondents were Dominican. There are sociodemographic differences between Dominican and other Latino groups in the United States that could differentially relate to critical themes revealed in this study. These include differences in age, education, income, marital status, and family constellation (Motel & Patten, 2012). There are also within-group differences in these demographic variables as a function of immigrant status (i.e., U.S.-born vs. foreign-born), which relate to social networks and other resources. For example, Hispanic groups have different socioeconomic and political reasons for immigrating to the United States. As a result, not all Latinos have equal access to resources (including access to health insurance or family social support networks). Although this study focused on Latinos of Dominican background, it should be noted that Latinos are a heterogeneous group. Nevertheless, the focus on Dominicans constitutes a strength of the study, given that little is known about the stroke experiences of this group.

Most of the study participants were foreign born. Therefore, the findings – particularly the observations of gender differences in roles and social support may reflect levels of acculturation and related beliefs associated with particular social norms. Specifically, stroke survivors' intrapersonal factors may vary based on level of acculturation such that norms may dictate expectations for receiving social support from particular providers. Also, caregivers are an important source of social support to stroke survivors. However, collecting data from caregivers to explore their perspectives fell outside of the scope of this phenomenological study of stroke survivors. Although study respondents discussed their perceived social support, research on the experiences and perceptions of the caregivers would elucidate the role of caregivers in the process of community reintegration among stroke survivors. These issues warrant more research.

4.3 Practice Implications

Despite these limitations, study findings provided evidence that could be used by multi-sector stakeholders to effect systems change and improve community integration for stroke survivors and others with functional impairments. An ongoing theme in the stroke literature concerns the importance of engaging in meaningful activities (Haslam et al., 2008; Patchick et al., 2015; Zahuranec et al., 2017). In fact, the inability to participate in valued activities is a significant predictor of decreased well-being among people with stroke (Zahuranec et al., 2017). As several others have noted (e.g., Zahuranec et al., 2017), these findings point to the importance of assessing not only limitations in functional abilities and activities of daily living, but to also consider limitations in community and social participation, as recommended by the 2002 WHO International Classification of Functioning Disability and Health (WHO, 2018).

For rehabilitation priorities, these findings warrant an emphasis on assuring that stroke survivors continue to engage in valued activities (Wolf et al., 2015; Jellema et al., 2016; Zahuranec et al., 2017) suggest, for example, that stroke survivors could be asked to provide a list of most-valued activities, which could then serve as a guide or “roadmap” (p. 6) by which to focus and design rehabilitative strategies and for identifying appropriate adaptive devices and other technology. Although additional work is warranted to further develop methods for using the patients’ valued activities lists in clinical care, this approach has the added benefit of improving the “patient-centeredness of care”. Such an approach aligns with the growing “precision medicine” movement of delivering “personalized care”. In other words, just as precision medicine can be used for targeting drug treatments for particular conditions, a similar concept, a “personalized values list”, can be applied to rehabilitation for people who survived a stroke. Furthermore, given that pain is a major predictor of well-being (Zahuranec et al., 2017), rehabilitative care needs to address fatigue, pain, and psychological well-being to facilitate community integration.

These findings also have implications for health and community organizations that provide care to stroke patients or whose services are of use to stroke survivors. Stroke care coordination needs to extend beyond rehabilitative care to include referrals and engagement of the patient in social services and other community programs that can support the community transitions for individuals with stroke and their caregivers or family members. These findings highlight the opportunity and great need to build capacity among social workers and other health paraprofessionals, such as community health workers or health navigators. One relatively easy and cost-effective method to build capacity is to integrate digital platforms that care teams can use to refer patients to needed community resources (e.g., NowPow.com, Healthify.us, and

GetHealthyHeights.org). These digital platforms are user friendly databases of local health, social service, and wellness resources with built-in functionality that enables the user to identify and select relevant information and resources to serve the unique needs of patients and clients. Moreover, along the stroke continuum of care model (see Figure B), multiple opportunities exist to address the health literacy of patients and their families. These include, for example, discussing available supports for community reintegration, and implementing community health workers and health/patient navigators who can assist stroke survivors throughout the continuum of care. Given that Latino stroke survivors are aging with their impairments, health, stroke, humanitarian, and disability advocacy organizations need to advocate for the inclusion of individuals with impairments in community life and expand the availability of support in communities.

Lastly, although the study focused on an inner city community, the growing senior population in the US -- along with a shift away from institutionalization to aging-in-place -- has placed a demand on social services, health care, transportation, and other senior related infrastructure that is relevant to inner-city, urban, and suburban areas (Frey, 2000). Assessments of state livability policies and practices highlight land use, transportation, and housing policies that enable aging in place; however, only some of these state policies explicitly require universal accessibility (Farber & Lynott, 2011), which accommodate older adults with functional impairments. Improving the livability of communities will involve greater enforcement of the Americans with Disabilities Act to ensure that buildings are retrofitted to meet universal accessibility guidelines. Similarly, an assessment of healthcare public may reveal gaps in coverage along the stroke continuum of care that hinders patients from receiving optimal care,

which, in turn, may impact their functional impairment and limit their participation in community life.

4.4 Concluding Comments

Despite the limitations, this dissertation research extends our understanding of post-stroke community integration by pointing to the ecological factors that impact survivors' behavior and choices. To the researcher's knowledge, this is the first qualitative study of the professional practices of medical social workers and social service providers regarding community integration of stroke survivors. Thus, the study fills a significant gap in research on this topic. In addition, the study contributed to the stroke literature on Latinos, an under-studied population. Given the dearth of research on the community integration experiences of Latinos (in addition to the very limited work on social and psychological adjustment to stroke among Latinos), future studies should further explore the interaction between the multidimensional factors revealed in the present study. Biological, psychological, social, and environmental well-being underlies quality of life for people with impairments. As the present data suggests, the conversation on community integration is too essential to survivors' quality of life to be "handed-off". Rather, it deserves to be "hand-held" from hospital bedside, past homecare, and up to the point at which the survivor reaches integration in community.

FIGURES AND TABLES

Figure A. Ecological Model of Community Integration Post-Stroke

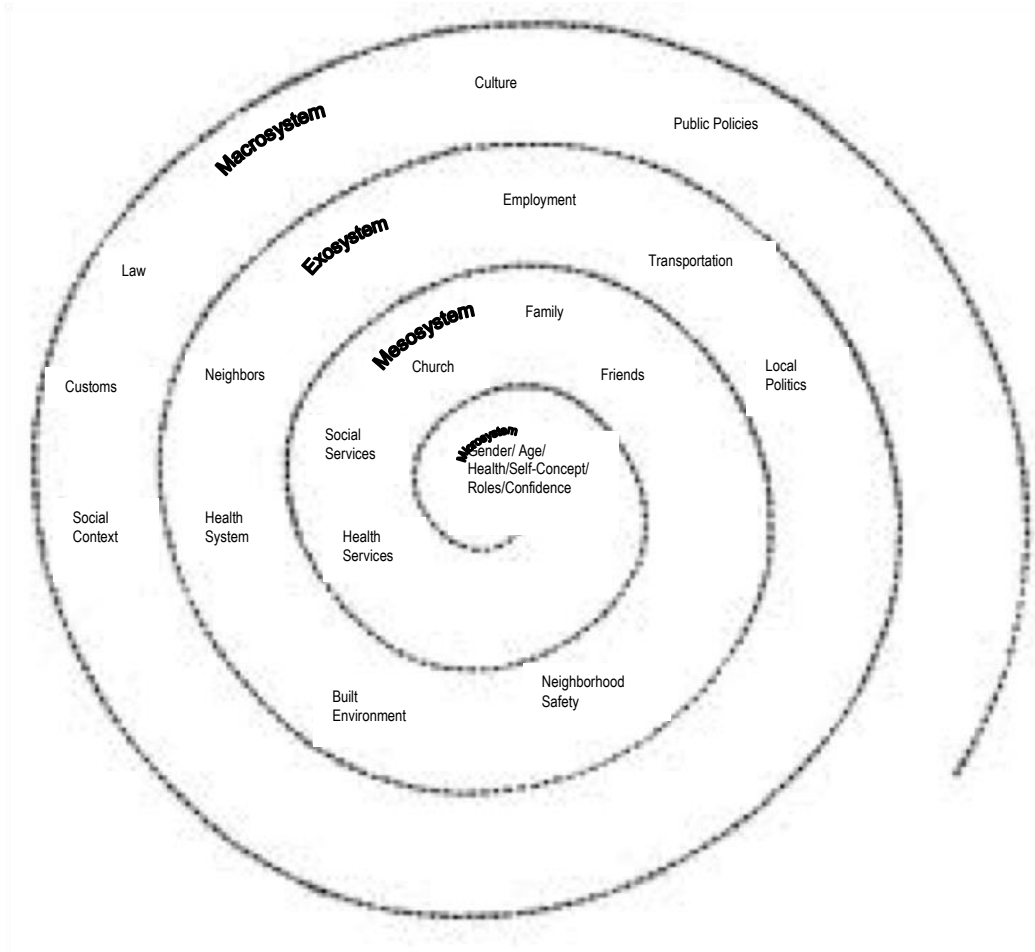


Figure A is a representation of Bronfenbrenner's Ecological Model of Human Development with examples of factors within each system. The model is represented as a spiral with blurred lines to denote the constant reciprocal interaction between systems that exert influence on the individual.

Table 1. Sample Interview Questions with Stroke Survivors

Microsystem	Mesosystem	Exosystem	Macrosystem
After your stroke, how did you come to know your way around your home?	After your stroke, how did you come to know your way around this community?	Do you feel part of this community?	Do you feel accepted in this community?
What types of activities do you do around your house?	What, if any, activities do you participate in this community?	What makes you feel part of this community?	What makes you feel accepted in this community?
What did you do after your stroke to help you get back to your activities?	What did you do after your stroke to help you get back to the community?	After your stroke, were there particular agencies or organizations that helped you? How did they help you?	
How do you get around in your home?		How do you get around in your community?	
Do you feel like you can be independent in your home?	Do you feel like you can be independent in this community?	What challenges, if any, have you encountered while getting around your community?	
How are you addressing your stroke risk factors?	Who in this community do you feel close to?		
Who helped you adjust to life after your stroke? How did they help you?	How do you get along with family/friends?	Do you feel safe in your community?	
	Are you aware of services in this community for stroke survivors?		

Table 2. Emergent Themes from Stroke Survivors Participant Data

Ecological Level	Definition	Theme(s)
Microsystem	Includes intrapersonal factors such as an individual’s self-esteem, identity, and self-concept, as well as psychological coping processes that influence adjustment to illness such as stroke.	1. Fear of Stroke Recurrence 2. Stroke Affect 3. Post-Stroke Identity 4. Limits to Social Participation 5. Poor Health Literacy
Mesosystem	Comprises the interrelation among a person’s individual setting and the relationships with family, friends, social service agencies, and health care providers.	6. Shrinking Social Networks Post-Stroke 7. Female Family Members Carry Greater Burden of Responsibility 8. Poor Understanding and Navigation of Social Services System 9. Accessibility to & Perceptions of Senior Centers
Exosystem	Contains social structures, including employment opportunities, public services, neighborhood characteristics, mass media, and health services that influence and may determine a person’s behaviors and social and other life circumstances.	10. (In)Accessibility of Public Transportation 11. Built Environment Limits Activity
Macrosystem	Includes the broader societal beliefs and values, and institutional cultures, laws and policies that impact the individual.	12. Cultural Ignorance 13. Punitive Public Policies

Table 3. Characteristics of Stroke Participants by Sample Type

	Neighborhood 60% (n = 18)	Clinic 40% (n = 12)	Total 100% (n = 30)
Sex			
Male	44.4% (8)	41.7% (5)	43.3 (13)
Female	55.6% (10)	58.3% (7)	56.7% (17)
Age			
Range	54-70	55-80	54-80
Average	64	66	65
Race			
Black	38.9% (7)	41.7% (5)	40% (12)
White	61.1% (11)	58.3% (7)	60% (18)
Language			
Spanish	72.2% (13)	83.3% (10)	76.7% (23)
English	11.1% (2)	(0)	6.7% (2)
Bilingual	16.7% (3)	16.7% (2)	16.7% (5)
Civil Status			
Single	16.7% (3)	33.3% (4)	23.3% (7)
Married	33.3% (6)	16.7% (2)	26.7% (8)
Separated	33.3% (6)	25% (3)	30% (9)
Divorced	16.7% (3)	25% (3)	20% (6)
Years Living in Northern Manhattan			
1-2 Years	5.6% (1)	(0)	3.3% (1)
5-10 Years	5.6% (1)	(0)	3.3% (1)
More than 10 Years	88)	100% (12)	93.3% (28)
Household Composition			
Alone	38.9% (7)	58.3% (7)	46.7% (14)
Spouse	33.3% (6)	16.7% (2)	26.7% (8)
Child	16.7% (3)	16.7% (2)	16.7% (5)
Roommate	11.1% (2)	8.3% (1)	10% (3)
Education			
Elementary or Less	16.7% (3)	25% (3)	20% (6)
Junior High	22.2% (4)	25% (3)	23.3% (7)
High School	27.8% (5)	41.7% (5)	33.3% (10)
Some College	22.2% (4)	(0)	13.3% (4)
College Graduate	11.1% (2)	8.3% (1)	10% (3)
Employment			
Part-Time	5.6% (1)	(0)	3.3% (1)
Unemployed	33.3% (6)	41.7% (5)	36.7% (11)
Retired	44.4% (8)	41.7% (5)	43.3% (13)
Disabled	16.7% (3)	16.7% (2)	16.7% (5)
Income			
Under \$10,000	72.2% (13)	66.7% (8)	70% (21)
\$11,000-\$20,000	22.2% (4)	25% (3)	23.3% (7)
\$21,000-\$30,000	(0)	8.3% (1)	3.3% (1)
\$31,000 and above	5.5% (1)	8.3% (1)	3.3% (1)
Time Post-stroke			
Less than 6 Months	(0)	50% (6)	20% (6)
6-12 Months	(0)	50% (6)	20% (6)
13-18 Months	27.8% (5)	(0)	16.7% (5)
19-24 Months	27.8% (5)	(0)	16.7% (5)
25-30 Months	22.2% (4)	(0)	13.3% (4)
31-36 Months	22.2% (4)	(0)	13.3% (4)
Currently Impaired			
Yes	11.1% (2)	50% (6)	26.7% (8)
No	88.9% (16)	50% (6)	73.3% (22)
Insurance Type			
Medicaid	55.6% (10)	66.7% (8)	60% (18)
Medicare	5.6% (1)	8.3% (1)	6.7% (2)
Medicaid & Medicare	38.9% (7)	16.7% (2)	30% (9)
Private	(0)	8.3% (1)	3.3% (1)

Table 4. Sample Interview Questions with Health and Social Service Participants

Microsystem	Mesosystem	Exosystem	Macrosystem
What is the process to determine the resources needed by an individual with stroke?	What are ways that your organization helps stroke survivors?	What has been your experience working with (NYPH/local community organizations) on facilitating the transition back to community for stroke survivors?	How is the organization financially supported? Are services funded by different sources?
What challenges have you encountered assisting stroke survivors?	How do your services facilitate the survivors' return to the community?	(Clinical Care Providers) What considerations, if any, are made when deciding the patient's rehabilitation needs?	
What are ways that you help the families of stroke survivors?	How does your organization accommodate people with physical and cognitive impairments?	(Clinical Care Providers) What is your role in planning the patient's discharge?	
What would help your ability to help stroke patients' transition back into community?	Who is eligible to access services?	(Clinical Care Providers) What protocols, if any, do you follow to assist patients with transitioning into community?	
	How do you stay informed of the resources available in the community that are relevant to the needs of stroke survivors?	(Clinical Care Providers) What is your current role in the stroke rehabilitation services provided at (NYPH/the Allen Hospital)?	

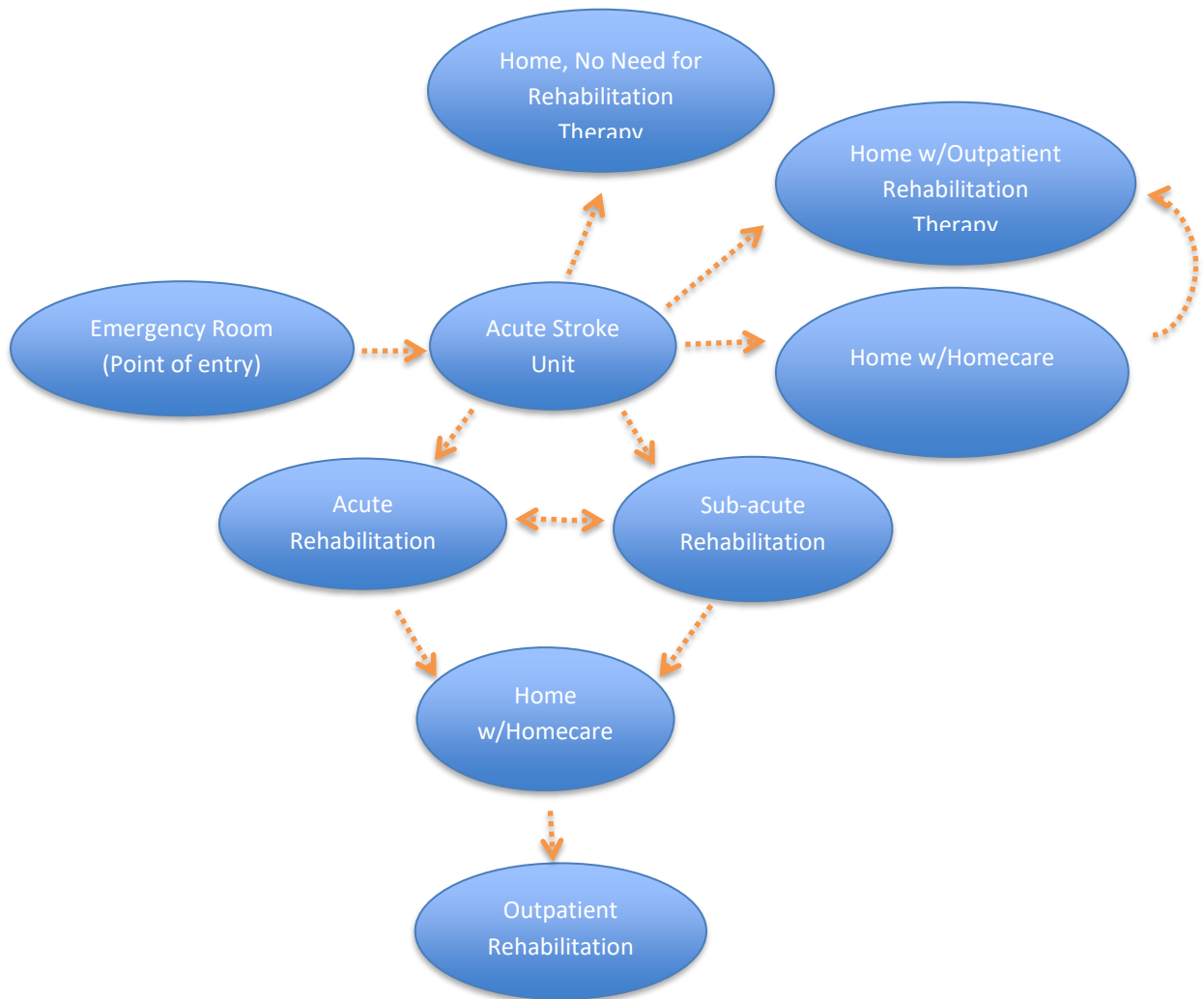
Table 5. Emergent Themes from Health and Social Service Participant Data

Ecological Level	Definition	Theme(s)
Microsystem	Perceptions on professional role and self-concept.	1. “Clueless” About the Health Care System
Mesosystem	Interrelation among a person’s individual setting and the relationships with co-workers, patients/clients, patients/clients’ family, social service agencies, and health care providers.	2. Knowledge of Community Based Agencies and Their Services 3. Discordance in Expectations Between Social Workers and Patients 4. Organizational Level Constraints 5. Organizational Culture
Exosystem	Contains social structures, such as social and health services, their structure, mission, and roles that influence and may determine a person’s settings.	6. “Handing-Off” the Patient to the Next Level of Care
Macrosystem	Includes the broader societal beliefs and values, public policies, and institutional cultures that impact the individual.	7. Financing, Funding, and Reimbursement Policies

Table 6. Characteristics of Health and Social Service Participants

		Total 100% (<i>n</i> = 20)
Sex	Female	100% (20)
Race	Asian	10% (2)
	Non-Hispanic White	55% (11)
	White of Latino Descent	35% (7)
Years Working in Northern Manhattan	1-2 Years	15% (3)
	5-10 Years	40% (8)
	More than 10 Years	45% (9)
Years in Current Position	2-5 Years	15% (3)
	5-10 Years	40% (8)
	More than 10 Years	45% (9)

Figure B. Stroke Continuum of Care Model



The figure depicts the types of medical interventions that constitute the stroke continuum of care. The arrows denote the different treatment pathways. Opportunities to discuss community integration are denoted by the dashed arrows.

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