

**Functional Mobility of Community-Dwelling Older Persons:
An Ethnographic Pre-Feasibility Study**

by

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Abstract

The purpose of this pre-feasibility study was two-fold: first, to examine perceptions and experiences of mobility challenges in the urban Brazilian community-dwelling older persons; second, to examine study participants' perceptions about a sit-to-stand activity. The method of exploration was qualitative focused ethnography. Convenience and purposive sampling were used to recruit 23 older persons living in Paquetá, Rio de Janeiro, Brazil. Data was collected via observant participation and semi-structured interviews. Data analysis utilized qualitative content analysis to describe and interpret the phenomena under study. Findings revealed that perceptions of urban Brazilian community-dwelling older persons with mobility are culturally transmitted and influenced by the social, physical and health environments they are part. Older persons' experiences with mobility challenges was an integral part of sense of self and strongly related to contextual factors. Accordingly, the experience of mobility challenged older persons with the sit-to-stand activity was dependent on their mobility expectations involving many factors that worked together to influence their activity beliefs and attitudes, preferences, behaviors, and cultural perceptions; however, the most noticeable shortcomings for participants' engagement in the sit-to-stand activity emerged as gaps in their personal and intrapersonal needs. The recommendations generated from my findings call for the design of implementation strategies of the sit-to-stand intervention that are tailored to this particular population's needs. This study contributes new information to the field of inquiry on mobility of older persons as it focuses on the perceptions of a specific age group, and attends to the interrelationships between health conditions and contextual factors affecting the mobility of older persons.

Preface

This thesis is an original work by Uirá Duarte Wisnesky. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Functional Mobility of Community-Dwelling Older Persons: An Ethnographic Pre-Feasibility Study”, No. 00081957, 20/06/2018.

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Table of Contents

CHAPTER ONE: INTRODUCTION	1
RESEARCHER POSITIONALITY	1
BACKGROUND	4
STUDY PURPOSE	8
RESEARCH QUESTIONS	8
SIGNIFICANCE OF THE STUDY	9
KEY TERMS	10
SUMMARY	14
CHAPTER TWO: LITERATURE REVIEW	15
AGING	17
Functional Capacity and Aging	18
MOBILITY	19
Mobility Spectrum	20
<i>Bed mobility</i>	25
<i>Breadth of transfer skills</i>	26
<i>Travel</i>	26
MOBILITY AND THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH	28
Mobility as an Activity	32
Participation and Mobility	35
Body Function and Structures and Mobility	37
Health Conditions and Mobility	39

Contextual Factors and Mobility	42
<i>Personal Factors Influencing Mobility</i>	42
<i>Environmental Factors Influencing Mobility</i>	49
PHYSICAL ACTIVITY AND MOBILITY	57
Physical Activity and Older Persons	58
Sit-to-stand Activity: An Activity to Improve Mobility in Older Persons	60
CONCLUSION	67
CHAPTER THREE: METHODS	70
STUDY APPROACH	70
METHODOLOGICAL PERSPECTIVE	72
Methodological Origins	72
Focused Ethnography	74
STUDY ASSUMPTIONS	76
Ethnography and the Constructivist Worldview	76
Ontological Assumptions	76
Epistemological Assumptions	78
STUDY DESIGN	78
Setting	79
Participants	83
<i>Sampling</i>	86
Data Making	87
<i>Ethnographic interview</i>	89
<i>The sit-to-stand activity</i>	92

<i>Participant observation</i>	93
Data Management Procedures	95
Data Analysis	96
<i>Content analysis</i>	96
Data Translation	99
<i>The translation procedure: step-by-step</i>	101
Writing an Ethnography	103
ETHNOGRAPHY AND ETHICAL CONSIDERATIONS	104
Risks and Benefits for Vulnerable Participants	104
Confidentiality	105
Autonomy of Participant Involvement	106
Informed Consent	106
Researcher's Safety	107
ESTABLISHING RIGOR	108
SUMMARY	111
CHAPTER FOUR: FIELD ACCESS AND STUDY CONTEXT	113
PRELIMINARY FIELDWORK	113
Pre-Entry Phase	115
<i>Contextualizing the field</i>	115
Participant Recruitment and Selection	139
<i>Participants socio-demographic characteristics</i>	141
CHAPTER FIVE: FINDINGS OF OLDER PERSONS' PERCEPTIONS	
AND EXPERIENCES OF MOBILITY CHALLENGES	147

THEME ONE: MY PAST, MY IDENTITY	147
Family-life Experiences	148
Past Experiences with Mobility	154
THEME TWO: MIRROR, MIRROR ON THE WALL, WHO AM I AFTER ALL?	161
I am Affect	162
I am Cognition	168
I am my Body	173
THEME THREE: CONTEXT MATTERS	179
Environmental Factors	180
Socio-Economic Factors	202
THEME FOUR: EXPECTATIONS AND NEEDS FOR MOBILITY	212
Expectations	213
Needs	216
SUMMARY	220
CHAPTER SIX: FINDINGS OF OLDER PERSONS' EXPERIENCES	
WITH THE SIT-TO-STAND ACTIVITY	222
THEME ONE: TO JOIN, OR NOT TO JOIN: THAT IS THE QUESTION	222
Structural Aspects	223
Individual Influence	225
THEME TWO: HOW DID IT GO?	228
Drivers	229
Obstacles	236
SIT-TO-STAND ACTIVITY WITHIN THE INTERNATIONAL	

CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH	242
SUMMARY	247
CHAPTER SEVEN: DISCUSSION	249
PERCEPTIONS AND EXPERIENCES WITH MOBILITY CHALLENGES	250
Culturally Transmitted Perceptions of Mobility	250
Mobility is an Integral Part of Sense of Self	253
(Dis)abling Contexts	256
Mobility Expectancies	261
EXPERIENCES WITH THE SIT-TO-STAND ACTIVITY	264
Establishing Intentions	264
The Experience with the Components of the Activity	267
The Personal Experience with the Activity	269
The Interpersonal Experience with the Activity	271
FINDINGS IN LIGHT OF THE INTERNATIONAL CLASSIFICATION OF	
FUNCTIONING, DISABILITY AND HEALTH	272
IMPLICATIONS	274
Implications for Patient Care and Nursing Practice	274
Implications for Nursing Education	277
Implications for Nursing Research	278
KNOWLEDGE SHARING STRATEGIES	279
STUDY STRENGTHS AND LIMITATION	280
REFERENCES	282
APPENDICES	373

List of Tables

Table 1	Participants' demographic data	144
Table 2	Participants' age distribution	146
Table 3	My past, my identity	148
Table 4	Mirror, mirror on the wall who am I after all?	162
Table 5	Context matters	179
Table 6	Expectations and needs	214
Table 7	To join, or not to join: that is the question	224
Table 8	How did it go?	230
Table 9	Sit-to-stand activity within International Classification of Functioning, Disability and Health	245

List of Figures

Figure 1	International Classification of Functioning, Disability and Health and Mobility	30
Figure 2	Wave two participants housing	182
Figure 3	Outdoor space of participants from wave three	184
Figure 4	Gravel and holes due to rain	191
Figure 5	Rubble on the streets of Paquetá Island	192
Figure 6	Holes in the sidewalk	193
Figure 7	Holes in the streets of Paquetá Island	194
Figure 8	Sidewalks damaged by roots of a tree	195
Figure 9	Ramps on the sidewalks	196
Figure 10	Model of the sit-to-stand activity within International Classification of Functioning, Disability and Health and Mobility	243

List of Appendices

Appendix A	Health Care Center Consent to Participate in the Study	374
Appendix B	Information Sheet and Consent Form	376
Appendix C	Demographic Data Survey	383
Appendix D	1 st Interview Guide	387
Appendix E	2 nd Interview Guide	390
Appendix F	Summary of the Connections Between Research Questions, Vehicles for Data Generation, Data to be Generated, Procedures, and Data Analyses	393
Appendix G	Description of the Sit-to-Stand Activity	395

CHAPTER ONE: INTRODUCTION

For this dissertation I conducted an ethnographic study to examine the perceptions and experiences of community-dwelling older persons in a mobility activity within the primary healthcare sector in Brazil. This dissertation is structured as seven distinct chapters. In Chapter One, I start with my positionality as a researcher, background information about functional mobility in community-dwelling older persons, and physical activity to frame my research purpose and questions. I conclude this chapter defining key terms to explain the meaning I assigned to concepts that were critical in communicating the intent and context of this research. In Chapter Two, I present a literature review which includes the search strategies and the background and the context of this study on older persons' functional mobility. This includes a presentation of the problem (mobility challenge) within the International Classification of Functioning, Disability and Health Framework. I finalize Chapter Two with a presentation of the sit-to-stand activity research that has been conducted thus far, and argue for the significance of the study. I dedicate Chapter Three to the research method and design of this ethnographic study. In Chapter Four, I contextualize the field, the positions I held within it, as well as how I accessed it. Findings are presented in Chapters Five and Six. Chapter Seven consists of the discussion of the findings, including the implications, recommendations, and areas for further research.

Researcher Positionality

The identities of researcher and participants are likely to influence the research process via our perceptions and the ways others perceive us (Bourke, 2014). By being aware of, *inter alia*, our own intentions, biases, values, views, gender, class, and location in time and space, we situate our approach to a research setting and how we might seek to engage with participants. It

is thus important for me to define my positionality in conducting research about mobility and physical activity in Brazilian older persons.

I am a Brazilian, middle-class woman and researcher with academic and professional knowledge of nursing, health history, health and societies, behavior practices and preventive care. My doctoral studies were sponsored by the *Conselho Nacional de Desenvolvimento Científico e Tecnológico* (CNPq, the National Council for Scientific and Technological Development), which is an organization of the Brazilian federal government under the Ministry of Science and Technology dedicated to the promotion of scientific and technological research and to the formation of human resources for research in the country.

Although my involvement as a graduate researcher with the thematic aging and mobility started in 2014, my interest in issues surrounding older persons began years before. Early in my nursing undergraduate studies in Brazil, I was fortunate to have professors who exposed me to issues of health and wellness faced by older persons. When I realized they were an understudied group in the country, I wanted to help change that. My curiosity involving older persons and their health during my rotation at a primary healthcare setting led to a research proposal related to the risk of contamination and infection due to the reuse of disposable syringes by older diabetic patients.

Because of this experience, I decided to dedicate my career to improving the health and wellbeing of older persons using nursing knowledge. In 2007, while living in Ottawa learning English as a second language, I volunteered at a continuing care facility and was assigned to therapeutic recreation services with older persons. During this time, I learned unique approaches to engage with frail older persons. This contrasted with my previous clinical experience in Brazil with community dwelling older persons. As a volunteer, I provided meaningful recreation time to

frail older persons through musical and social engagement. I was able to establish rapport with persons of all ages and backgrounds while contributing to the development of innovative programs.

In 2013, I decided to pursue my doctoral studies and the area of older persons pointed me towards issues of mobility they face. In the spring of 2015, I moved to Canada and started working as a research assistant on a research team dedicated to the area of gerontology. The research I was involved in concerned the process evaluation of a study aimed to analyze the effectiveness of reminders to support the sustainability, or ongoing uptake, of an affordable mobility innovation by healthcare aides in supportive living facilities (Slaughter, Estabrooks, Jones, Wagg, & Eliasziw, 2013). The process evaluation goal was to observe the elements affecting the effectiveness of knowledge translation interventions.

While working with the research team, I was exposed to other projects developed there and one project in particular drew my attention. It was an intervention study to assess the effect of the sit-to-stand activity on the mobility, function, and health-related quality of life of nursing home residents with dementia (Slaughter et al., 2015). The prospects offered by the proposed intervention seemed to be enticing and open to different possibilities. Wonders could be achieved by offering older persons with mobility challenges the possibility of improving their ability to move. Although the simple task of moving from a seated to a standing position is performed several times each day and seems to be a mundane task, the inability to perform this task can place profound limitations on an individual's ability to move freely, to be independent and to function in society.

The sit-to-stand intervention was a simple activity involving the act of repeatedly standing up from a chair and sitting down and could be integrated into the context of daily life.

My present research is built on evidence from studies on interventions for mobility maintenance in older persons. In the majority of these studies older persons who practiced standing up and sitting down had better mobility and ability to complete daily activities compared with a similar group who did not do the sit-to-stand activity. Therefore, the elegant simplicity of this intervention, which does not require specialized training or equipment, had the potential to be spread to different cultural and geographic contexts.

Older persons from Brazil, my home country, could also potentially benefit from this strategy! From my experience working in Brazil as a nurse, I observed that many older persons experienced mobility challenges. Therefore, if there was evidence that mobility challenged older persons' performance of the sit-to-stand task optimized their mobility and function, why not transfer this health-care strategy I witnessed in Canada to Brazil? In Brazil, where the health-care system is cost-constrained, we could definitely use a financially sound innovative intervention. Also, if these strategies demonstrate consistently improved outcomes irrespective of cultural and contextual variants, they could be employed by anyone independent of where they live or their culture. Therefore, this study aimed to shed light on the cultural variants regarding the implementation of the sit-to-stand activity.

Background

The aging process draws attention to the health conditions of older persons since this phenomenon is accompanied by a higher risk of disability and morbidities (Aijanseppa et al., 2005; Rodrigues, Scudeller, Pedrazzi, Schiavetto, & Lange, 2008). As people age, some physiological, psychological, and social changes happen (Dziechciaz & Filip, 2014). These changes can lead to a variety of syndromes and issues, which, in turn, can lead to poor health outcomes (Gajewski & Falkenstein, 2016). For instance, critical illnesses and chronic diseases

carry substantial risks of decreased functional capacity for older persons (Neuman & Eckenhoff, 2015). As well, functional incapability can worsen already poor health outcomes.

Functional capacity is one relevant indicator of health status in older persons and it is also closely related to quality of life (Aijanseppa et al., 2005). Functional capacity and incapability are seen in terms of maintenance of autonomy (Lima-Costa, Barreto, & Giatti, 2003), which for older persons can be conceptualized as the ability to perform self-care, self-maintenance and physical activity. Mobility challenges are the first signs of decline in functional capacity and a major problem faced by older persons. According to Katz, there may be a hierarchy in functional decline of older persons where basic activities learned last in early development, such as walking, are the first to decline as functional capacity deteriorates (Katz & Akpom, 1976; Spector, Katz, Murphy, & Fulton, 1987).

Mobility, simply defined as the ability to move safely from one place to another, is fundamental for engaging in daily activities (Lin, Lee, Chang, Yang, & Tsauo, 2017) and allowing older persons to lead independent lives. It encompasses a range of functional activities such as rolling from one side to the other, transferring from bed to chair, sitting, standing, getting up from a chair, walking, stair climbing, stooping and kneeling, driving, and getting in and out of cars or buses (Khokhar et al., 2001; Satariano et al., 2012).

The range of abilities associated with mobility is extensive and the factors influencing mobility are multidimensional. Challenges to mobility are generated when an individual is unable to efficiently move from place to place resulting in diminished participation in necessary or desirable activities (World Health Organization, 2007). Particularly for older persons, the ability to move safely and independently is highly associated with their ability to engage in activities of daily living. If an individual lives in an environment that does not provide

opportunities to overcome mobility challenges, she or he will have to either abstain from the activity or request assistance from others.

Mobility challenges may also impact individuals' quality of life (Gabriel & Bowling, 2004; Gagliardi, Marcellini, Papa, Giuli, & Mollenkopf, 2010; Hjorthol, Levin, & Siren, 2010). Reduced quality of life is commonly acknowledged as an adverse health outcome and, at the same time, a critical marker of other adverse health outcomes (Bilotta et al., 2011). Reduced quality of life as an adverse health outcome can be exemplified by a decline in mobility leading to isolation, loneliness and depression (Fonda, Wallace, & Herzog, 2001; Pristavec, 2016), which in turn, can lead to poorer quality of life (Chang, Chi, Yang, & Chou, 2010). Being mobile is related to psychological well-being and fulfills many utilitarian and psychosocial needs, besides also improving an individual's social networks and social interaction, providing independence, denoting status, and exercising cognitive skills (Mackett, 2015; Musselwhite, 2015). Conversely, poorer quality of life has been described as a marker of underlying conditions leading to adverse events such as disability and depression (Bilotta et al., 2010; Bowling, 2005). In other words, mobility challenges are major contributors to older persons' quality of life and functional disability, which is related to the difficulty or inability to independently engage in daily life activities (Rosa, Benício, Latorre, & Ramos, 2003).

In practice, a wide range of interventions has been developed to promote mobility. Special attention is given to interventions founded on the principle that some critical predictors of mobility decline are modifiable (Ross, Schmidt, & Ball, 2013). Physical activity, then, emerges as a possible intervention to improve or maintain mobility in older persons by remodeling critical determinants (Kelley, Kelley, Hootman, & Jones, 2009; Stathi, McKenna, & Fox, 2010). There is evidence that mobility-challenged older persons benefit from interventions

targeting muscular strength, flexibility, and balance (Nelson et al., 2007; Pate et al., 1995), such as the sit-to-stand activity.

The sit-to-stand motion is a transition movement (Bohannon, 2015) and one of the most frequently performed movements by humans (Galli, Cimolin, Crivellini, & Campanini, 2008). Rising from a sitting to a standing position is considered a prerequisite to walking and other functional activities. The sit-to-stand is also a simple activity involving the act of repeatedly sitting down and standing up from a chair, and is frequently completed in the context of daily life. Given the relevance of the ability to rise from a seated to a standing position and vice-versa, the sit-to-stand activity emerges as a likely intervention to effectively improve or maintain mobility in older persons. This is corroborated by studies (from developed countries) suggesting that repeated sit-to-stands can maintain or improve the mobility of older persons (Alexander et al., 2001; Dean, Channon, & Hall, 2007; Pollock, Gray, Culham, Durward, & Langhorne, 2014; Rosie & Taylor, 2007; Slaughter et al., 2015).

While some of the benefits and advantages of the sit-to-stand intervention have been well documented, the majority of this research has been conducted in developed countries. This makes the identification of the impact of modifiable determinants not clear for persons from developing countries, which, in turn, makes it more difficult to implement those interventions in these settings. Therefore, appropriate and effective interventions to improve mobility are not reaching many of those in need. There is a need for further research in countries such as Brazil, where increasing age, female sex, widow or single marital status, as well as having chronic diseases, lower level of schooling, lower income, and lower self-perception of health have a strong impact on older persons' functional capacity (Alves, Leite & Machado, 2010).

All things considered, it is not enough to solely transfer successful interventions from one country or setting to another. Before conducting an intervention study, it is important to first examine the context wherein the intervention would be introduced. I did this through a pre-feasibility study that used a focused ethnography design. I collected baseline data about older persons' perceptions and experiences with mobility challenges, and introduced a sit-to-stand activity to this group of interest. I then asked participants to share their experience about the sit-to-stand activity.

My initial plan was to tackle issues exclusively regarding older persons' experience about the sit-to-stand activity. However, I encountered a lack of studies about Brazilian older persons' perceptions and experiences with mobility challenge. Thus, a baseline understanding of the factors related to individual's cultural, social, physical, and health environments affecting their expectations, norms, values and behaviours around mobility became essential for potentially developing or improving the sit-to-stand intervention (Bauman, Reis, Sallis, Wells, Loos, & Martin, 2012). The likelihood of an intervention's effectiveness is increased if the factors known to hinder and/or facilitate participation are directly addressed within the context of the program (U.S. Department of Health and Human Services, 2008).

Study Purpose

The purpose of this pre-feasibility study was two-fold: (1) to examine the perceptions and experiences of mobility challenges in the urban Brazilian community-dwelling older persons; and (2) to examine study participants' perceptions about a sit-to-stand activity.

Research Questions

1. What are Brazilian older persons' perceptions and experiences of mobility challenges?

- a. How do factors relating to their cultural, social, physical, and health environments affect their expectations, norms, values and behaviors around mobility?
2. How do Brazilian older persons with mobility challenges experience the sit-to-stand activity?
 - a. What factors in their cultural, psychosocial, and physical/health environments (e.g., values, norms, expectations, resources and services) facilitate or hinder the appropriateness and usefulness of this activity in their daily lives?

Significance of the Study

If Brazilian society is to promote an extended period of independent living and higher quality of life for older persons, it is paramount that researchers and healthcare stakeholders understand how to best help this population maintain and improve their mobility. Thus, the significance of this study relates to taking the older person's context into consideration before introducing an intervention that has been successful in other countries.

This shift-away from a focus on developed countries to include research in a developing country may contribute both to research generation and application. A study without critical analysis of the contextual aspects runs the risk of imposing ethnocentric theories and cultural imperialism that can have a negative impact on the most vulnerable population. Therefore, transferring interventions designed to deal with mobility challenges without first studying them and then adapting them as needed to the context where they are being transferred is ethnocentric and can be counterproductive (Gavin, 2014; Matheson, 2009; Summerfield, 2012).

Likewise, researchers' findings point out that context-appropriate approaches have a better effect than traditional, non-contextually adjusted strategies on health outcomes (Smith, Rodriguez, & Bernal, 2011). By addressing contextual factors that are specific to the targeted group, it might be possible to maximize understanding, minimize risk, and take full account of behavior and values (Barr-Anderson, Adams-Wynn, Alhassan, & Whitt-Glover, 2014; Resnicow, Braithwaite, Baranowski, & Ahluwalia, 2001).

Finally, this study should contribute to the development of nursing knowledge, as it sheds light on challenges to mobility which are relevant to nursing practice. Nurses seek to promote people's health. In particular, the contributions to nursing are related to improving care by providing evidence about the significance of the context in which nursing interventions are applied (Green & Glasgow, 2006). As nurses, we are at the service and behest of society; thus, the significance of nursing approaches, informed by contextually adapting knowledge, lies in the difference it makes in the everyday practices in which nurses engage (Doane & Varcoe, 2008).

Key Terms

Activities of daily living. Activities of daily living is a term used to represent the set of common tasks that comprise one's daily self-care requirements (Shewell, Nugent, Donnelly, & Wang, 2016). Activities of daily living require basic skills and denote what an individual normally does in his/her daily living. The activity of daily living concept was initially proposed by Sidney Katz and his team and has since evolved into its present categorization of activities (Noelker & Browdie, 2014). Activities of daily living can be divided into basic activities of daily living and instrumental activities of daily living. Basic activities of daily living are related to self-care, such as bathing, showering, dressing, undressing, functional mobility such as transfers and bed mobility (Pedretti, Pendleton, & Schultz-Krohn, 2013). On the other hand, instrumental

activities of daily living require more advanced level skills in all performance areas and are related to the capacity to manage the living environment inside and outside the home.

Instrumental activities of daily living tasks demand care of others and of pets; communication management; home establishment and movement (house cleaning, meal preparation, and clean up); and community mobility (Pedretti et al., 2013). Accomplishment of these activities is necessary for continued independent residence in the community.

In this regard, mobility was observed within the broader sphere of activities of daily living. This was due to mobility's level of intermediate complexity situated in between basic and instrumental activities of daily living (Alves, Leite, & Machado, 2008a). Thus, mobility challenge may be indirectly observed by inability to perform basic and instrumental activities of daily living, such as taking a shower (or going to the toilet) and shopping (or answering the telephone), respectively (Guralnik, Fried, & Salive, 1996). Instrumental activities of daily living are not necessary for fundamental functioning, but they let an individual live independently in a community. Therefore, mobility might be less affected in regards to instrumental activities of daily living, since these types of activities can be purchased or supplied by others in ways that may not affect the individually as drastically.

Ageism. Ageism refers to the negative attitudes, stereotypes, and behaviors directed toward older persons based solely on their perceived age (Butler, 1969). It has been defined as a negative attitude toward aging based on the belief that ageing “makes people unattractive, unintelligent, asexual, unemployable, and mentally incompetent” (Atchley, 2004, p. 439). Ageism permeates our culture through media, language, and values and is composed of prejudice, beliefs, and attitudes as well as discriminatory practices (Wilkinson & Ferraro, 2002).

Aging. Aging is natural, individual dynamic process with multiple internal and external influences that move individuals along a continuum towards old age at varying rates (Neugarten & Neugarten, 1996). Internal influences are related to the accumulation of adverse changes occurring in cells and tissues over time (Tosato, Zamboni, Ferrini, & Cesari, 2007) resulting in an increased susceptibility to physical and cognitive disabilities (Manini, 2013). External influences are related to environmental factors, such as ultraviolet radiation, cigarette smoking, air pollution, social determinants, and cultural expectations, among others. Consequently, aging is the interrelationship of chronological age with biological, psychological, social, environmental, and historical aspects.

Country classification. Some international organizations classify countries by their level of development as measured solely by per capita gross national income (GNI) (United Nations, 2015). Accordingly, countries have been grouped as high-income, upper middle income, lower middle income and low-income. The World Bank dictated the threshold levels of GNI per capita as follows: a) low-income countries present less than \$1,035 GNI per capita; b) lower middle-income countries present between \$1,036 and \$4,085 GNI per capita; c) upper middle-income countries present between \$4,086 and \$12,615 GNI per capita, and d) high-income countries present more than \$12,615 per capita (World Bank, 2016)

Conversely, many international organizations, e.g., United Nations Department of Economic and Social Affairs (UN/DESA) and Economic Commission for Latin America and the Caribbean (ECLAC), employ a broader classification: The World Economic Situation and Prospects (WESP), which classify countries according to their basic economic conditions. For analytical purposes, WESP classifies all countries of the world into three broad categories: developed economies, developing countries, and economies in transition, the latter being a

classification of countries that are changing from central planning to free markets (United Nations, 2015). Although the world is still divided between richer and poorer countries, relationships among countries have changed; therefore, for the purpose of this study, the WESP classification will be employed due to their more comprehensive scope.

Developed countries. Kofi Annan, former Secretary General of the United Nations, defined a developed country as “one that allows all its citizens to enjoy a free and healthy life in a safe environment” (United Nations Conference on Trade and Development, 2000). For this study, I employed the term ‘developed countries’ for countries that have achieved a significant degree of industrialization relative to their populations, and have, in most cases, a high standard of living as measured by per capita gross national income, gross domestic product per capita, life expectancy, the rate of literacy, freedom index, poverty, welfare and others (United Nations, 2015). Examples of developed countries are Canada, Japan, Sweden and the United States.

Developing countries. For this study, I employed the term ‘developing countries’ for countries that have not achieved a significant degree of industrialization relative to their populations, and have, in most cases, a medium to low standard of living as measured by per capita gross national income, gross domestic product per capita, life expectancy, the rate of literacy, freedom index, poverty, welfare and others (United Nations, 2015). Example of developing countries are Argentina, Brazil, China, Israel, and South Africa.

Functional limitation. Functional limitation is related to the difficulty to accomplish everyday activities safely and independently without undue fatigue (Rikli & Jones, 1999). Thus, particularly for older persons, functional limitation is related to the inability to engage and develop basic and instrumental activities of daily living (Millan-Calenti et al., 2010).

Older persons. Here I use the term older person(s) instead of elderly, senior, older adult, or older people. Elderly might imply frailty. While the term elder implies wisdom, it also gravitates towards spiritual or community leaders or sages in the Indigenous context. Senior seems to confine – in Canada this term is mostly employed in a government context. Thus, the term ‘senior’ is mostly indicative of individuals within institutional arenas. To me, the word ‘person’ is perhaps more affirmative as it evokes the inherent personhood of every individual, reminds me that each of us has worth regardless of age, and that aging does not devalue anyone.

In this study, I adopted the World Health Organization definition, where older persons are individuals aged 60 or over, if they reside in developing countries, and individuals aged 65 and over if they reside in developed countries (World Health Organization, 2002a). I acknowledge the limitations of adopting an age cut-off that can potentially encompass individuals with a forty years range of age difference (60 to 100 years old) who have possibly lived very different life trajectories.

Social environment. The social environment includes the sociocultural and political elements that constitute one’s social environment and other socially “created” circumstances that makeup the community, society, or culture in which one participates (e.g. relationships, attitudes, policies, laws, and social and cultural norms, etc).

Summary

In this chapter I described the researcher’s positionality and briefly introduced the background for the issue of mobility challenges in community-dwelling older persons. I also identified the purpose of the study and the research questions. I concluded this chapter by defining key terms. In Chapter Two I examine the current state of knowledge about older persons’ mobility, with a focus on Brazil.

CHAPTER TWO: LITERATURE REVIEW

In this chapter, I present a literature review undertaken to introduce the background and context of this study. I discuss the general characteristics of mobility and the mobility spectrum. I also employ the International Classification of Functioning, Disability and Health framework (World Health Organization, 2007) as a guide to reflect on how the interaction of health conditions and contextual factors affect the mobility of older persons. Yet, mobility is a cultural concept, since culture frames and shapes how we perceive the world and our experiences. Thus, when discussing mobility within the International Classification of Functioning, Disability and Health framework, I introduce the cultural landscape of mobility in Brazil by describing the determinants of disability in the Brazilian adult population. It follows that putting individual and environmental-based determinants of mobility, such as sex, skin color, or health care access into the discussion, provided an opportunity to understand disability in the Brazilian setting. My goal in this section is to present determinants of mobility in view of the Brazilian cultural landscape.

Subsequently, taking into consideration the modifiable determinants of mobility challenges, I present a review of literature that includes a physical intervention to maintain mobility. I start by offering evidence in the literature showing the positive health benefits of physical activity. Having data suggesting that mobility-challenged older persons benefit most from physical activities targeting balance, as well as muscular strength and flexibility, I discuss the sit-to-stand activity, which is a suitable exercise to improve or maintain mobility in mobility-challenged older persons based on evidence located in published literature.

Multiple comprehensive searches for literature were undertaken using MEDLINE, CINAHL, SciELO, PsycINFO, HealthSTAR, EMBASE, and Abstracts of Social Gerontology databases. I performed searches to become thoroughly familiar with the topic and identify gaps

in the existing research literature. Searches were also conducted for relevant grey literature on the web sites of government agencies and organizations. The search employed various combinations of the search terms in the following categories:

1. Population: aged OR geriatr* OR gerontolog* OR elder* OR aging OR old age
OR advanced age OR late* life OR age-related OR seniors OR senior citizen* OR
retired OR older adults OR older persons
2. Population: community dwelling OR community living OR independent living
3. Phenomenon of interest/Intervention: sit-to-stand OR sit-to-stand OR sit OR
sitting OR stand OR standing OR rise OR rising OR rise up OR getting up OR
getting-up OR chair
4. Phenomenon of interest: mobility OR movement OR locomotion OR walking OR
physical mobility OR ambulation OR gait OR exercise OR activity OR task OR
falls OR therapy OR rehabilitation OR motor skills OR motor activity OR range
of motion OR equilibrium OR balance OR step OR stepping OR climb OR
climbing OR activities of daily living
5. Phenomenon of interest: risk factor* OR predictor* OR determinant*
6. Method: randomized controlled trial OR controlled clinical trial OR clinical trial
OR randomized OR randomly OR random OR random* OR allocat* OR random
assignment OR quasi-random OR quasi random OR pseudo-random OR pseudo
random OR trial OR groups OR double blind procedure OR double blind OR
single-blind procedure OR assign OR allocat* OR volunteer* OR quantitative
stud* OR comparative study OR comparative studies OR evaluation study OR
prospective study OR cohort study OR feasibility OR feasibility study OR pilot

OR pilot study OR program evaluation OR meta analysis OR multicenter study
OR multicentre study

Aging

In general, older persons are living longer than their predecessors of just a few generations ago. It is important to observe this phenomenon as it has important implications for the future of public health and health care. Globally, the proportion of individuals aged over 60 years in 1950 was 8%; in 2011 this proportion reached 11%, and is forecast to reach 22% in 2050 (World Economic Forum, 2012). The largest growth is happening in developing countries, where approximately 14% of the population is 60 or older (Shrestha, 2000). After Asia, Latin America has the highest percentages of older persons. Brazil in particular is the 6th country in the world with the highest number of older persons (Gragnolati, Jorgensen, Rocha, & Fruttero, 2011). In 1991, older persons in Brazil accounted for 7.3% of the population. In 2000, it was 8.6% followed by 10.2% in 2006. The current annual population growth of older persons 65 years or older is 3.84% and the average Brazilian life expectancy has reached 73.6 years (Instituto Brasileiro de Geografia e Estatística, 2013a).

Aging is a natural, complex, multifactorial, inherent phenomenon of all living beings (Hayflick, 2004; Kowald & Kirkwood, 1996). However, one should be aware of the difference between pathological aging and normal aging. Aging is not a disease. Age changes and pathology (diseases, impairments, morbidities, and disorders) are distinct conceptualizations because differently from pathology every human being undergoes normal changes during the aging processes. These normal changes occur in the functions of many systems of the body over time (Hayflick, 1998; Lin et al., 2017; Miller, 2009). For example, if one has diabetes, the probability of cardiovascular disease increases because of the effect of high blood sugar. It is not natural to

get diabetes; however, anyone who lives long enough will develop cataracts (or arterial stiffening and thickening, brown atrophy of the myocardium, calcific deposits in the aortic valve, presbyopia), which is a normal aging change (Lewis, 2002; Waller, 1988).

Functional Capacity and Aging

Overall, this research study focused on promoting functional capacity (and preventing functional disability) in older persons by studying their perceptions and experiences with mobility challenge and the sit-to-stand activity. Functional capacity is currently an important indicator of health in the older population. It involves independence to perform activities of daily life that are necessary for independent living (Lebrão & Duarte, 2003; Sanchez, 2000). The possibility of performing activities of daily living without assistance of another person characterizes independence or preserved functional capacity; the need for assistance to accomplish activities of daily living characterizes dependence or decreased functional capacity. Therefore, older persons' functional capacity is related to the autonomy and independence in their basic and instrumental activities of daily living and not by the presence or absence of diseases (Ministry of Health, 2007). Particularly, this threat to independent living can arise when older persons are not able to care for themselves, eat, take a shower, dress, go to the toilet, and transfer independently, as well as when their homes are no longer safe and suitable places for them.

The prevalence of physical disability among older persons is high. As the number of older persons in Brazil and worldwide rises, sustaining independent physical function in older persons is a central goal of public health. Since physical function and mobility challenge are associated with, but do not inevitably lead to physical disability, it is important to highlight these functional challenges in the ongoing functioning – disability continuum.

It has been established that mobility disability and physical disability are distinct. Mobility is fundamental to the health and well-being of older persons and is defined as the ability to move safely from one place to another (Lin et al., 2017). Within the functioning – disability continuum, mobility challenge can be considered a distal outcome compared with physical function. Evidence described elsewhere shows that physical function is associated with mobility challenge and these functional limitations are predictive of physical disability in older persons. Risk factors for mobility challenge and physical disability include, inter alia, age, ethnicity, sex, health conditions, previous disability, previous mobility challenges, and lower levels of physical activity.

Mobility

Mobility is a basic activity of individuals needed to participate in everyday life (Anderson et al., 2014). Unfortunately, mobility can be challenging for many people. In a study using a nationally representative survey, Iezzoni, McCarthy, Davis, and Siebens (2000) examined perceptions of disability among 142,572 non-institutionalized persons 18 years and older with lower-extremity mobility challenges in the United States of America. The researchers found that about 10.1%, which represents an estimated 18.98 million persons living in the community, reported at least some mobility challenges, with 3.1% (estimated 5.82 million) noting major mobility challenges. Of those reporting major challenges, 87.6% had experienced mobility challenges for longer than one year.

Particularly for older persons, mobility is critical to support satisfactory aging. In a study to examine the prevalence of and clinical markers associated with mobility challenges in 12,769 community-dwelling older persons aged 65 and older in the United States of America, Shumway-Cook, Ciol, Yorkston, Hoffman, and Chan (2005) reported that 46% of respondents

were classified as having ‘challenged mobility’. From these respondents classified as having challenged mobility, 31% were classified as having mild challenges (self-reported difficulty walking not requiring equipment or personal assistance), 11% were classified as having moderate challenges (self-reported difficulty walking requiring equipment), 4% were classified as having severe challenges (requiring the personal assistance of another to walk), and 1% were non-walkers.

Mobility challenges have a higher impact on the health and well-being of older persons when compared to any other age group. Such challenges often result in negative health outcomes and a cascade of deterioration (Satariano et al., 2012) such as reduced functional capacity to perform activities of daily living (Jette, 1980), increased burden of care affecting family members and health systems (Alexander, Galecki, et al., 2000), and restricted participation in needed or desired activities (Rosso, Taylor, Tabb, & Michael, 2013). In turn, these negative health outcomes are linked to a multiplicity of health conditions and increased mortality (Berkman & Kawachi, 2000a, 2000b).

Mobility Spectrum

We know that mobility challenges can have detrimental effects on health. It is known that difficulty in transferring and the ability to get in and out of a bed and rise from a chair are typical complications for older persons, impacting from six to eight percent of community-dwelling persons aged 65 and older (Leon & Lair, 1990; National Center for Health Statistics, 1987), and at least 63 percent of persons over age 65 residing in nursing homes (Mehr, Fries, & Williams, 1993). Transferring function may improve as a result of rehabilitation (Alexander, Grunawalt, Carlos, & Augustine, 2000), or decline as a result of acute and chronic illness, and hospitalization (Hirsch, Sommers, Olsen, Mullen, & Winograd, 1990).

Conventionally, the hospital environment (a tertiary care setting) has a biomedical emphasis, which focuses on medically managing illness states, not on improving or maintaining patient functioning (Kleinpell, Fletcher, & Jennings, 2008). Historically, this environment has been configured for the fast and effective delivery of care—not for improving patient function (Kleinpell et al., 2008). Hospitals are settings where older persons receive much health care; yet, a number of older persons are discharged in worse conditions than before their illness, and many do not recover. Each time an older person is hospitalized, regardless of the underlying medical condition, he or she has an increased risk of disability (Brown et al., 2009; Covinsky et al., 2003). At discharge, about one third of older persons are more disabled in their ability to perform activities of daily living (Landefeld, 2003), and research shows that this functional decline includes limitations in mobility (Bodilsen et al., 2016; Brown, Kennedy, Lo, Williams, & Sawyer, 2016; Zisberg et al., 2011).

Mobility is multifactorial and several factors have been found to be predictive of mobility challenges within the biological and contextual domain. In a cross-sectional analysis with a nationally representative sample to examine how the associations of chronic disease and mobility challenge have changed over a period of ten years, Hung et al. (2012) found no change in prevalence over the study period (p values > 0.14). The chronic diseases included in their study were hypertension, heart disease, heart failure, stroke, diabetes, cancer, chronic lung disease and arthritis.

Other studies on determinants of mobility challenge among community-dwelling older persons have showed that mobility challenge is highly associated with specific comorbidities, including foot and leg problems (Barr, Browning, Lord, Menz, & Kendig, 2005; Menz & Lord, 2001), diabetes (Bianchi & Volpato, 2016), stroke (Shaughnessy, Michael, Sorkin, & Macko,

2005; Wade, 1992), traumatic brain injury (Haffeejee, Ntsiea, & Mudzi, 2013), congestive heart failure, chronic lung disease (Hung et al., 2012), arthritis (Adamson, Lawlor, & Ebrahim, 2004), metabolic syndrome (Blazer, Hybels, & Fillenbaum, 2006), obesity (Bohannon, 2008; Jung et al., 2016; Ortega-Alonso, Sipila, Kujala, Kaprio, & Rantanen, 2008; Stenholm et al., 2009), reduced kidney function (Bowling et al., 2014; Fried et al., 2006), pain (Buchman et al., 2010; Eggermont, Shmerling, & Leveille, 2010; Liu-Ambrose et al., 2002; Mottram, Peat, Thomas, Wilkie, & Croft, 2008; Shah et al., 2011), depression (Carriere et al., 2011), low vitamin D and parathyroid hormone (Houston et al., 2013), high creatinine serum levels (Odden, Shlipak, & Tager, 2009), anemia (Patel et al., 2007), and fatigue (Avlund, Damsgaard, Sakari-Rantala, Laukkanen, & Schroll, 2002; Avlund, Vass, & Hendriksen, 2003; Tyagi, Perera, & Brach, 2015).

Besides chronic conditions, studies have shown that older persons with poor cognition and different cognitive abilities have an increased risk of mobility challenge (Atkinson et al., 2007; Ble et al., 2005; Buchman, Boyle, Leurgans, Barnes, & Bennett, 2011; Coppin et al., 2006; Hausdorff, Yogev, Springer, Simon, & Giladi, 2005; Intzitari et al., 2007; Sheridan & Hausdorff, 2007; Soumare, Tavernier, Alperovitch, Tzourio, & Elbaz, 2009; Von Bonsdorff, Rantanen, Laukkanen, Suutama, & Heikkinen, 2006; Yogev-Seligmann, Hausdorff & Giladi, 2008; Yogev-Seligmann et al., 2005). For instance, in a prospective, observational cohort study to examine the association of cognitive function with the risk of incident mobility challenge and the rate of declining mobility in 1,154 ambulatory, community-dwelling older persons, Buchman et al. (2011) found that cognition was associated with occurrence of mobility challenge and mobility decline. Mobility was assessed by asking participants to walk eight feet and turn around and measured by the time and number of steps taken on each task. They then asked participants to stand on each leg for ten seconds and used scores ranging from 0–5 (0 was given to those unable

to perform the task) to measure mobility. Cognitive function and clinical diagnoses were assessed using eighteen cognitive tests measuring episodic memory, semantic memory, working memory, perceptual speed, and visuospatial ability.

Alternatively, numerous researchers have suggested that contextual factors are also important determinants of mobility challenge. Mobility challenge in community-dwelling older persons is highly associated with specific individual determinants including older age (Clares, Freitas, & Borges, 2013; Mahant & Stacy, 2001; Pereira, Bastos, Del Duca, & Bos, 2012; Shumway-Cook et al., 2005; Zuccolo et al., 2012), feminine and undifferentiated gender roles (Ahmed, Vafaei, Auais, Guralnik, & Zunzunegui, 2016; Clares et al., 2013; Lagro-Janssen, Wong & Muijsenbergh, 2008; Merrill, Seeman, Kasl, & Berkman, 1997; Verbrugge, 1985, 1989) not having a partner (Clares et al., 2013; Lee & Carr, 2007; Mollenkopf et al., 2004; Pereira et al., 2012), lower education and income (Alves et al., 2010; Andrade, Silva, Galvão, & Pereira, 2015; Clares et al., 2013; Gregory et al., 2011; Idland, 2010; Meireles, Matsuda, Coimbra, & Mathias, 2007), and deficient psychological assets (Alves et al., 2010; Auais et al., 2016; Boyle, Buchman, & Bennett, 2010; Carriere et al., 2011; Delbaere, Crombez, van Haastregt, & Vlaeyen, 2009; Donoghue, Cronin, Savva, O'Regan, & Kenny, 2013; Idland, 2010; Norton et al., 2012; Nunes, Ribeiro, Rosado, & Franceschini, 2009; Rantakokko et al., 2009; Santos, Koszuoski, Dias-da-Costa, & Pattussi, 2007; Sessford, Jung, Brawley, & Forbes, 2015).

Along with the above individually-based determinants of mobility challenge, there are more broad-based determinants that act at the community, population, and national levels. Environmental determinants of mobility challenge are built and created elements (Chen, Matsuoka, & Tsai, 2015; Clark et al., 2009; Clarke & Gallagher, 2013; Cress, Orini, & Kinsler, 2011; Iwarsson & Wilson, 2006; Iwarsson, 2005; Yen & Anderson, 2012), social engagement

(Gardner, 2014), feeling safe (Mollenkopf et al., 2004), and place of living (Melzer & Parahyba, 2004; Mollenkopf et al., 2004). For instance, in a prospective study to observe the relationship between urban-built environment characteristics and mobility challenge of 1,188 older persons, Clarke and Gallagher (2013) found that when older persons have more accessible sidewalks, home-entry conditions, such as a safe front porch or an apartment elevator that works, they were significantly more likely to be more mobile. The authors measured mobility by assessing the number of days the participants went outside in a typical week (range, 0–7).

In one qualitative study, Gardner (2014) tried to understand how neighborhoods – as physical and social environments – influence mobility. The author unveiled that older persons' ability and willingness to move around their neighborhoods were challenged by a myriad of individual and environmental factors that changed from one day to the next. Concerned in particular with the social environment, Gardner (2014) shows how key social factors – social engagement and identity – play a critical role in the community mobility of older persons aging in place.

Before going any further, it is necessary to discuss the general characteristics of mobility and the mobility spectrum. Each activity on the mobility spectrum depends on a preceding one. The stages of rehabilitation and restoration of mobility are cumulative with each activity of the mobility spectrum depending on the attainment of a preceding, less complex skill. Independent sitting is unlikely to occur without the attainment of bed mobility. Independent transfer from bed to wheelchair will not be possible without the attainment of trunk control necessary for sitting. Individuals who do not have the skill or strength required to transfer from one sitting position to another will rarely demonstrate the strength and coordination necessary for ambulation. In the following paragraphs, I briefly describe this progressive movement, which ranges from the

simplest to the most complex movement activity one can perform. The mobility spectrum can be divided into three phases (Stolov & Hays, 2004): 1) bed mobility; 2) breadth of transfer skills, and; 3) travel, of which walking is but one example.

Bed mobility. Raising the head and limbs and turning in bed are the most primitive mobility functions. These functions help to protect individuals from decubitus ulcers, phlebitis, and atelectasis. The ability to rise to a sitting position at the edge of a bed and to maintain a free-standing balance with the back unsupported is next in importance and is necessary to perform transfer skills independently. In addition to the trunk strength required, the supine-to-sit task involves substantial trunk coordination and balance (McGill, 1991; Miller & Medeiros, 1987) as evidenced by the thoracic and spinal musculature recruited for axial rotation (McGill, 1991; Pope, Svensson, Andersson, Broman, & Zetterberg, 1987). Further, leg muscles often supplement trunk muscles in completing trunk flexion past 45 degrees of elevation (Flint, 1965; Miller & Medeiros, 1987).

Descriptions of supine-to-sit movement patterns suggest that the trunk and limbs may or may not move synchronously and usually show left-right asymmetric limb use throughout the rise (Ford-Smith & VanSant, 1993). Age-related and physical impairment-related differences in movement patterns also appear in supine-to-sit movement patterns. Healthier older persons differ from less healthy older persons, with the latter self-reporting rise difficulty in the leg movements used and in the synchronization of trunk and pelvic motions to facilitate rising (Alexander, Fry-Welch, Ward, & Folkmier, 1992). In addition, when comparing healthy older with healthy younger persons, the healthy older differ in how they use either upper limb for support, and are more likely to laterally flex their trunks and use their elbow and hip to achieve a pivot while rising from supine to sitting (Alexander, Fry-Welch, Marshall, Chung, & Kowalski, 1995). Thus,

the interaction (i.e., synchrony and symmetry) of these lower limb, upper limb, and trunk motions determines supine-to-sit performance. Most older persons are unable to maintain the long-sitting position with the knees extended because of tight hamstrings and a relative immobile back.

Breadth of transfer skills. The transfer spectrum includes movements from bed to wheelchair; or wheelchair to toilet, bathtub, shower, or car. The wheelchair-to-bed transfer can be done in two ways: 1) by a standing-pivot transfer, or; 2) by a sliding transfer. In the standing-pivot transfer, the individual slides to the edge of the chair, places the feet under him or her, leans forward, and pushes on the arms of the chair to rise to a standing position. The individual then pivots on his or her legs – usually about 90 degrees – before sitting again.

In the sliding transfer, the individual removes one armrest from the wheelchair, pushes downward with one hand on the other armrest and one in the bed, and then slides sideways off the chair onto the bed. The individual will be highly dependent if he or she can do only a sliding transfer and if the wheelchair does not have removable arms. Transfer is facilitated when the bed and chair heights are equal (about 20 inches from the floor), while the likelihood of a successful sliding transfer is reduced if these heights are unequal (Stolov & Hays, 2004). Skill in transfers is assured when the individual has free-sitting balance and good strength in the shoulder depressors and elbow extensors in at least one upper extremity. Either transfer technique may be used when strength of knee extensors and hip is insufficient, or when severe hip and knee joint flexion contractures are present.

Travel. In travel mobility, an individual may require standby, partial physical, or total physical assistance in bed mobility and transfer skills but be independent in travel skills. Free-standing balance is necessary before walking can be considered a realistic goal. Predicting an

individual's ability to master free-standing balance is based on the combined effect of several deficits of sensory and motor function. These include functional deficits of the following: 1) all afferent stimuli (i.e., visual, kinesthetic); 2) vertical perception; 3) sensorimotor coordination; 4) motor strength, and; 5) learning potential. Whether or not an individual can attain standing balance cannot usually be predicted until after at least a 2-week trial of daily training, and progress has been evaluated after sitting balance is achieved (Stolov & Hays, 2004).

Loss of full passive range of motion in the hip and knee extension or ankle dorsiflexion may contribute to the inability to attain standing balance. With loss of hip extension range of motion (such as seen in hip flexion contracture), the force of gravity falls anterior to the hip joint and requires active contraction of the hip extensor muscles. With loss of the knee extension range of motion, the force of gravity is posterior to the knee joint, requiring forceful quadriceps contraction to maintain standing balance. Quiet standing is possible using little muscle strength if the center of gravity can be carefully balanced with the hips and knees extension. Human quiet stance is often modeled as a single or double-link inverted pendulum pivoting only around the ankle joints in the sagittal plane (Sasagawa, Kanehisa, Ushiyama, & Kouzaki, 2009). The control of human biped stance and balancing are relatively simple prototypes of posture and movement control in general. The simplicity is mainly owing to the fact that the physics of the body sway resembles that of a single or double inverted pendulum. Clinically, postural control is often equated to equilibrium control of stance (Thomas, 2012).

Muscle strength may be lost as a consequence of atrophy associated with bed rest and illness (Arentson-Lantz, English, Paddon-Jones, & Fry, 2016; LeBlanc et al., 1997). Joint contractures, defined as limitation in the passive range of motion of a mobile joint, may also occur during long periods of immobility (Trudel, Zhou, Uthoff, & Laneuville, 2008; Wong,

Trudel, & Laneuville, 2015), and will thus have to be addressed prior to successful retraining of ambulation. In order to assure early ambulation, specific exercises should be implemented to increase knee extension strength, including quadriceps femoris and gastrocnemius-soleus to maintain better upright support with knees in extension.

Yet, a person's mobility is, in the broadest sense, dependent not only on her or his basic intrinsic abilities, but also on his or her health condition; body functions and structures; participation; and contextual factors. The following section is a discussion of mobility in view of the International Classification of Functioning, Disability and Health (World Health Organization, 2007) to observe the interaction of health conditions and contextual factors on mobility of older persons.

Mobility and the International Classification of Functioning, Disability and Health

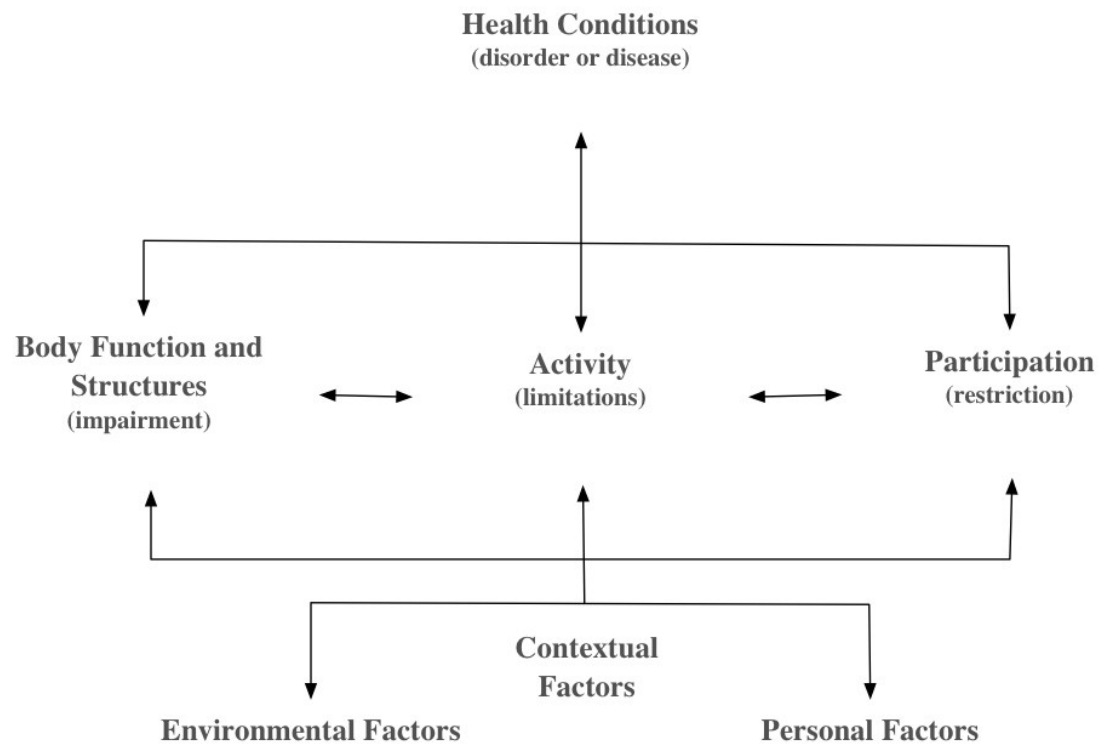
Mobility is defined as the ability to move safely from one place to another (Lin et al., 2017). This definition, in part, mostly describes an activity. However, to address the individual's need for independent and functional mobility, the concept of mobility must be broadened to encompass all dimensions influencing an individual's movement from one place (or position) to another. It is important to discard the concept of activity as the sole dimension of mobility. Even nondisabled individuals do not rely solely on the dimension 'activity' for movement from one place to another.

Within the International Classification of Functioning, Disability and Health (World Health Organization, 2007), mobility influences and is influenced by determinants within different dimensions, such as health conditions, body functions and structures, participation, and contextual factors (i.e., environmental and personal factors) (Figure 1). Thus, mobility challenge is a health outcome within the person – environment sphere contributing to the functioning –

disability continuum. The functioning – disability continuum is a dynamic interplay between the individual's capabilities and the demands of the environment, and how these interact to affect the level of activity and participation in a social world (Altman, 2001; Verbrugge & Jette, 1994). Still, disability is not a characteristic of an individual, nor is it an unavoidable outcome of particular health condition. It is rather a point of the human experience in the functioning – disability continuum. Consequently, disability occurs when difficulty in functioning at the body, person, or societal levels, in one or more life domains, is experienced by an individual with a health condition in interaction with contextual factors (World Health Organization, 2007).

Therefore, in a broader perspective, mobility challenges impact the functioning – disability continuum and, at the same time, is impacted by other health outcomes, such as impairments in body functions and structures, and participation restrictions. In turn, these three interrelated health outcomes, (impairments to body functions and structures, activity limitations, and participation restrictions) are all influenced by contextual (personal and environmental) factors (World Health Organization, 2007).

Figure 1. International Classification of Functioning, Disability and Health and Mobility



Note. Adapted from the World Health Organization (2007). *International Classification of Functioning, Disability, and Health*. Geneva: World Health Organization. Available from: <http://www.who.int/classifications/icf/en/>

The following section is the description of the dimensions of the International Classification of Functioning, Disability and Health and its relation to mobility. To better contextualize mobility in the study setting, I retrieved literature that employed different terms and variables to refer to determinants of mobility within the Brazilian context. These terms were: mobility, functional capacity (disability), and activities of daily living. This decision relies on different reasons, all related to the linkage between these three variables.

First of all, in Brazil (and in many other places) mobility has been considered within the context of functioning and disability by means of local and national health surveys (Alves et al., 2008a; Barbosa, Almeida, Barbosa, & Rossi-Barbosa, 2014; Ferreira-Agreli, Dias, Santos-Ferreira, Gomes, & Santos-Tavares, 2017). Functioning and disability are seen in terms of maintenance of autonomy (Lima-Costa et al., 2003), therefore, the inability or difficulty of the individual to perform basic or more complex physical tasks in some domain of life. Thus, the indicators preferentially used among authors and universally accepted in the literature to assess functioning and disability are (basic and instrumental) activities of daily living, and mobility (Alves, 2008). However, in many cases, in order to evaluate the context of functioning and disability, mobility is observed under the umbrella of activities of daily living – in opposition to observing these as two different insignias. This is due to mobility's level of intermediate complexity situated in between basic and instrumental activities of daily living (Alves et al., 2008a). That means that when mobility refers to the ability to move around, it has been measured through a hierarchical approach using activities of daily living. Thus, mobility challenge may be indirectly observed by the inability to perform basic and instrumental activities of daily living, such as taking a shower (or going to the toilet) and shopping (or answering the telephone), respectively (Guralnik et al., 1996).

This conceptual connection is substantiated by different studies. For instance, in research to investigate elements comprising the significance of disability for Brazilian older persons, Pereira, Firmo, and Giacomini (2014) found two themes linked to mobility: a) inability to pursue activities, and b) being a burden to the family. It is interesting to note that women frequently linked disability to being unable to pursue domestic activities, such as making food or washing clothes; and men mostly linked functionality to being able to work. As a 62 year old, man mentioned: *“because I do not walk, I am not able to work. I worked for 22 years and now I’m retired”* (Pereira et al., 2014, p. 3378). It is also interesting to observe that, in this same study, participants mentioned that ‘being a burden to the family’ was connected to mobility. This is exemplified by a 65 year old, man who says: *“I’m not afraid of death, if one says: you are going to die tomorrow, no problem. I’m afraid of, for example, [...] if I fall into a bed and cannot walk ... then I’m afraid to be a burden to others. It is preferable that we die”* (Pereira et al., 2014, p. 3381).

All considered, intrinsically related variables such as ‘physical mobility’ and ‘activities of daily living’ are employed to assess the bigger picture of the population’s ‘functional capacity’. Mobility, in turn, is defined as a category and an indicator of functional capacity, which is usually observed within the context of activities of daily living. Consequently, some researchers are able to observe mobility by focusing on two domains: overall functional capacity and ability to engage in activities of daily living, which makes it important to observe mobility when these are the only available perspectives.

Mobility as an Activity

Activity is one of the dimensions of the International Classification of Functioning, Disability and Health Framework, and is linked to the ability of an individual to execute a task or

action (e.g., standing up from a chair). Activity limitation occurs when there are problems at the level of individual capacities (Bickenbach, 2012, p. 56). This dimension, therefore, is perceived as comprising the integrated use of body functions in an intentional way to accomplish the individual's life tasks. The focus of the activity dimension is on the concrete limitation of the individual's performance in everyday life. These activity limitations can involve the individual's elementary or complex physical functions that require physical and mental competence, such as putting on a shoe and driving. The activity limitation which is the focus of this study is mobility challenge, which can be exemplified by transferring from one place to another, standing up from a chair and sitting down on a chair.

According to researchers' findings, functional disability is common in Brazil, affecting four of every ten adults (K. R. C. Andrade et al., 2015). Brazilian older persons, particularly, have a high chance of having functional disabilities (K. R. C. Andrade et al., 2015), with prevalence rates of functional disability in basic and instrumental activities of daily living of 16% and 26%, respectively (Giacomin, Peixoto, Uchoa, & Lima-Costa, 2008; Pereira et al., 2012).

In 2008, for the first time in Brazil, the National Household Sample Survey (PNAD) included questions related to functional disability to identify respondents' degree of dependence and the impact that other variables can generate on their functional capacity (Parahyba, Veras, & Melzer, 2005). To assess functionality, researchers employed a Likert-type scale in the survey with a set of seven questions measuring the degree of difficulty encountered by respondents in carrying out the following tasks: 1) eating, bathing or going to the bathroom without help; 2) pushing tables or performing household repairs; 3) stooping, kneeling or bending; 4) walking 100 meters; 5) running, lifting heavy objects, playing sports or doing heavy lifting; 6) climbing

uphill or on a ladder, and; 7) walking more than 1 km (Instituto Brasileiro de Geografia e Estatística, 2008). In response to each of these tasks, respondents were given the following options: 1) I am not able; 2) I have great difficulty; 3) I have some difficulty; 4) I have no difficulty.

In regard to the most basic activities of daily living, such as the ability to eat, bath or go to the bathroom without help, it was estimated that for the population aged 60 years and over, 15% had difficulty performing the most basic activities of daily living. The percentage of women with some difficulty (5.2%) was higher than among men (3.8%). Concerning the activities of pushing tables or performing household repairs, it was estimated as the age increased, the percentage of individuals with some difficulty increased. For the population aged 60 years and over, the proportion of those who had some difficulty performing the tasks of this group reached 46.9%.

In reference to the activities of stooping, kneeling or bending, it was revealed that as the age increased the percentage of individuals with some difficulty with stooping, kneeling or bending also increased to 53.9% of older persons aged 60 years and over having some difficulty performing these tasks. In respect to the activity of walking 100 meters, it was revealed that as the age increased the percentage of individuals with some difficulty when walking 100 meters increased to 27.0% of older persons aged 60 years and over having some difficulty when walking 100 meters.

Therefore, when a comparison of the overall prevalence of mobility challenge between older persons from Brazil and more developed countries is made, it is observed that both populations present similar numbers. National surveys in the United States of America showed that 46% of respondents who were over 65 years of age reported having ‘challenged mobility’.

Similarly, in Brazil, these numbers reached 53.9%. This similarity can be assumed to be related to different factors, many of which related to the inherent commonalities of the aging process.

Participation and Mobility

Participation is another dimension influencing mobility in the functioning – disability continuum. Mobility challenges can also undermine the individual's ability to participate in a wide range of activities. 'Participation' is the involvement in everyday life situations (World Health Organization, 2007), which is defined as the sum or course of human events and activities. Participation implicates judgment about the extent that an activity limitation influences the individual's ability to participate in life situations in comparison with an individual without activity limitation. It can be observed as the individual's involvement in "activities that are intrinsically social and occur in societally-defined contexts" (Chang & Coster, 2014, p. 1792). Societal involvement has been conceptualized as a continuum including 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, 5) helping others, and 6) contributing to society (Chang, Coster, & Helfrich, 2013; Levasseur, Richard, Gauvin, & Raymond, 2010).

Challenged mobility adversely impacts participation in one's personal and social life and may involve: a) community activities, such as participation in leisure, volunteer, religious and civic activities (Sundar, Brucker, Pollack, & Chang, 2016); b) activities that are productive, such as participation in education, employment or homemaking activities, and; c) activities that are part of the social domain and have been classified as structured or unstructured (Chang & Coster, 2014). Limited participation in any of these areas can diminish fulfillment of social roles, having

a negative impact on individual well-being and quality of life (World Health Organization, 2007).

Particularly in Brazil, researchers showed that functional disability is linked to poor participation. In a study with 1,995 Brazilian, community-dwelling older persons aged 60 years and older, Gontijo, Mambrini, Luz, and Loyola Filho (2016) reported that older persons with functional disabilities (self-reported difficulty of performing basic and instrumental activities of daily living) had higher odds of poor participation (self-reported low social capital measured by four indicators: neighborhood safety, perception of the physical environment, sense of cohesion in the neighborhood and perception of assistance from neighbors) (OR = 1.80; 95%CI 1.12 – 2.88).

Similarly, in a study with 2,344 adults (65 years and older) in United States of America, Norstrand and Chan (2014), reported a significant association of participation (self-reported social capital measured by five indicators: neighborhood trust, neighborhood support, neighborhood cohesion, neighborhood participation, and telephone interaction) with health outcomes (self-rated health, basic and instrumental activities of daily living). For example, for the health outcome self-rated health, neighborhood cohesion improved health among the young-old (65–74 years) (OR = 1.31, $P < 0.05$), while neighborhood trust (OR = 1.87, $P < 0.001$) and neighborhood participation (OR = 1.14, $P < 0.05$) improved health among the middle-old (75–84 years). For the middle-old, respondents who reported greater neighborhood trust (OR = 0.63, $P < 0.05$) and neighborhood participation (OR = 0.74, $P < 0.05$) were around 30% less likely to have an activity of daily living limitation. In terms of instrumental activity of daily living limitations, the oldest-old group (85+ years) with more neighborhood cohesion were 50% less likely to have an instrumental activity of daily living limitation (OR = 0.45, $P < 0.05$). On the other hand, those

who were 85 and older who reported higher levels of neighborhood trust were twice as likely to report an instrumental activity of daily living limitation (OR = 2.00, $P < 0.05$).

Therefore, when the relationship between mobility and participation in Brazil and North America is made, most participation indicators remained significant for older persons in both places. In view of this similarity, it can be assumed that positive mobility, independent of place, is paramount to older persons participation in socially-defined contexts, i.e., within the community setting, by means of strong community ties. It can be also argued that the dimension of participation might be particularly important for older persons due to their increasing physical frailty and reduced social networks (Nygqvist, Gustavsson, & Gustafson, 2006).

Body Function and Structures and Mobility

Mobility challenges can also be influenced by ‘body functions and structures’, which are represented by changes in physiological systems or in anatomical structures. In the International Classification of Functioning, Disability and Health (World Health Organization, 2007), ‘body functions and structures’ are conceptually linked to ‘impairment’, which is identified as “problems (deviation or loss) of body functions and structures associated with health conditions (disease or disorder)” (Bickenbach, 2012, p. 56). Therefore, impairment of ‘body functions and structures’ is seen as a deviation from traditionally assumed population parameters in the biomedical status of the body and its functions, and defining the constituents is undertaken primarily by those qualified to judge physical and mental functioning according to these standards.

This study does not include any physical assessment and data from patients’ charts; however, in accordance with the International Classification of Functioning, Disability and Health framework (World Health Organization, 2007), it recognizes that mobility challenges may

emerge from all body structures of lower extremities related to movement (e.g., structure of thigh, leg, ankle, foot), body functions related to neuromusculoskeletal and movement-related functions of lower extremity joints, bones, reflexes and muscles (e.g., mobility and stability of joint functions, muscle tone and power functions, motor reflex functions, and gait pattern functions), as well as cognition. The rationale for this relies on the fact that mobility challenges can cause detrimental health effects in the musculoskeletal system, and one's mobility challenge can arise from an array of different pathologies affecting the lower neuromusculoskeletal system.

For the skeletal and voluntary muscles, reduced mobility may result in muscular atrophy and a quick loss of strength and mass in the postural muscles of the back, legs and arms (Nigam, Knight, & Jones, 2009). Initially, muscles in the lower limbs, which typically resist gravitational forces, become debilitated. Skeletal muscles lose tone when the lower limbs no longer bear weight. In general, extensor muscles (such as the quadriceps femoris at the front of the thigh), which have a prime postural role, atrophy to a greater extent than flexor muscles (such as hamstrings). Decline in mobility and use of the muscles lead to atrophy and weakening of muscle strength at a rate of around twelve percent a week, and after three to five weeks of immobility, a good part of the normal strength of a muscle is lost (Jiricka, 2008).

When muscles are not properly used, they shorten. Intervention aiming at early motion may prevent muscle atrophy. However, atrophy of the quadriceps muscle (which may occur for example through the forced immobility due to a hip surgery) cannot be reversed through the use of isometric exercises (where joint angle and muscle length do not change) (Lorenz & Campello, 2012). It takes about four weeks to recover from atrophy caused by reduced mobility (Halar, 1994). Muscle strength can be maintained without loss or gain with daily muscle contractions of

20% or more of maximal tension for several seconds each day (Dittmer & Teasell, 1993). Disuse weakness is reversed at a rate of 6% per week with exercise (Nigam et al., 2009).

In addition, this loss of muscle mass precipitates decreased endurance levels through reduced muscle strength, metabolic activity and circulation, which, in turn, makes moving around even more difficult for the individual causing a sense of fatigue (Nigam et al., 2009). All this may affect the individual's motivation and lead to a vicious cycle of greater inactivity and muscle loss (Dittmer & Teasell, 1993). Proper balance, which is necessary to walk and prevent falls, also worsens when muscle weakness occurs. Joints that are not moved become tight and may develop contractures, reducing their function and range of motion.

In only 1-2 weeks of poor mobility, bone density begins to decrease, increasing the risk of osteoporosis and fractures. Maintaining normal bone function osteoblasts, which are responsible for building the osseous matrix of bone, depend upon the stress of mobility and weight bearing to perform their function (Nigam et al., 2009). Thus, during poor mobility and immobility, the process of building new bone decreases. Additionally, osteoclasts, which are responsible for breaking down existing bone matrix, still break down bone, resulting in a loss of bone density, leaving the bone structure soft and weak (Nigam et al., 2009). Even ordinary forces such as those encountered during wheelchair transfers, physical therapy activities or minor falls may cause fractures (Wisdom, Delp, & Kuhl, 2015). In postmenopausal women, bone loss is particularly rapid in the femoral neck, increasing the risk of fracture (Pacifci & Avioli, 2000).

Health Conditions and Mobility

Although “health condition” is not presented as a structured concept in the International Classification of Functioning, Disability and Health framework, it denotes the etiological base of the framework encompassing disabilities, diseases, disorders and injuries based on the

International Classification of Diseases (ICD) (World Health Organization, 2007, p. 3). The International Classification of Functioning, Disability and Health framework and the ICD are both part of the World Health Organization Family of International Classifications and are complementary when stipulating a wider and more meaningful picture of the experience of health of individuals and populations. That is, in the International Classification of Functioning, Disability and Health framework, health condition is generally assessed separately, though in a complementary manner, using the diagnosis of health conditions as classified in the ICD.

In this study, the health conditions included any disease or disorder that may impact mobility, e.g., stroke, traumatic brain injury, dementia, post-total hip replacement procedure, muscular dystrophy, or frailty. Age-related changes are also associated with challenged mobility, as for example sarcopenia (Buchner, 1997), reduced leg strength and reduced musculoskeletal functioning (Greve, Zijlstra, Hortobagyi, & Bongers, 2013), poorer coordination (Srisupornkornkool, 2014) or decreased postural balance, and reduced cardio-respiratory functioning (Rantanen, 2013) highly influences mobility. The most common health conditions affecting mobility are presented below. Please note these examples are not exhaustive and only include some of the most common health conditions affecting mobility. Common characteristics of mobility-challenged individuals include deficits in fine and gross motor functioning, with stiffness, spasticity, and/or loss of muscle strength.

Motor impairment is a common consequence of stroke (Wade, 1992), which usually affects the control of movement of the face, arm and leg on one side of the body (Warlow, 2008) and is seen in about 80% of patients (Pollock et al., 2014). Almost two-thirds of individuals in the post stroke phase have initial mobility deficits (Shaughnessy et al., 2005), and six months

after a stroke, more than 30% of survivors still cannot walk independently (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002; Patel, Duncan, Lai, & Studenski, 2000).

Individuals who suffered moderate to severe traumatic brain injury also present physical impairments (Haffejee et al., 2013). The main physical impairments that may potentially contribute to mobility limitations after traumatic brain injury include balance (Englander et al., 1996; McFadyen, Swaine, Dumas, & Durand, 2003), spasticity (Dumas, Haley, Ludlow, & Carey, 2004; Fock, Galea, Stillman, Rawicki, & Clark, 2004), contracture (Keenan, Mayer, Esquenazi, & Pelensky, 1999), muscle strength (Englander et al., 1996; Williams, Morris, Schache, & McCrory, 2010), and motor skill level (Dumas & Carey, 2002; Swaine & Sullivan, 1996) impairments.

Impairments in cognition and mobility are often related, that is, impairment in one is related to accompanying impairment in the other (Tolea, Morris, & Galvin, 2016). In contrast to cognitively “normal” individuals, older persons with cognitive impairment (Gure, Langa, Fisher, Piette, & Plassman, 2013) are inclined to perform poorly on mobility tests (Binder, Storandt, & Birge, 1999) and to report higher levels of disability (Ferrucci et al., 1993). Findings supporting this relationship are provided by evidence that dementia represents a major cause of functional dependence likely surpassing the effect of other risk factors (Aguero-Torres & Fratiglioni, 1998). In addition to cognitive impairment, individuals with dementia may undergo prominent non-cognitive symptoms (e.g., extrapyramidal signs, weakness, motor-neuron disease, apathy), which may further negatively impact mobility.

Frailty is a state in which a person does not have reserve capacity to overcome adverse events such as illness or injury, and precedes disability in activities of daily living (Fried et al., 2001; Rodriguez-Manas et al., 2013). Frailty and pre-frailty defined according to the frailty

phenotype-describing functional deficits in five areas have been associated with increased risks for falls (Fried et al., 2001) and older persons with higher levels of baseline physical frailty have more restrictions in mobility (Portegijs, Rantakokko, Viljanen, Sipilä, & Rantanen, 2016).

Contextual Factors and Mobility

‘Contextual factors’ represent a comprehensive background of one’s life. Contextual factors include ‘personal factors’, reflecting on an individual’s specific characteristics, and ‘environmental factors, reflecting the physical and material features of the person’s surroundings. They also include the accessible formal and informal social structures and services in the community, and the systems established in a culture. Personal factors are not classified in the International Classification of Functioning, Disability and Health framework. Environmental factors are organized in the framework and include individual environments (home, workplace, and school), service systems available in the community, and cultural systems (including laws as well as attitudes) (Altman, 2001). Therefore, contextual factors coupled with health conditions or impairments may yield disabilities reducing the individual’s mobility and social participation.

Personal Factors Influencing Mobility

Personal factors are the distinctive background of an individual’s life and living, including characteristics of the individual that are not part of a health condition or health states, and which can impact functioning positively or negatively (Grotkamp, Cibis, Nuchtern, von Mittelstaedt, & Seger, 2012). These factors may include age, gender, ethnicity, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level (World Health Organization, 2007, p. 15).

In Brazil, studies were performed to analyze the influence of contextual factors on older persons' functional disability (Alves, 2008; Alves et al., 2008a; Alves, Leite, & Machado, 2008b, 2010; K. R. C. Andrade et al., 2015; Brito, Menezes, & Olinda, 2015; Duca, Martinez, & Bastos, 2012; Ferreira-Agreli et al., 2017; Fiedler & Peres, 2008; Giacomini et al., 2008; Guerra, Alvarado, & Zunzunegui, 2008; Nunes et al., 2017; Parahyba & Simões, 2006; Parahyba, Stevens, Henley, Lang, & Melzer, 2009; Pereira et al., 2012; Rosa et al., 2003; Silva, Scazufca, & Menezes, 2013). In these studies, functional disability was the dependent variable measured by: a) mobility measures, using performance tasks such as difficulty walking 100 meters and difficulty climbing stairs, or b) difficulty performing basic and instrumental activities of daily living, using instruments such as Katz index or Lawton and Brody Scale. These authors found that at the personal level, older age, female sex, widow or single marital status, lower level of schooling, lower income, occupation, chronic diseases, and lower self-perception of health are the factors that are most strongly related to functional disability. The following is a description of each of these personal determinants of mobility.

Age. Older persons are living longer than their predecessors of just a few generations ago (He, Goodkind, & Kowal, 2016). Currently the group of older persons occupies a significant space in Brazilian society. In the period from 1999 to 2009, the relative percentage of older persons (60 years and older) increased from 9.1% to 11.3% (Instituto Brasileiro de Geografia e Estatística, 2010a). It follows that the chance of older persons having functional disabilities increases with age: it almost doubles for every decade of life lived ($p < 0,001$) (Pereira et al., 2012; Zuccolo et al., 2012). At age 60, Brazilian men can expect to live another 19 years: 39% with mild, 21% with moderate, and 14% with severe functional disability, respectively. At the

same age, Brazilian women can expect to live another 22 years with 56% experiencing mild, 32% moderate, and 18% severe functional disability (Camargos, Machado, & Rodrigues, 2008).

Studies involving older persons have identified a direct correlation between getting older and a decline in balance control (Baudry, 2016), muscle strength and mass (Klitgaard et al., 1990; Lindle et al., 1997). All these changes contribute to the prevalence of mobility challenges in older persons (Gabriel & Bowling, 2004). Mobility challenges, in turn, play a significant role in the pathogenesis of frailty and functional impairment contributing to several disease processes (Peterson, Rhea, Sen, & Gordon, 2010). In older persons, mobility challenges are predictors of falls, hospitalization, disability and mortality (Brach, Rosano, & Studenski, 2009; Den Ouden, Schuurmans, Arts, & Van der Schouw, 2011; Legrand et al., 2014; Volaklis, Halle, & Meisinger, 2015), suggesting that older persons who already have mobility challenges are likely to suffer greater adverse effects of aging.

Biological sex. Sex differences in function and mobility among older persons are well described (Alves et al., 2010; Barbosa et al., 2014; Brito et al., 2015; Merrill et al., 1997), but debatable (Rodrigues, Facchini, Thumé, & Maia, 2009). In Brazil, within the older adult population, women are the majority (55.8%) (Instituto Brasileiro de Geografia e Estatística, 2010a) and most studies show that being a woman is associated with significantly higher functional disability in basic activities of daily living (Alves et al., 2010; Fiedler & Peres, 2008; Parahyba et al., 2005). It is known that women usually report more functional problems than men (Lagro-Janssen et al., 2008). This association of sex and functional disability for women is possibly related to the fact that they present a higher prevalence of non-fatal disabling conditions with longer longevity, such as hypertension and diabetes, making women more susceptible to

functional disabilities in basic activities of daily living (Camargos, Perpétuo, & Machado, 2005; Pereira et al., 2012).

This relationship of being a woman and functional disability has been corroborated by research. In a study substituting women's mortality rates with men's mortality rates, researchers detected a greater impact on the survival difference than in the difference between sexes in the prevalence of functional disability (Leveille, Penninx, Melzer, Izmirlian, & Guralnik, 2000), suggesting the likelihood of higher incidence of functional disability among older women as compared to men. Meanwhile, research on the incidence of functional disability in older men and women has shown conflicting results, with some studies indicating higher incidence in women (Alves et al., 2010; Barbosa et al., 2014; Brito et al., 2015), others in men (K. R. C. Andrade et al., 2015), and still others with no difference between the sexes (Guerra et al., 2008; Oman, Reed, & Ferrara, 1999).

Marital status. In regards to marital status, living without a partner is positively associated with functional dependence (OR = 3,26) (K. R. C. Andrade et al., 2015). Additionally, widows and widowers are three times more likely to present with functional disability when compared to married older persons ($p < 0,001$) (Pereira et al., 2012). This can be linked to the disruptive and difficult role transition that an individual confronts in the face of the death of a spouse (Bradsher, Longino, Jackson, & Zimmerman, 1992). This is corroborated by a study that showed widows and widowers developed greater functional limitation 18 to 48 months after loss of a partner (Lee & Carr, 2007) than those who didn't lose a spouse.

Education and income. In Brazil, the level of schooling of older persons is still considered low: 30.7% have less than a year of education and a little less than 12% live with income per capita of up to $\frac{1}{2}$ minimum wage and about 66% are already retired (Instituto

Brasileiro de Geografia e Estatística, 2010a). On that account, education and income appear to have a protective effect. For example, a study showed that as education and income levels increase, the likelihood of Brazilian older persons being able to carry out activities of daily living also increases ($p < 0,001$) (Fiedler & Peres, 2008). Alves et al. (2010) demonstrated that Brazilian older persons with a net income lower than the minimum wage had an increased probability of being disabled ($p \leq 0.05$). It is important to note that education has a strong influence on health and economic advantages as it promotes access to information and better employment opportunities, opportunity for healthy habits, and access to health services (K. R. C. Andrade et al., 2015).

Chronic diseases. As individuals grow older, the more likely they are to have a chronic disease. In Brazil, this is corroborated by statistics showing that 77.4% of older persons declared having at least one chronic disease (Instituto Brasileiro de Geografia e Estatística, 2010b). From those, only 22.6% of persons aged 60 years and older declared having no disease. For those aged 75 years and older, this proportion drops to 19.7%. Nearly half (48.9%) of the older persons declared having more than one chronic disease and, in the subgroup aged 75 years and older, the proportion reached more than half (54.0%) (Instituto Brasileiro de Geografia e Estatística, 2010b).

In Brazil, chronic diseases have a strong impact on older persons' functional capacity (Muszalik, Kędziora-Kornatowska, & Kornatowski, 2009). Osteoporosis, hypertension, chronic obstructive pulmonary disease, and diabetes mellitus are the most frequently experienced health problems in older Brazilians (Li, Ford, Zhao, & Mokdad, 2009). This is corroborated by the last census performed in 2010, where it was shown that among chronic diseases, hypertension is the most prominent in all subgroups of older persons, with proportions reaching 50% (Instituto

Brasileiro de Geografia e Estatística, 2010b). Diseases like spine (or back) pain and arthritis or rheumatism appear, too, among persons aged 60 years and over: 35.1% and 24.2%, respectively. These chronic diseases are consistently associated with a higher prevalence of functional disability and mobility limitations (Cornoni-Huntley, Foley, & Guralnik, 1991; Kriegsman, Deeg, & Stalman, 2014).

It is worth noting that according to the national census, the number of diseases reported by respondents increased with age (Instituto Brasileiro de Geografia e Estatística, 2008). Up to the age of nineteen, the percentage of respondents who reported having three or more diseases was close to zero, for the 50-64 years age group, it increased to 17.1%, and for those 65 years of age or older, it reached 28.3%. For this last age group, considering only women, this percentage increased to 33.3%.

Self-perception of health. In addition to chronic diseases, older persons' self-perception of health is associated with functional disability. The probability of functional disability is higher for the older persons who rate their health as poor (Alves et al., 2010; Nunes et al., 2009). This is corroborated by Rosa et al. (2003) who found that individuals who have a poorer perception of their health are nine to eleven times more susceptible to moderate and severe dependence. It follows that the self-perception of health status is associated with functional disability and reflects an integrated perception of the individual, which includes the biological, social and psychosocial dimensions (Santos et al., 2007).

In the last census, 77.4% of Brazilian older persons declared having chronic diseases, while 45.5% declared their health condition as very good or good (Instituto Brasileiro de Geografia e Estatística, 2010b). Only 12.6% said they had poor health or very poor health, of which the majority were older persons aged 75 and older, of Black or Pardo ethnicity, living with

family income up to half of minimum wage. To such a degree, these data show that precisely those with an expected profile of greater vulnerability have, in fact, a perception of their health status as bad or very bad (Instituto Brasileiro de Geografia e Estatística, 2010b).

Ethnicity/race. Regarding ethnicity (i.e., skin color or race), the last census performed in 2010 showed that Brazil had a population of 191 million, of which 91 million were classified as White (47.7%), 82 million as Pardo (43.1%), 15 million as Black (7.6%), 2.1 million as Yellow (1.1 %), and 764,000 as Indigenous (0.4%). In addition, the majority of older persons self-declared themselves as Whites (55.4%) (Instituto Brasileiro de Geografia e Estatística, 2010b).

In Brazil, the National census is performed by the Brazilian Institute of Geography and Statistics – IBGE, and is responsible for getting data of Brazilians self-declared ethnicity. They offer the following five options: White, Black, Yellow (i.e., East Asian), *Pardo* (i.e., a Portuguese word that encompasses various shades of brown from different ethnic miscegenation), and Indigenous (i.e., Native or Aboriginal). For a better socio-historical comprehension of the construction of ethnicity/race in Brazil, please refer to the government document:

‘Características étnico-raciais da população: classificações e identidades’ from the Instituto Brasileiro de Geografia e Estatística (2013b).

It follows that, in Brazil, there is a significant relationship between ethnicity and disability regarding activities of daily living (Guerra et al., 2008). In a study with a Brazilian urban population of older persons exploring ethnic inequalities and functional disability, Guerra et al. (2008) showed that the odds of disability were higher among Indigenous older men compared with White and Black men (OR=3.24; IC=95%; $p<0.05$). The odds of disability were lower among Black women compared with White and Indigenous women (OR=0.42; IC=95%; $p<0.05$). However, a different study analyzing the prevalence of disability and associated factors

in Brazilian older persons found that, after adjusting the analysis, disability relating to basic activities was associated with non-White skin color, independent of gender (CI = 95%, $p=0.01$) (Del Duca, Silva, & Hallal, 2009).

These results are correlated to cases found in the United States, where ethnicity is strongly associated with prevalence of disability. Mendes de Leon et al. (1997) showed that Black–White differences are linked to lower socio-economic status in Black respondents compared to their White counterparts. In Brazil, similar results were found showing that among Indigenous people the prevalence of functional disability seems to be at least partially explained by their greater exposure to disadvantages during the life course, compared to Whites (Guerra et al., 2008). In contrast, selective mortality among older Black women may account for the lower odds of disability among Black and *Pardo* groups.

Environmental Factors Influencing Mobility.

Within the International Classification of Functioning, Disability and Health framework (World Health Organization, 2007), the environmental factors dimension describes the structural and social context in which one lives, works, and participates. The structural environment includes all aspects of the physical environment, including all built and created elements, technology, geographic and climate-related features, and all natural elements that one experiences directly. The social environment includes the sociocultural and political elements that constitute one's social environment and other socially “created” circumstances that make up the community, society, or culture in which one participates (e.g. relationships, attitudes, policies, laws, and social and cultural norms, etc.). Thus, from the perspective of the individual, environmental factors describe the context in which one's experience of health is situated, encompassing those phenomena that are specific to a given experience at a particular place and

time (Day, Theurer, Dykstra, & Doyle, 2012). In the next section, I describe the structural and social environment and its relationship to mobility in Brazil.

The structural environment

Within the macro-level of the structural environment, the natural environment and human-made changes to the environment are animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people, as well as, the characteristics of human populations within that environment (World Health Organization, 2007). Concerning the inanimate physical environment, cities emerge as areas where there is great flux in population mobility and favorable conditions for accessibility are fundamental to being able to move safely, especially for persons with mobility challenges.

Several studies describe the association between neighborhood environments and health status and health behaviors (Heath et al., 2006; Khan et al., 2009); many of these studies focus on older persons and the design features and walkability of their neighborhoods (Yen, Michael, & Perdue, 2009). The design of sidewalks and streets is important for the health of older persons. Design features have been documented to be critical for ensuring walkability for accessing services, for physical activity, and for promoting and maintaining social engagement (Fisher, Li, Michael, & Cleveland, 2004; Gao, Fu, Li, & Jia, 2015; Li et al., 2005; Rosso, Auchincloss, & Michael, 2011).

In Brazil, where around 85% of the population live in urban areas (Instituto Brasileiro de Geografia e Estatística, 2010a), a study mapping the environmental barriers for older persons to access healthcare in a city showed lack of traffic lights and lack of well-maintained sidewalks impeded the access of older persons to health services (Almeida, Béda, & Menezes, 2012). Besides the lack of investments in conservation of the existing infrastructure, this problem may

be connected to the change in goals and investments regarding the urban infrastructural planning in the last decades.

In Brazil, there has been a steady increase in the use of cars, which is evidenced by a continuous increase of cars *per capita* over the years. According to the National Association of Public Transport (Agência Nacional de Transportes Públicos, 2001), in 1970 there were 30 inhabitants per car, in 1990 this rate increased to 9 inhabitants per car, in 1995 this rate increased even more: 6 inhabitants per car, reaching 4 inhabitants per car in 2015. As a consequence of this increase, there was a demand for better road infrastructure in the major centers, which influenced public administrators to invest more in infrastructure for motor vehicles in the urban spaces. It further neglected spaces for non-motorized vehicles, which ultimately lead to a significant worsening for movement of non-motorized transport because of narrowing sidewalks to widen the lanes and increasing the exposure of the pedestrian to the risks of crossing roads (Godim, Azevedo Filho, & Porto Filho, 2001).

This information is corroborated by Carvalho (2006) who notes that, in practice, what has been observed is a large number of pedestrians using very precarious roads, which have irregular sidewalks, deteriorated shoulders, and sidewalks blocked by parked cars. Sidewalks or public walkways are basic components of a road and their main function is to ensure adequate conditions for pedestrian movement. However, on the sidewalks of many Brazilian cities, one may encounter superficial defects, insufficient widths, unnecessary ramps, fixed obstacles and poorly trimmed vegetation, which can compromise the functionality of such infrastructures.

Conversely, within the micro-level of the structural environment, the home environment is the primary context in which older persons move about, perform daily activities and participate in social life. Accessible and well-designed dwellings support continued

independence at old age, which is associated with positive health outcomes (Mahler et al., 2014; Wahl, Fange, Oswald, Gitlin, & Iwarsson, 2009). The conditions and characteristics of the built environment are therefore important to mobility. Housing environments that hinder mobility, performance of daily tasks, and participation in social life have negative health consequences, particularly for the older segment of the population (Granbom, Iwarsson, Kylberg, Pettersson, & Slaug, 2016).

The social environment.

Support and relationships are an important part of the social environment. Support and relationships come from individuals or animals who provide practical physical or emotional support in the form of nurturing, protection, assistance and relationships to other persons. This support and relationship occurs in homes, places of work, in schools or at play and in other locations where daily activities occur (World Health Organization, 2007). In regard to mobility, family structure plays an important role. In a study conducted in Europe comparing the prevalence, incidence and recovery time from disability among older persons living in the community, it demonstrated that social ties function as a protective factor from disability in old age (Zunzunegui et al., 2005). In addition, when the incidence of disability is considered, family ties have higher protective effects than non-family ties (Giacomin et al., 2008). In Brazil, it is observed that living alone is associated with higher levels of functional disability in older persons (Pilger, Menon, & Mathias, 2013). Nonetheless, in Brazil, only 15.7% of older persons live alone (Instituto Brasileiro de Geografia e Estatística, 2010b); 24% of older persons live with a partner, 38.3% live with their children, 10.2% live with a family member who is not their child, and 11.8% have a different arrangement than the ones previously mentioned.

Conversely, merely 1% (84,000) of older persons live in nursing homes (Camarano & Kanso, 2010). This fact can be attributed to the historical roots and cultural norms. In Brazil, the first nursing homes emerged as Holy Houses of Mercy (*Santa Casas da Misericórdia*), which are charities disseminated by the former Portuguese Empire in the colonial era. These charities are linked to the Catholic Apostolic Roman Church's brotherhood (private origin) and their mission is to assist, treat and support the poor. For a detailed description of the history and impact of the Holy Houses of Mercy, please refer to Franco (2011), Seabra (2008), and Gandelman (2001).

According to Lima (2005) not only the poor benefited from these services, but also the sick, destitute, disabled, outsiders, soldiers, beggars, vagabonds, prostitutes, criminals and sailors. Therefore, until the eighteenth century, all the socially excluded groups were treated in the same way, independent of age. Not until the beginning of the nineteenth century, was there a separation of these groups of people, with older persons being recognized as a unique group. Yet, it was not until the end of the last century that many of these groups were allocated in different institutionalized spaces.

It follows that nursing homes, an institutionalized space for older persons, engendered a place with negative connotation in Brazil, being generally used when referring to the institution of the destitute older person and evoking a negative image of poverty and abandonment (Lima, 2005). This is substantiated by Ribeiro and Schutz (2007), who affirms that nursing homes are an ancient modality that assist older persons outside their family realm, bringing isolation, physical and mental inactivity, and therefore a reduction in their quality of life. Furthermore, in Brazil, nursing homes present a precarious reality; that is, they offer well below the minimum conditions for satisfactory aging (Tomasini & Alves, 2007).

Another inherent part of the social environment is related to health care. Health care for older persons is paramount to preserving older persons' autonomy for as long as possible. Therefore, it should be mentioned that strategies and policies underwent an important reorientation in the early 1990s in Brazil. It began with the implementation of preventive and health promotion actions, through the introduction of the Family Health Strategy in 1994. The Family Health Strategy is responsible not only for prevention actions, but also for the recovery and rehabilitation of more common health problems. This program has multi-professional teams in basic health units, which are responsible for the monitoring of a defined number of families, located in a delimited geographical area. The Survey of Basic Municipal Information (MUNIC, Instituto Brasileiro de Geografia e Estatística, 2009a) states that 5,290 Brazilian municipalities (95.1%), have the Family Health Strategy; that is, this program is widely disseminated among municipalities, with the number of multi-professional teams reaching 31,759. In many Brazilian states, the program covers all the municipalities.

Still, the MUNIC data should be analyzed in conjunction with the information of coverage of the potential target population of the Family Health Strategy. In this sense, the National Household Sample Survey in 2008 (Instituto Brasileiro de Geografia e Estatística, 2008) investigated whether households were enrolled in the Family Health Strategy and whether individuals had health insurance. It found a number of older persons (32.5%) did not have their domicile enrolled in the program, nor did they have private health insurance (Instituto Brasileiro de Geografia e Estatística, 2010b). This vulnerability was observed when older persons had a household income per capita of up to two minimum wages, making up two-thirds of the older adult population without any public or private health coverage. It is noteworthy that, in the State of Rio de Janeiro, 49.1% of older persons, or almost half, were in this situation.

Lastly, policies are also part of the social environment. In Brazil the Law 10,098 (Brasil, 2000) establishes general norms and basic criteria for the promotion of accessibility by persons with reduced mobility. These norms were established to ensure social integration through the exercise of individual and social rights, based on respect for dignity and social justice, in order to enable individuals with physical limitations to access education, health, work, leisure, and social security. Additionally, in the area of health, the Brazilian Constitution guarantees access to health promotion, home visits, differentiated medical care and specific health programs (Brazil Const., 1988), in such a way that these individuals have access to the network of specialized rehabilitation and habilitation services, as well as appropriate treatment in public and private health facilities. However, as mentioned earlier, in reality, the infrastructural or the economic environment do not reach full accessibility and integration.

Thus far, I have used the International Classification of Functioning, Disability and Health (World Health Organization, 2007) to describe what determinants, within the framework dimensions, might be of interest and relevant to the study of mobility challenge in older persons. It is critical to note the importance of identifying and acknowledging intrinsic and sometimes non-modifiable (or hard to change) determinants of mobility challenge, such as older age, gender, lower income, poor structural and social environment, in order to narrow, be better informed, and target groups that will greatly benefit from potential interventions. Along with the above individually-based determinants, the structural and social environments – which are the more broad-based determinants that act at the community, population, and national levels – influence one's culture and social attitudes. It means that all these determinants together are the bedrock for understanding the concepts of health, functioning (or disability), and mobility in a given culture. Societal attitudes refer to prevailing beliefs espoused by and influenced by

governments, cultural orientation, historical background, or other prevailing conditions (Daruwalla & Darcy, 2005).

In the next section, I identify an activity to improve modifiable determinants of mobility challenge. The modifiable determinants of mobility challenge to maintain or improve physical functioning are related to the following International Classification of Functioning, Disability and Health' dimensions: 'health condition', and 'body function and structures'. That is, regarding 'health condition', it was found that physical activity improves one or more mobility functions of older persons after stroke (Allison & Dennett, 2007; Barreca, Sigouin, Lambert, & Ansley, 2004; Barreca, Masters, & Sigouin, 2007; Britton, Harris, & Turton, 2008; Cheng, Wu, Liaw, Wong, & Tang, 2001), brain injury (Canning et al., 2003), diabetes (Pariser, Ann DeMeuro, Gillette, & Stephen, 2010), hip-replacement (Ozdemir & Tosun, 2017), under hemodialysis treatment (Matsufuji et al., 2015), with dementia (Slaughter et al., 2015), and with different conditions affecting the lower limb (Flynn, 2007).

It follows that the negative consequences of these mentioned health conditions may be improved by means of changes in 'body functions and structures', through physical activity. This is substantiated by research results showing that physical activity improves older persons leg strength, power, dynamic balance and functional mobility (Bean et al., 2010; Guadalupe-Grau, Fuentes, Guerra, & Calbet, 2009; Ramsbottom et al., 2004; Whitehurst, Johnson, Parker, Brown, & Ford, 2005) at a rate of 6% a week with physical activity (Nigam et al., 2009). That is, if mobility challenge effects can be reversed with physical activity, the sit-to-stand activity might be a suitable approach to be considered. The following section is an introduction of physical activity and mobility in older persons, as well as the sit-to-stand activity.

Physical Activity and Mobility

The World Health Organization posed the question: “As people are living longer, how can the quality of life in old age be improved? How do we help people remain active and independent as they age? How do we strengthen health promotion and prevention policies especially those directed to older people?” (World Health Organization, 2002b, p. 5). As mobility declines with age (Guralnik et al., 1996) and is associated with changes in sensory, cognitive, and physical functioning (Guralnik & Lacroix, 1992; Salive et al., 1994), it is suggested approaches be used to promote older persons’ ability to perform needed or desired activities in order to improve their quality of life. Four main types of approaches are believed necessary to maintain mobility: cognitive training, educational mediation, physical activity, and changes in lifestyle factors (Motl & McAuley, 2010; Ross et al., 2013).

Grounded on the premise that some determinants of mobility challenges are modifiable and thus, may translate to maintained or improved mobility, the main focus of this study was on a physical activity approach. Based on previous research, physical activity holds promises for maintaining older persons’ mobility (Motl & McAuley, 2010; Ross et al., 2013). Physical inactivity or sedentary behavior appears to intensify the changes in physiologic and structural systems that occur with the aging process (Motl & McAuley, 2010).

Evidence from research has established multiple physical and mental health benefits of physical exercise for men and women over the age of 65 (Kelley et al., 2009; Stathi et al., 2010). These benefits are reflected in positive effects on daily functioning, balance, strength, endurance, flexibility, as well as other health-related factors in older persons (Buchner, Beresford, Larson, LaCroix, & Wagner, 1992; King, Rejeski, & Buchner, 1998). The American College of Sports Medicine gives an overview of the benefits of physical activity for older persons and also offers

directions on the type and the minimum intensity of these activities (Chodzko-Zajko et al., 2009; Nelson et al., 2007).

Although physical activity and exercise are intersecting terms, they are not identical. Exercise refers to planned, structured and repetitive movement aimed at improving or maintaining one or more components of physical fitness (Chodzko-Zajko et al., 2009; Hui & Rubenstein, 2006). Conversely, physical activity is a broad term used to describe all body movement that comprises contraction of skeletal muscles and that increases energy expenditure (Chodzko-Zajko et al., 2009). Everyone performs physical activity in order to sustain life (Caspersen, Powell, & Christenson, 1985). In daily life, physical activity can be categorized into occupational, sports, conditioning, household, or other activities (Landi et al., 2010). In this specific study, when physical activity is mentioned, it focuses on the perspective of activities of daily living, therefore, linked to the concept of being essential for one's living.

It follows that mobility has a level of intermediate complexity situated in between basic and instrumental activities of daily living. Mobility refers to the ability to move around and can be measured through a hierarchical approach, starting with simple tasks such as transferring from the bed to a chair and advancing to more complex tasks such as short and long-distance walking or stair climbing (Guralnik et al., 1996). Mobility is therefore an ideal focus of action in order to assist older persons to maintain activities essential to their living.

Physical Activity and Older Persons

In a study of 91,375 Australians aged 65 and older to determine the strength of the relationship between physical activity (with exercise as a sub-category) and physical function in older persons, Yorston, Kolt, and Rosenkranz (2012) found a positive relationship between physical activity and physical function, with older persons who are more physically active being

less likely to experience functional limitation than their more-sedentary counterparts who were participants reporting no (or 0 minutes of) physical exercise. Measures of physical activity engagement, such as participants' frequency, intensity, duration, and type of activity, were obtained from the Active Australia Survey. Participants self-reported the number of times they engaged in different types of physical activity (leisurely, walking continuously for at least 10 minutes; vigorous, that makes one breathe harder or puff and pant; and moderate, e.g., gentle swimming, social tennis, vigorous gardening, or work around the house) and the hours and minutes spent doing each in the 7 days before questionnaire completion.

Particularly, to mobility challenged older persons, researchers found evidence of positive effects of physical exercise on mobility and physical functioning (Buchner, 1997; Rantanen, 2013). A meta-analysis performed by de Vries et al. (2012) provides an interesting picture of the effect of physical exercise on mobility, physical functioning, physical activity and quality of life for older persons with mobility problems, physical disability and/or multi-morbidity. They found that physical exercise has a significant positive effect on mobility of older persons with mobility challenges when compared with a group not performing exercise, with no difference in the effectiveness of short interventions compared with interventions of longer duration. Additionally, it was observed that there was no difference in effect on mobility between high-intensity exercise interventions and low-intensity exercise interventions. Lastly, when group and individual exercise interventions are compared, both are able to produce positive effects on mobility. Nevertheless, the effect of individual interventions seems to be somewhat larger than the effect of group interventions.

de Vries et al. (2012) meta-analysis did not conclude that one intervention type (e.g., strength training, balance training, functional and task-related training, or endurance training)

was more effective than another. Meanwhile, the best known and widely accepted physical exercise guideline, from the Centers for Disease Control and Prevention and the American College of Sports Medicine, states that older persons benefit from exercises targeting muscular strength and flexibility (Pate et al., 1995). According to this guideline strength and flexibility exercise may contribute to better balance, coordination, and agility, which in turn may help older persons perform needed or desired activities and prevent falls and disability (Pate et al., 1995). More recently, the physical exercise guideline from the scientific community American College of Sports Medicine added new specifications for the older population by complementing it with balance exercises (Nelson et al., 2007). Balance is defined as the ability to maintain the position of the center of mass relative to the base of support (Shumway-Cook & Woollacott, 2012). The preferred types, frequency, and duration of balance training are unclear and not specified in the clinical guideline.

Taken together, there is strong evidence in the literature that physical activity has a range of physical and psychological health benefits for persons of all ages (Garber et al., 2011; Picorelli, Pereira, Pereira, Felício, & Sherrington, 2014). Evidence to date suggests that mobility challenged older persons benefit most from carefully designed activities targeting balance, as well as muscular strength and flexibility (Gillespie et al., 2012; Howe, Rochester, Neil, Skelton, & Ballinger, 2011; Liu & Latham, 2009). The next section describes the sit-to-stand exercise, which shows evidence of being a suitable exercise to improve or maintain mobility in mobility-challenged older persons.

Sit-to-stand Activity: An Activity to Improve Mobility in Older Persons

In the last few years we have seen an increased research interest in physical activities to improve older persons' mobility. As mentioned earlier, mobility is defined here as the ability to

move safely from one place to another (Lin et al., 2017). However, mobility is a progressive process ranging from the simplest to the most complex movement activity one can perform. The position of least mobility, lying in bed, is the same for all. The end point of the mobility spectrum, however, is not as precise, as it depends also on the intrinsic ability of the individual. To some, it is being able to ascend Mount Everest. For this research, it is the ability of older persons to negotiate the chair or bed or move from one room to another, as determining factors in whether his or her future will extend beyond room confinement.

Functioning in daily life as an independent individual involves having the ability to stand up from a seated position. This ability is one of the most frequently performed functional tasks, and it is an essential prerequisite to walking and independent self-care (Alexander, Galecki, et al., 2000; Alexander, Grunawalt, et al., 2000). The inability to efficiently complete this task has been associated with adverse outcomes such as increased risk of falling (Zhang et al., 2013), increased risk of experiencing recurrent and more severe falls (Moreland, Richardson, Goldsmith, & Clase, 2004), reduced functional capacity (Jette, 1980), increased burden of care (Alexander, Galecki, et al., 2000), increased mortality risk (Laukkanen, Heikkinen, & Kauppinen, 1995), and participation restriction.

The sit-to-stand movement, regarded as a fundamental mobility task for human life, is a complex neuromotor activity (Dall & Kerr, 2010; Grant, Dall, & Kerr, 2011) demanding adequate leg strength and satisfactory coordination of multiple body segments to be effectively and safely accomplished (Chorin, Cornu, Beaune, Frère, & Rahmani, 2016; Hughes, Myers, & Schenkman, 1996). Balance, also, must be maintained while the center of mass is moved forward from its initial base of support (the seat) to its final, smaller base of support (the feet) (Riley, Krebs, & Popat, 1997). The center of mass is also moved to a higher position in space, which is

mechanically less stable (Roebroek, Doorenbosch, Harlaar, Jacobs, & Lankhorst, 1994). The movement of the lower extremities and trunk into extension must be properly timed with the center of mass motion. For example, if the knees were to begin extending too early, before the center of mass had moved far enough forward, then the individual would fall backwards onto the seat. Also, forces generated in the lower extremity and trunk muscles must be appropriately timed, and of correct amplitudes, to move the body to its new position while balance is maintained (Riley et al., 1997).

The sit-to-stand movement occurs in different phases. Schenkman and colleagues (Ikeda, Schenkman, Riley, & Hodge, 1991; Jeng, Schenkman, Riley, & Lin, 1990; Riley, Schenkman, Mann, & Hodge, 1991; Schenkman, Berger, Riley, Mann, & Hodge, 1990; Schenkman, Riley, & Pieper, 1996) have divided the sit-to-stand movement into four phases: (1) Flexion-momentum phase, which begins at movement initiation and continues until just before the buttocks lift off from the seat; (2) Momentum-transfer phase, which begins at lift-off from the chair and continues until maximum dorsiflexion of the ankle is reached; (3) Extension phase, which begins just after maximum dorsiflexion of the ankle is reached and continues until the hips first cease to extend; and (4) Stabilization phase, which begins just after the hips cease to extend and continues until all motion associated with stabilization from rising is completed.

Conversely, the stand-to-sit movement is based upon similar planning processes as the sit-to-stand movement. However, it occurs in an inverted pattern, if compared to the sit-to-stand movement, as one happens with and the other against gravity (Mourey, Pozzo, Rouhier-Marcet, & Didier, 1998). That is, if trunk angular displacements in space are considered, standing up and sitting down can be considered inverse movements. Although the initial position and mechanical conditions related to gravitational effects differ between standing up and sitting down, acromion

trajectories in the sagittal plane show similar forms. Thus, up and down acromion trajectory does not vary in movement planning (Mourey et al., 1998).

Two primary strategies have been suggested for the execution of the sit-to-stand movement (Schenkman et al., 1990; Weiner, Long, Hughes, Chandler, & Studenski, 1993): (1) ‘momentum transfer’, in which hip and trunk flexion are used to generate momentum which can then be transferred to the whole body, and (2) ‘stabilization’, in which trunk flexion is not used to generate momentum but rather to position the center of gravity of the body closer to the base of support at the time of seat-off. The momentum transfer strategy is characterized by the center of gravity of the body being located behind the center of pressure (in some cases this may also be behind the base of support) at the time of seat off, a relatively greater amount of trunk and hip flexion, a relatively greater hip flexion velocity, and a relatively greater hip joint moment but smaller knee joint moment (Hughes, Weiner, Schenkman, Long, & Studenski, 1994). In this strategy, the feet are also usually brought closer to the chair, thus making it easier to bring the center of gravity closer to the base of support.

On the other hand, the stabilization strategy is characterized by the center of gravity being located close to the base of support at the time of seat-off, a relatively smaller amount of trunk and hip flexion, a relatively smaller hip flexion velocity, and a relatively smaller hip-joint moment but greater knee-joint moment (Hughes et al., 1994). Of course, these two strategies are not mutually exclusive: forward flexion might act both to move the center of gravity closer to the base of support as well as generate momentum, which is called the ‘combined strategy’ (Hughes et al., 1994). Which of these strategies is employed seems to be dependent on the individual’s functional ability, and is influenced especially by strength and balance. Hence the stabilization strategy is used more by older persons and other individuals with functional limitations, while

the momentum-transfer strategy is used by younger individuals and/or persons without functional limitations.

Thus, it is suggested that sit-to-stand training supports balance, strength capacity, and satisfactory coordination of multiple body segments, which in turn are important aspects of mobility. Consequently, the sit-to-stand exercise may function as an effective approach to directly improve mobility and functional capacity; therefore, improving the ability to perform needed or desired activities. Studies have been developed to explore the effects of the sit-to-stand activity with some evidence that this activity may be effective and desirable (Flynn, 2007) to assist to improve function (Barreca et al., 2004; Granacher, 2012).

In a meta-analysis study on interventions for improving sit-to-stand ability following stroke, Pollock et al. (2014) identified thirteen studies encompassing a total of 603 participants. This meta-analysis represents a significant body of evidence regarding the effectiveness of sit-to-stand on a range of outcomes including time taken to sit-to-stand and lateral symmetry (weight distribution between the legs) during sit-to-stand in the population of individuals with stroke, who were already able to sit-to-stand independently [standardized mean difference (SMD) -0.34; 95% CI -0.62 to -0.06, seven studies, 335 participants; and SMD 0.85; 95% CI 0.38 to 1.33, five studies, 105 participants respectively, both moderate quality evidence]. With this analysis, it was concluded that repetitive sit-to-stand training leads to beneficial outcomes for individuals receiving stroke rehabilitation.

In a randomized controlled trial with sixty community-dwelling older persons designed to compare the effects of functional home exercise of repeated sit-to-stands, Rosie and Taylor (2007) determined that the intervention group had a statistically significant improvement in Berg Balance Scale mean score, 1.67 ± 2.64 points, $P = 0.001$ (control group 0.73 ± 3.63 points, $P =$

0.258), indicating an improvement in balance over the 6-week exercise period. The group performing the sit-to-stand intervention started with 10 repetitions and was instructed to increase repetitions by 5 a day or as they were able, until they reached the number of repetitions they were comfortable with to a maximum of 50 sit-to stands a day. This study showed that 6 weeks of home-based sit-to-stand training improves balance.

All considered, given the relevance of older person's capacity of rising from a seated to a standing position to mobility, the sit-to-stand exercise emerges as a likely intervention to effectively increase muscle strength reducing the risk of falls (Cheng et al., 2001) and increasing associated benefits on mortality, morbidity, disability, and costs to health and social care (Connelly, 2000; Munro, Nicholl, Brazier, Davey, & Cochrane, 2004; Sherrington, Tiedemann, Fairhall, Close, & Lord, 2011). However, more studies are needed to verify the effectiveness of the sit-to-stand intervention for the older person, mobility-challenged population.

As Pollock et al. (2014) selected for their meta-analysis adults from all age groups and solely after stroke individuals, it became necessary to explore the current state of knowledge about the sit-to-stand activity for mobility of the older population independent of health condition. Therefore, I performed a scoping review published elsewhere to identify the current state of knowledge about the sit-to-stand intervention to improve older-people mobility, and the gaps in knowledge regarding this intervention.

Of 2,197 papers reviewed, four studies met the inclusion criteria. All selected studies were exclusively of quantitative nature. The internal quality of the four studies was mixed. Publications provided a range of sit-to-stand interventions with durations ranging from 5 weeks to six months. The frequency of the sit-to-stand activity fluctuated from three to seven times/week and 15 to 45 minutes each time. Different professionals prompted the activity

(professional physical therapists, registered practical nurses, investigators and participants, and health care aides).

Three themes were identified in the study: (1) sit-to-stand activity as an intervention; (2) generalizability of findings; and (3) sustainability. In most studies, participants showed significant improvements in performance of the sit-to-stand activity and motor function. Some studies lacked adequate methodological rigor. There was an absence of theoretical frameworks guiding the studies. A gap in the literature on effective interventions for different populations of older people and settings remained. Taken together, with an increasing number of older persons expected to require some kind of mobility intervention in the future, effective interventions for mobility among older persons continue to be a growing field of research interest (Webber, Porter, & Menec, 2010).

Additionally, all included studies were limited to affluent countries; therefore, studies focusing on low and middle-income countries are needed. While there is promising evidence indicating the positive effects of the sit-to-stand activity for mobility-challenged older persons, there is not enough evidence to claim its transferability, i.e., the capacity of primary studies results to be useful beyond the original populations of those studies. To illustrate this idea of transferability, consider the sit-to-stand intervention that has been fairly tested in developed countries and has showed promising results in improving or maintaining older persons' mobility (Pollock et al., 2014; Rosie & Taylor, 2007). Such an intervention may not be readily applicable to a setting in which cultural and normative influences, as well as social norms, about the role of older persons do not support their engagement in physical exercise (Bettenhausen & Murnighan, 1985; Brownson, Baker, Housemann, Brennan, & Bacak, 2001). Therefore, transferability is dependent upon the conditions under investigation, some of which are baseline participant

characteristics (e.g., sex, age, severity of the disease), geographic setting, cultural context, political or health care systems (Rothwell, 2005).

Conclusion

The concept of mobility designates an activity that individuals undergo in order to participate in everyday life. These activities can be broadly divided into bed mobility, a breadth of transfer skills, and travel undertakings, which one employs to move within and between environments. Nonetheless, being an activity is but one of the many dimensions surrounding the concept of mobility. Along with the activity dimension, mobility also embodies dimensions related to ‘health condition’, ‘body functions and structures’, ‘participation’, and ‘contextual factors’.

A pivotal portion of understanding the emergence of any problem is discerning its path. Understanding the processes leading to mobility challenge is critical to efforts aimed at prevention or postponement of disability in older persons. For instance, if we examine only one dimension of mobility it may be misleading. Similarly, misconceptions can also happen if we do not recognize the particular cross-cutting influences of different dimensions in a given setting. Hence, a more reliable picture may be drawn by identifying the particular paths and features of the different dimensions of mobility and how they cross-cut each other.

To engender this study, I took Brazil, a developing country, as my departing point to compare to more developed countries. My premise was that biological dimensions of mobility were similar among older persons, independent of place. This means that one’s mobility challenge may arise from an array of different ‘health conditions’ affecting distinctive ‘body structures and functions’ in the lower neuromusculoskeletal system. Mobility challenge in older

persons is often related to the presence of multiple chronic diseases and injuries, and their interaction, all affecting the lower neuromusculoskeletal system.

Thus, I conjectured the mobility dimensions ‘activity’ and ‘participation’ were the ones that would present the first distinctions when comparing older persons from different countries. But surprisingly enough, the mobility dimensions ‘activity’ and ‘participation’ showed similar characteristics in Brazil and more developed countries: the overall prevalence of mobility challenge between older persons was around 50%, with a significant association between participation and mobility in both places.

At this point, I turned my attention to the last mobility dimension: ‘contextual factors’. By presenting the contextual factors of mobility in Brazil, a more comprehensive picture of the research setting was taken. After acknowledging intrinsic and sometimes non-modifiable (or hard to change) determinants of mobility challenge, e.g., age, biological sex, income, I identified an approach to improve modifiable determinants of mobility challenge: the sit-to-stand activity.

The approach employing the sit-to-stand activity was selected due to indications in the literature of its physical and psychological health benefits. This activity also offered the possibility of working on balance, muscular strength and flexibility of older persons, which are areas of mobility older persons most need attention. As much as there has been research pointing to the benefits and advantages of the sit-to-stand activity, to date the majority of this research has been conducted in developed countries, making the identification of the impact of modifiable determinants not clear for developing countries.

While introducing any given activity, it is paramount to understand the influence of contextual factors on mobility of older persons in order to reduce the negative health consequences of mobility challenge. This is why I decided to examine perceptions and

experiences of mobility challenges in urban Brazilian community-dwelling older persons; and to also study participants' perceptions about a sit-to-stand activity.

CHAPTER THREE: METHODS

The aim of this chapter is to offer the reader an overview of the research procedures I employed to examine the perceptions and experiences of mobility challenges in urban Brazilian community-dwelling older persons and to examine study participants' perceptions about a sit-to-stand activity. It is divided into six sections. I start by introducing the study approach followed by methodological perspective, assumptions for this study, study design, ethical considerations, and rigor.

Study Approach

Many factors can affect the successful implementation and validity of an intervention. Therefore, the primary purpose of employing a pre-feasibility (or preliminary feasibility) and feasibility approach is to assess the prospects for successful implementation of a potential intervention (or intervention study) and to reduce threats to the validity of these interventions (or studies).

Pre-feasibility studies offer a general view of the potential intervention using an analytical lens that allows the researcher to make a recommendation on the suitability of a feasibility study (Mesly, 2017). A pre-feasibility study can be developed either as an independent piece of research or as an integral part of the project development process. Either way, it is a vital study that determines whether a full feasibility study should be undertaken, or not. Pursuing a pre-feasibility study prior to a full feasibility study may provide a valuable opportunity to evaluate the likely success of the potential intervention protocol and optimize its design or, if necessary, to make the decision not to proceed with it. Therefore, a pre-feasibility study increases confidence among researchers, funding agencies, and potential users regarding a given intervention.

In this research, a pre-feasibility study was warranted due to the need for unique consideration of the topic, in view of the possible differences of Brazilian community-dwelling older persons' sociocultural health beliefs and behaviors when compared to studies published with populations from developed countries. It follows that culture can be a resource or a drawback for the sustainability of an intervention (Cooper, 2004). Culture and values provide impetus, facilitate means needed to assist the implementation of an intervention, and substantially define individuals' vision of the intervention purposes and ends (Cooper, 2004). Culture and values are instrumental as they form individuals' daily expectations, fears, drives, attitudes, and actions, but they are also formative because they mold people's ideals and inspire their dreams for a fulfilling life.

A pre-feasibility study that takes into consideration culture may encompass ethical, behavioral, and social issues in order to inform the design of a feasibility study or intervention protocol in clinical practice (Coreil et al., 1998). Culture and sustainable interventions are deeply interwoven because culture is essential in shaping human behavior (Brislin, 1993). Recognition of culture and values are the foundation for successful interventions. Thus, this pre-feasibility study specifically aimed to answer the following research questions: 1) what are Brazilian older persons' perceptions and experiences with mobility challenges? and 2) how do Brazilian older persons with mobility challenges experience the sit-to-stand activity?

Note that I have been using the term sit-to-stand intervention in the literature review. This was done because these studies employed experimental and clinical interventions. From here on, since I am discussing the sit-to-stand approach as a potential intervention for a future intervention study, I employed the term 'activity', as the sit-to-stand activity. My primary goal in

this study was not to recommend it as a clinical intervention for research, but observe the likely success of this activity in view of the Brazilian context.

Methodological Perspective

Focused ethnography was the qualitative approach selected to examine perceptions and experiences of mobility challenges in urban Brazilian community-dwelling older persons and to examine study participants' perceptions about a sit-to-stand activity. Therefore, in the following section, I discuss the methodological origins and key characteristics of focused ethnography.

Methodological Origins

Traditional qualitative research methodologies are linked to specific academic disciplinary origins (Guba & Lincoln, 2006). Ethnography is a qualitative research methodology traditionally rooted in the field of cultural anthropology (Creswell, 2009; Grove, Gray, & Burns, 2009). Anthropology is an academic discipline that focuses on the study of cultural observation and comparison (Agar, 1993). Culture encompasses a web of wide-ranging, symbolic, shared, patterned, integrated systems of language, behavior and rituals (Chiseri-Strater, 1997) that may be dependent upon locality, purpose, integration, selection, conformity, process, and possibility (Benedict, 1934). In this research study, culture was understood as a learned and socially constructed behavior that is transmitted through interactions in order to give meaning to our worlds (Geertz, 1973). This meaning is given by shaping our perceptions and subsequently conditioning our cognition.

Ethnography is the study of the cultural meanings of everyday life, whose main interest is the perspective of members of that culture (Spradley, 1979, 1980). As defined by Aamodt (1991), an ethnographic study allows a researcher and others to understand an individual's experience and behavior within their context. However, rather than studying people, Spradley (1980) asserts

that ethnography means learning from people. This is done by observing language use and patterns of interaction, such as cultural norms, rules, and/or customs, among members of a defined cultural group (Spradley, 1979, 1980).

Thus, ethnography assists the researcher to understand human actions and behavior from the emic and etic point of view (Olive, 2014). The emic approach seeks to understand a certain culture based on its own referential, that is, from the participants' point of view. On the other hand, the etic approach refers to an interpretation of aspects of another culture from those who observe it, that is, from the researcher's point of view. In other words, the etic approach is the external view of observers and researchers who are looking from the outside in a comparative and descriptive posture, while the emic approach is the inner vision, the observers who are looking from within, from a particular, unique and analytical posture describing thoughts and actions primarily in terms of the participants' self-understanding—terms that are often culturally and historically bound.

For this study, the emic approach was the main perspective; but, the etic approach was unavoidable and necessary. Further, it allowed me to link cultural practices to external, antecedent factors, such as economic or environmental conditions that would not be salient to cultural insiders (Harris, 1979). Therefore, it was extremely important that given knowledge of particular culture or social group was first observed from the emic approach. However, unlike the etic approach, emic is not automatic, unavoidable, and implicit (Rosa & Orey, 2012). On the contrary, the researcher must strive to use it, for this is equivalent to seeing the world with the eyes of the other.

While ethnography is traditionally rooted in the field of anthropology, researchers from different disciplines have employed its principles, practices, and procedures to study phenomena

in which the influence of culture is fundamental to its understanding. Ethnography keeps evolving and is influenced by numerous variations of the terms ‘culture’ and ‘groups’ within the ethnographic methodology literature to match different disciplinary perspectives. This has influenced the development and differentiation of this methodology over time to include distinct approaches. In health sciences, focused ethnography, a particular form of ethnography, has evolved to specifically address characteristics of health related qualitative research.

Focused Ethnography

Focused ethnography was the selected methodology used in this study because of its congruence with the topic of interest. Researchers employing focused ethnography address a distinct cultural phenomenon within a specific context among a small group of persons (Higginbottom, Pillay, & Boadu, 2013; Roper & Shapira, 2000). In this study, the cultural phenomenon was one’s experiences of mobility challenge and the sit-to-stand activity. My cultural group included older persons who are community-dwelling, born and reside in Brazil, and shared mobility challenge experiences. This cultural group shared the same cultural context. For example, they were born in Brazil, have an average income of 100 American dollars per month (Beltrão, Camarano, & Kanso, 2004) and life expectancy of 73 years at birth (Instituto Brasileiro de Geografia e Estatística, 2010a). They also have been part of the rapid growth in the aging population that has not been closely accompanied by corresponding socio-economic growth and health care improvement. As a result, these Brazilian older persons have experienced aging within social and economic inequalities (Palloni & Peláez, 2003).

In focused ethnography, the researcher enters the field with a background knowledge and specific research questions formulated in response to a specific problem, which will be answered by data produced over a short period of time (Higginbottom et al., 2013). My background

knowledge was developed while growing up in Brazil – from birth to 24 years old, as well as during my time working as a research assistant for Dr. Susan Slaughter. The research I was involved in concerned the process evaluation of a study aimed to analyze the effectiveness of reminders to support the sustainability of an affordable mobility innovation by healthcare aides in supportive living facilities (Slaughter, Estabrooks, Jones, Wagg, & Eliasziw, 2013). In addition, while working with the research team, I was exposed to other projects that were conducted and one project in special called my attention. It was an intervention study to assess the effect of the sit-to-stand activity on the mobility, function, and health-related quality of life of nursing home residents with dementia (Slaughter et al., 2015).

In the end, equipped with this background knowledge and in view of the rise in the prevalence of mobility challenges among people as they get older, the following research questions were formulated: 1) what are Brazilian older persons' perceptions and experiences of mobility challenges? 2) How do Brazilian older persons with mobility challenges experience the sit-to-stand activity? To answer these questions, I collected data over a much shorter period of time (over twelve weeks) compared to traditional or medical ethnography (over several months or years) (Roper & Shapira, 2000).

Finally, in focused ethnography it is anticipated that the researcher's findings will reveal cultural behaviors and norms in response to a specific question and will either contribute to cultural theory development and/or improve professional practice (Higginbottom et al., 2013, Roper & Shapira, 2000). Thus, my study's particular contributions to the nursing discipline related to improving care by revealing the significance of the context of mobility and mobility activities in which nursing actions are applied (Green & Glasgow, 2006).

Study Assumptions

After discussing the methodological origins and key characteristics of focused ethnography, in this section I discuss specific assumptions underpinning this study and why they are congruent with my purposes.

Ethnography and the Constructivist Worldview

‘Constructivism’, one of several interpretivist schools of thoughts, is concerned with the ways in which people construct their worlds (Williamson, 2006). Constructivists argue that human beings construct their own social realities in relation to one another through interpretations and actions based upon those interpretations; thus, all knowledge is contingent to political, social and cultural discourses. In the constructionist’s view, meaning is constructed, and coming into existence in and out of our engagement with the world (Crotty, 1998). There is no meaning without a mind. Meaning is not discovered, but constructed. In this understanding of knowledge, it is clear that different people may construct meaning in different ways, even in relation to the same phenomenon (Crotty, 1998). One’s particular construction of reality might be shared with many other people, but other people could construct the same reality in quite different ways. Hence, reality is subjective and experiential. That object over there that looks like a table might actually be used as a chair over here.

Ontological Assumptions

Ontology refers to the nature of, the structure of, or what is known about reality. The ontological assumption of a constructivist worldview is based on multiple alternative realities, i.e., meanings, coexisting and being co-constructed in part through social context and past experience. Therefore, there is not one single reality, or truth, but an interpretation of it, which can be shared by many individuals (Schwandt, 1998).

From a constructionist standpoint and using an ethnographic lens for data collection and analysis, data were generated from two sources, older persons and me, which was consistent with the notion of multiple realities co-constructing the meaning of mobility and the sit-to-stand activity (Risjord, 2010). Consequently, perspectives derived from the older persons and me about the study topic were a negotiated and ongoing process whereby both of us built and rebuilt meanings as we confronted new information and experience. From this constructivist perspective, paradoxes and differing perceptions had room to reign because such uneasy circumstances filled the constructivist inquiry process (Rodwell, 1998). That is, if reality depended on perspective, and every source in the research spoke their individual truth, then everything about constructivist research was paradoxical with possibilities of co-construction of meaning.

In addition, a constructivist ontology in dealing with a pre-feasibility study was justified. If, in the grand scheme of things, this research end goal was to evaluate the likely success of transforming the sit-to-stand activity into an intervention, it was sensible to take into consideration how the target group, mobility challenged older Brazilians, negotiated and co-constructed meanings of what was accepted and rational and relevant for them. Successful evaluation of feasibility studies or intervention can, thus, be based on perceptions of how a given group perceive reality in their social context (Vatn, 2005). Humans react or behave according to their subjective and circumstantial perception of the reality around them. The researcher may thus create knowledge, theory and meaning from subjective descriptions of a phenomenon (Creswell, 2003; Mackenzie & Knipe, 2006; Tribe, 2001).

Epistemological Assumptions

Epistemology is a way of understanding and explaining how we know what we know; therefore, referring to knowledge (Schultz & Meleis, 1988) and the relationship between the knower and what can be known (Guba & Lincoln, 2006). In the constructivist worldview, “the investigator and the object of investigation are assumed to be interactively linked so that the ‘findings’ are literally [co]-created as the investigation proceeds” (Guba & Lincoln, 2006, p. 111). In this study, knowledge was co-created with the participants through conducting interviews and observations, and validation of the study findings with the participants (see Study Methods and Rigor section).

Additionally, this study aimed to explore the pre-feasibility of the sit-to-stand activity for Brazilian community-dwelling older persons using an analytical lens to inform us about the prospects of a successful implementation of the sit-to-stand activity. That is, though the sit-to-stand intervention is a validated intervention in developed countries, employing a constructivist approach allowed the researcher and participants in Brazil to construct their own meaning regarding the activity by building on their previous knowledge and experience. The principal outcome of this feasibility study was an understanding of the experiences of Brazilian older persons with mobility challenges regarding the sit-to-stand activity.

Study Design

The following section of this chapter describes the techniques and procedures I used to gather and analyze data related to the two-fold study purpose: to examine perceptions and experiences of mobility challenges in urban Brazilian community-dwelling older persons and to examine study participants’ perceptions about a sit-to-stand activity. The ethnographic approach has evolved to “encompass such a range of perspectives and activities that the idea of adhering to

an ethnographical position, as though there were only one, is faintly ridiculous” (Mason, 2002, p. 55, italics in original). Thus, several authors influenced my ethnographic perspective for data collection, data analysis, and interpretation of the study findings, in particular, Roper and Shapira (2000), Spradley (1979, 1980) and Schensul and LeCompte (2010, 2012a, 2012b, 2012c, 2012d, 2015, 2016). In employing methods that have been used successfully in many different analyses, this study gained a measure of validation. Although the steps are listed linearly, they were not necessarily followed in sequence.

Setting

Ethnography takes place where the experience and the world unfold for participants, which is called the field (Speziale, 2011). The Family Health Strategy unit at “Unidade Integrada de Saúde Manoel Arthur Villaboim” (UISMAV), a healthcare center located in Paquetá, an island in Rio de Janeiro – Brazil, was selected as the setting for the study.

The Family Health Strategy is a community-based approach in the Brazilian Unified Health System whose purpose is to provide primary health care – the first level of health care for the population – for defined populations by deploying interdisciplinary health care teams (Macinko, Matthew, & Harris, 2015). The Brazilian Unified Health System was established in the Brazilian Constitution of 1988 (Brazil Const., 1988) in the scope of social security. Thus, it represents one of the greatest policies of social inclusion in the history of the country.

The Brazilian Unified Health System is public and also has a universal dimension, since it indiscriminately covers all Brazilians with services of healthcare, sanitary surveillance of food and medicines, epidemiological surveillance, blood, organ transplants and many other services. As with the majority of the countries worldwide, the Brazilian Unified Health System is not classified as an “ideal type” model (in the Weberian sense) of health system. The ‘ideal type’ is

the central analytic and explanatory device employed by Max Weber. He discussed these types and their uses in several places, notably in three methodological essays: (a) ‘Max Weber: collected methodological writings’ (Bruun & Whimster, 2012), (b) ‘The methodology of the social sciences’ (Weber & Shils, 1949), and (c) and in some passages in the first chapter of his book ‘economy and society’ (Weber, Roth & Wittich, 1968, p. 3-26).

Currently very few countries, have health systems that fit into the “pure” format of one of the three classic types, that is, the national health system (with state provision and financing exclusively by taxes); the social security system (with funding exclusively made through payroll contributions); and liberal health system (based only on market forces) (Santos, Ugá, & Porto, 2008). The Brazilian Unified Health System is a mixed health system, which combines elements of the public and private spheres, both in the scope of service provision and in the financing of services (Costa Romano & Gurtler Scatena, 2014). Specifically, in the healthcare field, the Brazilian Unified Health System is exclusively responsible for covering 140 million individuals (Mendes, 2013). In addition, 48 million of Brazilians use the private, supplementary health system – many of them accessing the Unified Health System in circumstances where the private system has limits of coverage (Mendes, 2013). This means that the private health sector provides services in a complementary manner, under the guidelines and rules (contract) of the public system.

Thus, within the Brazilian Unified Health System, the Family Health Strategy is an integral part of the public system (not in a complementary way) working as a “gateway” to the local health system and the primary level of care, connecting patients to more complex services, if needed. Furthermore, the users of the Family Health Strategy are individuals from all socio-economic groups (M. V. Andrade et al., 2015). Therefore, the Family Health Strategy is not an

isolated part of the Unified Health System, but a component with articulations to every level of care serving all socio-economic groups. In this way, with a better knowledge of the clientele and a more patient-centered follow-up, and by the means of referrals, it is possible to rationalize the use of the technology and the most expensive therapeutic resources (Secretaria de Políticas de Saúde, 2000).

It is recommended that each health team at the Family Health Strategy should be responsible for between 600 and 1,000 families (2,400 to 4,500 inhabitants). The Family Health Strategy at the UISMAV had two teams serving 5,520 individuals. The nucleus of each Family Health Strategy team must at least include a physician, a nurse, a nurse assistant, and four to six full-time community health agents. Community health agents are part of the multiprofessional healthcare team but also live in the community and have a close relationship with its members. They promote activities related to disease prevention and health promotion through educational actions. It is believed that their activities transcend the health field in that they are responsible for observing multiple aspects of the population's living conditions.

At the UISMAV each team was composed of one physician, one registered nurse, one licensed practical nurse, and five community health agents. Unfortunately, this family health strategy did not have a physical or occupational therapist. The nurses and physicians were the individuals who assessed the patients and, to a lesser extent, visited the homes of patients with mobility challenges. Overall, the health care providers of the health care team are expected to know the families and the territory, identify the health problems and situations of risk in the community, develop a program of activities to address the determinants of the health / disease process, develop educational and intersectorial actions related to health problems, and provide full assistance to the families under their responsibility in basic health care.

Given the number of different possible settings where community-dwelling older persons could be found, this setting was selected because of two factors: The high proportion of the older persons in relation to the total population of the city of Rio de Janeiro, and my familiarity with this specific healthcare context. At the time of the study, the city of Rio de Janeiro had 6,321,000 inhabitants and was the city in Brazil with the third highest number of older persons: 2.4 million (Instituto Brasileiro de Geografia e Estatística, 2010a). Paquetá Island was one of the three neighborhoods in Rio de Janeiro with the highest proportion of older persons. It had 5,520 inhabitants, of which 21.2% were 65 years and older; therefore, there was an increased possibility of identifying relevant and information-rich cases related to the phenomenon of interest (Luborsky & Rubinstein, 1995).

Another factor for the selection of this setting was my strong family ties to the Island, where I lived during my childhood and spent weekends and summer vacations during my early adulthood. Therefore, I was familiar with the structure and functioning of the sub-culture and its healthcare system, which helped me to gain access to participants for research purposes. This scenario provided me with a better emic perspective, since I was able to more easily view the world as a member of that culture viewed it, as well as provide possible rationale for my own and others actions. This emic view, for example, enabled me to explain some of the nuances of the participants' perspective of mobility and the sit-to-stand activity.

On the other hand, I no longer lived there and, for this study, I brought with me my researcher lens. This lens provided me with an etic perspective and gave me structures, criteria and tools developed outside this culture and which I could use as a framework for studying this culture (Willis, 2007). Further, it allowed me to connect cultural practices to external, antecedent factors that may not be salient to the participants (Harris, 1979).

While critics would claim such involvement could undermine the objectivity of a study, I counter-argue that my insider status facilitated my access to the participants and their willingness to open up and share intimate life events with me (Dolan, Donnelly, & Hogan, 2009). According to Wall (2015) this insider status is one of the main features of focused ethnography where the researcher has “[...] insider or background knowledge of the cultural group” on his or her favor. Additionally, the term ‘objectivity’ is a poor concept when talking about interpretivist traditions.

Furthermore, in order to ensure my knowledge of the culture and/or nursing did not lead to a superimposition of my perceptions on participants, I employed reflexivity. Reflexivity is developed when the researcher is “able to look at a situation or a concept from various perspectives and to reflect on his or her own changing positioning within the discursive circumstances” (Al  x & Hammarstr  m, 2008, p. 170). Being reflexive entailed being sensitive, flexible, and paying attention to the situation as a way of counterbalancing detrimental power relations.

Participants

After the health care center was identified, the next phase was to secure health care center consent to participate in the study. Accessibility was initiated with messages to the head nurse responsible for the Family Health Program at the UISMAV with follow-up messages to document the conversation and provide additional information on the study. The head nurse and the director of the healthcare center agreed to allow me to conduct my dissertation research at UISMAV (Appendix A).

First, to select potential participants, the health care team, together, conducted initial screening to identify eligible participants. In this initial screening, the health care team were asked to select (a) older persons (60 years and older) that (b) had any kind of mobility challenge

and (c) did not present any pre-existing diagnosis of cognitive challenge and whom they found cognitively sound based on their contact with them. After potential participants were detected, the registered nurse from each team in the Family Health Unit asked them to ‘consent to be approached’, where individuals were asked in advance if they agreed to put their contact details on a register list so that they could be approached to take part in a health research study.

After potential participants agreed to put their contact details on the register list, they were contacted by me, the researcher, to receive more details about possibly participating in this study. This contact occurred in person. At this point, I introduced myself to the potential participants, explained the study, and went through the information letter with them. Based on this initial interaction, I was also able to observe potential participants’ understanding of the study purpose and what was required from them. If potential participants appeared to have no cognitive challenge and decided to participate in the study, their informed written consent to participate in the study was obtained (Information Sheet and Consent Form in Appendix B). I reassured each participant about his or her rights. In addition, all data were collected with permission from participants in compliance with research ethics review board at the University of Alberta and in Brazil. For further details refer to the Ethics section in this chapter. There was a possibility that after the consent was given and during the field work, participants’ conditions may change and they may start to show some kind of cognitive challenge. It was determined that if during the observations and interviews I observed this change, I would not proceed to collect data from the participant and would inform the health care center about my concerns.

In addition, it was determined beforehand that if I was not able to recruit the number of participants from the health care center to proceed with this research, I would (i) advertise the study in public places such as supermarkets and churches with the consent of the respective

responsible authorities and (ii) ask participants to refer me to other potential participants among their acquaintances. After obtaining the informed written consent to participate in this study, potential participants were selected according to inclusion criteria, which is the list of characteristics that researchers determine beforehand to be essential for eligibility in the sample of participants.

The inclusion criteria for older persons were:

1. Self-reported perception of mobility challenge
2. Live in the community (be community-dwelling)
3. Reside in Brazil
4. Be ≥ 60 years of age. This age was chosen as it is consistent with the age established by the Brazilian National Policy for Older Persons (1994) and the World Health Organization definition of older persons in developing countries
5. Able to understand and communicate with the researcher in Portuguese
6. Able to provide written informed consent in Portuguese
7. Considered by the health care team to have good cognitive competence

The exclusion criteria for older persons were:

1. Self-reported inability to sit-to-stand
2. Observed inability to sit-to-stand by the researcher
3. In an institution
4. Unable to understand and communicate with the researcher in Portuguese
5. Unable to provide written informed consent in Portuguese
6. Considered by the health care team to have poor cognitive competence

Sampling. Purposive sampling was employed to select participants for this study (Patton, 1990). Maxwell (2013) defines purposive sampling as a strategy in which particular settings, persons or activities are selected deliberately in order to provide information that cannot be obtained as well using other strategies, such as theoretical sampling, where “sampling necessitates building interpretative theories from the emerging data and selecting a new sample to examine and elaborate on this theory” (Marshall, 1996 p. 523). That is, in purposive sampling, the researcher intentionally selects (or recruits) participants who have experienced the central phenomenon or the key concept being explored in the study (Creswell & Plano Clark, 2011), which in this study was the mobility challenges experienced by older persons.

Purposive sampling, also called judgment sampling, is a selection tool employed to select an informant due to the qualities the informant possesses. “It is a technique that does not need underlying theories or a set number of informants” (Tongco, 2007). In other words, the researcher decides what needs to be known and looks for individuals who can and are willing to provide the information by virtue of knowledge or experience (Bernard, 2002). It is particularly exemplified through the key informant technique (Bernard, 2002), wherein one or a few individuals, in this case mobility-challenged older persons, are asked to act as guides to a culture. Key informants are observant, reflective members of the culture of interest who know much about the culture and are both able and willing to share their knowledge (Bernard, 2002; Tongco, 2007).

Sample size. According to Marshall (1996), a qualitative sample size is one that sufficiently addresses the research question. That is, sample sizes in qualitative research should not be so small that it is difficult to achieve informational redundancy. At the same time, the sample should not be so large that it is difficult to undertake a deep, case-oriented analysis

(Sandelowski, 1995). One important factor that determines sample size is the richness of the collected data, including observations, and more specifically the quality of the interviews demonstrated by the richness of the events, incidents, and examples shared by the interviewed participants (Morse, 2000; Sandelowski, 1986).

It was determined that sampling would be discontinued when informational redundancy was achieved (Lincoln & Guba, 1985). Informational redundancy often dictates the sample size, such that participants are recruited until the topic has been fully investigated and no new interpretations are generated from additional participation, and the information provided therefore becomes redundant (Patton, 1990). Although participants and their information are unique, redundancy in general themes and concepts becomes evident with ongoing data analysis. The number of participants needed to reach informational redundancy varies based on the research question and quality and types of data provided. However, my anticipated final sample size was twenty participants, since this was consistent with the average sample sizes of two studies of exercise/physical activity with the older adult population using focused ethnography (Bruner & Chad, 2013; Graham & Connelly, 2013).

The steps to collect data and analyze its meaning are described below. Though each step is described as if it was linear, in reality, they were circular and overlapping with one another. I moved back and forth among the steps reflecting the iterative nature of qualitative research.

Data Making

According to Mayan (2009) there has been a shift from the use of the term data collection to data generation or data making. According to the author, “the term data generation or data making is more aligned with the tenets of any ‘post’ perspective, such as the one I am employing here – constructivism. Referring to data as being collected implies that “data preexist, ready to be

picked like apples from a tree” (Richards & Morse, 2013, p. 119). It is understood that we do not initiate a study as disinterested bystanders but, rather, come to it with interests and assumptions. In interaction with the data source we create, or make, data. The researcher must make decisions about where to point the camera, which images to focus on and which ones to scan (and later delete), which sounds to strain to hear and which ones to block out, which questions to ask the interview participant and which ones to let go.

Data was generated during home visits. Four means of data making were used: collection of demographic data (Appendix C), participant observations, two semi-structured interviews (Appendix D and Appendix E), and field notes. This study also included the sit-to-stand activity. The sit-to-stand activity was employed as a vehicle to assist the participants articulate their experience by providing means for accessing subjective experiences (Burles & Thomas, 2014), and elicit more details and narratives with potentially greater richness than what is typically generated in a traditional interview (Clark-Ibanez, 2007). Please refer to Appendix F for a summary of the connections between my research questions, vehicles for data generation, the data to be generated, procedures, and data analysis.

For data collection, I had planned to employ photo-elicitation. My plan was to jointly with participants, take photographs of their surroundings to help them think about challenges to mobility. However, at the beginning of the data collection, I noticed that this study would not be enhanced by the use of photo-elicitation because things that affected their mobility (by helping or making it difficult for them to mobilize, e.g., their favorite spaces and chairs), were within their surroundings. Therefore, photographs were not needed to make things visible because they were readily available to be seen and talked about.

Therefore, after prospective participants gave written consent to participate in the study, I pursued six home visits. In the first home visit, I asked them to respond to the socio-demographic survey (Appendix C), and pursued the first formal interview (Appendix D) focused on the first research question: what are Brazilian older persons' perceptions and experiences with mobility challenges? During the first visit, and after pursuing the first formal interview, I taught participants the sit-to-stand activity. This first visit took approximately one hour.

From the second to the fifth home visit, I followed up with participants to identify how they were performing the sit-to-stand activity, the frequency, if there were any adverse effects, as well as to informally inquire about their perceptions and experiences regarding the sit-to-stand activity. These follow up visits took approximately 15 minutes each. My preference for in-person visits, instead of follow ups via telephone, relied on the cultural environment in which these older persons lived – an Island where it was very common to casually visit your neighbors. Also, according to previous experiences of the health care team at the Family Health Program at the UISMAV, follow ups with patients via telephone have had a low rate of success.

My sixth and last visit was devoted to the second formal interview focused on the second research question (Appendix E): how do Brazilian older persons with mobility challenges experience the sit-to-stand activity? Additionally, for the second interview, I had a separate set of questions for participants who decided to no longer do the sit-to-stand activity but still agreed to do the interview. This last visit took approximately half an hour. During all encounters at the participants' home, I pursued participant observation and informal conversations as a data making activity.

Ethnographic Interview. Interviewing is a critical activity in ethnography with questions inspired by observing unconscious, habitual behaviors of the participants. Following

the consent to participate in the research, participants were invited to take part in up to two individual interviews, one before and one after the four-week sit-to-stand activity. In particular, the first interview contemplated questions regarding the participants' socio-demographic characteristics. Please, refer to the two interview guides in Appendix D and Appendix E for details.

These formal, in-depth, open-ended interviews were face-to-face and audio-recorded, lasting from 20-60 minutes. These in-depth interviews enabled me to investigate facts of the topic in ample detail so as to deepen my knowledge of the topic (Schensul & LeCompte, 2012b). Open-ended interviews meant that the participants were not asked to select from a series of alternative choices and that I was not only free to ask further questions beyond those used to begin the interview but also was open to any and all relevant responses.

According to Spradley (1979) an ethnographic interview is “a particular kind of speech event” (p. 55). However, unlike friendly conversations, the ethnographic interview includes: (a) an explicit purpose, which involves reminding participants that the interview has a purpose and direction; (b) ethnographic explanations, wherein the ethnographer translates the goal of the study and elicits the participant's cultural knowledge in terms appropriate to the participant; and (c) ethnographic questions designed to collect the participant's perspective (Spradley, 1979).

Interviews' timeline. Before each interview began, I described my project to the participants again, and reinstated the previously signed informed consent. From there, I verbally asked participants if they were still willing to be part of the research project. If they agreed to proceed, I explained my focus of interest for each interview.

In the first interview, I elucidated my interest in learning their perspectives of mobility challenge (i.e., the condition that the intervention aims to influence). During the first interview, I

asked participants to tell me about how they felt about their mobility capabilities, to point out spaces and/or objects in their life that they connected to their mobility (how they felt about them, where they have come from, what elements were missing, and any other reactions that they had). In this way, the interview moved from the concrete (a cataloguing of the objects in their lives) to the socially abstract (what the objects in the lives meant to them)

The second interview was held at the end of the fieldwork, after the four-week, sit-to-stand activity. The purpose of the second interview was to reflect back on the experiences of the last days of the intervention. Before the second interview, I reminded the participants of my interest in learning about their individual's beliefs and values regarding the sit-to-stand activity. Using the sit-to-stand activity, I intended to elicit experiences and memories from participants.

The interview that resulted from the elicitation of recent memories of the sit-to-stand activity might have been different from the conventional ethnographic interview (Harper, 1986). The activity served as stimulus in the interview. Because the sit-to-stand activity may not have made sense to the interviewee without its concrete experience. Also, the sit-to-stand activity may not have made sense to the interviewer in the same way it did to the participants. If we realized how different our interpretation of the activity was, it could lead the participants to become the teacher about their reality.

After each response from participants, I repeated back to them my understanding of what they had just told me and at the end of each interview, I debriefed with participants, as well as checked and discussed with them my emerging hunches. At that point, participants assisted me with my interpretations, so we could discuss and negotiate agreements and disagreements about the interviews (Olesen, 1994; Waitzkin, 1991). This is frequently termed in the literature as member-checking, but also as informant feedback (Onwuegbuzie & Leech, 2007), respondent

validation (Mays & Pope, 2000), member validation (Schwandt, 2007), or dependability checking (Tobin & Begley, 2004). Member checking or member validation is the process of “taking ideas back to research participants for their confirmation...[and/or] to gather material to elaborate your categories” (Charmaz, 2014, p. 111). This was done to validate the construction of the data and ensure agreement in the representation, as participants had the opportunity to discuss and negotiate the meanings of the interviews (Karnieli-Miller, Strier, & Pessach, 2009; Lincoln & Guba, 1985; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

The sit-to-stand activity. On the first home visit, I asked participants to perform the sit-to-stand activity once a day, daily for four weeks in order to assist them to elicit and articulate the experience of the activity. Therefore, the activity was employed solely as a method to generate data. In Appendix G, the sit-to-stand activity is described. At that point, I gave the participants the opportunity to ask questions and attempt the sit-to-stand activity.

During the 4-week activity, I supported participants by weekly visits, which was discussed with participants to accommodate their schedule. In the course of the visits, I engaged in participant observation, as well as in informal ethnographic interviews. “Informal ethnographic interview occurs whenever the researcher asks someone a question during the course of participant observation” (Spradley, 1980, p. 123). After the four-week intervention with weekly visits, I conducted the last set of face-to-face interviews.

Before participants started to perform the sit-to-stand activity, data making procedures mainly focused on the first research question: what are Brazilian older persons’ perceptions and experiences with mobility challenge? After participants started to perform the sit-to-stand activity, data making procedures mainly focused on the second research question: how do

Brazilian older persons with mobility challenges experience the sit-to-stand activity? Please refer to Appendix F.

Participant observation. Participant observation refers to a process of learning through exposure to or involvement in routine activities of participants in the research setting (Emerson, Fretz, & Shaw, 2007). Participant observation allowed me to legitimize my presence in the setting; identify and build relationships important to the future of the research endeavor; capture the context and physical environment where mobility occurs, and; provide insights regarding interactions (Coker, Ploeg, Kaasalainen, & Fisher, 2013).

Particularly, this participant observation included the following topics relating to the participants mobility and sit-to-stand activity: noting the arrangement of their physical space; the presence and arrangement of individuals within that space; the specific activities and movement of individuals in a scene; the interaction among individuals in the scene (and with the researcher); sequence of events and any interruptions; the specific words spoken; nonverbal interaction, including facial expressions, and circumstantial and background data about the key roles in the household. Please note that despite other individuals being in participants' homes during the course of data making, they were not part of my data. In particular, I was able to observe how well participants were doing the sit-to-stand activity and which factors facilitated or hindered the appropriateness and usefulness of the sit-to-stand activity in their daily lives. The timing and the duration of each observation was negotiated with each of the participants.

As participant observer, researchers become a research instrument as they reflect and document the emotions and feelings of the participation. Spradley (1980) expressed the importance of the researchers being introspective, which is to be able to use their own feelings to assess the feelings of an experience following an observational activity. The researcher must

have the ability to be both researcher and participant, gain explicit awareness of the participation, and view every angle of the activity through documentation of these events.

As the research instrument, my close connection to the culture of this setting required me to maintain an awareness of the situation. Spradley (1980) described that when one is very close to the culture being observed, the tacit or cultural awareness outside one's knowledge may be overlooked. Since this awareness was brought to my attention, the familiarity with this culture was used to my advantage because less time was needed to become familiar with this specific culture.

There are many types of participation for a participant observer. For this study, I engaged in a continuum of roles varying from passive participant to a moderate, or minimally active participation. My position was supported by Hammersley and Atkinson (2007), who argue that there is no single theoretical standard typology of participation; rather, it is on a continuum. As a passive participant, the researcher is "present at the scene of action but does not participate or interact with other people to any great extent". Thus, a passive participant will be involved in a social situation by means of their presence in the field. Conversely, when I engaged in moderate participation I sought to maintain a balance between being an insider and an outsider, between participation and observation (Spradley, 1980, p. 60). During moderate participation, I supported participants by guiding and instructing the sit-to-stand activity.

Field notes. An important tool for making the ethnographic record of a social situation in ethnographic studies are field notes. Field notes are a tool whereby a participating observer transforms portions of his or her experience into notes (Emerson et al., 2007). In this study, by field notes, I meant written or otherwise documented records of observational data produced by fieldwork (Hammersley & Atkinson, 2007). This written or otherwise documented record

included descriptions of: a) informal conversations and more formalized interviews; b) photographs, maps and drawings of physical environments that facilitated or hindered their mobility and appropriateness and usefulness of the sit-to-stand activity; c) patterned mobility behaviors, which embodied and exemplified culturally significant knowledge and attitudes. Therefore, field notes were employed during every instance of data making after every contact with participants, i.e., not just after or during participant observation, but also after informal conversations and interviews.

Data Management Procedures

In order to establish and maintain responsible ‘data stewardship’ practices, I digitalized all components of the ethnographic record after data was collected. Within every digitalized ethnographic record, all personal identifying information was removed and each participant was assigned a code. A copy of the list that matches the participants’ names to their code was kept in a locked filing cabinet and another copy was encrypted on a computer that was protected by a password. Data was only shared with the members of the research team after all identifiers were removed (Boruch & Donnelly, 2015).

Also, after all personal identifying information was removed, data was catalogued, sub-filed, and stored by participant code. All the digitally recorded data (e.g., field notes, transcripts) were saved in encrypted and password-protected files on my personal computer on a password-protected secure shared drive, i.e., Dropbox®. The hard copy of all ethnographic data was stored in my home office in a locked filing cabinet. The digitally recorded and hard copy data will be stored for five years after the study ends.

To maintain a systematic record of the study data and to assist with data management and analysis, a software program (i.e., NVIVO, QSR International, 2000) was employed. Advantages

of using a computerized data management system rather than a paper-based one included its capacity to assist the researcher to record, store, index, edit, sort, browse, code, and link study documents digitally. The qualitative analysis software assisted data management efforts in numerous ways. For example, this software allowed the efficient aggregation of data, as well as keyword searching (i.e., key-word in context). Keyword-in-context is a computer-aided, not automated, tool which a researcher employs to find highly used symbols (words or phrases) to observe trends of overproduced concordances and participants use of language (Wood, 1984).

Data Analysis

“The purpose of ethnographic analysis is to organize the data and then make sense of what you [the researcher] have learned during the research experience” (Roper & Shapira, 2000, p. 91). In ethnographic studies, data analysis requires intimate knowledge of the data. It begins with the recording of the first field notes, and ends only after informational redundancy is achieved and the final report is written. However, in between the first field notes and informational redundancy, the ethnographic record is coded and categorized into meaningful pieces, which are then examined for themes – patterns that explain the phenomena of interest (Roper & Shapira, 2000).

Like many other qualitative studies, data making and analysis occurred simultaneously, as the aim of data analysis was to provide a rich, detailed description of the culture (Richards & Morse, 2013). All the data were analyzed in the form of written words. Observations and informal conversations were converted into field notes, and audio-recorded interviews were transcribed.

Content analysis. Qualitative, inductive content analysis was used to analyze the transcripts. This is described as a process for making valid inferences from the data in order to

increase understanding and gain new insights about the phenomenon (Elo & Kyngäs, 2008). In the beginning of the process of analysis, as soon as possible after each interaction with each participant, I jotted hand-written field notes. Then, I re-accessed the data by checking for accuracy, italicizing or bolding words for emphasis, and inserting in the appropriate places paralinguistic features (e.g., body language, gestures, facial expressions, tone and pitch of voice) that I might have recorded in the field notes.

The steps that followed were (1) coding and categorization; (2) memoing, and; (3) theming. I described each step as if there were a linear process in the analysis. In fact, there was nothing linear about the analysis of ethnographic data. I moved back and forth among the steps. Although memoing is described as though it occurs exactly at mid-analysis, it actually did not; it happened continually as I moved through the analysis. Memos were my own thoughts about the data that, combined with my coding, led to the development of themes.

Coding and Categorization. Coding was a means of segmenting the data into smaller pieces by identifying key concepts and underlying patterns in the data (Kvale & Brinkmann, 2009). This process was conducted using NVivo. Initially, I re-read the transcript to become more familiar with the data and obtain a sense of the whole (Tesch, 1990). Subsequently, key words and phrases were highlighted line-by-line with analytic notes being recorded in the margins. Then, when important words and phrases were identified and labeled, I created codes based on words and ideas within the data (also known as open coding). At first, codes were broad and generic to help make sense of the data, and more abstract codes were developed as the analysis progressed (Hammersley & Atkinson, 2007). With each new concept that appeared, previous data was reviewed to add additional codes where appropriate.

As the coding process continued, categories were created linking together the relationships between codes and ideas within the data. To assist in the development of categorization, data was reorganized by grouping together related codes rather than by chronological order. Using NVivo, a data matrix was generated to summarize data and to compare and contrast the experiences of each participant (Roper & Shapira, 2000). The final categories were the ones that re-occurred frequently in the interviews and were central concepts in answering the research questions. A summary was then written for each category, which was then reviewed for homogeneity (Mayan, 2009).

Memos. During this whole process, I constantly formulated analytic memos, which are free-style records of the ideas or insights the researcher has about the data. This strategy was used to assist me in making conceptual leaps from raw data to those abstractions that explain research phenomena in the context in which it was examined (Birks, Chapman, & Francis, 2008). In this study, memos were written constantly throughout the research process.

In contrast to field notes, analytic memos are records of the researcher's developing ideas about codes and their interconnections (Groenewald, 2008). These memos are a documentation of the researcher's thinking processes rather than a description of a social context. By theorizing from the data, memos transform field note descriptions into theoretical accounts. Thus, memos are a form of coding that is done as the researcher collects data and reviews interviews, observations, and relevant documents. They often pull together notations that have commonalities and allow one to make connections between pieces of information. These categories may guide the researcher's decision to follow some avenues for more intensive investigation, while ignoring less promising aspects of the project (Roper & Shapira, 2000).

Themes. Themes are relationships between the codes, categories, and the larger patterns woven throughout the data that make up the “cultural scene” (Spradley, 1979). With ongoing analysis of the interviews, developing themes were incorporated into following interview questions. This assisted me to identify patterns between participants and to confirm or reject emerging concepts (Kvale & Brinkmann, 2009). Hammersley and Atkinson (2007) state that theorizing involves moving between ideas and the data and identifying relationships; ideas are used to make sense of the data, and data are used to change our ideas. Ideas do not simply ‘emerge’ from the data, instead the researcher draws on existing knowledge of the phenomenon, experiences in the field, and the analytic work completed throughout the research process (Hammersley & Atkinson, 2007). These resources are important for making sense of the data, but are not used to impose interpretations or prejudgments on the data.

Data Translation

Translation from one language to another must be considered as an issue in its own right to maintain the integrity of the research, especially in an ethnographic study. In qualitative research, the translator must aim to achieve credibility to reach valid findings (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015). In this study, translation was required because the study participants and some of the researchers spoke different languages, Portuguese and English respectively, and the target language for the final report and for subsequent peer-reviewed publications will be English (Nurjannah, Mills, Park, & Usher, 2014) and Portuguese.

I worked as a translator-moderator conducting the interviews in the participants’ native language (Van Nes, Abma, Jonsson, & Deeg, 2010). I did not employ a professional translator to back translate the interviews from English to Portuguese. I was confident I was a suitable choice to be the translator-moderator and that there was no need to employ a professional translator to

back translate the interviews. That was due to the fact that I am fluent in both the source language, which is my mother tongue, and the target language, English. In addition, I am sufficiently educated to be familiar with the concepts and with the formal and specialized language used in the data (Birbili, 2000; Chen & Boore, 2010). I had easy access to the memos I wrote and was able to incorporate these memos into the process of translation. Thus, my bilingual abilities helped me construct meaning, analyze and reflect on this construction, as well as transfer the data to the English language (Edwards, 1998; Temple, 2005). In this research, only one translator-moderator was used to ensure the consistency and conceptual congruency of both the oral and written translation processes (Larkin, de Casterle, & Schotsmans, 2007; Twinn, 1997). As the process of data collection and analysis is developed in parallel in ethnography, my position of translator-moderator was fundamental to the process of concurrent data collection and analysis. Additionally, during the translation of the first three interviews a Brazilian nurse, who is proficient in Portuguese and English, assisted me with the translation.

After I conducted the translation of the interviews from Portuguese to English, the interviews were analyzed by two supervisors and me. I am a Brazilian, PhD candidate with 1) a Bachelor of Science in Nursing, 2) a Licentiate degree in Nursing, 3) a Master of Arts in History of Health, and; 4) a Master in Social Sciences with a minor in Health and Society. My native language is the same as the participants, Portuguese. My advisors are Canadians. One has French as her mother tongue and is fully bilingual in French\English, the other has English as her native language. All data was generated in the participants' native language. I conducted the data analysis with some initial assistance from both of my Canadian supervisors. My supervisors participated in the analysis process by checking the coding for intellectual rigor, we discussed the results of initial coding, and they guided me as I moved forward with the coding process.

The translation procedure: step-by-step. The translation procedures occurred in different moments. First, all information material submitted to participants, consent, as well as the guiding questions were forward translated from English (the original language used to develop these items) into Portuguese by myself. Later on, after the interviews were produced, I transcribed the first three interviews in Portuguese. After these three interviews were transcribed in Portuguese I translated them into English and a Brazilian nurse, who is proficient in Portuguese and English, examined the original and translated versions observing their differences and comparability. Subsequently, the English translation of the interviews and their original Portuguese versions were sent to both supervisors who reviewed the transcripts with me to discuss strategies for interviewing. Then, I coded the interviews and discussed my coding with my supervisors (Armstrong, Gosling, Weinman, & Marteau, 1997). Each code produced was accompanied by a set of quotes in both Portuguese and their respective English translations. After the supervisors received and analyzed a subset of the codes, we debriefed, discussed and negotiated agreements and disagreements about the codes (Olesen, 1994; Waitzkin, 1991).

Once my supervisors and I came to an agreement about the nature and congruence of the codes and the data therein, the coding continued to be treated in the source language, Portuguese. Van Nes et al., (2010) advocate the use of the original language for as long as possible to avoid the potential of limiting the quality of the analysis. Abstract thinking, required as part of the abductive logic applied in ethnography data analysis, is less difficult in the original language. A researcher trying to engage in complex, abstract thinking in a language other than their first language may be distracted from important findings in the data because they are trying to understand the finer points of language (Nurjannah et al., 2014).

Following the completion of the coding in Portuguese, I looked for patterns to form categories. When I completed the formation of categories, I sent a translated copy of these themes in English to the supervisors. Each of the categories produced was accompanied by a set of quotes in both original Portuguese and their respective English translations. After the supervisors received and analyzed a subset of the categories, we debriefed, discussed and negotiated agreements and disagreements about the categories (Olesen, 1994; Waitzkin, 1991).

Later, I proceeded in establishing themes, which was conducted in Portuguese, aimed to construct the “cultural scene” (Spradley, 1979). Each theme produced was accompanied by both original quotes in Portuguese and their respective English translations. Then, the themes were translated into English and the supervisors and I again debriefed, discussed and negotiated agreements and disagreements about these themes (Olesen, 1994; Waitzkin, 1991).

During all stages, my supervisors and I discussed the most appropriate conceptualizations using a dictionary and a thesaurus. Word choices made by researchers were discussed to find the closest meaning in English. This entire process allowed researchers to share meaning making about high level conceptual analysis and also to share understanding of two different cultures. I provided the necessary translation and explained each code, category and theme, in depth as it was constructed. I also checked memos related to data analysis and included these memos in the discussion. Memo translation was conducted orally and as needed. Temple (2002) notes that the emphasis of translation should not be solely on the precision of word choices because translation, in this sense, is about recreating meaning rather than revealing it. Discussion can be used as a procedural tool for achieving conceptual equivalence because these oral translations aid understanding. Furthermore, discussion can be considered to be a process of decentering,

especially when it is found that some phrases cannot be translated accurately into the target language because of differences in culture and language (Su & Parham, 2002).

Writing an Ethnography

Although writing is a continuous process throughout data collection via observation field notes, code and identifications, construction of negative cases, and creation of new questions and lists, Spradley (1980) explained that an ethnographer's best way to learn to write an ethnography is to actually to write an ethnography. Once this process is in the final phase of study, Spradley (1980) provided suggestions and stated the "nature of ethnographic writing as part of the translation process" (p. 161).

An ethnographer, as a translator of a cultural scene, has two major tasks to clearly accomplish for ethnographic writing. The first task is to make sense of the cultural patterns observed. Decoding and analyzing the cultural behavior, the artifacts, and the knowledge must be clear, in-depth, and fully engaged with the cultural scene in order to effectively correspond the final translation of the social situation. The ethnographer's second task is to clearly communicate the cultural meanings to an audience that may or may not have prior knowledge of a particular cultural social situation. In all reality, the ethnographer must be bi-lingual in a cultural sense. The ethnographer must hold intimate knowledge of the audience's culture and the cultural situation being translated.

Therefore, instead of viewing ethnography as one task, the researcher should see it as a series of steps. The first step is to select an audience that will be reading the ethnography (e.g., the readers of a scientific journal or thesis). Step two is to select a thesis that will be presented. Step three is to make a list of the topics and create an outline. Step four is to write rough drafts of each part of the outline. Step five is to revise the outline and create section headings. Step six is

to edit the rough draft. Step seven is to write the introduction and conclusion. Step eight is to insert examples and edit the copy. Step nine is to write the final draft.

Ethnography and Ethical Considerations

This research study was submitted for ethical review by the Health Research Ethics Board at the University of Alberta and the Research Ethics Board in Brazil. Because I am a PhD candidate at the University of Alberta and the study was conducted in Brazil, ethical approval from both Boards was required. In this section, I discuss the main ethical considerations of the study. It is acknowledged that the great variation and complexity of fieldwork situations make it difficult, if not impossible, to adopt a single set of standards for all ethnographers (Spradley, 1979). Despite difficulties in achieving a code specific enough to use as a mechanism of social control, a code of ethics can help improve anthropological practice (Cassell, 1987).

First, I believe the therapeutic imperative of nursing (advocating for safe patient care/beneficence, safe nursing practice environments, and advocating for nurses) takes precedence over the research imperative of advancing knowledge should a conflict arise. Second, I believe that research participants are collaborators and co-creators of the research enterprise: they are participants, not objects or subjects. Last, so that fieldwork is existential and authentic, there must be trust between participants and the researcher. Although I invited individuals to participate in the study, being admitted into the participants' world was, without a doubt, a privilege. The following are the main ethical consideration of the research: (a) the vulnerability of the research participants (risks and benefits), (b) confidentiality, (c) autonomy of participants' involvement, (d) informed consent, and (e) researcher's safety.

Risks and Benefits for Vulnerable Participants

To address the vulnerability of the research participants (risks and benefits), I:

- (1) Provided participants with an information letter outlining the purpose, risks and benefits of the study.
- (2) Informed prospective participants that participation in this study was voluntary and that they could decide to no longer participate at any time during the data collection
- (3) Made clear that participants were free to withdraw from the study at any time without any repercussions to their health care
- (4) Made clear to participants that they could refuse to answer any question
- (5) Provided the contact of a health care provider to assist participants, if they felt distressed or were injured during the research process.
- (6) Paused the recorder in the event that participants became distressed during the interview, and I asked whether they wanted to continue after the pause.

During the interviews participants did not ask to pause, I also did not observe participants being upset. Participants did not mention becoming injured as a result of the sit-to-stand activity; however, they related some fatigue after doing it.

Confidentiality

Confidentiality is a principle under the Belmont principle of benevolence and will receive special attention. Confidentiality refers to the obligation of the researchers to respect the privacy of the individuals they study, safeguarding entrusted information from what is said and observed in confidence and not identifying specifically from whom or how information has been obtained (Schensul & LeCompte, 2012b). The ethical duty of confidentiality includes obligations to protect information from unauthorized access, use, disclosure, modification, loss or theft. To ensure confidentiality of the research participants, I:

- (1) Maintained awareness that when research was conducted in the participants' home possible violations of privacy could occur. I was cautious to maintain the boundaries of the participants' confidentiality. Participants may have felt comfortable and safe in their home environment leading them to share more than they had originally planned (Daly, 1992).
- (2) On completion of the study, I will store all data in a locked file cabinet designated for this purpose and maintain the data as guided by university policy, in sealed envelopes clearly marked with study name, name of researcher, and dates of study for five years
- (3) Stored the list of participants' names, contact information, and consent forms in a locked cabinet separate from study material while the study was ongoing.
- (4) Made sure the transcriber I used was informed about confidentiality of research data

Autonomy of Participant Involvement

To ensure autonomy, I:

- (1) Assigned a pseudonym and codes to each participant to disguise and de-identify them in ways that may prevent others from being able to identify them.
- (2) Gave participants my contact information so that if they desired to have their information not included in the study in the first two weeks following their participation in the study, materials would be removed and kept in a sealed envelope separate from study materials.

Informed Consent

During the research, I:

- (1) Obtained informed consent from all participants for the observations and interviews.

- (2) Negotiated and renegotiated the informed consent to reflect the dynamic nature of qualitative research, as I believe the term ‘informed consent’ is not static. Because there may be unforeseeable events and consequences while conducting a study, a static term for consent was not appropriate.
- (3) Informed participants of the parties who had access (e.g., research team) to the data. This allowed participants to decide about the adequacy of the protections and the acceptability of the possible release of private information to the interested parties.

Researcher’s Safety

To ensure my own safety, I (Williamson & Burns, 2014):

- (1) Before home visits, checked out the location of the home to be visited either through local knowledge (health care team or locals) and familiarized myself with location, entry, and exit from the area.
- (2) Scheduled the visits within office hours and in daylight.
- (3) Carried the minimum equipment necessary to the interview and the minimum amount of cash
- (4) Ensured my mobile phone was fully charged, had emergency contact numbers programmed in, and kept the phone switched on at all times.
- (5) Dressed appropriately for the research setting: flat shoes, trousers, smart casual.
- (6) Provided no personal details to the participant beyond my information provided on the participant information sheet.
- (7) Parked my bike as close to the participant’s home as possible ensuring it was parked so that the exit could be prompt.

- (8) During home visits, always made sure someone knew where I was and the timeframe for my visits. I also had arrangements to contact someone to let them know I had finished and was on my way home.
- (9) Conducted the interview in a public room at the participants' home where possible.
- (10) Identified the safe exits from the participant's home as I went in.
- (11) Made sure to contact my supervisors for guidance if I had to deal with issues in the field.

Establishing Rigor

It is possible that different researchers observe the same phenomenon and produce distinctive but equally valid accounts of it (Agar, 2006; Hammersley, 1990; St.Pierre, 1999). Any qualitative research is, therefore, an interpretation – but one interpretation is not necessarily more correct or truer than another (Agar, 2006). Yet, rigor is an essential concern in the conduct of any given research. Rigor is characterized when research methods are justified, the process is transparent, the outcomes are defensible, and the findings are viewed as applicable by research consumers” (Collins, 2015, p. 241). Tracy (2010) has identified a number of criteria for operationalizing the trustworthiness of qualitative data encouraging scholars to reflect and adapt the variety of crafts available and develop their own style. In this section, I describe specific criteria that I incorporated in this study to increase the trustworthiness of the results.

- (1) A worthy topic is necessary for a research study to be relevant, timely, significant, interesting, and make a unique contribution to the field. To meet this criterion, I selected mobility as a topic that has not been significantly researched within the older population of developing countries. Therefore, the merit of researching this topic relies on an active effort to not commit cultural imperialism by assuming the sit-to-

stand activity is appropriately transferable beyond the cultures in which it has been tested.

- (2) Sincerity is used to refer to authenticity and genuineness. When the researcher is honest and transparent about the process of inquiry and his/her personal role in the study then sincerity is demonstrated. Sincerity comes from reflexivity about researcher's subjective values, biases, and personal inclinations as well as transparency about the methods. To achieve sincerity, I wrote a reflexive journal, where I logged the details of how my assumptions and personal reactions may have influenced the results of each interview and observation, as well as wrote to myself (a) my agenda as a researcher i.e., my background, previous scholarship, the genesis of the project (why the study was undertaken and why it matters, and to whom); (b) my assumptions as an individual, i.e., it is more beneficial for older persons to be active, mobility is a suitable means to engage in activities of daily living instead of simply going beyond daily needs to, for example, discover new places; (c) my process, i.e., if there was more than one step in the analysis and if there were any opportunities to reassess or revise the process of data making; (d) the intersubjectivity of the findings: other individuals who co-constructed and reviewed the interpretation of the data, i.e., supervisors, committee members; (e) self-interrogation, i.e., if I found any contradictory or disconfirming data, or if everything fit neatly into tidy categories; (f) audit trail, i.e., a track of my choices, hunches, and interpretations (Probst, 2015).
- (3) Credibility reflects trustworthiness and plausibility of research results. To achieve credibility, I provided thick descriptions and concrete details (detail-oriented and

context-specific data provision), along with participants' voices and experiences. In attempting to provide a thick description, data was shown through quotes from which readers will be able to reach their own conclusions. Equally importantly for credibility, accuracy of representation was attempted through crystallization of meanings between the principal investigator and two supervisors, who guided me through all these steps. According to Tracy, "the goal [of crystallization] is not to provide researchers with a more valid singular truth, but to open up a more complex, in-depth, but still thoroughly partial, understanding of the issue (Tracy, 2010, p. 844)". Additionally, member checking was employed as a reflexive mode of knowledge production (Cho & Trent, 2006). It ensured agreement in the representation, as participants had the opportunity to discuss and negotiate the meanings of the interviews.

- (4) Resonance is the term Tracy (2010) uses to describe the ability of the study results to affect the audience and promote empathy and identification with the participants. It can be achieved through clear, comprehensible writing that is targeted to a specific audience, as well as through transferability, which is the potential of the study to be relevant in other contexts and with other populations. It was addressed by the detailed descriptions of the participants and their context, so that readers can judge if the characteristics of this study are similar enough to their own context to allow transferability of the findings.
- (5) The criterion of significant contribution refers to theoretical, heuristic, and practical significance of the study. I addressed the significance of this study at the end of Chapter One. It is my hope that this study focusing on the pre-feasibility of a mobility

- intervention generates further debate and inspires future research. I also hope that my study will help to maintain the mobility of older persons.
- (6) A high-quality study must be an ethical study. To address the procedural ethics requirement, I sought permission to conduct this study from the health research ethics board in Canada and Brazil. In addition, I paid attention to ethics during the study. I also made an effort to avoid deductive disclosure, i.e., the identification of an individual's identity using known characteristics of that individual, by being as neutral as possible in my description of participants and their stories.
- (7) Meaningful coherence, in Tracy's (2010) framework, is present if the study achieves the proposed goal, the methods match the research paradigm, and the reviewed literature is connected with the results and the conclusions of the study. To address this criterion, I selected methods and procedures that fit my stated goal. Furthermore, I have linked the background literature to my research questions. I also relied on my supervisors' and committee's expertise and other graduate students' suggestions on whether the study was coherent and consistent.

Summary

The purpose of this study was to examine the perceptions and experiences of mobility challenges in urban Brazilian community-dwelling older persons and to examine study participants' perceptions about a sit-to-stand activity. Thus, in this chapter I have discussed the methodological perspective and assumptions for this study, as well as identified the method and rationale for the current study based on the nature of the inquiry. Likewise, I have discussed the detailed plans and processes that I used in conducting study, which include the study setting, the

population, the sample and sampling, methods or strategies for data making, the analysis, and rigor as well as the ethical considerations.

CHAPTER FOUR: FIELD ACCESS AND STUDY CONTEXT

In this chapter, I describe the surroundings, environmental forces, and situational opportunities and constraints of the study and the characteristics of the community-dwelling older persons who participated in this research study. As qualitative research is particularly context-sensitive, I also offer the reader relevant details about my presence in the field and, therefore, my process of co-construction of meanings.

Preliminary Fieldwork

Before this research, I already had some understanding of the culture of Paquetá Island and of the structure and functioning of the Brazilian health care system. Yet, my membership role was peripheral (Adler & Adler, 1987). I am a Brazilian, female, middle-class, young adult who does not participate in the core activities of the participants in this research, community-dwelling older persons living in Paquetá Island, and have spent the past ten years of my life studying and living abroad. I was situated in the ‘space between’, I held a membership in the group without a complete sameness within the group (Dwyer & Buckle, 2009). In this regard, just having a partial membership in the group being studied could only go so far in reaching a more refined understanding of their mobility experience. Understanding their experiences would require more than simply sharing some commonalities of our culture. It would require going beyond and noting the ways in which we were similar and then start to observe ways in which we were different.

Therefore, understanding participants’ mobility experience implied that I be able to identify, describe, and explain it using reflexivity regarding my “space between” (Fay, 1996). That required the ability to construct a situational identity that not only considered my research-based self, but to examine the parts of me that have historically, socially, and personally created

my standpoints as well as my ongoing formation of situationally created selves (Reinharz, 1997). Reinharz (1997) uses the word ‘selves’ referring to the variety of inner attributes researchers create and/or bring to the field. The author reveals approximately 20 different selves she brought to the field. They were divided into three major groups: (a) research-based selves: being sponsored (removing herself from the sponsor), being a researcher, being a good listener, being a person who has given feedback, being a person who is leaving; (b) brought selves: being a mother, having relatives, being a woman, being a wife, being an American, being a Jew, being academic, being 33 years old, being a dance enthusiast, being a daughter, and; (c) situationally created selves: being a resident (“temporary member”, not true member), being a worker, being a friend, being a psychologist/social worker, being chronically exhausted, sick, and sometimes injured.

Hence, it seemed advantageous to spend some time observing the contextual (physical, social and healthcare) environment first-hand. The time spent on the Island and at the healthcare organization prior to contacting potential research participants not only assisted me in building my situationally created selves, but also helped me to understand some contextual determinants of participants’ health. Here, I am assuming that health is not only dependent on the living conditions and health of the population, but also on the context in which health services are offered, the participants’ living space, as well as the environment and healthcare processes at the healthcare center. This process of constructing my situationally created selves and becoming more familiar with participants’ contextual determinants of health started with a pre-entry phase divided into distinct moments. In the first moment, I tried to revisit the country and state history, and understand the Island history and environment. In the second moment, I accessed the healthcare center and became more familiar with the research context of health and healthcare.

The last and third moment, which occurred during the process of recruitment and selection of participants, I became more familiar with the sub-cultural group of Brazilian community-dwelling older persons living on the Island. In the next sections, I describe my pre-entry phase.

Pre-Entry Phase

I received permission from the healthcare center to recruit potential participants two years before I started the co-production of data with study participants. After the healthcare center was identified and access to their physical space, gatekeepers and patients was granted, I submitted my research proposal to the University of Alberta Health Research Ethics Review Board in Canada, where I am studying. After approval of the research project in Canada, I submitted my research project to the National Commission for Research Ethics (*Comissão Nacional de Ética em Pesquisa*) in Brazil and they appointed the Centro Universitário do Distrito Federal as my Institutional Review Board. This research project was approved by the Canadian and Brazilian ethics review boards under the numbers Pro00081957 and 2.878.399, respectively. The events in between the granting of my access to the field and my first contact with potential research participants are described here.

Contextualizing the field

Brazil. Situated in South America with over 8.5 million square kilometers of area, Brazil is the fifth largest country in the world. Its 7,400-kilometer shoreline is exceeded by 15,700 kilometers of land borders. Brazil is bathed by the Atlantic Ocean and has one of the largest hydrographic basins in the world. Rising to an average elevation of 1,000 metres above sea level, Brazilian highlands are made up of low mountains, hilly uplands, and tabular plateaus. The country is divided into five regions (Northeast, North, Midwest, Southeast and South) and has 26 states and one Federal District. It borders Venezuela, Guyana, Suriname, French Guiana,

Colombia, Peru, Bolivia, Paraguay, Argentina and Uruguay. This means that it borders almost all the countries of the South American subcontinent, except Chile and Ecuador.

Brazil is also one of the most populous countries in the world, but, despite having over 210 million inhabitants it is qualified as sparsely populated by the fact that it has 22.4 inhabitants/km². According to Schneider (1996), “Brazil is so diverse that generalizations about it run serious risk of being either bland platitudes of the lowest-common-denominator-variety or averages that mask great variations” (p.1). Hence, to better grasp the research study context I highlight some distinctive characteristics of this region to move towards the setting of this study – Paquetá Island in the city of Rio de Janeiro. Before I outline such a trip, however, a few fundamental facts must be presented. First, Brazil is a federal nation in which the states enjoy considerable autonomy and are potent political actors. Second, Brazil is increasingly a highly urbanized country. It was 36% urban in 1950 and 56% by 1970. In fifty years, between 1950 and 2000, the urban population increased by 633.4% and in the year of 2000 it was 81% – a very high sustained rate of urbanization (Guerra & Vitte, 2004). In excess of one in three Brazilians live in fifteen metropolitan regions of over one million inhabitants, with nearly half of these in greater São Paulo and Rio de Janeiro.

Rio de Janeiro. Undoubtedly the different regions of Brazil are very unique and particular. The Southeast region, which includes the state of São Paulo, Rio de Janeiro, Minas Gerais, and Espírito Santo contains the greatest concentration of population with over 80 million persons, is heavily urbanized – and of high economic activity (Instituto Brasileiro de Geografia e Estatística, 2013a). With 11% of the country’s area, the southeast has 42% of the nation’s population as well as nearly 62% of the GDP and over 70% of its industry. Rio de Janeiro

provides 11% of the GDP and occupies sixth place in exports (Instituto Brasileiro de Geografia e Estatística, 2013a).

The same size of Switzerland (with a population pushing 17 million) Rio de Janeiro is one of the cultural capitals of Brazil. With its world-famous white sand beaches and sunny weather, Rio de Janeiro is notably in the center of Brazil's multibillion-dollar tourist industry. Social inequity is concentrated not only in its colorful hillside *favelas* but also in the extensive belt of industrial suburbs that surround the city proper to the north and west; it is also the seat of a large bureaucratic middle-class. Its commerce and employment fluctuate with the national economic situation.

Favela means a Brazilian shack or shanty town; a slum located within or on the outskirts of the country's large cities. The meaning of *favela* denotes popular housing built in an informal, precarious way and without infrastructure. Most of the housing in the *favelas* do not have aspects necessary to guarantee the health and well-being of those who live there, such as a sewage network, garbage collection, collective transportation, water or energy supply, among others. *Favelas* are usually built of wood or masonry – the latter may even contain a little comfort, but despite this, there has been no planning or any supervision by competent bodies and, therefore, these places become densely populated with houses with no spacing and divided by small alleys. In Brazil, *favela* is linked to marginalized groups, social exclusion and lack of assistance, being located in irregular areas and becoming a neighborhood after disorderly housing expansion. Favelas can be found on hillsides and even on banks of streams or rivers.

Paquetá Island. Paquetá Island is situated in the Guanabara Bay, which is the most prominent coastal bay in Brazil. The metropolitan region of Rio de Janeiro surrounding Guanabara Bay – often referred as the continent – has nearly 11 million residents, including

those in the city itself and in the ring of largely working-class suburbs forming a horseshoe around it (Perlman, 1976). Several of these have populations in the 400,000 to over a million range. Domestic, largely untreated, runoff from at least 7.81 million inhabitants discharge directly into the Bay. Guanabara Bay is bordered by 6000 industries, with more than 6000 additional industries in the drainage basin, and is home to two oil refineries responsible for the processing of 17% of the national oil. The bay itself measures 384 km², with Islands constituting 56 km² of its area. One of these Islands is Paquetá.

Paquetá Island covers an area of just over 1.2 km² and is divided into two parts connected by a narrow called Ladeira Vicente, which is around 100 meters wide and gives the Island the shape of an eight if seen from above. The Island is located approximately 20 kilometers from Praça XV, in Rio de Janeiro's downtown, and on the northeast of Guanabara Bay. The streets on the Island are not made of asphalt. They are made of cobblestones and clay, a type of coarser sand. The Island contains more trees than the continent.

The first record of Paquetá Island is from 1555, when André Thevet, cosmographer of the expedition of Villegagnon, arrived in Paquetá in his mission to establish France Antarctica. Estácio de Sá, a Portuguese soldier and officer, who travelled to the colony of Brazil on the orders of the Portuguese crown to fight the French colonists, defeated the French and colonized the new lands. In 1565 the city of São Sebastião of Rio de Janeiro was founded (Thevet, 1953; 1997).

In that same year (1565), the Island of Paquetá was donated by Estácio de Sá to two of his trip companions. The northern part was given to Inácio de Bulhões and the southern part given to Fernão Valdez. The division of the Island between Bulhões and Valdez was based on the Ladeira Vicente narrow, a natural demarcation which has influenced the different lifestyles on

each side. The southern side of the island colonized faster while the northern side was characterized by the development of a farm, Fazenda São Roque, which had an extensive agricultural area and raised livestock.

In 1908, water was ducted by submarine pipelines to Paquetá. The sewage collection and treatment system was completed in 1912 and was a pioneer system in Brazil. Street lighting, as well as the electricity distribution service to homes, was inaugurated in 1918. The energy comes from a bigger neighboring Island, Ilha do Governador, through submarine cables.

Today, Paquetá is a neighborhood in the city of Rio de Janeiro, linked to the downtown sub-prefecture (AP-1 - Planning Area-1). It is considered to have a seasonal population with approximately 2200 households (between residents and vacationers). According to the latest demographic census (Instituto Brasileiro de Geografia e Estatística, 2010c), people who move to the Island are trying to escape the city's heavy road traffic and inflated real estate prices, as well as wishing to live in a place with a low index of urban violence. It is common to witness children on the street playing with each other and adults hanging out at the doorsteps of their houses until late at night.

Results from the last national census in 2009 revealed that there were 4,500 people permanently residing on the Island. Of these 4,500 individuals, 20.8% are older persons, a percentage surpassing the national average that is around 12% (Instituto Brasileiro de Geografia e Estatística, 2009b). Statistically, it makes Paquetá the neighborhood with third oldest population in the city of Rio de Janeiro. The majority of the population is White, 10.9% are Black, 25.6% are *Pardo* and 0.1% are Indigenous. About 90% of the households have treated water and 99.57% have treated sewage. The average family on this Island is composed of three individuals, with an average income per capita of R\$ 457.61 Brazilian Reais (IPEA, 2000). By

comparison, people living in the state of Rio de Janeiro have an average income of R\$ 794 and R\$ 1,039 Brazilian Reais, respectively. To contextualize, the Human Development Index (HDI) of the city of Rio de Janeiro was of 0.799 in 2010, which places this municipality as a High Human Development range (between 0.700 and 0.799). The dimension that contributes most to the HDI of the municipality is longevity with an index of 0.845 (Atlas do Desenvolvimento Humano no Brasil, n.d.).

Due to historic events previously mentioned, the Island is divided into two “sub-neighborhoods” and this division plays an important role in the local culture. One of the sub-neighborhoods ‘Campo’, which in Portuguese means countryside, is a name inherited from the farm previously located there, Fazenda São Roque. It is situated at the north side of the island facing the bottom of Guanabara Bay from which there is a view to a mountain range and a national park, Serra dos Órgãos. The other sub- neighborhood ‘Ponte’ was named because of its location at the docking bridge for the ferries. It is situated at the south side of the island facing the city of Rio de Janeiro and the entrance to Guanabara Bay.

The neighborhood of Paqueta is completely atypical in relation to the other neighborhoods in the city of Rio de Janeiro because: (1) it is an island with a ferry as the only way to get in and out; (2) private cars are not allowed; people walk or use bicycles, rickshaws (bicycles pulled by cyclists), electric carts, boats and canoes (Instituto Brasileiro de Geografia e Estatística, 2009b); (3) the streets are gravel rather than asphalt to preserve its original bucolic appearance; (4) the neighborhood is quiet and safe in comparison to other neighborhoods in Rio de Janeiro proper, and (5) goods arrive on the Island by either passenger or cargo ferry.

From Monday to Friday, there is a reduced flow of people on the Island. In contrast to many neighborhoods on the continent, older residents usually get together at the public squares

at Ponte sub-neighborhood and, sitting on the benches they chat with each other and play board and card games. Those who work on the continent usually get the first ferries in the morning and return by the end of the afternoon. However, when Saturday and Sunday comes, Paquetá receives a significant number of visitors and depending on the weather, they crowd its 12 beaches.

There are nine hills on Paquetá: São Roque, Castello, Covanca, Costallat, Pedreiras, Paineiras, Vigário, Veloso, and Cruz. Currently, there has been a growth of housing constructions, *favelas*, on almost all hills. However, it is important to emphasize that unlike what happens on the continent, the *favelas* of Paquetá are not controlled by drug trafficking groups. The reason is simple: leaving the Island is logistically complicated for those who need to escape from the police. Just like in all parts of the world there are drug sales but without the use of weapons, which compared to the continent is already a huge advantage (Carneiro, 2016).

Leisure options in the public space also happens on the squares, Tamoios Park and, in particular, Darke de Mattos Park, whose attractions include a vast lawn with century-old trees, a trail that leads to the top of the Veloso Hill and a viewpoint with panoramic view of Guanabara Bay. Of the other types of leisure activities, seasonally there is the traditional Samba party at *Paquetá Iate Clube*. The *Casa de Artes* is where major cultural events happen, such as recitals, exhibitions, courses, workshops, serenades, cinema, chorinho music, among others. At *Casa de Artes* there are also social projects of an artistic nature with children and young people promoting spectacles that preserve and divulge the historical-cultural attributes of Paquetá.

Of course, the options for entertainment are much greater on the continent, which does not stop residents of Paquetá from crossing the sea to enjoy the cultural vivacity of the continent. The bohemian nightlife of Rio de Janeiro does not match the bucolic atmosphere of the Island.

The last ferry connecting the Island to the continent departs at midnight on weekends and bars in Paquetá do not usually stay open after midnight.

In terms of gastronomy, there are restaurants. Some target more the residents of Paquetá due to the simpler and cheaper menu options. Others serve a smaller clientele of residents who have greater purchasing power and also tourists. Most of these establishments are informal environments that do not boast an aristocratic air of sophistication. For those who want to spend the night on the Island, there are four hotels, three inns and a seaside resort. During holidays, rooms are usually booked well in advance; a sign that tourism has generated good business for the local lodging sector. These lodges are mainly family-based ventures.

On the Island there are no big supermarket chains. It has a small main market, which is opposite to the ferry station, in addition to two more on other areas of the Island. There are also some bazaars, some small businesses, two bakeries, an internet cafe, an ice cream parlor, a drugstore, a liquor distributor, a pet store, a newsstand, a home building material store, a decoration shop, a beauty salon, an electronics repair shop, a real estate agent, a gas distributor, a bank branch, and other small establishments.

The cost of living for the residents is one of the worst problems faced on the Island. The transportation of goods from the continent to Paquetá significantly raises the price of the products. Most things usually arrive via small private vessels. Taking into account that most residents have a simple standard of living, they usually leave the Island to go to supermarkets near downtown Rio de Janeiro that offer lower prices and an added advantage of having the purchases delivered to the ferry to Paquetá. This strategy has been adopted by many residents of the Island.

Real estate speculation on the Island has accompanied the rise of this sector that has occurred in all regions of Rio de Janeiro in the last eleven years, but with less force in Paquetá. It is still possible to pay a little more than a thousand and a half Brazilian Reais for rent for a two-bedroom condo on the Island, while in the more exclusive parts of the city this amount more than doubles. The condos on Paquetá are actually a set of houses with two floors where the playground is the public space, such as squares, parks and beaches. For all this, the cost of housing is still one of the high points.

The public services provided on the Island are the fire department, police, urban cleaning and maintenance, electric energy, water and sewage, and post office. It is interesting to note that there are only three police officers on the island at each shift, which lasts for two days. According to the police, the homicide rate is close to zero and assaults are on the verge of extinction. The main complaints are loud noise and aggression between family members or neighbors. In contrast, in 2018, the city of Rio de Janeiro documented 1, 987 fatal crimes (murder, theft followed by death, bodily injury followed by death and death resulting from confrontation with the police) (Instituto de Segurança Pública, 2019).

The three schools on Paquetá are public. One offers pre-school until the 5th year, where about 300 children are enrolled. The second one offers classes from the 6th to the 9th years, with approximately 170 students enrolled while the high school has 150 students. Taking into consideration that according to the Demographic Census (Instituto Brasileiro de Geografia e Estatística, 2010a), Paquetá has a population of 424 children between ages 4 and 14, it is possible to estimate that the great majority of the children and young people study in the Island.

The Integrated Health Unit Manoel Artur Villaboim, subordinated to the Municipal Health Department, has an emergency department open 24 hours per day seven hours per week, with the most serious cases being transferred by helicopter to other hospitals on the continent. In addition, the healthcare center has an ambulatory (outpatient) care offering medical appointments for family doctors, gynecology, pediatrics, dentistry, physiotherapy, psychiatry, among others. As with other public service providers, ambulances are allowed to circulate unrestrictedly across the island.

The neighborhood of Paquetá did not go through the same “modernizing” processes that occurred in the city of Rio de Janeiro, in part due to the fact that it is located 20 kilometers from downtown Rio de Janeiro in the middle of the Guanabara Bay (Carneiro, 2016). Belonging to an environmental and cultural protection area, the Island has a large part of its buildings listed as special cultural or physical significance. Hence, facades from the 19th century and earlier form a rustic and bucolic atmosphere. Legislation prohibiting the movement of motor vehicles, with the exception of those who provide public services, limits internal locomotion, which can only be done on foot or by bicycle. In the midst of an epidemic of urban violence, Paquetá is the neighborhood in Rio with the lowest crime rates, because it has nearly no serious incidents (Carneiro, 2016).

The Island of Paquetá paradoxically encompasses the village pattern – with the logic of community, space, and close contact – and the city pattern – with some anonymity, being in the crowd, in the mix) (Magnani, 1996). The daily flow of residents of Paquetá to the continent brings the two realities together. Indeed, residents live in a village pattern, but their constant travel to the city to work and pursue other activities offers them the possibility of experiencing

the city life style. Thus, due to Paquetá's geography and history, there is an intense connection to the continent and constant articulation between both life styles.

A good definition of Paquetá was made by a resident of the Island, named Fábio Lacerda, when he said: "this is a beach farm" (Carneiro, 2016, p.38). There, it is still possible to witness an authentic community of fishermen living along with traditional families who have been there since the beginning of its occupation, along with intellectuals and artists who have chosen the Island due to its bucolic lifestyle, and children and grandchildren of Northeastern immigrants who arrived there decades ago in search of a better life.

In addition, there are many beaches and green areas on the Island. Having more trees and green areas than the continent, summer days feel less sultry to residents of Paquetá. Different from the continent, every resident lives steps away from a beach or a park. According to researchers, natural environments are increasingly being considered as key settings for health promotion (Hansen-Ketchum, Marck, & Reutter, & Halpenny, 2009; Hansen-Ketchum, Marck, Reutter, & Halpenny, 2011; Mitchell & Popham, 2008). There is indication that engagement with natural environments can have a range of physical, psychological and social health benefits. It has been argued that when adults are in contact to natural environments, they increasingly engage in physical activities (Coombes, Jones, Hillsdon, 2010; Thompson Coon, Boddy, Stein, Whear, Barton & Depledge, 2011). In addition to physical health benefits, there is evidence suggesting that interaction with natural environments can have a variety of psychological health benefits including improved mood and happiness (Barton & Pretty, 2010; Thompson Coon et al., 2011; White, Alcock, Wheeler, & Depledge, 2013, White, Pahl, Ashbullby, Herbert & Depledge, 2013), reduced stress (Grahn & Stigsdotter, 2003; Ulrich et.al, 1991), restored cognitive ability (Berman, Jonides & Kaplan, 2008; Berto, 2005; Kaplan & Kaplan, 1989) and increased

connection to nature (Hartig, Kaiser & Bowler, 2001). In addition, it has been suggested that natural environments might promote increased social contact by making available vital meeting places creating opportunities for social activities to take place (Maas, van Dillen, Verheij & Groenewegen, 2009; Maas, Verheij, de Vries, Spreeuwenberg, Schellevis & Groenewegen, 2009). Next, I describe the history of the Family Health Strategy program in Paquetá and its current context.

Contextualizing the healthcare center

History of Paquetá's Family Health Strategy program. From 1964 to 1985, Brazil was ruled by a military dictatorship. The healthcare system in the country was divided between a social security system funded through payroll contributions and a national health system provisioned by the state. The former was heavily encouraged and had actions directed at the individual health of formal workers and was concentrated mainly in urban areas. The latter was under the control of the Ministry of Health and its actions were directed mainly to rural areas and the poorest sectors of the population, and mainly aimed at preventive activities.

In this context, the health policies of the military governments sought to encourage the expansion of the private sector. Thus, they expanded the acquisition of services through social security and provided corporate incentives for contracting private companies or physicians' cooperatives that provided health services to their employees (Almeida, 1998). Policy makers also sought to privatize part of the state medical services, which were then considered inadequate because they were not profitable. During the 1970s, a strong private medical care structure was built, favoring curative medicine. The private network was financed by more than 80% by the State and resources for health were minimal.

In 1988, with the promulgation of the new Federal Constitution, the process of returning the country to a democratic system was put in motion. Within this context, health became an individual right and the process of creating a public, universal and decentralized health system was initiated. Several factors influenced the creation of this new health system. At the international level, in September 1978, the Conference on Primary Health Care, held in Alma-Ata, proposed the attainment by all peoples of the world by the year 2000 of a level of health permitting them to lead a socially and economically productive life. Primary health care was the key to attaining this target as part of development in the spirit of social justice.

At the national level, the creation of both the *Centro Brasileiro de Estudos de Saúde (Cebes)* [Brazilian Center for Health Studies] and the *Associação Brasileira de Pós-graduação em Saúde Coletiva (Abrasco)* [Brazilian Association of studies in Collective in 1976 and 1979 respectively, influenced the healthcare reform (Escorel, 1999; Paim, 2008). In addition, the development of social movements had an important role in the genesis of this process, with the main ones being the popular and physicians' movements for health.

The popular movement emerged from groups supported by the Catholic Church and left-wing militancy in poor neighborhoods on the outskirts of large cities. It had as one of its main goals the improvement of the health conditions in these regions. In the 1980s, these groups engaged with national meetings for community medicine achieving national expression. Shortly, they changed their focus from local community-based actions to demand (a) mechanisms for socially controlled health care services, (b) betterment of social security, (c) development of preventive actions, and (d) the improvement of living conditions that would enable the achievement of health. On the other hand, the physicians' movement emerged from their criticisms of the health system and struggles of the category for labor rights. Led by medical

associations and unions, strikes and other mobilizations demanded better working conditions and changes in the health system (Paiva & Teixeira, 2014).

The Family Health Strategy was one of the initiatives proposed to ensure health as a social and constitutional right (Cohn, Edison, & Karsch, 1991). The Family Health Strategy focused on the reorganization of primary healthcare guaranteeing the provision of services to the Brazilian population and strengthening the principles of universality, accessibility, comprehensiveness and equity of the Brazilian Unified Health System (Paiva & Teixeira, 2014). It sought to stimulate the organization of local systems taking into consideration local social actors and their realities. The Family Health Strategy objectives were: to know the reality of families enrolled in the program, to identify health problems, to develop local health promotion strategies with the community, to provide integral assistance, and to develop educational processes aimed at self-care of the individual. The Family Health Strategy guidelines were: to work in multidisciplinary teams, to create local planning and programming, and to respect the principle of comprehensiveness and to take into account the complexity of health needs ranging from low, to moderate, or complex.

In 1995, Paquetá Island was the setting of the first Family Health Strategy pilot project in the city of Rio de Janeiro. The pilot project was developed on Paquetá Island because its geography provided an enclosed environment to first test the Family Health Strategy. In theory, its delimited territory was to facilitate the testing of the Family Health Strategy (Lima, 2014). In two years from implementation, the evaluation of the Family Health Strategy program showed some increases in health outcomes. For instance, there was an improvement of the integration and hierarchy between the different sectors of the healthcare center (UISMAV) and other levels of care with an above average performance when compared to the period prior to the

implementation of the Family Health Strategy program; better use of the healthcare workforce capacity with interdisciplinary teams working in a more integrated way; full implementation of health programs for women, children, adolescents and older people with increased retention of patients; creation of various educational programs and community activities, among others (Cazelli, 2003).

Nevertheless, despite being a pilot project with a positive evaluation, this Family Health Strategy project was not a feasible model to be replicated in other communities in the city of Rio de Janeiro. This was due to the high ratio of health care professional teams to population (1 Family Health Strategy involved 130 families or 1,350 residents. This meant that this pilot model for the Family Health Strategy program was very expensive and thus a major factor preventing its continuity at this clinic or elsewhere. However, the pilot project did lead to the establishment of two teams for the whole Island of Paquetá.

Importantly, these previous experiences left some positive impressions and served as a source of inspiration for healthcare approaches currently used on the Island, e.g., high regard for interdisciplinary teams with the presence of a social worker, nutritionist, and physical education professionals, and, a more generous ratio of physicians to inhabitants (around one physician to 400 families) when compared to other Family Health Strategy programs in Brazil (Município do Rio de Janeiro, 1999). In addition, every Family Health Strategy's team has a registered nurse. The presence of the nurse in the Family Health Strategy has been fundamental for the consolidation the program. This is because the diverse responsibilities nurses have – e.g., the organization of the program activities, the management of the healthcare center, as well as the direct and indirect assistance to the individual, family and community (Caçador, Brito, Moreira, Rezende, & Vilela, 2015).

Current context of Paquetá's Family Health Strategy program. At the time of the study, the Family Health Strategy unit at UISMAV had two teams serving 4,973 individuals, of which 1,401 (556 males and 845 females) were individuals 60 years and older. The nucleus of one Family Health Strategy team included two physicians, one registered nurse, one licensed practical nurse and five community health agents. The nucleus of the second Family Health Strategy team included one physician, one registered nurse, one licensed practical nurse and five community health agents.

Participant observation of the healthcare teams of the Family Health Strategy on the Island allowed me to capture the micropolitics within these teams and apprehend ways in which realities/subjectivities were created and incorporated in the process of care. Following the identification of the healthcare center, better understanding of its goals and ways of operating, it was time to gain its assistance and endorsement to recruit potential participants. Next, an informal process began by making myself known to the relevant gatekeepers. Before entering the field, the head nurse provided me with a list with different sites and activities where I might locate myself for observation within the healthcare center. Intending to engage in passive observation, my rotation sites and activities included (a) the health care center's physical activity program, (b) both Family Health Strategy team's meetings, and (c) the interactions and routine activities happening in the organization's corridors. During this nine-month preliminary fieldwork I observed the physical space, relationships, attitudes, policies, laws, and social and cultural norms revolving around the healthcare providers and users of the healthcare center.

On my first day at the unit, I arranged with the head nurse, who was also the manager, a time during which she would be able to introduce me to the healthcare teams. Since I had arrived a little early, I sat down and waited for her in the corridor outside the director's office. Pencil and

paper in hand, I wrote down some thoughts about that moment, my expectations and fears of being in a new place. During this time, many people passed by: some were looking for the head nurse, some opened the direction room door looking for someone only to find an empty room, some looked at me acknowledging my presence but not saying anything to me, some were entertained in their own thoughts and work and did not acknowledge I was sitting there. After twenty minutes, from a small room in the hallway, a woman opened the door and cordially greeted me and asked if I was looking for someone. I gave her a smile and asked if she knew the whereabouts of the head nurse. She gave me a warm smile and responded negatively. I waited for some time until the head nurse arrived.

The head nurse finally arrived and invited me to walk around with her. She showed me the physical structure of the healthcare center. Patient care was divided between ambulatory and emergency services, with healthcare professionals specifically allocated to each sector and with different roles and working schedules. Health professionals working in the emergency area worked twelve hours followed by 36 hours of time off and health professionals working in the ambulatory area, which included the ones affiliated to the Family Health Strategy, worked weekdays from 9 am to 4 pm. The emergency area had a receptionist at the entrance, one licensed practical nurse and one physician at all times. The physical structure included a waiting room, where the reception desk was located. To the right of the waiting room was the staff resting room with some bunk beds. To the left of the waiting room, there was a corridor with two consultation rooms on the right side. Each was furnished with a weight and height scale, a table, two chairs, one examination table, a closet with medical supplies, and an electrocardiogram machine. On the left side of the corridor there were two inpatient rooms (one for males and one for females) with an incubator in the female inpatient room.

The ambulatory area had an entrance separate from the emergency area. The entrance door was located at the end of a ten-step stair. Opening a glass door, one arrived at the reception (admission room) area. Inside, there were two community health agents behind two desks close to each other; each with a computer on their desk. Each community health agent was part of one of two healthcare teams: Campo and Ponte and, therefore, responsible for just attending patients served by their own teams. Having a pre-set schedule, community health agents from each team rotated daily in this admission role. When community health agents were at the reception desk, they were responsible for: keeping a certain order and dissipating any wave of chaos; assisting patients to navigate the healthcare system, controlling the admission of patients with appointments and making new appointments for them, and, electronically registering individuals from their specific region in the health information system (Sistema de Informação da Atenção Básica [SIAB]) used by the Family Health Strategy. To be registered in the system, individuals needed a copy of their identification and health insurance card. Within the health information system there were three forms of data entry: (a) one for family registration, (b) one for health information, and (c) one for information on healthcare services output and markers for evaluating it. Community health agents were responsible for collecting data regarding family registration, which informed healthcare teams of patients' basic data regarding their socioeconomic, health (referred morbidity) and housing characteristics. A door behind and to the left of the community health agents' reception desks led to a patio, where there was a cafeteria, a vaccine room, a blood collection room, and a warehouse. Through this patio one also had access to the emergency area.

On the left of the reception area, there was an auditorium with a desk on the opposite side of the entrance door and many chairs lined up on each side of the room. Usually, this auditorium was reserved for health education sessions, staff celebrations such as farewell parties, and a few

meetings when other smaller rooms were unavailable. In this room, there also was a small kitchen with a microwave oven.

On the right of the reception area, there was a corridor. On the left side of the corridor, there were two rooms. The first room was occupied by a registered nurse and the second room by a physician, both were part of the same team responsible for attending patients from the Ponte area. On the left side of the corridor there were three rooms. The first room was occupied by a registered nurse and the second room by a physician, both were part of the same team and responsible for attending patients from the Campo area. The third and last room on the left side of the corridor was the pharmacy, where a pharmacist and a pharmacist assistant worked. The pharmacy occupied a space of about 20m² with a storage place in the back and an opening in the glass partition to allow for dispensing medications. This glass partition separated the two environments: the pharmacy and the corridor, where patients walked freely.

At the end of the corridor, and opposite to the pharmacy door, there was another corridor. Walking through this corridor, on the left side was a dressing room; a mental health room; a dentist's room; a community health agents' room; and, an information technology room. On the right side of this corridor, there was a bathroom, a water fountain, a door to the outside space where the physical activity program occurred; a waiting room for the dental patients and, an administration room. At the very end of this corridor was the director's office.

On the first day, the head nurse introduced me to the healthcare center staff, which made my presence more legitimate. These introductions happened in a rather casual manner, which is typical and a cultural norm in Brazil (Ferreira, Fischer, Milfont, Porto, & Pilati, 2012). I often was introduced as a Brazilian nurse researcher who worked in Canada. The head nurse held a professorship position at a large federal public university in Rio de Janeiro and often showed

great respect for the conduct of my research at the health care organization. Over the following months I spent at the healthcare center, the staff gave some accounts of the academic work and research they were involved in there as well as the subsequent products of their research, including presentations at conferences, the completion of thesis research, and publications in peer reviewed journals. It should be noted that despite important efforts, this tendency to promote academic production in the primary health sector is not the typical cultural norm at Family Health Strategy units. When research is promoted, it commonly finds resistance from different sectors within healthcare organizations and also from higher education institutions in Brazil (Cyrino et al., 2012). Given the above, it seems that this kind of environment, where there are efforts to scientifically gather data to comprehend the needs of the healthcare providers and users, is highly dependent on leadership style and management orientation. The conduct of my study research was indeed facilitated by the leadership style at this specific Health Family Strategy unit.

Yet, at times, when I was introduced to the staff, I could feel some uneasiness and skepticism that I considered to be due to my (imposed) presence in their space. These feelings emerged when the staff would glance at me sideways or frown while talking to me. If the formal process of accessing their environment required me to consider the healthcare center's operational hierarchy and guidelines regarding professional codes, the informal process of accessing this same environment seemed to demand an ability to detect and regard the boundaries of the access granted. Thus, to overcome the present uneasiness, I started to mindfully and actively "read the room".

When I first arrived at the set locations, the healthcare staff would start a conversation right away and talk about their jobs, their routines, the problems they usually encounter there,

and their wishes and hopes for the organization. In these situations, I would usually make a conscious effort to engage in active listening, trying to convey to the speaker both my verbal and non-verbal messages of attentiveness by maintaining eye contact, nodding my head and smiling, agreeing simply by saying ‘mmm hmm’, or mirroring some of their facial expressions. I would also try to refrain from my usual habits of fidgeting my foot and looking at my wrist watch. Yet, the habit that I sometimes caught myself doing was interrupting their speech, which despite being a Brazilian cultural way of showing interest in the conversation could also be interpreted as somewhat antagonistic.

At other times, during these initial moments of my presence at the rotation settings, an opening greeting between the healthcare staff and me would make my presence known to them but, it would be followed by some crucial seconds without any form of verbal communication between us. Through these situations, I would try to observe their body language and be understanding of their current workload and professional/personal space. In addition, though I was feeling quite uncomfortable in some of these situations, I would attempt to act in a non-threatening manner such as minimizing eye contact so they would not feel I was staring at them, as well as frequently smiling but in a softer manner so as to show my acceptance of that present situation.

In either of these situations, whether there was a rapid acceptance of my presence in their space or some reluctance toward me being there, I would always make an effort to clarify my research study (its objectives, timeline and resources). I would restate my role as merely an observer who was not part of the healthcare team and was not performing some kind of inspection or evaluation of their work. I often found that their acceptance of my presence in their space was faster when I was able to make these points clear but also identify and address their

concerns and suspicions. As time went by and more interactions with the healthcare providers happened, it became more comfortable to be there as an observer. I felt that my presence at the healthcare center became legitimized around 3-4 weeks after my initial introduction. Once my presence was legitimized, I could identify gatekeepers and reinforce my selection criteria for the pre-screening of potential participants. In addition, once potential participants were located and I started the recruitment process, these same gatekeepers vouched for the legitimacy of my research making potential participants more comfortable with me and my presence in their home.

Observations of the Physical Activity Program. The Carioca Fitness Program, a physical activity program, is linked to the Family Health Strategy units and run by physical education professionals to promote community physical activity. To join this program, people can refer themselves or be referred from one of the sub-programs offered by the health care center: hypertension, diabetes, women's health, prenatal, mental health, adolescent health, and others. The fitness program emphasizes accessible and regular physical activity to users of the municipal healthcare network in Rio de Janeiro. Within this program the population has access to practices aimed at promotion of physical, mental and social well-being. This program offers a physical structure containing ten pieces of gym equipment on which to perform aerobic, resistance and joint mobilization exercises. In addition, it offers recreational classes, such as hiking, dancing, fitness and stretching, and health promotion initiatives (i.e., smoking cessation campaigns) that attend to different age groups and to specific health needs.

At the Family Health Strategy in Paquetá, group recreational classes and work out sessions using gym equipment with supervision of a physical educator were offered every weekday during the mornings and afternoons. The physical educator was also responsible for collecting information about users' personal, family and medical history as soon as they enrolled

in the program. An anthropometric and functional evaluation was performed at their first day in the program, which was repeated every 6 months. Physical exercises were prescribed according to the unique needs of each user. Blood pressure was monitored before and after activity and blood glucose tests were performed for diabetics. A qualitative evaluation was made using the SF36 questionnaire [The Short Form Health Survey] to analyze the quality of life of users. Also, periodic meetings are held to promote the importance of adopting healthy habits to improve health and quality of life. The SF36 is a measure of health status commonly used to evaluate individual patients' health status, research the cost-effectiveness of a treatment, and to monitor and compare disease burden. It consists of eight scaled scores: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, and mental health.

The clientele who usually enrolled and participated in the activities were older persons, with females making up the majority of each group. Despite functioning during most hours of the day and not having a defined time spot in which each individual could join the gym, members habitually used to go at the same time of the day and gather with the same members they had gathered with on previous days. A few members just concentrated on their workout sets. Most members would take long pauses between workout sets, engaging in conversations and joking around. It seemed to be a very enjoyable time for them. It was a time that seemed to go beyond merely completion of physical activities; the participants seemed involved in socialization activities that were leading to the formation or strengthening of friendships.

Observations from Family Health Strategy team meetings. Team meetings were scheduled once every week. Both teams, each responsible for different areas of the Island, met separately on different days of the week for an average of three hours. The place of the meeting

was the health community agents' room. Meeting participants arranged themselves in a circle, which allowed better contact among them. These meetings seemed to represent an interdisciplinary space of sharing for those who were involved in the day-to-day activities of the health center and in rethinking or re-organizing the care provided.

Always present in these meetings were the nucleus of the Family Health Strategy (one physician, one registered nurse, one licensed practical nurse, and five or six health community agents). Other professionals who constituted the staff of the healthcare center, but were not part of nucleus of the Family Health Strategy, also participated in these meeting but with varied frequency. Among these other professionals were: (a) the managers, who were the head nurse and the director. The head nurse was present in the majority of the meetings and the director participated whenever there was some need and/or based on availability; (b) the oral health team, which involved a dentist and a dental hygienist who had an office in the healthcare center, and; (c) administrative assistants and general service assistants, who participated in the meeting when there was some need to adjust some healthcare tool via information technology, or when there was some need to exchange information among them and the nucleus of the Family Health Strategy regarding areas of patient care. Most of the time, the person responsible for the information technology sector was summoned to clarify or educate the rest of the team about data entry for health information.

Most times there were snacks served during or at the end of these meetings. Often times, these snacks were provided by members of the team, where they shared among all members the final cost, or they were donated by community members. During the meetings, teams had a pre-established agenda with priority topics to be discussed. One of the participants, usually the registered nurse or manager, noted down the issues that came up throughout the week to discuss

them in the meeting. However, issues outside the pre-established meeting agenda, but raised at the meeting, were also welcomed to be discussed there. Interruptions of the meetings were frequent generating controversy: Who is interrupting? A patient or a healthcare provider? What is the need of the person interrupting? What is the actual urgency? Sometimes, it was not an easy task to focus on the meeting as people would come and go as if there was no interest in what was going on inside the meeting.

The meetings were extended beyond the walls of that room with informal meetings happening all the time. These informal meetings with exchanges of opinions seemed to assist each member to process what was discussed in the room, therefore, assisting the decision-making process and even strengthening interpersonal relationships. In the meeting environment, there seemed to be some conflicts, difficulties, and diverse interests, but with opportunities to think collectively made possible the coexistence of the differences. Overall, these meetings fostered communication, exchange of ideas, and shared decision-making with elaboration of intervention strategies that were developed according to the availability of resources. The most recurrent topics at these meeting were case management, availability of medication, and bureaucratization of their services.

Participant Recruitment and Selection

During my nine-month preliminary fieldwork, I had the opportunity to spend a satisfactory amount of time with healthcare providers from both Family Health Strategy teams such that good relationships were established (Caine, Davision, & Stewart, 2009). From the first to fifth month, I spent four days a week, with an average of five hours per day, in the healthcare center. In between the sixth and the ninth month, I spent an average of two days a week and three hours per day in the healthcare center. When the study entered the participant recruitment and

selection phase, nurses and physicians were initially responsible for the pre-screening of potential participants and were asked to pre-select (a) older persons (60 years and older) who (b) had any kind of mobility challenge and (c) did not present any pre-existing diagnosis of cognitive challenge based on their own contact with them. Therefore, the healthcare team worked as gatekeepers standing between me, the data collector, and the potential participants. The nine-month contact with the teams at the healthcare center before participant recruitment enabled me to carefully reinforce characteristics that potential participants should have and negotiate my entry in the field.

There were multiple gatekeepers that I connected with as I recruited research participants. The first were the aforementioned nurses and physicians. Community health agents were the second gatekeepers because they held the list of pre-screened potential participants that had consented to be approached. Community health agents would give me information regarding each potential participants' usual mood, their family dynamics. They also would let me know who I shouldn't contact due to their much-deteriorated health status, or because they had died since the list was produced. Most of the time, I encountered a third gatekeeper at the potential participant's home in the form of their children, other family members, or their caretakers. During my contact with gatekeepers, I felt that I had to tailor information about the research study and its goals depending on who the gatekeepers were, and at the same time, be sensitive about how I framed the selection criteria so as not to reflect negatively or reinforce stigmas.

Usually after introducing myself during my first contact with potential participants, I would explain the study and go through the information letter with them and their gatekeepers. This was done to reassure potential participants and their family members about their rights. None of the participants were cognitively impaired, but some had some degree of functional

illiteracy. Functional illiteracy is reading and writing skills that are on a basic level. Functional illiteracy is contrasted with illiteracy in the strict sense, meaning the inability to read or write simple sentences in any language. The characteristics of functional illiteracy vary from one culture to another. None of the participants' functional illiteracy was due to neurological, mental, speech, hearing, vision, or comprehension disorder. All participants who were functionally illiterate had a lower level of reading skills, but no difficulties in functioning in society, i.e., problems with active, independent functioning in daily life.

Participants socio-demographic characteristics. The health care providers gave me the list of 'consent to be approached' with a total of 51 potential participants on it; this list was prepared many months before I attempted to approach potential participants face-to-face. From these 51 potential participants, some had passed away (n=5), some refused to participate (n=4), some had moved away (n=3) and some were not eligible to participate at the time I approached them (n=16). In the end, I recruited 23 participants. The sociodemographic survey, interviews and participant observation provided data about the general characteristics of the participants. These demographic characteristics are summarized in Table 1.

The participants in the study represented a diverse group of men and women. Approximately twenty (87%) were female, while three (13%) were male. Ages ranged from 60 to 98 years with the median age of 82 years (Std. = 9.5) (see Table 2). Fifteen (65%) of the participants declared themselves as White, followed by 5 (22%) *Pardo*, and 3 (13%) Black. While sixteen participants listed themselves as being currently widowed (69.6%), three (13%) were married, three (13%) were single, and one (4.3%) was divorced. Fifty-two percent (52%; n=12) had completed grade 4, 22% (n=5) had completed grade 8, 13% (n=3) completed high school, and 13% (n=3) had never gone to school.

Interestingly, 22 (96%) of the participants lived with someone, generally a child or caretaker, while only one (4%) lived alone. The majority of participants (65%, n=15) needed a mobility device to assist them to move around. Sixty-five percent (n=15) needed assistance with activities of daily living. The most common health conditions included hypertension (52%, n=12), diabetes (49%, n=11), arthrosis (39%, n= 9), arthritis (17%, n= 4), and osteoporosis (13%, n=3); with pain (65%, n=15) being the most negative symptom mentioned by participants. It was probable that the participants' health conditions affected how they experienced mobility.

The majority of participants (52%, N=12) were religiously affiliated with the Roman Catholic Church followed by Assembléia de Deus (22%, N=5), Spiritism (13%, N=3), Umbanda (9%, N=2), and one (4%) who was not affiliated with any religion. According to Mafra (2007), the Assembléias de Deus are a group of Pentecostal denominations in Brazil founded by Daniel Berg and Gunnar Vingren who came to Brazil as missionaries from the Swedish Pentecostal movement in the beginning of the 20th century. Assembléias de Deus are related to worldwide Pentecostal movement, and some groups are affiliated with the Assemblies of God.

According to Fernandes (2008) Spiritism is a doctrine born in France during the nineteenth century. Its main postulates are: the immortality of the soul, the possibility of communicating with the dead and reincarnation. Allan Kardec, pseudonym of the Lyon pedagogue Hippolyte-Léon Denizard Rivail, was the main person responsible for its dissemination and also author of works on the subject. Spiritism is present in more than thirty countries worldwide, including Brazil.

Conversely, Umbanda is one of the most popular Afro-Brazilian religions. According to Stone (2015), it originated in the southeast of Brazil in the 1930s (although many adherents contend its origins are much older) and syncretises spiritual traditions such as Candomblé (which

is a religion that originated from West African beliefs, venerating the Orixas – the pantheon of deities, and other African divinities), Catholicism, indigenous spirituality, Kardecism, and in more recent decades, New Age beliefs. In some ways, Umbanda is a spiritual representation of the miscegenation and diversity of the Brazilian populace.

Participants who were affiliated to the Catholic Church found it important to participate in the weekly Sundays' mass. The Island of Paquetá had one main Catholic Church and one chapel, Ponte and Campo, respectively. In the main Church, the Sunday masses occurred both at 10:30 am and 6 pm. From Monday to Friday there was mass once a day at 8 am and Saturdays at 6 pm. The Chapel was only opened on Sundays for the weekly mass of 8:30 am. Usually Catholics had a higher economic status and used to be active members of the church, but due to their mobility challenges, they decreased their participation throughout the years.

Participants who were affiliated to the Assembléia de Deus participated more than Catholics did in their religious services. Their worship times were Mondays, Wednesdays, and Saturdays and Sundays at 7 pm. Usually, they had a lower economic status but tighter community ties. Conversely, participants affiliated to Spiritism and Umbanda did not participate in their religious services. On the Island, there was one Spiritism center and no Umbanda center. According to participants, the Umbanda religion demanded a great deal of energy and participation, which made them feel inept. On the other hand, participants affiliated with Spiritism were for the most part housebound.

Note that I collected, analyzed and reported data trying to not compromise the identities of my participants. Thus, I purposely did not include participants' diagnosis in order that community members not recognize them. This safeguard was aligned with one of the main ethical considerations of the research: confidentiality.

Table 1

Participants Demographic Data

Pseudonym	Biological Sex	Age	Ethnicity	Marital Status	Live Alone	People living at the same household†	Use of Mobility Device	Need help with activity	Religion
Acacia	Female	89	White	Widowed	No	2	Yes	Yes	Catholic
Luz	Female	60	<i>Pardo</i>	Single	No	1	Yes	Yes	Spiritism
Florian	Male	81	Black	Widowed	No	2	Yes	No	Catholic
Butterfly	Female	68	White	Widowed	No	1	No	No	Pentecostal
Oak	Male	89	White	Married	No	5	No	Yes	Pentecostal
Fox	Male	75	White	Married	No	3	Yes	No	Pentecostal
Juliette	Female	88	Black	Widowed	No	3	Yes	Yes	Catholic
Lily	Female	98	White	Widowed	No	1	No	Yes	Catholic
Rose	Female	97	White	Widowed	No	1	No	Yes	Spiritism
Carnation	Female	77	<i>Pardo</i>	Widowed	No	1	Yes	Yes	Pentecostal
Lavender	Female	83	Black	Married	No	2	Yes	Yes	Umbanda
Daisy	Female	74	<i>Pardo</i>	Divorced	No	2	No	No	Not declared
Sky	Female	71	<i>Pardo</i>	Single	No	1	Yes	Yes	Catholic

Petal	Female	83	White	Widowed	No	2	Yes	No	Catholic
Flora	Female	81	White	Widowed	Yes	0	Yes	Yes	Catholic
Ella	Female	82	White	Widowed	No	3	No	No	Catholic
Eva	Female	70	<i>Pardo</i>	Widowed	No	2	Yes	Yes	Spiritism
Misty*	Female	79	White	Widowed	No	1	Yes	Yes	Catholic
Jade	Female	83	White	Widowed	No	2	Yes	Yes	Pentecostal
Summer*	Female	80	White	Widowed	No	1	No	No	Catholic
Spring	Female	87	White	Widowed	No	3	No	No	Catholic
Star*	Female	92	White	Widowed	No	1	Yes	Yes	Umbanda
Sonata	Female	93	White	Single	No	1	Yes	Yes	Catholic

* Misty, Summer and Star only agreed to participate in the first interview

†Excluding the participant

Table 2

Participants Age Distribution

Age		
N	Valid	23
	Missing	0
Mean		81.74
Mode		83
Std. Deviation		9.440
Range		38
Minimum		60
Maximum		98

CHAPTER FIVE: FINDINGS OF OLDER PERSONS' PERCEPTIONS AND EXPERIENCES OF MOBILITY CHALLENGES

At the beginning of each interview, I consciously tried to put the participant at ease so we could have a comfortable and fluid interaction. To facilitate this, I paid careful attention to their language style and tried to adjust my own language to that style. Also, every time I felt that I was not able to convey my questions to the participant in a clear way, I tried to provide clarification about the question and offer prompts when the participant hesitated. Conversely, when I was not sure if I understood the participants' responses, or if an account they had given was unclear, I would ask them for clarification and repeat back to them my understanding of what they had said. At the end of each interview, I debriefed with participants. Also, I was able to check and discuss with them my emerging hunches during the four-week follow-up visits.

One of the main focuses of this research was to examine urban Brazilian community-dwelling older persons' perceptions and experiences of mobility challenges. This chapter presents the analysis of the data from participant observations and interviews. Four themes emerged from the analysis: (1) 'My Past, My Identity'; (2) 'Mirror, Mirror on the Wall, Who Am I After All?'; (3) 'Context Matters'; and (4) 'Expectations & Needs'. Each of the four themes, and their respective sub-themes, are described with supporting excerpts from the transcripts and field notes.

Theme One: My Past, My Identity

During the interviews, participants' recollections of their past came up rather frequently. Based on the summative accounts that emerged in the field, I tried to understand the logic of the participants regarding the construction of their trajectories from one point in their functioning continuum to another. Thus, under this theme, the meanings of participants' past and its relation

to their current mobility were revealed. Participants' responses to questions regarding their experiences with mobility challenges that involved their past experiences and the construction of their identity were placed into two sub-categories: family-life experiences and past experiences with mobility. Sub-themes related to their current views of themselves and their mobility challenge are outlined in Table 3

Table 3. My past, my identity

Sub-themes	Categories
Family life experiences	Care-seeking experience Lack of resources Access to healthcare Family responsibilities
Past experiences with mobility	Socializing Working Past health conditions

Family-life Experiences

Challenges with mobility was an experience well known to participants. Most Brazilian families, regardless of social class, have already had a family member or have known someone who dealt with mobility challenges. For some participants, their earliest memories of mobility challenge were linked to their family-life experiences. Participants recounted their family-life experiences as part of their own mobility experience, in particular, those care-seeking and family-responsibility memories. The influence of these experiences on their perception of their current mobility is described below.

One of the goals of this study was to determine Brazilian community-dwelling older persons' perceptions and experiences of mobility challenges. To start to answer that, one of the

questions in the interview protocol was “what are the factors influencing your mobility?” Participants, in different ways, noted that health and mobility were connected to their **care-seeking experience**. Initially, the responses to this question were broad and general. Petal, for instance, began touching the subject by stating that: “I am not sure, but my mom had a problem in her leg since she was single. She dragged her legs to walk”¹. However, as I began to probe deeper, I started to obtain responses that were more specific. Petal, at that point, started to convey her experience with the healthcare system, specifically that of **lack of resources** and unsatisfactory **access to care**.

At that time, you know, we only would go to the physician when we were dying. It was very difficult to see a doctor. Only people with money could travel to see or pay one [physician] to come to their house. It was a very difficult time; things were not easy.² Right after her account, I summed up points she had made: “so your mother had this problem on her leg and you have had some health problems in the past that currently hinder your mobility”³. She paused and nodded in agreement. I continued by asking her how she perceived the difference between the care in her mother’s time and today’s time⁴. Petal looked at me and revealed that she never had thought about the similarities of their conditions and taking a deep breath she proceeded:

My dear, I thank God for everything. You know, my son supports me, takes me to my [medical] appointments for physiotherapy. In our family, we take care of each other. You

¹ “Eu não sei mas a minha mãe tinha um problema na perna desde que ela era solteira. Aí ela puxava da perna”

² Mas naquela época você sabe né, só se ia ao médico quando estava morrendo. Era muito difícil conseguir ver um médico. Só gente com grana que podia viajar para ver um ou pagar para eles virem na casa. Era um tempo muito difícil, as coisas não eram fáceis.

³ Então sua mãe teve esse problema em sua perna. Você já teve alguns problemas de saúde que hoje dificultam a sua mobilidade

⁴ Como você vê essa diferença entre o cuidar no tempo de sua mãe e hoje com você?

know, I have my pension, nothing is lacking. My son and daughter-in-law even wanted me to go more to the physiotherapist. They worry about me, but I am already at an age where there are no miracles. My mother had none of that, had no doctor, no money; but she lived as long as God wanted. No one goes before his or her own time. There are people who have everything, can do everything and die like that, unexpectedly. I think what has to be will be.⁵

Petal's feelings of lack of control over life events, predestination and feelings of powerlessness appeared to be a mediator in her care-seeking behavior. Similar to Petal, Butterfly shared comparable experiences of proper access to healthcare:

At my mother's time, no one used to go to the doctor. People would only go when they were very sick. My mom used to say that my grandmother limped. But my mother was healthy. She worked hard, she weeded. She worked hard to raise her children. It was very hard. Later she became ill too, and died after having a stroke. She only stayed at the hospital for a short period of time and passed away. She was all swollen too, so she stopped walking, she was weak after the stroke.⁶

One week later, during one of my follow-up home visits with Butterfly, we returned to the subject of her family. We began our conversation by talking about the brevity of life, her own life, and her tireless path to both work and raise her children. Butterfly expressed her discontent

⁵ Minha filha, eu agradeço a Deus por tudo. Aqui na família nós tomamos conta um do outro. Sabe, meu filho me ajuda, me leva e traz nas consultas, na fisioterapia. E eu tenho minha pensão, não me falta nada. Meu filho e minha nora até queriam que eu fosse mais ao fisioterapeuta. Eles se preocupam, mas eu já estou numa idade que não há milagres. Minha mãe não teve nada disso, não tinha médico, não tinha grana; mas ela viveu até quando Deus quis. Ninguém vai antes da hora. Tem gente que tem tudo, pode tudo e morre assim do nada. Acho que o que tem que ser será.

⁶ A minha mãe, naquele tempo ninguém ia em médico. Só ia quando ficava muito doente. Diz a minha mãe que quem andava mancando era a minha avó. Mas a minha mãe ela tinha saúde. Ela trabalhou muito, ela capinava. Ela trabalhou muito para criar os filhos. Dava muito duro. Depois ela adoeceu também e morreu com derrame. Ela só ficou em pouquinho no hospital e faleceu. Ela ficava toda inchada também, aí ela parou de andar, estava debilitada com o derrame.

with her current mobility situation. She said she did not have any desire to leave her home to walk around. In the past five years, she has had to rely on other people to run errands, such as going to the bank, and she has also abstained from participating in church activities, which she used to like very much. I then asked if a better financial situation, access to care or more assistance from her family would encourage her to go out more often. Butterfly responded that having more financial resources had nothing to do with being able to leave her home. According to her, her mother and grandmother did not have prompt access to healthcare, as she presently did, and had very different experiences of illness and mobility challenges. She went on to say that despite not leaving her home, health care providers from the Family Health Strategy visited her every now and then, and that was enough to meet her needs. She finished by saying that she is grateful for having them visit her every now and then, but she did not think she would go to the healthcare center to seek attention for her mobility issues if they did not visit her. Her fear of leaving her home was beyond their control, she stated.

Some participants, even if they knew they had a mobility challenge, did not seek help finding appropriate answers. It seemed that, health-seeking behavior was preceded by a decision-making process that was further governed by their past life experiences. For this reason, I believe that the phenomenon of mobility awareness and care seeking were not homogenous and depended on contextual, sociocultural, and economic factors. Other participants recounted a similar story of **access to health care**. However, contrary to Butterfly and Petal, who revealed conformity with their actual situation, Flora believed she still had to be prepared for some unforeseeable event since she experienced a childhood with uncertainties:

Yeah, I was little. Back then, we did not even have a doctor or anything. We had no doctor there in the city; it was really in the rural area. I only went to see a doctor for the

first time long after [I was] already a grown up. Today there is the SUS [universal healthcare], it is no longer like that, but I do not trust it, I pay my [private] healthcare plan. God forbid if someday, something happens to me, I have to be prepared. My body is already falling apart. Whatever I can do, I will do to get better. I have my health plan booklet here, with all the doctors and their specialties. Next week I already made an appointment to go to the geriatrician. We have to take care of ourselves.⁷

From participants' statements, they perceived restrictions to access to health care in their earlier years due to their family's lack of resources and access to healthcare services. These experiences were a common denominator among some participants; however, their current attitudes in relation to their care-seeking behavior differed.

Participants' **family responsibilities** also played a role in their mobility. During childhood, many participants had assigned roles within their families, which were attached to specific chores and obligations. Work as a physical contribution to the family routine was a solid memory participants had from their early years. These memories not only assisted them in building their perception of mobility but left some physical burdens they carried to later life. In their interviews, participants often referred to the type of work they did in the past that influenced their present mobility experience. Not all participants experienced that kind of family dynamics, and when they did, they experienced it on different levels, i.e., home care, homemaking, or outdoor work. Yet, it appeared that the burden of these activities during their childhood dictated some of their present mobility experience.

⁷ Sim, eu era menina. Naquela época, não tinha médico nem nada. Não tínhamos médico lá na cidade, era uma cidadezinha do interior. Eu só fui ver um médico pela primeira vez muito tempo depois, eu já era moça. Hoje tem o SUS, não é mais assim como antigamente, mas eu não confio, pago meu plano de saúde. Deus me livre se algum dia algo acontece comigo, eu tenho que estar ligada. Meu corpo já está caindo aos pedaços. O que eu puder fazer eu faço para melhorar até tenho meu livrinho do plano de saúde aqui, com a lista de todos os médicos e especialidades. Semana que vem mesmo eu já marquei de ir no geriatra. Temos que cuidar da gente, né.

Jade, for example, described her routine chores during her early childhood as strenuous: “I weeded, I farmed with pain. I harvested coffee. [When] the coffee beans were ripe, I filled [the basket] at my waist [with the beans]. It sometimes would be like that [positions her body bent forward], then I would lean over there [changes the direction from where she was previously bent], working”⁸. Due to that, Jade pointed out that she suffered from back problems, which ultimately hampered her mobility later in life:

When we are young it is one thing but after the person starts getting older, it [the pain] gets worse [...]. It was like this, I had suffered since I was a girl, and I suffered from pain in the spine. Then when I was growing up, I went to work on the farm, right, but I always had that little bit of pain [...]. Then after a short while I got married, I started having children, then I started to work to help, I was silly, right, I went to take a shower, I filled the pot [with water], I put it in the sink and I heard a clicking noise, I said: “and now that”. Then I stayed for fifteen days in bed. It was over from these days onwards. It was like this, and now I am like this. It is hard for me to move around, it is lots of pain. But in the old days we had to help at home; otherwise we would get spanked.⁹

Other participants also echoed these same family dynamics. Rose’s childhood memories encompassed physical work. She did not work in the field like Jade; she was responsible for the house chores, which, according to Rose, also contributed to her mobility challenge:

⁸ Eu apanhava café. O cafeeiro cheio, eu enchia de café até na cintura, aí quando eu tirava às vezes ficava assim [mostra a posição do corpo curvada para frente], depois ficava assim inclina pra cá [muda a direção que estava previamente inclinada], trabalhando.

⁹ A gente moça é uma coisa mas depois que a pessoa vai ficando mais velha aquilo vai aumentando. Foi assim, eu já sofria desde menina, eu sofria uma dor no ‘espinhaço’. Aí quando depois fui crescendo, fui trabalhar na roça mesmo, né. Aí depois de um tempinho eu me casei, fui tendo filho, depois eu fui trabalhar pra ajudar, a gente besta, né, aí eu fui tomar o banho, enchi o pote, botei na pia, aí fez “tra”, quando fez “tra”, aí eu disse: “pronto”. Aí eu fiquei quinze dias de cama. Desses dias pra cá acabou-se. É assim, e agora eu tô assim. Está muito difícil para mim me mexer, é muita dor. Mas antigamente era assim a gente tinha que ajudar em casa senão a chibata comia.

I did not go to school, no. I started to work when I was nine years old. Dad died, my mother had five children [...] I did not go to school because I went to work, and I went to work early, I said to my daughters: “Mom did not play with dolls, Mom played with other peoples’ dishes, but I’m happy because I have three children who graduated.”¹⁰ I am having these [mobility] problems and constant pain due to the difficult situations in the past, because I really had to work since I was little, it was too much, but life back then was not easy, but my children will not have to go through that, no.

In summary, participants in this study described engaging in the world of adult work even as children and youth. This work was necessary for family dynamics and economy. However, the early, awkward, and frequent bending, lifting and carrying of loads might have had some developmental and musculoskeletal implications. Participants pointed to the high exposure to this type of work in their childhood as the beginning of their challenges with mobility.

Past Experiences with Mobility

Still seeking to expand on factors influencing participants’ mobility, some more specific experiences in their past were highlighted. These experiences seemed to go beyond their family-life experiences. When prompted to clarify their feelings about their mobility capabilities with the questions: “what happened to you that you are having these mobility challenges?” and “how and when did it come about?” Several responses were provided. Generally, participants pointed out that their challenges with mobility started either after an accident, e.g., a fall, or over a period of time, usually during a period post-retirement. Overall, these responses related to their

¹⁰ Eu não tive aula, não. Eu fui trabalhar com nove anos. Papai morreu, minha mãe ficou com cinco filhos [...]. Eu não tive aula porque eu fui trabalhar, e fui trabalhar cedo, eu disse para as minhas filhas: “mamãe não brincou de boneca não, mamãe brincou com os pratos dos outros, lavando”, mas eu sou feliz porque eu tenho três filhos formados. Eu estou com esses problemas [de mobilidade] e essa dor que nunca passa por causa dessas coisas difíceis lá atrás na vida, tipo eu tive mesmo que ajudar desde de pequena, era pesado, mas também a vida antigamente não era fácil, mas meus filhos não terão de passar por isso não.

memories regarding their ability to socialize, work, and their past, and sometimes still present, health conditions.

Participants' descriptions of positive mobility experience were often related to the **social** and active lives they had in the past. There was a general consensus that being mobile was a means for **socialization**:

You know that currently I cannot walk, I want to walk. I'm here [in the wheelchair] but if I was good I would be sitting there at the table in the bakery talking to other people, I would go to the beach to walk, I used to walk, I used to do water aerobics, I would do everything. But now, I cannot do anything, I'm disabled, right.¹¹ (Sky)

For Lily, mobility experiences were positive when she was able to do things she enjoyed when she was younger. She told me that at an event catered for older persons and promoted by the Family Health Strategy' group at a public park in the Island, she felt alive and happy again. According to her, at that moment, she was able to do the same activities she enjoyed as a young adult:

You know he [the Family Health Strategy's physician] came and picked me up in the chair and said: "can you dance?" I said: "I can", then, I left dancing and he came after me [laughs]. I left [to dance] and did not even look back to see where I was, if I could I would stay there all the time, he still brought me there, but if I could I would not stop. I was sitting and he came to take me out to dance, the doctor, so ... I said to myself, "I will go after him, I will and he will go teaching me, back and forth", he was teaching me,

¹¹ Agora você sabe que eu não consigo andar, minha vontade é de andar. Eu estou aqui [na cadeira de rodas] mas se eu estivesse boa eu estaria sentadinha ali na mesa na padaria conversando, eu iria até a praia caminhar, que eu caminhava, eu fazia hidroginástica, eu fazia tudo. Mas agora eu não posso fazer nada, eu estou inutilizada, né.

right. I was learning in that way, I stayed there that day by myself, now it's all over. I do miss the dance, the [carnival] groups. Dancing is life and warms my spirit.¹²

Then, I followed up asking if she would like to move more, to dance. Lily quickly responded that: "I'm angry if I sit down, I want to be able to dance, to jump, to have a swim in the sea, because I used to swim in the sea, now I cannot anymore"¹³. Many other participants shared Lily's experience. Lavender, for example, said:

Before I exercised, I danced, I went to the dance and I used to dance all night, nonstop.

Now I am like this. I will tell you, I danced a lot, but now with this knee I cannot, right. I was exercising at the hospital. I wanted to go back to the gym [...] I wanted to dance again, to do everything, to go to the dances. [This] is my goal; I cannot stay like this no. I want to walk around.¹⁴

For these participants, being able to dance was a part of their identity, a way of unveiling their perceptions, values, and attitudes regarding living and moving. Daisy joined the chorus by saying that:

It's just that [the mobility problem] discourages me. I was very social, I used to go out a lot. I went there to the ferry wharf ... I rode my bike. Gosh, I used to ride a bike, I used to

¹² Você sabe que ele [Doutor da ESF] veio e me apanhou na cadeira e falou: "você pode dançar? " eu falei: "posso", aí eu saí sambando e ele veio atrás de mim [risos]. Eu saí [pra dançar] nem olhei para trás pra ver onde eu estava, se deixasse eu iria ficar o tempo todo lá, ele ainda me trouxe, mas se eu pudesse não parava. Eu estava sentada e ele [doutor da Estratégia Saúde da Família] veio me tirar para dançar, doutor, então ... eu falei: "eu vou atrás dele, eu vou que ele vai me ensinando, pra lá e pra cá, pra frente, pra trás", ele ia me ensinando, né. Assim fui aprendendo, fiquei lá naquele dia só, agora acabou tudo. Eu sinto falta sim da dança, de bloco [de carnaval]. Dançar é viver, isso aquece minha alma.

¹³ Eu tenho raiva se eu sentar, quero poder dançar, poder pular, poder tomar banho de mar, porque banho de mar eu tomava, agora não posso tomar mais

¹⁴ Antes eu fazia ginástica, ia ao pagode, seresta, eu dançava a noite toda sem parar, agora estou assim. Eu vou te contar, eu dancei muito, mas agora eu não posso com esse joelho, né. Eu fazia ginástica lá no hospital. Eu queria voltar lá para a ginástica [...]. Eu queria voltar a dançar, fazer tudo, ir nos pagodes. [Esse] é o meu objetivo, eu não posso ficar assim não. Eu quero passear por aí.

cycle. After I had surgery [on my] leg, I walked, I had a normal life. I used to dance and party.¹⁵

Participants' descriptions of positive mobility experience were often related to their ability to **work** as they had in the past. Although participants evoked their ability to participate in social activities and their ability to execute different tasks, other participants linked their mobility experience to their ability to be productive and part of the workforce. According to Fox, being mobile meant being able to contribute to the family income: "Not being able to walk, I cannot work, right. [I cannot] sell my stuff that I used to sell. I liked [to work], because selling things helped, right. And she [his wife] is not retired yet."¹⁶ Oak echoed it by saying that:

I keep thinking that before I worked, walked, ran, jumped, and today I do not do anything ... I used to work pushing a trailer. I pushed it myself [when he was sick] when I got a little bit better I used to spend the whole day working. Then, I was not able to go out anymore, I could not walk anymore ... I stopped working and I think I was even dead. I like to walk. I would like to walk at least around the house but I cannot; if I try, I fall. I do not walk anywhere. I do not like staying at home.¹⁷

If male participants linked their mobility experience to their ability to be productive and part of the workforce outside their homes, female participants linked their mobility experience to their ability to also be productive at home. In particular, Jade mentioned the following:

¹⁵ É só isso [problema de mobilidade] que me desanima. Eu era muito social, eu saía muito. Eu ia lá para as barcas ... Eu andava de bicicleta. Poxa, eu andava de bicicleta, eu pedalava. Depois que eu operei a perna, eu andei, eu tinha vida normal. Eu dançava, e ia a baile.

¹⁶ "Não podendo andar, eu não posso é trabalhar, né. Vender minhas coisas que eu vendia. Eu gostava [de trabalhar], porque vendendo as coisas ajudava, né. E ela [sua esposa] não é aposentada ainda".

¹⁷ Eu fico pensando antigamente eu trabalhava, andava, corria, pulava e hoje eu não faço mais nada [...] Eu trabalhava na carroça [de vender milho]. Eu trabalhava forçado [quando ele estava doente] quando eu melhorava um pouco eu passava o dia trabalhando. Aí depois eu não pude ir mais na rua, eu não pude mais andar [...] Eu parando de trabalhar eu acho que eu fiquei até morto. Eu gosto de andar. Eu gostaria de andar pelo menos pela casa mas não posso, se eu tentar eu caio. Eu não ando pra canto nenhum. Eu não gosto de ficar em casa.

I worked like this to help at home, it was not working, it was helping to wash the clothes for her, to make her coffee ... I liked to go there to wash clothes. I walked everywhere; I really liked to walk, right. I would go out first, I would walk here, go for a walk. Now it is hard, I cannot do much.¹⁸

Eva also mentioned that being mobile was to be able to contribute to the family by being productive at home:

I would wake up, make coffee, clean up the house; I was cleaning the house at all times. I would sweep everything here, I would sweep it all up, wash it, spread water with the hose, I would not stop. Just stopped to sleep, I did not stop. Nowadays, each step I take consumes all my energy, I do not know anymore, I really am not the same.¹⁹

The next accounts are representative of how **past health conditions** affected participants' perceptions of mobility. Having a health condition can pose major challenges to an individual's life, due to medication's adverse effects, treatments, lifestyle changes and; often, the uncontrollable nature of the condition. In the face of past health conditions and sometimes the threat of being vulnerable while moving around, participants were forced to live a life with more restrictions:

I had cancer surgery and it is going to be ten years [since surgery]. I take a medication, I believe, at first, he [the doctor] was going to suspend it; but it seems that there is a new law saying to extend it for ten years. In the beginning, this drug would make me feel dizzy and weak. Since then I avoid going out. I can become dizzy and there are dogs on

¹⁸ Eu trabalhava assim pra ajudar no lar, não é trabalhando, é ajudando lavar os panos dela, torrava o café dela. Gostava muito de ir lá lavar roupa, depois engomava. Eu andava pra todo lado, eu gostava de andar mesmo, né. Eu saía, de primeiro, eu saía andando aqui, fazia uma caminhada. Mas agora está osso, eu não posso fazer muito.

¹⁹ Eu acordava, fazia café, arrumava a casa, toda hora eu estava arrumando a casa, eu varria tudo, aqui a rua eu varria isso tudo, lavava, jogava água com a borracha, eu não parava. Só parava para dormir, não parava mesmo. Hoje cada passo me toma toda a força, eu não sei mais, realmente não sou a mesma

the street, many dogs, and they can lunge at you. I did not like that period very much. I'd rather be safe here at home. [I] already broke my leg many years ago. I also took a tumble here near the hospital. That is why I stopped going outside. I would go and walk, I would go to the doctor too. Then, I took a tumble here on the curb ... I hit my head, I think I lost stability because here it is never clear when you walk by the corner of the sidewalk, or it is wet or it is full of bicycles, so the person sometimes has to go to the street, and to go down alone, without a support, it is difficult, that is where I ended up falling down. I did not want to fall, that was one of the reasons I stopped going out alone. Then I got scared because there are no resources here and my daughter stays with me, she takes care of me the whole day [...] I do not feel like I have a lot of balance. I mean to walk, I am afraid to fall, I have to overcome it – this fear. On the street, I am afraid of falling and staying in a bed. I walk a lot looking at the ground all the time. I get scared and freeze up.²⁰ (Ella)

These self-imposed restrictions due to fear regarding experiences with health conditions in the past re-emerged and many memories came to light with an intensity of sensations, reactions and feelings that were lived in the past but were still present. It was common for participants to identify their own body with their mobility challenges, as highlighted by Sonata:

²⁰ Eu fiz a operação do câncer e vai fazer dez anos. Tomo remédio, acredito que, a principio ele [o médico] ia suspender mas parece que tem uma nova lei que disse para prorrogar por dez anos. No início esse remedio me fazia sentir tonta e cansada. Desde então eu evito sair na rua. Eu posso ficar tonta e tem muitos cachorros na rua, muito cachorro, então eles viam assim, em cima, então foi uma fase que eu não gostei muito. Eu prefiro ficar segura aqui em casa. [Eu] já quebrei a perna há muitos anos. E também levei um tombo aqui perto do hospital. Por isso eu deixei de sair. Eu ia e passeava, eu ia ao médico também. Ai eu levei um tombo aqui na curva [...] Eu bati com a cabeça, eu acho que desequilibrei porque aqui você indo pelo canto nunca a calçada está livre, ou ali está molhado ou está cheio de bicicleta, então a pessoa às vezes tem que ir para a rua, e eu para descer sozinha, sem um apoio, é difícil, ai foi onde eu acabei caindo. Ai não quis mais [sair], foi uma das razões que eu deixei de ir sozinha. Ai eu fico apavorada porque aqui não tem recursos e minha filha fica comigo, cuida de mim o dia todo [...] Eu não me sinto assim, com muito equilíbrio. Eu digo para andar eu tenho medo de cair, eu tenho que perder isso – esse medo. Eu tenho medo na rua de cair e ficar numa cama. Eu ando muito assim olhando para o chão o tempo todo. Eu fico com medo e travo.

I have been taking injections for a couple of years now. But I am afraid to walk down the street. And she [the physician] said I had shingles. It has been three years now. I have terrible pains that come and go. After I had Herpes I stayed in bed, I do not know how long. I felt dizzy. I do not know ... I fell often. The day I had ... that I was dizzy I would sit down for a long time. "I did not feel I was myself" I talked to myself: "What did happen to me? I did not believe that was happening to me. Getting herpes after being old. In the beginning, I cried a lot, a lot. I wanted a miracle at any cost. I wanted God to be there! Even now it is difficult to accept. I am always afraid to wake up and having it back."²¹

Besides conditioning participants' perceptions of themselves and their mobility, the lack of positive outcomes with previous treatments also affected how participants dealt with their mobility challenges:

I was doing physiotherapy, but it did not work. The more she touched me, the worse I was. It did not help. She did not do what the doctor ordered. Then it got worse, so I stayed for three days without even walking. It hurt to a point of crying, so I decided not to go anymore. Instead of me getting better, I got worse. I used to walk, I wanted to improve, if it is to get worse there is no use, right. Then, she also gave a medicine to take, but that medicine was what really killed me, it gave me pain that I could not take. The medicine that she prescribed was for the knee. I will tell you, it would be better to drink

²¹ De uns anos para cá eu já tomei diversas injeções. Mas eu tenho medo de andar na rua [...] E agora ela [médica] falou que eu tive Herpes. E já vai fazer três anos. Eu tenho dores terríveis que vão e vem. Depois que eu tive a Herpes eu fiquei de cama não sei quanto tempo [...] Eu sentia tontura. Eu não sei... eu caí muitas vezes. O dia que tinha... que eu tinha tontura eu ficava muito mais sentada. No início eu ficava "Nossa, não sou eu que estou aqui!" "Eu falava:" O que aconteceu comigo?" Eu não acreditava que era eu. Depois de velha ter Herpes. No início eu chorava muito, muito, mas eu chorava muito. Eu queria um milagre, de tudo e qualquer maneira, queria que Deus fosse lá! Até hoje é difícil aceitar. Eu fico com medo de acordar e isso ter voltado.

poison, you know. After that, I stopped trusting them, my life is pain, I do not know what it is to wake up without pain.²² (Rose)

Past health conditions may affect the way individuals face their present life situations, giving it meaning and refining approaches to deal with it. It is important to take into account that attitudes and responses to perceived problems, or illnesses, are socially constituted and may indicate a shared world of practices, beliefs and values. In dealing with a given health condition, individuals formulate, (re) produce and transmit a set of methods, practical recipes and generic propositions according to the sociocultural universe of which they are part.

Theme Two: Mirror, Mirror on the Wall, Who Am I After All?

In this second theme I provide a description of participants' construction of their internal models (representations) of mobility. This theme is concerned with the influence of participants' current views of themselves, and their worlds, on their perceptions of mobility. To observe internal models – perceptions, thoughts, and intentions regarding mobility and mobility challenges, I paid close attention to participants' verbal reports as well as non-verbal cues. I asked participants to describe specific situations, places and events regarding their mobility. These descriptions shed light on participants' ways of thinking, feeling and reacting towards their mobility capability and surroundings. Sub-themes related to their current views of themselves and their mobility challenge are outlined in Table 4.

²² Eu andei fazendo fisioterapia, mas não adiantou não. Quanto mais mexia, mais piorava. Aqui não ajudou não. Ela não fez o que o médico mandou. Aí piorou, aí eu fiquei três dias sem andar mesmo. Mas doía de chorar, aí eu decidi não ir mais não. Pode suspender que eu não vou mais não, em vez de eu melhorar, eu piorei. Aí eu andava né, eu queria melhorar, se for para piorar aí não adianta, né. Aí, ela passou um remédio também para tomar, mas aquele remédio então foi que matou mesmo, olha era dor que eu não aguentava mesmo, gente. Foi para o joelho que ela passou mais, vou te contar, melhor beber veneno, sabe. Depois disse eu parei de crer, minha vida é resumida a dor, eu não sei o que é acordar sem dor. (Rose)

Table 4. Mirror, mirror on the wall who am I after all?

Sub-themes	Categories
I am affect	Feeling fear Missing the freedom Feeling like a burden Feelings of anger and distrust A sense of shame Feeling low Getting discouraged and avoiding A sense of hope Feeling valued and worthy
I am cognition	I am informed Fatalism Rejecting Having impetus Negotiating barriers Adapting
I am my body	My body appearance My body function My illness My physical body My age Adjusting

I am Affect

Emotions represent multifaceted psychological and physiological states that, to a greater or lesser extent, indicate occurrences of value (Dolan, 2002). That is, the ability to express an emotion is the ability to ascribe value to events in the world (Friston, Tonini, Reeke, Sporns, & Edelman, 1994). Value in this sense refers to an individual's facility to sense the world and then evaluate whether events in its environment are more or less desirable, more or less positive, and then to develop adaptive responses (TenHouten, 2009). Thus, undergoing mobility challenges

can be an experience accompanied by different emotional processes and, consequently, diverse ways of dealing with them. To elicit participants' emotions, I asked them to share with me how they felt about their mobility capabilities, as well as occurrences of frustrating moments due to their challenged mobility. Participants recognized a range of emotions linked to their mobility, such as **fear**:

I broke my legs many years ago. I fell down near the hospital and because of that I quit going outside. I used to go out for a walk, but I fell down here on the corner and after that I did not want to leave [the house] anymore. That was one of the reasons I stopped going out by myself. I get worried. There are no resources here and my daughter stays at home with me, she takes care of me the whole day [...] I fell down three, four years ago. [It happened when] I was going to get some sun, but after that I do not sunbathe anymore. My whole problem is the fall, I am afraid because there is no way to get it [plaster] casted here [at the Island's healthcare center]. I hear doctors talking about accidents with older adults and I am afraid, right. I used to catch some sun out there for about five minutes [per day] [...] I do not feel too much balance to walk, I am afraid of falling. I have to overcome it, this fear. But I am afraid of falling and staying in bed. When I walk, I walk looking at the floor at all times. Sometimes, while walking I get scared and freeze.²³

(Ella)

²³ Eu já quebrei a perna há muitos anos. Eu levei um tombo aqui perto do hospital e por isso eu deixei de sair. Eu saía e passeava, aí eu levei um tombo aqui na curva aí não quis mais sair. Essa foi uma das razões que eu deixei de ir sozinha. Aí eu fico apavorada porque aqui não tem recursos e minha filha fica comigo, cuida de mim o dia todo [...] Essa queda já deve ter uns três, quatro anos. Mas eu ia pegar sol, mas depois disso não pego mais. Meu problema todo é cair, eu tenho medo porque aqui não tem como engessar. Eu justamente assisto os médicos falando de acidentes em idosos e fico com receio, né. Eu antes pegava sol lá fora por uns cinco minutos [...] Eu não me sinto assim, muito equilíbrio para andar eu tenho medo de cair. Eu tenho que perder isso, esse medo. Mas eu tenho medo de cair e ficar numa cama. Quando eu ando, eu ando muito assim olhando para o chão o tempo todo. As vezes quando eu ando, eu fico com medo e travo.

The experience of falling prompted different emotions in other participants. Lily, who needed the assistance of her daughter to move around, did not allow her multiple falling experiences affect her desires to be more independent. In fact, according to Lily, her daughter and full-time caretaker felt distressed and fearful whenever Lily attempted to move around without her assistance. Lily was not fearful, she just **missed her freedom** to move independently:

I enjoyed my life a lot, but I would still like to go for walks [...] I miss everything, to go for walks, to walk around, to visit my relatives, to celebrate with them. But my daughter fears I am going to fall and she does not have the strength to hold me. I fell many times. I fell when I went to the bathroom by myself. I also fell alone at home. My daughter went shopping and when she came back, I had fallen. I went outside and fell down. I had to stay there on the floor until my daughter got back home. I fell down and could not get up. Ahhh, but I would like to go for walks. One of the times I fell, I was not expecting it. I always liked the Carnival, then during Carnival I was so excited to see the street blocks that when I stepped down on the sidewalk I slipped. If it was not for my daughter holding me, I would have fallen on my face, again. It was just my daughter and I; it was difficult to get up. I like to walk fast, but I am clumsy. I love to be outside, yes. Staying at home is boring, right.²⁴

²⁴ Eu já passei bastante na vida, mas ainda gostaria de dar minhas voltinhas [...] Eu sinto falta de tudo, de passear, de poder andar, de visitar os meus parentes, de festejar junto com eles. Mas minha filha fica com medo d'eu cair e ela não ter forças para me segurar. Eu já caí várias vezes. Eu já caí quando fui ao banheiro sozinha. Eu também já caí sozinha em casa. Minha filha foi fazer compra, quando ela voltou, eu tinha caído. Na verdade, eu fui para fora e caí. Eu tive que ficar esperando por ela no chão, caí e não consegui levantar. Ahhh mas eu gostaria de ir na rua. Numa das vezes que eu caí, eu não estava esperando, eu sempre gostei de carnaval, aí um carnaval eu estava tão afoita para ver os blocos que quando eu desci essa calçadinha eu escorreguei, senão fosse minha filha me segurando eu iria cair de cara, de novo. Estava eu e minha filha, foi difícil levantar. Eu gosto de andar correndo, mas sou estabánada. Eu adoro a rua, sim. Ficar em casa é enjoado, né.

This incapability to move independently and care for herself was usually accompanied by a **feeling of burden**, which was not unusual for this group of older persons:

I used to go to Mass a lot, but now I walk just a little and already have knee pain. Every time I went for a walk on the Island, I would go into the church, I would pray a little, and leave. I always enjoyed going to Mass. Now I watch Mass on the television. Now it is just my daughter and I. She works a lot in the house, in the household chores, and I am a nuisance to her. It is embarrassing, she carries this burden. My daughter likes to stay home after she finishes her chores here. She finishes, sits in her armchair, turns on the light, and reads a book. She says she has no strength to go out, she only stays inside.²⁵
(Lily)

At other times participants' inability to attain their desired goals precipitated a composite of different emotions such as **anger and distrust**:

I really, really do not need to do any activity. That is a waste of time. Nothing will get better, I have tried everything. I know, I am a smoker, but I do not want to quit smoking. I know I have to go for walks. I know, but I do not need help. I am good as it is now. Just leave me alone. I have tried many times different things. They did not work. All a waste of time. I do not believe it will do any good for me. What do you think? Truth be told, I do not feel good. It is annoying to start something and nothing. Sometimes, it is

²⁵ Eu ia muito à missa, mas agora eu ando só um pouco e já sinto dor no joelho. Toda vez que eu ia dar uma volta na ilha, eu entrava na igreja, eu ia rezar um pouquinho, e vinha embora. Mas eu sempre gostei de ir à missa. Agora eu assisto a missa na televisão no canal trinta e quatro. Agora é só eu e minha filha, ela no serviço dela, dentro de casa, nos afazeres domésticos, e eu na amolação. É chato, ela carrega esse fardo. A minha filha gosta de ficar em casa depois que termina os serviços aqui. Ela acaba, senta na poltrona dela, acende a luz, e vai ler um livro. Ela fala que nem força tem para sair na rua, só fica dentro de casa

heartbreaking. So, please just don't. I feel embarrassed, I feel impotent. Total shame.²⁶

(Summer)

Shame was also an emotion elicited by participants. It was attached to participants' perceptions of failure to comply with some standards or ideals and usually affected their social life. For example, when asked about frustrating situations due to their mobility challenge, Butterfly said:

I walk slowly, like a turtle. That is inconvenient. I am from Assembléia de Deus, I went every Sunday ... Sometimes people want to come to my house and everything. If I say they can come, I know that everyone would come, but then I feel ashamed, because it is that thing, I cannot clean my house, right. I can hardly stand long enough to make lunch, I have no energy, and I cannot keep my house tidy, pretty, so that is why I do not want anyone here visiting me. Then, I do not invite them because of it. I cannot clean my house very well.²⁷ (Butterfly)

The adverse impacts of mobility challenges on an individual's mood was also highlighted. Some participants voiced having **low mood** in reaction to their mobility challenge:

When I could not walk anymore, I got depression. I was depressed, I was very nervous, I cried for nothing. Every now and then I cry for nothing. I cry about anything that crosses

²⁶ Eu realmente não acho que preciso fazer nenhuma atividade. É uma perda de tempo. Nada vai melhorar, eu já tentei de tudo. Eu sei, sou fumo, mas eu não quero parar. Eu sei que tenho que dar umas caminhadas. Eu sei, mas não estou precisando de ajuda. Eu estou bem assim como as coisas estão. Apenas me deixe aqui na minha paz. Eu já tentei muitas coisas. Não funcionou. Tudo uma perda de tempo. Eu não acredito que isso vá fazer qualquer nada mim. O que você acha? E na verdade eu não me sinto legal. É chato pra caramba começar essas coisas e nada. Por vez acaba com a gente. Então, por favor, nem, nem. Eu me sinto desconfortável, impotente. Uma vergonha sem tamanho.

²⁷ Eu ando devagar, igual a uma tartaruga. Isso é chato. Eu sou da Assembléia de Deus, eu ia todo domingo... Às vezes o pessoal quer até vir na minha casa e tudo. Se eu falar pode vir, vem cá, eu sei que todo mundo viria, mas aí eu fico com vergonha também, pois é aquele negócio, eu não posso arrumar a minha casa direito. Eu mal consigo ficar em pé para fazer o almoço, eu tenho não tenho ânimo, não tenho como manter minha casa arrumadinha, bonitinha, então, por isso que eu não quero ninguém aqui me visitando. Ai eu não chamo por causa disso. Não consigo arrumar minha casa direito.

my mind. I got depressed. I am making it up as I go, I am here, I am distracting myself, I want to forget everything.²⁸ (Sky)

These low moods experienced by participants also came with **discouraging** feelings and a desire to **avoid** emotional or physical pain:

I am already discouraged to live. I have wanted to die, you know. I just did not die because they have not given me poison yet. If I reach the cabinet with poison, I am going to die. I cannot stand to be in this bed anymore, my life is over. I cannot even get from the bed to the living room anymore. I really want to die.²⁹ (Oak)

Conversely, when other participants reflected on their mobility, they shared more optimistic emotions. Despite having challenges in their mobility, these challenges acted as motivators to participants' pursuit of activities. Despite some chronic health conditions, Acacia, for example, described feelings of **hope**:

I think I will not get worse. I have to get better. Yesterday, it is funny that yesterday, I took two steps in the living room and I was like that, I wanted to get up and walk like that [shows a walk with an erect posture] with the cane in my hand, because I walk curved [with a hyperkyphotic or forward leaning posture]. With the cane in my hand, I tried and took three steps here in the room [laughs]. I say, "Oh my God, will I still walk straight?" I

²⁸ Quando eu não pude mais andar, eu caí em depressão. Fiquei em depressão, fiquei muito nervosa, chorava à toa. De vez em quando até hoje eu choro a toa. Qualquer coisa assim que me passa pela cabeça eu choro. Entrei em depressão. Eu vou levando, estou aqui, vou me distraindo, quero esquecer tudo.

²⁹ Eu já estou desanimado da vida. Eu já tive vontade de até morrer, sabe. Eu só não morri porque ainda não me deram veneno ainda. Se eu alcançar o armário onde tem o veneno eu ainda vou morrer. Eu já não aguento mais ficar nessa cama, minha vida acabou. Eu não posso mais nem sair da cama para a sala. Eu quero mesmo é morrer.

took three steps. I cannot get worse. My God will not let me fall down. I will get better. I might not improve much, but worse I think I will not get; but I have to earn it.³⁰

Others referred to overcoming their mobility challenges as giving them a **sense of worth**. Sonata suffered from back pain she described being like one million needles poking her at the same time. On my first visit to Sonata, she seemed to live with a great deal of pain. This scenario started to change during the visits that followed. After agreeing to pursue the sit-to-stand activity, one night when her daughter got home from work, Sonata showed her daughter her accomplishments. She said:

I did not tell my daughter I was doing it. I surprised her. At the end of the evening, when she got home, I asked her to close her eyes. I then positioned myself in front of the chair and started to sit down and stand up. You should have seen her facial expression, she was flabbergasted. It has been many years since I was able to move without pain, this little exercise made me feel good. Some days I am not able to do the exercise because the pain is excruciating, but when I can do it, it is wonderful. My daughter is really proud of me, as am I.³¹

I am Cognition

To know means to give an account of mental processes and mental models (Turvey, 1992). Multiple participants described mobility in terms of the mental perceptions they had of

³⁰ Eu acho que pior eu não vou ficar. Tem que ficar melhor. Ontem, engraçado que ontem, eu dei dois passos ali da sala e eu fiquei assim, eu queria me levantar, e andar assim [ereta] mas com a bengala na mão, mas eu queria andar assim [ereta] porque eu ando encocada [curvada]. Mas com a bengala na mão, eu tentei e dei três passos aqui na sala [risos]. Digo, “ai meu Deus do céu será que eu ainda vou andar direito?” Dei três passos. Não posso piorar. Meu Deus não vai me deixar cair. Vou melhorar. Posso não melhorar muito, pior eu acho que eu não vou ficar, mas eu que tenho que fazer por onde.

³¹ Eu não falei para minha filha que estava fazendo isso. Eu quis fazer uma surpresa. A tardinha, quando ela chegou em casa, eu falei para ela fechar os olhos. Eu então fiquei em frente da minha cadeira e comecei a sentar e levantar. Você tinha que ver a cara da minha filha, ela estava admirada. Já tem tanto tempo desde que eu pude fazer isso sem dor, com esse exercíciuzinho eu me legal. Tem dias que eu não consigo fazer o exercício porque a dor é um martírio, mas quando posso fazer, é maravilhoso. Minha filha está muito orgulhosa de mim, e eu muito mais.

themselves and their surroundings. When asked “what do you think you or we could do to decrease your mobility challenge?” participants responded by reasoning with a set of representations, symbols and ways of solving the problem. Participants were aware of their mobility challenges and were often **informed** of their health condition and ways of dealing with it:

Look, I have these problems with my leg. The physician already told me that I have to walk. He said there is no cure, you know. There is treatment. The varicose veins will always be here, but the pain can be softened. I already had lesions [varicose ulcers], because of that it took a while to heal. It was painful. I wear these compression stockings and I know I have to walk. But I stay more at home. I should do a little more exercise because I know I am being a bit lazy, right. But sometimes I walk with my cane. But I go and I stop. I walk and I stop. I walk and I stop. When my daughter is here we go in the plaza and walk a little. She has to pull me, do you understand?³² (Carnation)

Some participants believed that events in their lives were beyond their control. This **fatalistic**³³ view was described in regard to a lack of interest in improving mobility:

I carry on with my life. I feel good, I sleep well, I eat well. I do not feel anything, no. My plan now is to stick around here. I do not have to do anything, right. I am retired, I am 81

³² Olha eu tenho esses problemas na perna. O médico já falou que eu tenho que caminhar. Ele disse que não tem cura, sabe. Tem tratamento. As varizes estarão sempre aí, mas a dor pode ser amenizada. Eu já tive feridas [úlceras varicosas] por causa disso. Levou um tempo para cicatrizar. Foi uma gastura. Eu uso essas meias de compressão e eu sei que tenho que caminhar. Mas eu fico mais em casa. Eu deveria fazer um pouco mais de exercício porque eu sei que estou sendo um pouco preguiçosa, né. Mas as vezes eu ando com a minha bengalinha assim. Mas eu vou e paro. Eu ando e paro. Eu ando e paro. A minha filha quando está aí, vamos lá na praça, caminhar um pouco. Eles me puxando, entendeu?

³³ Fatalism has an affective content, but is not usually regarded as an emotion. Fatalism is rather seen as a particular case of resourcefulness, which has been shaped from a combination of anticipation and acceptance, and their associated functions of exploration and incorporation, respectively (TenHouten 2007, pp. 85–88).

years old. I will do what now? I may appear young, but I am 81 years old. This knee will not improve any more. It already has had it. I walk with a cane.³⁴ (Florian)

In the far past, Florian's Sundays were reserved for playing soccer with his friends. Due to his mobility challenge, Florian does not play soccer anymore. Instead, he enjoyed getting together with his friends on the weekends, while having some beers and chatting about the old days.

These meetings occurred in bars in front of the wharf or at one of the beach kiosks in the Island. Knowing this piece of information, I asked Florian how he would continue pursuing his weekend activities and meeting his friends outdoors. His thoughts were paradoxical; there was the enjoyment he experienced in meeting his old buddies, the disbelief about being able to improve his mobility, and the desire, now, to spend most of his time confined in his home. He responded that:

My daughters put me in a rickshaw here, if I have to go somewhere. I go to have some beers with my friends. I go to the wharf. In the street, I walk accompanied. I do not walk alone anymore ... just with my daughters. My grandchildren take me there to the beach, down there. I drink my beer, I have lots of fun.³⁵

Other participants were not fatalistic. They were aware of their mobility challenge. They had a desire to and knew they could get better. Yet, they did not envision any benefit from engaging in extra activities. Luz exemplified this by stating that she did not move her left leg and the exercises she did resting in bed twice a day were sufficient. She received the attention of a

³⁴ Eu vou levando a vida. Me sinto bem, durmo bem, como bem. Não sinto nada, não. O meu plano agora é ficar por aí. Não tenho que fazer mais nada, né. Estou aposentado, 81 anos. Vou fazer o que, agora? Posso estar novo na aparência, mas 81 anos que eu tenho. Esse joelho não melhora mais não. Já deu o que tinha que dar. Eu ando de bengala.

³⁵ Minhas filhas me põem dentro do táxi aí se tiver um lugar que eu tenho que ir. Eu vou lá tomar cerveja com aquela turma. Vou lá nas barcas, lá na ponte. Na rua, eu até ando acompanhado. Eu não ando mais sozinho... com as minhas filhas só. Os meus netos me levam aí para a praia, lá para baixo. Tomo minha cerveja, faço miséria aí.

physical therapist twice a week, for which she paid out of pocket. When I introduced the sit-to-stand activity to Luz and asked her if she would like to do it, she **rejected** the possibility:

I do not know about this thing of getting up and sitting down. I do not think so ... I am already walking to the entrance of the other bathroom and even then it starts to hurt a lot here. Then I might lose my balance. I think I am going to ruin my knee. I already do this [sit-to-stand movement] weekly. Sometimes I get up here, because my butt gets really tired from laying down all day, so I get up sometimes.³⁶

Some participants were motivated and revealed some **impetus** to endure their mobility challenges.

I amputated my toe that leaned on my little toe [the fourth toe] but I still walked anyway. I was not able to walk by foot, but I got much better, my foot is almost all good. I get kind of dizzy, but I go anyway. Sometimes I walk an hour from here to there, sometimes I walk even more than an hour. You have to move on, if I just stay like that what pleasure will I have in life?³⁷ (Fox)

Other participants described themselves as responsible for their actions and behaviors, and often **negotiated** their limits:

On Sunday my son took me there to walk to the cemetery street and I could not handle it, halfway I moaned and said, “I cannot [walk] anymore”. I could not walk anymore and he said, “come on, you have to walk”. Then I sat a little on the bench there on the beach,

³⁶ Sei lá, esse negócio de levantar e baixar. Eu acho que não...Eu já vou andando até a entrada ali do outro banheiro. Mas aí começa a doer muito isso aqui. Aí eu começo a balançar. Eu acho que vou estragar o meu joelho. Isso [sentar e levantar] eu já faço semanalmente. Às vezes eu levanto aqui, porque cansa muito a bunda ficar deitada o dia todo, aí eu vou e levanto às vezes

³⁷ Eu amputei meu dedo que encostava no mindinho, mas eu ainda andava assim mesmo. Eu não estava aguentando andar a pé mas aí eu melhorei muito pé, está quase bom o pé. Eu fico meio tonto, mas eu vou assim mesmo. Às vezes eu ando uma hora daqui pra ali, às vezes até mais de uma hora eu vou caminhando. Tem que seguir em frente, que se ficar só aqui assim que prazer que eu vou ter na vida?

there I would sit for five minutes and he would say: “let’s go, otherwise you will cool [your body] off, let’s go”. Because he wanted to take me there in the [park] dark. I complained but I like to walk with my son. I do not walk anymore, but it is not because of arthritis or arthrosis. It is because I am really lazy and honest [laughs]. But I walk, I get up to chat with my neighbor, the neighbor comes to chat here. (Petal)³⁸

Interestingly, many participants spoke of their ability to **adapt** as one way to improve their mobility. Not feeling safe using mobility devices, Rose made some adaptations to live in her home. These adaptations enabled her to continue functioning in her daily life:

I do not use canes to walk. I walk holding here [points to the wall]. I got one [cane], but I do not like it, I gave it away. I have a new walker upstairs [second floor of the house], but I do not want to [use it], the walker has wheels, I am afraid, it skids a lot, then I am going to fall there. I walk holding on to the walls that are firmer. I put my hand here and from here I put my hand there [pointing to different places on the wall], and I am living, right, and I get where I want to go. I just do not go up the stairs [to the second floor]. It has been one a year since I went up there, it has been a year, it is a lot, it is a lot of pain. Before, my son would take me up there, and I would lean on him, and to go down he would go ahead of me and I would lean on him. Last year it

³⁸ Domingo meu filho me levou lá para andar até o cemitério e eu não aguentava, eu gemia pelo meio do caminho e falava: “eu não posso mais”. Eu não podia mais andar e ele: “vamos, tem que andar”. Aí eu sentava um pouquinho no banco ali na praia, aí eu sentava por cinco minutos e ele falava: “vamos senão esfria [o corpo], vamos embora”. Porque ele queria me levar lá no [parque] Dark. Eu reclamo mas eu gosto de andar com meu filho. Eu não anda mais não é por causa da artrite ou da artrose não. É porque eu sou preguiçosa mesmo e honesta [risos]. Mas eu ando, eu levanto e vou bater papo ali com a vizinha, a vizinha vem bater papo aqui (Petal)

got worse. This one is the worst [points to one of the knees], you know [...] I bathe on my own. I use a chair. I have a chair, I go in the chair and sit down.³⁹ (Rose)

I am my Body

Participants described their mobility in view of their own body capability and image. Mobility was perceived in a variety of ways. These descriptions included components of both **appearance** and **functioning**. The former is exemplified by Summer's statement:

I am not what I used to be anymore. I cannot think about that anymore. My legs are filled with varicose veins, I only wear pants. I can only see this problem, it is a shame. It is nerve-racking to think that my legs are over, I am over. That is the reason I avoid at all costs going outside. I am broken up. That is very ugly. It does not hurt, but it is a dreary situation⁴⁰.

Summer added that the **appearance** of her legs was something that strangers were not shy to point out, which made her feel even less inclined to go outside.

It is always like this, I do not go out on the street anymore because children point and ask what is it in my legs, and their parents look with disgust. How can I leave my home like

³⁹ Eu não uso bengala para andar. Eu vou segurando aqui [aponta para parede]. Eu ganhei uma, mas não gosto, dei. Eu tenho um andador lá em cima [segundo andar da casa] novo, mas não quero, o andador é de roda, eu tenho medo, derrapa muito, aí eu vou cair aí. Eu vou segurando nas paredes que é mais firme. Eu boto a mão aqui e daqui eu boto a mão lá [aponta para diferentes lugares na parede], e vou levando, né, e chego onde eu quero. Eu só não subo mais as escadas [para o segundo andar]. Tem um ano que eu não vou lá em cima, tem um ano, é muita coisa, é muita dor. Antes meu filho me levava lá para cima, e eu ia escorando nele, e para descer ele ia na frente e eu me apoiava nele. E de um ano para cá o negócio piorou. Esse que é o pior [aponta para um dos joelhos], sabe [...] Eu tomo banho sozinha. Eu uso a cadeira. Tenho cadeira, eu vou na cadeira e sento

⁴⁰ Eu não sou mais o que eu era antigamente. Não posso mais me ligar nisso. Minhas pernas estão cheias de veias, eu só ando de calça. Eu só enxergo essa bexiga, é uma vergonha. É desesperador pensar que minhas pernas estão acabadas, eu estou acabada. É por isso mesmo eu evito a todo custo sair lá fora. Eu fiquei desgostosa da vida. É muito feio isso. Não dói nem nada, mas é uma situação chata.

this? Go through this embarrassment? A temperature of 40 degrees, it is impossible to dress in pants. My life is like that now. I am the old lady with the gammy leg⁴¹.

Most of the time, less positive views of their own bodies were due to participants' health conditions and, therefore, the **functioning** capabilities of their bodies. Misty, for example voiced an intrusive symptom, pain:

I have pain in both of my knees. I also have pain behind here [shows popliteal fossa region] that will not leave me alone. I cannot walk from here to there without stopping. I take a first stop, I take three stops until I get to the corner, and then I still have to take one more stop to get to the hospital. Then I get very tired [...] I do not do anything. I cannot do anything. I walk very seldom. Just here in the house. Right now I was saying to myself: "I have the doctor at two o'clock today. When it is half past one, I will call the boy to take me because I get very tired. This week for me to get to the pharmacy was a torment. And to go to the grocery store? I just want to sit down. I take the man's crate [to sit down], I take the girls' seats. This is hell."⁴²

It was not only pain that hindered participants less positive views and perceptions of their bodies. Other functioning capabilities of the body also played an important role in participants' experience of mobility. Many participants who suffered from incontinence at the time of the research voiced an overall negative mobility experience. These participants often refrained from

⁴¹ É sempre assim, eu não saio mais na rua porque crianças apontam e perguntam o que é na minha perna, os pais olham com nojo. Como eu posso sair de casa assim? Pra passear essa vergonha? Um calor de 40 graus, não da para ficar de calça. Minha vida é essa agora. Eu sou a velha da perna bichada.

⁴² Eu tenho dor nos dois joelhos. E aqui atrás [mostra região da fossa popliteal] que eu também tenho uma dor que não me deixa em paz. E eu não consigo andar daqui pra lá sem parar. Eu dou uma primeira parada, eu dou umas três paradas até chegar na esquina, pra depois. Ainda dou mais uma parada pra conseguir chegar no hospital. Aí eu fico muito cansada [...] Eu não faço nada. Não chego a fazer nada. Eu ando muito pouco. Só aqui dentro de casa. Agora mesmo eu tava dizendo pra mim mesma: hoje eu tenho a doutora as duas horas. Quando for uma e meia eu chamo o menino pra me levar que eu fico logo muito cansada [...] Essa semana pra mim chegar na farmácia foi um tormento. E pra ir no mercado? Eu fico querendo me sentar. Eu pego os caixote do homem [para sentar], eu pego os banco das meninas. É um inferno.

pursuing activities outside their household. Butterfly ceased to leave her house due to her incontinence. She said, “I walk slowly. I do not even want to walk because [...] of that medicine, the Thiazide, that medicine makes us pee too much. It is all the time, and if I am at the street? How am I going to do it?”⁴³ In addition, body functions also limited participants in their own homes. Misty stated that having incontinence has limited her life in many ways:

There are days, my dear, that I wake up during the night, it is hell. I no longer drink water. I only drink water after six o'clock. I do not drink juice, I do not eat oranges to have time to get to the bathroom. Because [my] knee hurts so much that I have to hold myself. The other day I said, “Doctor [of the Health Family Strategy], I’m becoming a lizard. I walk crawling on the walls”. From here on, here is the bathroom, up there in my bed I cannot have anything on the way. Nothing. Oh, sometimes I wake up two, three times a night. Sometimes there is no time at all. Sometimes when I sit on the toilet I do not even take my panties off. Go with panties and everything. Then I take those [panties] off and go to the shower. Look, it is rough. My God, what kind of life is this, huh?⁴⁴

Yet, incontinence not only limited participants’ life activities, but also contributed to situations that caused participants’ injuries. Petal recounted that besides the struggle to walk to the bathroom during the night, she also has gotten injured as an outcome of it:

⁴³ Eu ando devagar. Eu nem tenho vontade de caminhar por causa disso [medo de cair] e também outra coisa, aquele remédio, o Tiazida, aquele remédio faz a gente fazer xixi demais. É toda hora, e se estiver na rua? Aí danou-se, como é que vai fazer?

⁴⁴ Tem dias, minha filha, que eu levanto agora de noite, é um inferno. Eu já não bebo água. Só bebo água depois de seis horas. Eu não bebo um suco, não chupo uma laranja pra dar tempo de eu vir no banheiro. Porque o joelho dói tanto que eu tenho que tá me segurando. Outro dia eu disse: ‘doutor [do ESF], eu to virando uma lagartixa. Eu venho me arrastando pelas paredes’. Daqui desse pedaço daqui, aqui é o banheiro, até lá na minha cama, não pode ter nada no caminho. Nada. Ah, às vezes eu acordo duas, três vezes por noite. Às vezes não dá nem tempo. Às vezes quando eu sento no vaso não tiro nem a calcinha. Vai com calcinha e tudo. Aí eu tiro, aí eu vou pro chuveiro. Olha, é uma coisa. Meu Deus, que vida é essa, hein?

But every now and then there are some hot potatoes to handle at night, you know? I defecate all night. I get out of my bed here in a hurry to go to the toilet and I cannot run, no. And when I get there, on the way in there [points to the bathroom] already xuuu [makes a noise of liquid coming down]. This week, around three, four am, at dawn, I did not even have time to sit down, I was a big mess [laughs]. And sometimes it happens during the whole night. Now it's been a while, you know. Last week it happened at the night of Sunday to Monday. And when it's not that [fecal incontinence], it's urinating too, there is no time [to get to the toilet]. Sometimes I get hurt along the way trying to run to the toilet.⁴⁵

Some participants suggested that besides changes in their health conditions and accompanied pain, their mobility experiences were also linked to their **age or internalized ageism**:

The issue is in my legs. It is a lot of pain, a lot of pain, my dear. It is in my knee, I have arthrosis. The issue itself is the knee. The knee troubles me a lot, you know. When it is not one thing it is another. When we get older, you know how it is; everything starts to end, that is life. Everything begins to tumble. But what can we do? We are born and we die, life is like that, and aging is part of that. Enjoy while you are young, it gets worse afterwards. Getting old is not easy, as time goes on it gets worse, it is one thing after another. I still feel a bit of numbness in my legs because of the varicose veins. The varicose veins hurt a little. When the weather warms up, they start to heat up, to burn.

⁴⁵ Mas de vez em quando aparece uns abacaxizinhos de noite aí, sabe? Fico fazendo coco a noite toda (risos). Eu saio da minha cama aqui com vontade e não dá para correr, não. E quando eu chego ali, na entrada ali [aponta para banheiro] já xuuu [faz barulho de líquido descendo]. Essa semana mesmo, 4 e pouco, três e pouca na madrugada eu não tinha nem como me abaixar, fico uma sujeira só [risos]. E as vezes aqui é toda noite isso. Agora tem dado um tempinho, sabe. Na semana passada teve de domingo para segunda de noite. E quando não é isso, é xixi também, não dá tempo. As vezes eu me machuco no caminho, tentando correr para o banheiro

That is why I walk with difficulty. When I walk, I walk upstairs to go to the bathroom, to go take a shower. There are nights that I spend the night sitting because of the pain. I walked, but in the last year walking got worse.⁴⁶ (Rose)

However, for some participants, the changes brought on with **aging** seemed to reinforce the need to work towards its betterment and towards a more normal life. Participants' views of their bodies made them feel motivated to hold on to their mobility:

Look, things are not like they used to be, we start to rust. I am not a young lady anymore, so I have to work with what I have. Does my body hurt? It hurts. But I am always active. I wake up in the morning and the housekeeper is already here. She makes coffee, she sets the table and I come out, I talk to her. She brings breakfast, that whole thing and then I go walking around. I walk, I participate in what they are going to do. Thank God, I still walk. In the afternoon I walk, I go in the room, I come out here and there are always people here with me, so I do not have this thing, but when it starts to hurt, it is bad. I have to force myself to get out of bed, otherwise I will languish.⁴⁷ (Jade)

⁴⁶ O negócio é as minhas pernas. É muita dor, muita dor mesmo, minha filha. É no joelho. uma artrose. O negócio mesmo é o joelho, o negócio é o joelho. O joelho acaba muito comigo, sabe. Quando não é uma coisa é outra. A idade vai chegando, aí sabe como é que é; tudo vai se acabando, coisas da vida. Tudo começa a degrading. Mas fazer o que? A gente nasce e morre, a vida é assim, e envelhecer é parte disso. Aproveita enquanto voce esta nova, depois tudo piora. A velhice não é fácil, cada ano que passa fica pior, é uma coisa atrás da outra. Eu ainda sinto um pouquinho de dormência nas pernas por causa das varizes. As varizes doem um pouco. Quando o tempo esquenta, elas começam a esquentar, a arder. Por isso tudo que eu ando com dificuldade. Quando eu ando, eu ando escorando pra ir no banheiro, pra ir tomar um banho. Tem noite que eu passo a noite sentada por causa da dor. É eu andava, mas de um ano para cá que piorou mais para andar

⁴⁷ Olha as coisas não são como eram antes, a gente vai enferrujando. Eu nao sou mais uma mocinha, então eu tenho que trabalhar com o que eu tenho. O corpo dói? Doi. Mas, assim, eu sempre fico ativa. Eu acordo de manhã, aí a menina já tá aí, já fez café, já botou mesa e eu venho cá pra fora, converso com ela, traz o café da manhã, aquela coisa toda e depois eu fico por aí zanzando. Fico andando, fico participando do que vão fazer, do que não. Graças a Deus, eu ainda ando. De tarde eu ando, vou lá no quarto, venho aqui fora e sempre tem gente aqui comigo, então pra mim não tem essa coisa, não, mas quando começa a doer, aí é ruim. Eu tenho que forçar senão eu vou definhar

At other times participants described their bodies as a space that sometimes was not under their control. This body was the result of **changes and adjustments** and an interplay between effort and outcome:

Either I beat the disease, or it conquers me. Now I do it alone, before I did not, before it was all with my son - bandage, bath. But now I am well. Before I did not even stretch my leg, now I can even stretch them. Before it was everything with him. My head has always been good, but my body did not obey me. It has been a hard fight, staying in bed, wheelchairs. It is like my body does obey my head. Now I can come on the porch, later I walk in, lie down and watch TV. I wake up in the morning and have breakfast, which my son makes. My son leaves my lunch already prepared, I just warm it up. I mean, I am doing things on my own.⁴⁸ (Sky)

Sometimes these **changes and adjustments** meant having to accept the assistance of family and close friends. When participants were not able to perform their usual activities as they did before, they engaged in adaptive processes to maximize gains and minimize losses in response to everyday demands and functional decline:

My desire was to go to the bathroom. I can go, thanks to God. However, I cannot take a shower by myself. I have a friend who is like a daughter; she comes from time to time to help me shower. But when she cannot come, I fill the jug with warm water from the sink, with the sponge I rub myself, and the head I wash in the sink outside. I do this because I

⁴⁸ Ou eu venço a doença, ou ela me vence. Agora eu faço sozinha, antes eu não fazia, antes era tudo com meu filho – curativo, banho. Mas agora eu fiquei boa. Antes eu nem esticava a perna, agora eu ainda consigo esticar. Antes era tudo com ele. Eu sempre estive bem da cabeça, mas o meu corpo não me obedecia. Tem sido uma luta difícil, ficar na cama, de cadeiras de roda. E como o corpo não obedece minha cabeça. Agora eu posso vir na varanda, depois eu entro, deito e vejo televisão. Eu levanto de manhã e tomo o meu café que o meu filho deixa preparado. Meu almoço meu filho já deixa preparado, é só esquentar. Quer dizer, eu estou, eu estou fazendo as coisas sozinha

have to put the walker in the shower but then I cannot lower myself. [...] and to walk around the house I walk slowly because otherwise ... [demonstrates her walking slow and supporting herself on the walls] and like that I go about doing things [...].⁴⁹ (Acacia)

Theme Three: Context Matters

Within a greater perspective of health, individuals cannot be understood outside their context. The conditions in which individuals live their everyday lives are also determinants of their mobility. Those conditions include the social, economic, and physical environment, which influence health status, health behavior and lifestyle. This theme is concerned with contextual factors participants perceived as influencing their mobility capabilities. Sub-themes related to participants' context are outlined in Table 5.

Table 5. Context matters

Sub-themes	Categories
Environmental factors	Indoor physical environment Outdoor physical environment Neighborhood safety Natural environment
Socio-economic factors	Social support and networks Social participation Social comparison Financial status

⁴⁹ Minha paixão era eu poder usar o banheiro. Eu uso graças a deus. O banho no chuveiro é que eu não posso tomar sozinha. Eu tenho uma amiga que é que nem uma filha. E ela vinha de vez em quando me dar banho. Mas quando ela não pode vir eu pego o caneco encho a pia d'água ponho a água morna, com a esponja me esfrego, e a cabeça eu lavo no tanque. Eu faço isso pois eu tenho que botar o andador lá dentro mas ai eu não posso me abaixar. [...] E para andar pela casa eu ando devagar porque senão ... passo pra aqui, daqui para ali [mostra o andar devagar e às vezes apoiando nas coisas]. E assim vou fazendo as coisas [...]

Environmental Factors

There are many factors in the environment that are important to health. My description of contextual features prior to the start of this investigation was described in Chapter 4, ‘contextualizing the field – Paquetá Island’. However, during my observation period on the Island and in participants’ homes, I learned many details about their environmental living conditions. These observations are presented in two categories: (a) the physical environment, composed of the interaction of built-in objects, which are created and constructed by humans and can vary widely in terms of their complexity, size, and purpose, and; (b) the natural environment composed of non-human-made surroundings and conditions in which all living and non-living things exist. Both built-in and natural environments played a significant role in the level of mobility challenge participants encountered.

One of the observed built-in environments was participants’ **indoor physical environment**. Home indoor and near indoor spaces served basic needs of living, including cooking and eating, entertaining, bathing, sleeping, and storage. A glance at the details revealed some variety in the ways in which these activities were accommodated in the houses. Participants’ housing and close boundaries (veranda, yard, and immediate sidewalk areas) were observed during my visits with them. To better organize and manage the research, I recruited participants in waves. Waves were linked to participants’ area of living and, therefore, presented similar environmental characteristics. Wave one was composed of residents of one area of the Campo neighborhood. Their houses usually had one level with 2+ bedrooms and verandas. In their living rooms, they socialized sitting on their sofas and/or armchairs. Every house had separate rooms for sleeping and rest. Some bathrooms had insufficient space for walkers, stools, or the equivalent, in showers/baths and the showers presented a curb/level difference, in

opposition to barrier-free showers. Typically, a shower has three walls, and the entrance is covered by a door or a curtain. 'Curb' refers to the threshold, or where one enters the shower when the door or curtain is open. A single-curb shower pan has a raised curb or edge at the threshold, about 2 to 6 inches high, that one must step over to enter the shower. Conversely, a barrier-free shower pan does not have a curb, although it may have a very low edge. All bathrooms were without grab bars in showers/baths/toilets. Wave one participants had kitchens near to the place where meals were served. Their kitchens had furnishings and equipment for cooking that did not demand complex maneuvers (more than one operation) and good precision in handling and fingering controls and operable hardware equipments. The exterior of their houses had irregular walking surface without handrails or resting surfaces, with one of the houses having stairs at the entrance.

Wave two participants also lived in the Campo neighborhood. Their houses were typically two storeys high and had 2+ bedrooms. Usually the bedrooms were in the upper level, with necessary dwelling functions located on the lower level; this required participants to climb stairs at least once a day (see Figure 2). The stairs connecting the upper and lower levels of their houses had handrails on both sides. The lower level had outdoor verandas where some participants socialized. They also had living rooms for everyday socializing with sofas and/or armchairs. Bathrooms had insufficient space for walkers, stools, or the equivalent, in showers/baths with shower stalls. There was a shower curb/level difference. Most bathrooms had no grab bars at showers/baths/or toilets. Wave two participants' kitchens and dining rooms were close together. Their kitchens had furnishings and equipment for cooking that did not demand complex maneuvers (more than one operation) and good precision in handling and fingering

equipments. The exterior of their houses had irregular walking surfaces without handrails or resting surfaces.

Figure 2. Wave two participants housing



Wave three participants lived in the Ponte neighborhood, in a community with some houses up on the hill. Their houses usually were between one and two storeys high and had between 1-2 bedrooms without verandas, with one exception. Most houses had rooms for everyday socialization with sofas and/or armchairs, as well as separate rooms for sleeping and rest. All bathrooms had insufficient space for walkers, stools, or the equivalent, in showers/baths

with shower stalls with curb/level difference. All bathrooms had no grab bar at showers/baths/or toilets. Wave three participants had kitchens near to the place where meals were served. Their kitchens had furnishings and equipment for cooking that did not demand complex maneuvers (more than one operation) and good precision in handling and fingering equipments. The exterior of their houses had irregular walking surfaces without handrails or resting surfaces with all houses having at least one flight of stairs at the entrance. The streets leading to most houses in this neighborhood were composed of ramps and stairs (see Figure 3). Sections of these streets had handrails, but not all. Despite not having proper handrails all the way up, Butterfly was thankful for at least having these handrails. Butterfly, who did not leave her house very often, said that:

I walk with a lot of difficulty, a lot of difficulty, it is good that there are those handrails to go up and down the hill. It is wonderful, it helps a lot. But if it was not for those [handrails] there, it would be terrible. I am even afraid of going down [the hill], of falling.⁵⁰

⁵⁰ Eu ando com muito sacrifício, muito sacrifício, ainda bem que tem aqueles corrimões ali no morro para subir e descer. Aquilo ali que é uma maravilha, ajuda muito. Mas se não fosse aquilo [corrimões] ali, seria terrível. E eu tenho medo até de descer, de cair.

Figure 3. Outdoor space of participants from wave three



Note: handrails on the right side of the ramp

Wave four participants lived in two different areas in the Ponte neighborhood. Their houses usually were one storey high and had 2+ bedrooms with verandas, which some of them used to socialize. Their living rooms were also used for everyday socializing. Their living rooms had sofas, chairs and/or armchairs. Most participants had separate rooms for sleeping and rest. Most bathrooms had insufficient space for walkers, stools, or the equivalents, in showers/baths with shower stalls with curb/level difference. Most bathrooms had no grab bars at showers/baths/or toilets. Wave four participants had kitchens near to the place where meals were served. Their kitchens had furnishings and equipment for cooking that did not demand complex maneuvers (more than one operation) and good precision in handling and fingering equipments. The exterior of their houses had irregular walking surfaces and most had no handrails or resting surfaces. Ella, who lived in a house but was moving back to a condominium she previously lived in with her family, said that living in a place with handrails was critical:

At the end of the month I am going to move to another address. We are running out of time to pack up here and move out. So, we are going to an apartment we lived in before.

There are stairs, a flight of ten steps. I can climb, but when I lived there they did not have a handrail. Now that we are going back to live there I asked them to put it in, right.⁵¹

To further understand the significance of participants' indoor environment to their mobility, I asked them to take pictures of spaces and objects that affected their mobility. I had planned to discuss these pictures with them during our first interview. However, when I asked participants to show their favorite spaces in their home, they usually pointed to places and objects close to us. Typically, their favorite spaces were within rooms for everyday socializing. Therefore, the need

⁵¹ No fim do mês eu vou me mudar para a rua [nome da rua]. Estamos correndo contra o tempo para arrumar aqui e nos mudarmos. Então nós vamos para um apartamento que já moramos. Há escadas, um lance de dez degraus. Eu consigo subir, mas antigamente quando eu morei lá não tinha corrimão, mas agora que vamos voltar a morar lá eu pedi que colocassem, né.

to take pictures to show and elicit memories from participants became irrelevant. Instead, during the first interview we talked about these objects and places, which were around us. When I inquired about what these spaces meant to them, they responded that the living room was the space to be during the day and where the interaction with their families and friends happened:

I wake up and go to the kitchen. I make my coffee and come into the living room. Here I watch television, sit on my couch and do my things. I do not stay in my bedroom, I am not sick or anything so don't stay in that room all day. We age and the body no longer responds as it used to. If we surrender, then everything ends. If we let the pain take over and we just lie in bed, it is like waiting for death to come. So, I get up and come here to the living room and I do not stop and I chat with the neighbors, a lot of people come here to have a cup of coffee with me, I love to have visitors.⁵² (Carnation)

Within participants' living rooms, they frequently pointed to sofas and chairs as spaces where they spent most of their time. Butterfly liked her sofa because that was the only space she had for herself:

Butterfly: I feel very good here, the only place I have to rest is here. Sometimes I sit down, if I want to lie down, I lie down. I do not like to leave my house. Here inside my house I walk a lot.

Interviewer: and would you like to have another chair or sofa, or is this sofa good enough?

⁵² Eu acordo e vou para a cozinha. Faço meu cafêzinho e venho para a sala. Aqui eu assisto TV, sento no meu sofázinho e vou fazendo minhas coisas. Ficar no quarto eu não fico não, não estou doente nem nada para ficar no quarto o dia todo. A gente envelhece e o corpo já não responde mais como antigamente. Se a gente se entregar, aí acaba tudo. Se deixar a dor toma conta e a gente só fica deitado na cama. Isso é esperar a morte chegar né. Então eu levanto e já venho aqui para a sala, e fico zanzando e converso com os vizinhos, muita gente passa aqui pra tomar um cafêzinho comigo, eu adoro receber todo mundo

Butterfly: it is good. It is all good. Because I am on the sofa then I go to bed, too. Oh, it is good. The sofa is good because it is harder, then, the body stays more upright. Because in bed I do not know, we get kneading, sitting. On the couch is a little better because it is a little harder.⁵³

Often times, participants' placement of their chairs were, according to them, in strategic spaces:

When I am in the kitchen doing things, for example, I am going to peel an onion and I have a lot of difficulty, [to peel] a potato I have difficulty in the joints, I get more tired ... ahhh [exhale as if she felt fatigue]. I stand there, my God, my back, then, I come and sit on the chair. After, I get up to do it again.⁵⁴ (Acacia)

Most participants had no desire to change their preferred sitting spaces. Fox, for instance, said that if his chair broke, he would have to get one in the same exact model:

Interviewer: in which places do you spend most time at home?

Fox: in that chair. I lean there and it has the arms to stay here. I think that is good for my back. I take a nap there sometimes.

Interviewer: so, this chair is perfect? Or would you like another chair?

If this chair breaks, I have to find another one just like that. Wow, I really like this chair⁵⁵.

⁵³ *Butterfly*: Me sinto muito bem aqui, o único lugar que eu tenho para descansar é aqui. As vezes eu sento, se der vontade de deitar, eu deito. Eu não gosto de sair da minha casa. Eu aqui dentro da minha casa eu ando que é uma beleza

Entrevistadora: E a senhora gostaria de ter uma outra cadeira ou sofá, ou esse sofá está ótimo?

Butterfly: Não, está bom. Está tudo bom. Porque eu fico no sofá depois vou lá para a cama também. Ai tá bom. O sofá é bom porque ele é mais durinho aí o corpo fica assim até mais em pé. Porque na cama a gente fica sei lá, amassado. Ai no sofá é um pouquinho melhor porque ele é um pouco mais duro.

⁵⁴ Quando eu estou na cozinha fazendo as coisas, que, por exemplo, vou descascar uma cebola e tenho muita dificuldade, uma batata tenho dificuldade nas articulações eu fico mais cansada...ahhh [expira ar como se fosse cansado]. Eu fico aí meu Deus as minhas costas, aí eu venho e sento um pouco na cadeira. Depois eu vou de novo fazer

⁵⁵ *Entrevistadora*: E quais os lugares em casa que o senhor passa mais tempo?

Fox: Nessa cadeira. É eu me escoro, tem os braços pra ficar aqui. Eu acho que é boa para minhas costas. Eu dou um cochilinho as vezes aqui

Entrevistadora: Então essa cadeira está perfeita? Ou o senhor gostaria de outra cadeira?

Fox: Essa cadeira aqui se quebrar eu tenho que arrumar uma do jeito dessa. Nossa eu gosto muito dessa cadeira

Conversely, when the space where participants spent most of their time was not a space of their choice, it had negative connotations:

Interviewer: and you spend most time sitting here in your wheelchair?

Sky: yeah, then when I get really tired I lie down.

Interviewer: so, you spend most time either in the wheelchair or in bed (...) And what does the wheelchair represent to you? When you think about your wheelchair what do you think?

Sky: oh, I think of getting out of it and walking, getting out and walking, and I am going to do it, I am by the power of Jesus. I will be able to walk. I did not get up before, now I get up and stand up and everything. The doctor said: “it is going to take a while”, but I will get out of it, God willing.⁵⁶

The outdoor physical environment is a key part of an older person’s environment (Barnes et al., 2007) that helps to maintain and promote participation in daily life and can contribute to deterioration in participation (Glass & Balfour, 2003; Law et al., 1996). During the period, I spent on the Island, I closely observed the outdoor spaces, e.g., sidewalks and street paths. In general, the neighborhood sidewalks presented some deterioration, which was potentially unsafe to pedestrians. These perceived dangers on the outdoor spaces were often mentioned by the participants:

⁵⁶ *Entrevistadora:* E a senhora passa mais tempo aqui sentada na sua cadeira de rodas?

Sky: É, depois quando eu fico muito cansada eu vou e deito

Entrevistadora: Então a senhora passa mais tempo na cadeira de rodas ou na cama (...) E o que a cadeira de rodas representa para você? Quando a senhora pensa na sua cadeira de rodas o que a senhora pensa?

Sky: Ah, eu penso em sair dela e andar, sair e andar, e eu vou conseguir, e vou lá, pelo poder de Jesus eu vou conseguir andar. Eu já não levantava, eu já levanto e fico em pé e tudo. A médica falou: “vai demorar”, mas eu vou conseguir se Deus quiser

I do not walk by myself, my daughter walks with me. First because the ground out there [in the yard] is not straight, I can stumble and fall. My daughter walks holding my waist, with one hand on my abdomen and one hand around my back; because if she is holding my arm and I fall, I can break my arm. There are a lot of things in the yard, the ground is very uncertain. Not here. In that area there [closer to the entrance of the house] is so so, but there is also a lot of [exposed] tree roots, it is bad. Before I used to go down there, but not anymore, I cannot bear it anymore because of my knee. At night, it gets very dark around here. I cannot walk outside, I already do not see very well, right, any stumbling I am done.⁵⁷ (Lily)

Participants perceived unsafe conditions near their homes, but these conditions extended further away as well. The Island as a whole was seen as an unfriendly environment to walk around. Many participants viewed the outdoor environment not just as a barrier to mobility, but as a barrier to independent living. This view was synthesized by Petal. When asked what level of mobility she wanted to achieve, she responded:

To walk by myself. That would be nice. I do not want to depend on others, but here in Paquetá the street is full of gravel and holes, it is terrible. And I stumble a lot, I trip all the time, but the street is horrible, everything is full of problems, right. I want at least to be able to go to the bakery; otherwise I will stay here depending on the caretaker my whole life. I cannot take a walk anymore. The streets are very bad. In the past, I used to go with

⁵⁷ Eu não caminho sozinha, minha filha anda junto comigo. Primeiro porque esse chão ali fora [no quintal] não é reto, eu posso tropeçar e cair. Minha filha anda segurando minha cintura, com um braço na frente outro atrás, porque se ela estiver segurando meu braço e eu cair, eu posso quebrar meu braço. No quintal é muita coisa, o chão é muito incerto. Aqui não, nesse pedaço aqui [mais perto da entrada da casa] está mais ou menos, mas também tem muita raiz de árvore, aí fica ruim. Antigamente eu ainda ia lá embaixo, mas hoje em dia não mais, eu não aguento por causa do joelho. De noite então fica muito escuro por aqui, aí não dá para andar lá fora, eu já não enxergo muito bem, né, qualquer tropeço já era.

my son and walk on the beach. I used to take a big walk around the Campo [neighborhood], I used to go for walks, but lately the streets are awful. I stumble, I bump into every piece of gravel. I hold his arm with one hand and a cane with the other hand, but I still stumble on the gravel, because there is a lot of gravel. It does not help when it rains. It gets difficult to walk, to raise the legs, the street gets heavy [the streets are made of clay], I do not know, the mud, I raise my legs and stumble on the gravel. And the sidewalk is worse, full of holes and bumps.⁵⁸

Pictures of the gravel and rubble are shown in Figure 4 and Figure 5.

⁵⁸ Andar sozinha, né. Aí tudo bem. não quero depender dos outros mas aqui em Paquetá a rua está cheia de pedras, de buraco, está um horror. E eu tropeço muito, toda hora eu estou tropeçando mas a rua também está horrível, tudo cheio de problema né. Eu quero pelo menos esta parte aí, poder ir a padaria, senão eu vou ficar aqui dependendo de babá [cuidadora] a vida toda. Para dar uma volta não dá mais não. As ruas estão muito ruins. Antigamente eu ia até com meu filho dar umas voltas na praia, eu dava uma volta grande pelo Campo, eu dava uma volta mas depois que as ruas ficaram horrorosas. Eu vou topando, eu vou topando em tudo quanto é pedra. Eu vou segurando no braço dele e de bengala na outra mão mas mesmo assim eu vou topando nas pedras, porque é muita pedra. Aí quando chove parece que não ajuda. Fica difícil para andar, levantar a perna, fica pesada a rua, sei lá, a lama, aí eu vou levantar e vou topando pelas pedras. E na calçada nem se fala, tudo esburacado e solavancado.

Figure 4. Gravel and holes due to rain



Note: Erosion of clay streets due to the rain causing exposure of naturally occurring gravel

Figure 5. Rubble on the streets of Paquetá Island



Note. Streets with broken stones of irregular sizes, shapes and textures

Outdoor conditions on the Island prompted participants to change their routines. Juliette, for example, voiced that the holes on the street discouraged her from going outside:

I am just going from here to the bathroom and back, and that is it. That is because the street here is full of holes, so it is unpleasant to leave. Better to stay at home and be safe.

Going outside to the street, it does not work. Then I stay here.⁵⁹

⁵⁹ Eu só vou daqui para o banheiro e do banheiro para cá, e pronto. É que a rua aqui está muito cheia de buraco, aí é ruim para sair. Melhor ficar em casa e inteira. Vai para a rua, não dá certo. Aí eu fico aqui.

These holes Juliette referred occurred both on the sidewalks and on the streets as shown in Figure 6 and Figure 7.

Figure 6. Holes in the sidewalk



Note. Holes in the sidewalk due to the collapse of quays

Figure 7. Holes in the streets of Paquetá Island



Note. Holes in the cobblestone streets due to poor conservation and maintenance

At other times, the natural environment coupled with built-in environments was a potential source of hazard. For example, the development of surface roots of any large tree, when it reaches a certain age, is natural; the risks of living nearby those trees should not be minimized. Star lived on a street with an unusual number of trees with surface roots and to walk around her neighbourhood became problematic:

It is hard. It is very dangerous to walk outside. We have no way. The other day I tripped on these trees, on the roots that sprout on the sidewalk. If it is not these holes on the

street, it is these sidewalks all broken up because of the trees. You have to be very careful because if something breaks it is bad, really bad⁶⁰ (Star)

Figure 8 illustrates the conditions of some sidewalks on the Island.

Figure 8. Sidewalks damaged by roots of a tree



In addition, poorly planned outdoor spaces hindered participants' ability to move around. Sky, who had her wheelchair as her sole means of locomotion, was limited to her home environment:

⁶⁰ Fica difícil. É muito perigoso andar aí fora. A gente não tem como. Outro dia eu tropecei nessas árvores, nas raízes que brotam na calçada. Se não são esses buracos na rua, são essas calçadas toda arreventada por causa das árvores. Tem que ter muito cuidado mesmo porque se quebra alguma coisa fica ruim, ruim mesmo

Yes, I spend most time sitting in this wheelchair. I want to get out and walk, but I cannot even do that. I do not have anyone to accompany me. My son works all day and only gets home at night. I cannot use my wheelchair to go out, there is lots of gravel and mud. On the sidewalk is even worse. There are holes, gaps and nonsensical ramps. How do I go around all these on my wheelchair? It is not easy.⁶¹

Figure 9 illustrates the sidewalk ramps Sky is referring to.

Figure 9. Ramps on the sidewalks



⁶¹ Sim eu passo mais tempo sentada nessa cadeira, mas eu queria sair e andar, mas nem sair na rua eu posso. Eu não tenho ninguém para me acompanhar. Meu filho trabalha o dia todo e só chega a noite. Na rua não dá para andar de cadeira de rodas, muito pedregulho e lama. Na calçada pior ainda. Tudo cheio de buraco, vãos e umas rampas doidas. Como é que eu vou passar por isso tudo com a minha cadeira de rodas? Não é mole não

Many participants did not walk further than within the premises of their homes. Walking by foot or going by wheelchair were not suitable means of transportation for them. Participants, then, had to use the available transport system in order to meet daily material needs, and guarantee access to health care. However, the available transport system did not always meet participants' needs. Flora, who had an accident while embarking on the ferry, revealed a lack of structure to serve individuals who, like her, had a challenged mobility:

At the ferry exit door, my friend's husband was holding me on this side and another friend of mine was holding me on the other side. At that time, they had not put that catwalk there yet. The ferry was that height [from the wharf] for us to get out [shows a rise of 30-40 centimeters]. With the waves the ferry rocked back and forth, people had to jump [from the ferry to the wharf]. Then when it was my turn, I went to jump but my legs were short and I fell down. I fell from the ferry on those hard iron plates [the wharf floor]. I moaned with pain, "ow, ow, ow", and the lady working at the ferry went after me and picked up a book and filled it out but did nothing. Now I have this knee pain that started after the fall in the ferry. After I fell down, another man has already fallen, he even fractured his hips and everything. But now they got their act together and put that catwalk there, it was high before but now it is low, thanks to God! But the ferry still rocks back and forth, you have to be careful.⁶² (Flora)

⁶² Olha o marido da minha amiga estava segurando deste lado e meu amigo do outro lado na saída da barca. Naquela época ainda não tinham colocado aquela placa ali. A barca ficava dessa altura para a gente descer, [mostra uma elevação de 30-40 centímetros]. Quando a barca balançava com as ondas ela ia e voltava, as pessoas tinham que saltar. Aí quando foi a minha vez eu fui saltar, minhas pernas eram curtas, e eu bá, cá daquele negócio, naquelas placas de ferro duras, aí eu queixei de dor" ai, ai ai", e a moça da barca foi atrás de mim e pegou uma caderneta e encheu mas não fez nada. Agora eu tenho essas dores no joelho que começou depois da queda nas barcas. Depois da minha queda já caiu um senhor que quebrou a bacia e tudo. Mas agora tomaram vergonha e botaram aquela passarela que a gente vai, que antes era alto mas agora está baixo, graças a Deus! Mas ainda balança pra lá e pra cá, tem que tomar cuidado.

A few participants reported that in addition to the structural issues in the outdoor environment, the occurrence of free-roaming dogs on the Island was a common problem affecting their outdoor mobility:

I started walking less after we moved. A tree fell down and obstructed the passage on the sidewalk for a long time. I think I lost my balance and hit my head. I think I lost my balance because I was going down walking on the edge because the sidewalk was never free. It was wet, or with fallen trees, or full of bicycles. So, one sometimes has to go to the street, and for me to go down by myself [from the sidewalk to the street] without support, it is difficult, that is where I ended up falling. Also, there was a time with a lot of dogs on the street. It was a lot of dogs, so they came like that [mimics a mad dog] lunging on you, so it was a time that I did not like very much. I used to go to the park. I really enjoyed going to the park, but there were dogs wanting to bite me.⁶³ (Ella)

Neighborhood safety was also a factor hindering participants' participation:

I do not leave, I stay locked in the house until my daughter arrives. Before, the gate was always open. But now my daughter is afraid because once a woman, not an old woman, she was half drunk and came and pushed the gate. She came in here, at the home. Thank God that day my daughter was here. But that has been a long time ago. Then it happened again. I do not know what it was. I do not know. A man came in here, because whoever passes the gate here sees everything inside. I was not alone that day. My daughter was

⁶³ Eu também passei a andar menos depois que nós mudamos. Uma árvore caiu, caiu e ficou muito tempo impedindo a passagem na calçada. Eu acho que desequilibrei e bati com a cabeça. Eu acho que desequilibrei porque aqui eu ia indo pelo canto da rua pois nunca a calçada está livre, ou ali está molhado, ou tem árvores caídas, ou está cheio de bicicleta. Então a pessoa às vezes tem que ir para a rua, e eu para descer sozinha [da calçada para a rua] sem um apoio, é difícil, aí foi onde eu acabei caindo. Mas também teve uma fase com muito cachorro na rua, era muito cachorro, então eles viam assim [gesticula um cão raivoso], em cima, então foi uma fase que eu não gostei muito. Eu ia no [parque] Darke [de Mattos]. Eu gostava muito de ir no Darke. Mas tinha cachorro querendo morder

here with me. Then the man pushed the gate and stood there on the step and looked at me he said, “It seems like my house here. My house. I think it is”. When he saw my daughter he said, “This is not my house, no. This is not my house”. But he would not leave. Then we got scared, so now I keep the gate locked. Often times, the doctors knock on the door but I do not listen and they cannot get in because I keep the door locked.⁶⁴ (Sonata)

While some participants voiced feeling unsafe on the Island, others expressed being afraid of going to the city:

My husband died in 1979. I live alone with God, but where I lived in Rio there were many muggings, I was mugged many times. I think that is why I got so scared. I lived in the North zone. After that I never took a bus again. Now I only take cabs or else I do not leave the house. I think I cannot even get up on the bus, I cannot pass the bus turnstile, I am afraid to ride on buses because of robbery. Every time I took the bus I saw only robbery. I was already robbed on the bus to Tijuca, God forbid! I am terrified, I was mugged in my house and that is why I left there. A machine gun of this size, they loaded everything I had and that is why I got nervous, I got really nervous.⁶⁵ (Flora)

⁶⁴ Eu não saio, fico trancada dentro de casa até minha filha chegar. Antes o portão sempre ficava aberto. Mas agora a minha filha tem medo porque uma vez uma mulher, não é assim velha não, mas ela estava meio embriagada e chegou e empurrou o portão. Entrou aqui em casa. Ainda bem que nesse dia minha filha estava aqui. Mas isso já faz tempo. Depois outra vez também. Eu não sei o que foi. Eu não sei. Um homem entrou aqui, porque quem passa no portão ali enxerga tudo aqui dentro. Aí esse dia eu também não estava sozinha. Ela [filha] estava aqui comigo. Aí o homem empurrou a porta e ficou aí no degrau e olhando para mim falou, “aqui parece a minha casa. A minha casa. Acho que é”. Quando ele viu a minha filha ele falou, “é, aqui não é a minha casa não. Aqui não é a minha casa. Mas ele não ia embora. Então a gente fica com medo, aí eu fico com o portão trancado e muitas vezes os médicos veem me visitar e eu não escuto eles chamarem

⁶⁵ Meu marido morreu em 1979. Eu moro sozinha com Deus, mas lá onde eu morava no Rio dava muito assalto, eu fui muito assaltada. Eu acho que foi por isso que eu fiquei assim medrosa. Eu morava na zona norte. Depois disso nunca mais peguei ônibus não. Agora só vou de táxi ou senão não saio de casa. Acho que em ônibus eu nem subo, não passo naquelas roletas, eu tenho medo de andar em ônibus por causa de assalto. Toda vida que eu pegava o ônibus e ia para o lado do Méier eu só via assalto. Eu já fui assaltada no ônibus para a Tijuca, Deus me livre! Eu tenho pavor, eu fui assaltada na minha casa, por isso que eu saí de lá. Uma metralhadora deste tamanho, carregaram tudo que eu tinha e por isso que eu fiquei nervosa, eu fiquei muito nervosa

The **natural environment** also emerged as a contributor to mobility challenge. Environmental noise had an impact on participants' activities and living conditions. Oak, for instance, preferred to spend his time in his room, which was located on the second floor of his home and apart from the house's focal point of interpersonal interactions, due to outside environmental noise: "I spend more time up there [in the bedroom]. There is more noise here [in the living room], right.

Upstairs is quieter, I would rather be quiet, in peace.⁶⁶

The climate was also an important contributor to participants' mobility. The state of Rio de Janeiro has a tropical climate, which is characterized by constant high temperatures (at sea level and low elevations) with all months of the year having average temperatures of 18° Celsius or higher. Most parts of the state of Rio de Janeiro have a tropical savanna climate along with a tropical monsoon climate from December to March when the city has long periods of heavy rain. However, the state capital, the city of Rio de Janeiro, has a tropical rainforest climate (Alvares, Stape, Sentelhas, Gonçalves & Sparovek, 2013), which is marked by having at least 60 mm of rainfall every month of the year. This makes for a hot and wet environment. In the last years, climate changes have affected Rio de Janeiro. In the past, an average daily high temperature was 30° Celsius, but Rio de Janeiro has registered temperatures above 40° Celsius in recent summers. The temperature on the Island is the same as in the city; however, the Island is more timbered than the city. These last temperature changes were felt by participants and hindered their mobility:

I do not do anything. I cannot do anything. I walk very little. Just here in the house. Right now, I was telling my daughter, "today I have a doctor's appointment at two o'clock.

⁶⁶ Eu passo mais tempo lá em cima [no quarto]. Aqui [na sala] tem mais barulho, né. Lá em cima é mais calmo, eu prefiro ficar sossegado, na paz.

When it is half past one, I will call the boy [rickshaw driver] to take me there”. First because of the sun, I get very tired. I even go there on the beach. The sun is strong, but I stay there in the shade, it is cooler there. I do not stay in the sun, I stay in the shade. But with this heat, there are times that out of nowhere I get so tired. But it is not always, no. Now we are talking about going in the sun, I think I am tired of just watching the sun.⁶⁷

(Misty)

In addition to the hot weather, participants complained about the effects of the humidity. During one of my encounters with Luz she was talking about the difficulties of living with challenged mobility. Then, I asked her if some days are better than others or if she felt that way most days. She replied the following:

When the weather changes like this, I feel bad all day. When it is hotter it is really bad. I get dizzy, I get sick. But I almost do not sit down because my daughter no longer wants me to sit much because I already do not walk much anymore. And this chair stays here, but then when I feel very hot, Our Lady. I go to the water tank and toss some water on my head, on my neck. I sweat too much. That is why I do not like the heat. Because even in the cold I sweat a lot. But I do not push myself, no, I try to be quiet so I do not get dizzy. Then I stay quiet.⁶⁸ (Luz)

⁶⁷ Eu não faço nada. Não chego a fazer nada. Eu ando muito pouco. Só aqui dentro de casa. Agora mesmo eu tava dizendo pra minha filha, “hoje eu tenho a doutora as duas horas. Quando for uma e meia eu chamo o menino [conductor] pra me levar.” Primeiro por causa do sol que eu fico logo muito cansada. Eu até vou ali na praia, o sol é forte, mas eu fico lá onde tem sombra, lá é mais fresco. Não fico no sol, fico na sombra. Mas com esse calor tem horas que do nada eu fico assim meia cansada. Mas não é sempre não. Agora falou em ir no sol, eu acho que eu já fico cansada só de olhar o sol

⁶⁸ Quando o tempo muda assim, fica ruim o dia todo. Agora, quando está mais calor é muito ruim. Me dá essa tontura eu já fico coisa. Mas eu não sento quase nessa, que a minha filha já não quer que sente muito porque eu já não ando muito. E essa cadeira fica aqui, mas aí quando eu sinto muito calor Nossa Senhora. Vou lá no tanque e jogo água na cabeça, no pescoço. Eu transpiro demais. Por isso que eu não gosto de calor. Porque mesmo com o frio eu transpiro muito. Mas eu não abuso não, tento ficar quieta para eu não ficar tonta. Aí eu fico lá na minha.

Socio-Economic Factors

Many socio-economic factors are important because they create and shape patterns of mobility, disability and healthcare utilization. Socio-economic factors include the previously mentioned socio-demographic characteristics, such as participants' gender, age, ethnicity, marital status, level of education, housing and income. However, additional factors such as social networks, social participation, social comparison, and financial status played important roles in participants' mobility.

Social support and networks involve a set of social actors and a set of relational ties and situational factors (e.g., resources and demands) connecting these actors. The result of social networks is a subjective sense of belonging, being accepted, loved, wanted, respected, and valued and required by someone (Fu, Anderson, Courtney & Hu, 2007). Participants' social network shaped ways in which they dealt with mobility. Social actors from participants' networks were their family, friends, neighbors, healthcare providers and caregivers. Situational factors were based on participants' needs for assistance to develop basic activities of daily living, instrumental activities of daily living, or simply companionship.

Participants' families engaged in different roles and were the main source of social support. One of the most important roles of family members was assisting participants in accomplishing activities of daily living. Occasionally, participants needed more comprehensive support to pursue activities. Lily, for example, lived with her daughter, who was her full-time caregiver and helped her with basic activities of daily living:

Now it is just my daughter and I. She does the chores in the house and I just feel like an annoyance. I wake up and she brings me breakfast in bed. Then I get up and go to the bathroom. My daughter takes me to the bathroom, she does not let me go to the bathroom

by myself, then she leaves me there for a little, and then I come to the room and stay here, I read the magazine, I look only at the pictures, then I sit in bed, then when it is six o'clock I turn on the television, then I have a cup of coffee before bed, then I go to my bed and I lie down and sleep.⁶⁹ (Lily)

Sometimes participants required assistance to meet needs with instrumental activities of daily living. Acacia, for example, had challenged mobility but was able to live independently for most of the day. She just required assistance to perform certain types of activities:

I wash the duvet in the washing machine. My son puts it there and hangs it on a clothesline. I ask him to put it on the clothesline. It is the machine that washes them and then they are ready to hang [...] I just do not hang the clothes because I cannot lift my arms and I cannot stand up for that long.⁷⁰ (Acacia)

Acacia and Lily lived with family members in the same household, which possibly made it easier for them to request and access their support. Other participants, who lived by themselves, still benefited from the assistance of family members but had to engage in some sort of advanced planning. Petal, who required assistance from her son to pursue instrumental activities of daily living, used to plan in advance their week activities:

A while back I started to do physiotherapy. My son would pick me up and take me to physical therapy. It was hard for him because he lives in Rio. Then he had to work and at

⁶⁹ Agora é só eu e ela [filha], ela no serviço dela dentro de casa, afazeres domésticos e eu na amolação. Eu levanto e ela traz meu café na cama. Depois eu levanto, eu vou ao banheiro, minha filha me leva, não deixa eu ir sozinha ao banheiro, aí ela me deixa lá um pouco, e depois venho para a sala e fico aqui, leio a revista, eu fico olhando só as figuras, depois eu sento na cama, aí quando chega às seis horas eu ligo a televisão, aí tomo um cafézinho antes de dormir, depois vou para minha cama e deito e durmo

⁷⁰ Eu lavo o edredom na máquina. Meu filho que bota lá e ele que bota minha roupa na corda. Eu peço para por na corda. É a máquina que lava e depois pronto. Eu só não estendo a roupa por causa do meu braço, eu não consigo levantar e também é difícil ficar de pé esse tempo todo.

eleven o'clock, at lunch time, he would pick me up, take me to the physiotherapy, have lunch, drop me off at the ferry station, and go back to work.⁷¹ (Petal)

Participants' children were the main social actors of participants' social networks and regularly formed the basic structure of it; but they were not the only ones. Extended family members were also a part of participants' social network and viewed as part of their safety net. An extended family may constitute kin members including aunts, uncles, siblings (brothers and sisters), cousins and in-laws. Carnation, for example, owned her house and had one of her children living on the Island, but opted to invite her brother to live with her:

My brother lives with me here. [He lives] here on the side of my house, he stays in a small room. My brother does everything for me. I also do not like to stay still for very long, I do one thing here and there. I have a cleaning person but my brother also helps. I cook, if I have to sweep, I sweep, because I do not like anything dirty, I never had [...] I like everything clean, I am picky, I am too picky [laughs] I used to even clean the stairs by myself. Now my brother does everything for me. When things are dirty, my brother does the heavy cleaning. He does, he sweeps, but it is not the same as I do. Now, I depend on my brother, I sit down and he does everything. I just watch [laughs]⁷² (Carnation)

Interestingly, it was not uncommon for participants to reach out to 'fictive kinships' – people with no blood relationship (such as friends and neighbors) to participants. Fictive kinship is a

⁷¹ A um tempo atrás eu comecei a fazer fisioterapia. Meu filho me pegava e me levava na fisioterapia. Ficou uma mão de obra para ele muito grande porque ele mora no Rio. Aí ele tinha que trabalhar e onze horas, na hora do almoço, ele me pegava, me levava para fazer a fisioterapia, acabava de lá almoçava, me deixava nas barcas e ia para o trabalho.

⁷² Meu irmão mora comigo, aqui né. Aqui do lado da minha casa, ele fica num quartinho. Quem faz tudo para mim é meu irmão. Eu também, eu não gosto de ficar muito parada não, eu faço uma coisa e outra, eu tenho uma faxineira, mas meu irmão me ajuda também, entendeu? É eu faço um almoço, se tiver que varrer a casa eu varro, porque eu não gosto de nada sujo, nunca gostei [...] Eu gosto de tudo limpinho, eu sou até chata, eu sou até chata demais [risos] Porque até a escada eu limpava, agora é tudo o meu irmão que faz para mim, e as coisas mais pesadas assim quando está sujo, ele [irmão] faz, dá uma varridinha, mas não é a mesma coisa da gente fazer [...] Agora, eu só fico na aba do meu irmão, eu fico sentada ele fica fazendo tudo. Eu só fico olhando só [risos]

term used by anthropologists and ethnographers to describe forms of kinship or social ties that are based on neither consanguineal (blood ties) nor affinal (by marriage) ties, in contrast to true kinship ties. For more details on the idea of kinship, please refer to Schneider (1984). The use of fictive kinships sometimes occurred when participants already had the support of their family members but choose to supplement their safety net with fictive kinships. Acacia lived with her two sons but felt more comfortable reaching out to her neighbor for assistance with basic activities of daily living:

You know I wish I could use the bathroom [...] I cannot take a shower by myself. Then, I have a friend who is like a daughter to me [...] she comes every now and then to help me with my shower ... I have another neighbor that every other day gives me a shower.⁷³
(Acacia)

Participants not only relied upon family structure based on blood relationships and/or fictive kinships. A few participants, many of whom lived by themselves, received support from formal caregivers. This support varied and sometimes was in the form of encouragement:

Now I have a caregiver. They stay 24 hours with me, one stays during the day and the other during the night. I am always with them. I am too lazy to walk. There are days when they [the caregivers] and my son say, “let’s go, let’s go, let’s go”, they bug me. This one [referring to the daytime caregiver] bugs me a lot [laughs]. She tells me to drink water, to walk and not to sleep sitting in this chair.⁷⁴ (Petal)

⁷³ Você sabe que é minha paixão era eu poder usar o banheiro [...] O banho no chuveiro é que eu não posso tomar sozinha. Aí eu tenho uma amiga que é que nem uma filha [...] e aí ela vinha de vez em quando me dar banho [...] E eu tenho uma outra vizinha, quando a vizinha vem, dia sim dia não, eu tomo banho de chuveiro

⁷⁴ Agora eu tenho acompanhante. Elas ficam comigo 24 horas, uma fica na parte do dia e a outra na parte da noite. Eu sempre fico acompanhada. Eu tenho preguiça de andar. Tem dias que elas [as cuidadoras] e meu filho começam e falam: “vamos, vamos, vamos” me enchem o saco. Essa aqui então enche o saco [risos]. Fala para beber água, a caminhar e a não dormir sentada nessa cadeira

At other times, formal caregivers assisted participants in pursuing instrumental activities of daily living:

Look, I do not need help doing housework, like doing the dishes or going to the bathroom. Now I go to the bank with the girl who works for me. It is hard for me to walk alone, I am afraid, but it is more because of the holes, right? But now I am using more the rickshaw but I have to walk by foot, right? I have to walk, right?⁷⁵ (Flora)

Participants also relied on healthcare providers to improve their mobility:

I did some physical therapy at the healthcare center, I did physiotherapy, but now it has been almost three months I am at home without being able to walk, because I do not know, I was discouraged, right. Sometimes, we do not feel right. The healthcare providers give me support, encouragement, and everything. But I feel a bit of dismay, so I avoid going out much, right. But the healthcare providers always come here. They talk and explain everything that I have to walk, that I cannot stop going to the physiotherapy, that depression kills. If I need anything they come. They are great, they give a lot of support. I will try to walk, as the doctor of the family health strategy asks me.⁷⁶ (Spring)

It is noteworthy that a few participants' social networks had adverse effects on participants' mobility. It happened when family members intended to assist participants' mobility but in fact perpetuated the problem. An example was family members, often with the best of intentions, not

⁷⁵ Olha eu não preciso de ajuda para fazer coisas de casa, tipo lavar a louça ou ir ao banheiro. Agora ao banco eu vou com a menina que trabalha comigo. É difícil para mim andar sozinha, eu tenho medo, mas é mais por causa dos buracos, né. Mas agora eu estou andando mais de eco-táxi mas tem que andar a pé, né? Eu tenho eu caminhar, né?

⁷⁶ Eu fiz um pouco de fisioterapia aqui no hospital, fazia fisioterapia, mas agora tem quase três meses que eu tô aqui dentro de casa sem poder estar andando, porque, sei lá, tive desânimo, né. A gente tem horas que não é a gente. O pessoal do hospital dá uma força, incentiva e tudo. Mas dá um pouquinho de desânimo, então eu evito de sair muito, né. Mas o pessoal do hospital sempre vem aqui. Eles falam e explicam tudinho que eu tenho que andar, que eu não posso parar a fisio, que depressão mata. Se eu preciso de qualquer coisa eles vem. Eles são ótimos, dão uma força enorme. Vou tentar caminhar, como a [doutora da estratégia saúde família] me pede

allowing participants to move around to pursue needed or desired activities. The practical effect was that participants did not have to do the activities themselves, deteriorating even more their mobility challenge and shielding them from awareness of the harm it may do and the need or pressure to change:

I have to get my act together [laughs]. I will get up in the morning and walk a little.

Thank God I walk well, just my knee hurts. But my husband and son do not let me do anything, they do everything for me. I wake up and sit on this armchair, I spend the whole day here watching television; sometimes, I do not even go to bed and sleep right here. But I have to go for a walk, I have to, I am the lazy one to walk [...] before I used to go to the gym, I went to serenades, I danced all night without stopping, now I am like this. I will tell you, I danced a lot, but now I cannot because of my knee, right. I was going to the gym at the healthcare center. I wanted to go back to the gym. I am going to walk on the beach with my dog because my husband is lazy.⁷⁷ (Lavender)

Having social networks did not only afford participants with instrumental and emotional support; but also assisted them to **participate** and remain **socially connected**. It seemed that participants' type of social networks influenced their participation in social activities, such as membership in civic groups and churches. To the vast majority of participants, religious or spiritual activities were a venue to engage socially and/or remain socially connected:

⁷⁷ Eu tenho que tomar vergonha na cara [risos]. Eu vou levantar de manhã e andar um pouquinho. Graças a Deus eu ando bem, o meu joelho que dói. Mas meu marido e meu filho não me deixam fazer nada, fazem de tudo para mim. Eu acordo e venho sentar aqui na poltrona, eu passo o dia todo aqui assistindo televisão, de vez em quando na noite eu nem vou pra cama e durmo aqui mesmo. Mas eu tenho que dar uma caminhada, tem que dar, eu que sou preguiçosa para andar [...] Antes eu fazia ginástica, ia ao pagode, seresta, eu dançava a noite toda sem parar, agora estou assim. Eu vou te contar, eu dancei muito, mas agora eu não posso com esse joelho, né. Eu fazia ginástica lá no hospital. Eu queria voltar lá para a ginástica. Eu vou andar na praia com o meu cachorro, pois meu marido é preguiçoso

When I walk down the street, everybody greets me. I joke, people leave me alone, leave me alone. In the church then, everyone [talks to me]. Oh, I like it. I really like it. We have gatherings, we had gatherings in the houses and everything, I participate. Just as a minister I remained for five years, the responsibility is great. As a minister, we have that attitude of being able to participate, interact with people, to go in people's homes to do what we have to do. I am from the church ... I am very animated, then, I calmed down, thanks to God. But I like a lot to go [to the church], it makes me feel very good.⁷⁸

(Spring)

In Christianity, a minister is a person authorized by a church, or other religious organization, to perform functions such as teaching of beliefs; leading services such as weddings, baptisms or funerals; or otherwise providing spiritual guidance to the community. Other participants found that participating in religious activities and worship practices motivated them to move around:

Yes, I stay more at home now, right. I cannot walk too much, I cannot even work. Then I either stay home or go to church. I go on worship days, I go to church on days of worship. There are weeks I go up to four times. I am from the Assembly of God. But my church is here [points to the church near to his home]. It is right here. Nearby [laughs].⁷⁹(Fox)

⁷⁸ Quando eu ando aí na rua, todo mundo mexe comigo.... Eu brinco, gente, me deixa em paz, me deixa. Na igreja então, todo mundo. Ah, eu gosto. Gosto muito. A gente faz uns encontros, a gente fazia encontros nas casas e tudo eu participo. Só como ministra, eu fiquei cinco anos de ministra e a responsabilidade é bem grande, que a gente e ministra, a gente fica com aquela postura de poder participar, interagir com as pessoas, de ir na casa das pessoas fazer o que a gente tem que fazer. Sou da igreja... muito assim alvoraçada, aí fui me acalmando e graças a Deus eu tô assim. Mas eu gosto demais de ir [a igreja], me faz muito bem

⁷⁹ É, eu fico mais em casa agora, né. Não posso andar muito, nem trabalhar. Aí ou eu fico em casa ou vou para a igreja. Eu vou dia de culto, dia de culto eu vou para igreja. Tem semana que eu vou até quatro vezes. Eu sou da Assembleia de Deus. Mas a minha igreja é aqui ô [mostra a igreja no morro]. É aqui em frente. Aí do lado aí [risos]

Sometimes, religious gatherings were the only event compelling participants to leave their houses:

I went to a wedding. It had many things to eat, it was fun. The church was full, there was not enough space, we could not even move. I saw many people who ... many people who I have not seen for a long time. It was good. The wedding was on Saturday. Then I kept the energy and went to the church on a Saturday and Sunday. Then Sunday I went to supper. I had the Holy Supper. It has been a long time since I have had [holy] supper. Because in the Catholic Church it is a communion wafer, right? Here in the Evangelic it is supper. But my leg was hurting. When we arrive at the church there, as we enter, there is still a staircase to climb, but it was good. It was very good.⁸⁰ (Butterfly).

While social networks were important to participants' ability to live more or less independently; they also influenced how participants **compared themselves socially** to others. Participants sometimes evaluated their mobility based on how they stacked up against others. One way of comparing themselves was to use somebody faring better than them:

Now, I have to walk less, I want to walk, I want to, I say "my God", I see others running, I want to run but I cannot. But one of these days I am going to walk. My friends, we are almost the same age, they walk, they go to the gym, they run. One of these days I am going to walk too.⁸¹ (Flora)

⁸⁰ Eu fui no casamento. Tinha bastante coisa para comer, foi divertido. A igreja encheu, que não cabia que não dava nem para se mover. Eu reví muitas pessoas que... muitas pessoas que muito tempo que eu não via há muito tempo. Foi bom. O casamento foi no sábado. Aí eu entrei no pique e fui sábado e fui domingo. Aí domingo eu fui para a ceia. Tinha a Santa Ceia. Que já tem muito tempo que eu não tomava a ceia. Por que é que na igreja Católica é hóstia, né. Aqui na evangélica é ceia. Mas a minha perna estava doendo bem. Aí quando chega na igreja ali, que a gente entra, ainda tem uma escadaria para subir, mas foi bom. Foi muito bom.

⁸¹ Agora, eu tenho que andar menos, eu quero andar, eu quero, eu digo: "meu Deus", eu vejo os outros correndo, eu quero correr mas não posso. Mas nesses dias eu vou andar. Minhas amigas, a gente tem quase a mesma idade, elas andam, fazem ginástica, correm. Um dia desses eu também vou andar

However, comparing themselves to people who fared worse also served as a way for them to value their current mobility:

I think I have great health, God is very good. Every day I thank him because what I see here on the television, I see people, what it is like ... I saw a person without hands and working, I am saying, it encourages those who are sick. For example, I think I am great, I do not have anything to complain⁸² (Ella)

The role of **financial status** was also recognized as an important element affecting participants' mobility. The vast majority of participants were retired and had their pension attached to their government social security. It was not uncommon for retirees to have their pension payment delayed at times for months and that affected their ability to focus on their health:

This [money] is an important thing. If I had more money, if I had, it would make things easier. I cannot even explain what I would be able to do [if I had more money]. They stopped my payments, I have not received money for five months now. My daughter is looking after it to see if the government will release my pension. They [the government] cut off my wife's pension two or three months ago and mine five months ago. I did not receive the 13th salary, I did not receive anything. I am not too tight yet because I have a little savings, right. But I get anxious. I have to focus on my priorities first, such as the bills, food, and so.⁸³ (Oak)

⁸² Eu acho que eu tenho uma ótima saúde, Deus é muito bom. Todo dia eu agradeço a ele porque o que eu vejo aqui na televisão, eu vejo as pessoas, como é que é (...) eu vi uma criatura sem as mãos trabalhando, dizendo, isso incentiva quem está doente. Eu por exemplo me acho ótima, não tenho do que reclamar

⁸³ Isso era uma grande coisa. Se tivesse mais dinheiro, se tivesse iria facilitar as coisas. Eu nem sei explicar o que eu poderia fazer. Eles cortaram meu salário, já há cinco meses que eu não recebo dinheiro. Ai a minha filha está correndo atrás pra ver se vai sair no INSS. Cortaram também o dela [esposa] há dois ou três meses atrás e o meu foi já há cinco meses. Não recebi décimo terceiro não recebi nada. Eu não estou muito apertado ainda porque eu tenho uma poupançazinha, né. Mas eu fico aperrado, eu tenho que focar nas prioridades primeiro, tipo as contas, comida e tal.

Note that is not uncommon in Brazil to have delays in pension checks, especially when there is an economic crisis in the government. The 13th month's salary is not a bonus, but a legally mandated payment due all workers and pensioners. Employers pay salaries on a monthly basis in Brazil, but because the payments cover four weeks, the 13th payment at the end of the year compensates for the extra days worked each month.

Sometimes participants' lack of financial resources was not that fragile, but it still restrained their ability to prioritize their health, for example, hindering their ability to engage in physical activities:

My neighbor told me now there is a girl who is teaching water aerobics, here on the Island. She will give me the address for me to go there. I say: "well, let's see, right? If it is not too expensive, right?" Everything here is expensive. It looks like she wants a hundred and fifty Reais [per monthly] to have classes twice a week. I mean, it is eight times a month. A little expensive because besides the monthly fee, there are other things. For now I cannot walk there. I will have to get the rickshaw. Using the rickshaw I will already spend ten more Reais. Two times a week, it is twenty Reais [to get to the class].

Have you seen how much these classes are going to cost? Two hundred reais.⁸⁴ (Misty)

At other times, participants' lack of financial resources affected their ability to pursue activities of daily living:

Recently, my daughter hired a cleaning lady to work here. I need help. She helps me and everything. I have to take care of myself, because I do not have the money to pay her all

⁸⁴ Minha vizinha me disse também tem uma moça que agora, tem uma, tá fazendo hidroginástica, aqui na ilha. Que ela também vai me dar o endereço pra mim ir lá. Eu digo: bom, vamo ver né. Se não for também muito caro, né? Que aqui tudo é caro. Parece que ela quer cento e cinquenta reais. Duas vezes por semana. Quer dizer, são oito vezes no mes. Um pouco puxado porque além da mensalidade tem outras coisas. Por enquanto eu não posso ir a pé. Eu vou ter que ir de carrinho. De carrinho já gasta mais dez reais. Duas vezes por semana mais dez reais, mas vinte reais. Você já viu quanto é que vai sair essa academia? Mais duzentos reais.

the time, right? We do not. They want a lot of money. I hired one just to cook my meals because I cannot stand up. If I stand up, I have to lean on the wall. I talked to her about cooking my meals. That was last year. Do you know how much she wanted? I gave, three months, R\$ 450.00 per month. My pension is one thousand and something [Reais]. I pay the electric bill, I pay the water bill, I pay condominium fees. I buy medicine, I buy diapers. I still had to pay 450 [Reais] to the cleaning lady. So I have to stretch my money. I have to iron it to stretch it. Because I do not want to buy things and owe money, I do not like to buy on the cuff [credit]. Everything is expensive. So, what do we live for? We only survive and when the money cannot pay the cleaning lady, I have to force myself to cook. Often it is not possible, then I eat only a small piece of bread.⁸⁵ (Rose)

Theme Four: Expectations and Needs for Mobility

What we aim to achieve from an intervention – our expectation – has a substantial impact on what we actually experience (Brown, 2013). In this section, I first describe participants' mobility expectations, which refers to participants' future-directed beliefs and desires regarding their mobility. Subsequently, I describe participants' felt needs. If need is defined as a discrepancy between a present state of affairs and a desired state of affairs as asserted by an 'owner' of the need or an 'authority' on need (Beatty, 1981), felt needs are changes deemed necessary by individuals to correct the deficiencies they perceive in their health (Wade, 1989). Thus, in this section I highlight what participants' expectations are and their needs to achieve

⁸⁵ Minha filha arrumou uma faxineira ainda agora, para vim. Eu preciso de ajuda. Ela me ajuda e tudo. Eu tenho que me cuidar, porque não tem dinheiro para pagar o tempo todo, né? A gente não tem. Elas querem um dinheiro. Eu arranjei uma aí só para fazer uma comida porque eu não consigo ficar em pé. Se eu fico em pé, eu tenho que ficar escorada. Eu falei com ela pra fazer uma comida. Isso foi no ano passado. Sabe quanto ela queria? Eu dei, três meses, R\$450,00 por mês. Eu ganho mil e pouco. Eu pago luz, eu pago água, eu pago condomínio. Eu compro remédio, eu compro fralda. Ainda tinha que tirar os 450 para a faxineira. Então, o meu dinheiro tem que esticar ele. Passar a ferro para esticar. Porque eu não quero comprar e ficar devendo. Não gosto de comprar fiado. Está tudo caro. Então, o que a gente vive? O que a gente vive? A gente só sobrevive e quando o dinheiro não dá para pagar a faxineira, eu tenho que forçar para fazer a comida, muitas vezes não dá, aí eu como só um pãozinho mesmo

desired mobility status. To shed light into participants' expectations and needs, participants were asked questions regarding factors influencing their mobility and desired ways to overcome them. Sub-themes related to their mobility expectations and needs are outlined in Table 6.

Table 6. Expectations and Needs

Sub-themes	Categories
Expectations	Engaging in activities Being more active Participating
Needs	Material resources Built environment Informational resources Health needs Psychological support

Expectations

Participants who desired to improve their abilities to engage in activities of daily living, be more active, or have a life without fear usually compared their mobility desires with previous experiences of similar events. Petal described that it was problematic to pursue simple basic **activities of daily living**. She used her past capabilities as a point of departure to her current desires:

Well, you know, I guess it is hard for me because I used to be very independent and active. I cleaned up my house, I cooked, I was a good cook. I did not stop, I walked up and down running household errands, handling hot potatoes. Now, I need help to go to

the toilet, to go to the toilet! I have faith I can get better, I have to have faith. It is hard not being able to even go to the toilet without any issue⁸⁶. (Petal)

Female participants linked their desire to improve their mobility to their ability to keep pursuing domestic activities:

Interviewer: and what would you like to do if you could move better?

Butterfly: I want to clean my house and it is difficult, to mop the floor, even to sweep it is difficult. It is hard for me to do all the things in the house [...] I wanted to get well and do everything I did before. Because who is going to cook for me, who is going to help me with anything?⁸⁷

Male participants usually aspired to improve their mobility to engage in **activities of remunerative employment** outside their homes:

Since my toe has been amputated it has been difficult to walk as I walked. I want to get back to work. I have hope, I would like to be back selling my little things, I would sell still, sell little things on the street, I was going to sell. I just wanted to go back and sell my little things. I worked in the country for seven years. I have always worked⁸⁸ (Fox)

Participants also wanted to **be more active**; and their goals varied from being able to go to the gym to being able to go dancing. Their desire to be more active was often related to their desire

⁸⁶ Bom, sabe como é, eu acho que pra mim é difícil porque eu era bem independente, eu era porreta. Eu limpava minha casa, cozinava, eu era boa na cozinha. Eu parava, andava para cima e para baixo resolvendo problemas, descascando abacaxis. Hoje em dia, caramba, preciso de ajuda para ir ao banheiro, para ir ao banheiro! Eu tenho fé que eu posso sim ficar melhor, eu tenho que ter fé. É bem difícil não poder nem ir ao banheiro sem problemas.

⁸⁷ *Entrevistadora:* e o que a senhora gostaria de fazer se a senhora pudesse se movimentar melhor?
Butterfly: Eu quero arrumar a minha casa e está difícil, passar um pano de chão, até para varrer está difícil. Tá difícil para eu fazer minhas coisas tudinho dentro de casa [...] Eu tinha vontade de ficar boa e fazer de tudo que eu fazia. É porque quem é que vai cozinhar para mim, quem é que vai me ajudar em alguma coisa?

⁸⁸ Desde que eu amputei meu dedo, ficou difícil andar como eu andava. Eu quero voltar a trabalhar. Eu tenho esperança, eu gostaria de voltar a vender minhas coisinhas, ia vender ainda, uma besteirinha na rua, eu ia vender. Eu só queria voltar a vender minhas coisinhas. Trabalhei na roça por sete anos. Sempre trabalhei

to participate in social gatherings. Daisy summarized that sentiment during one of our conversations:

Daisy: of course, I would like to go out, hop on my bike and ride all over. Biking was enjoyable. I would like to ride my bike again. Everybody knows everybody in the Island. I hopped on my bike and went around, stopping now and then to talk to friends.

Interviewer: and do you think you could bike again?

Daisy: I am not sure, I hope I could, but after the thing I had in my legs I am not sure. I am not aware of my body anymore, sometimes I feel nothing, I feel numb. I do not know.

Interviewer: so, you do not think that is possible to bike anymore?

Daisy: maybe, but I do not know. I know I should be able to go out and everything by now, I really wish I could do all these things. The doctors say I can, but I do not feel I can, as much as I want. Riding my bike was something I really enjoyed. I enjoyed to go to the serenades too. I loved to dance. I wish I could do all these things again⁸⁹

Some wanted to be more mobile to invest in their interpersonal relationships. Their social **participation** was linked to their ability to visit family and friends:

I cannot go out alone anymore. I am old, but I would like to visit my siblings and nieces and nephews. No one comes here to visit me anymore. If I could go out I would visit

⁸⁹ *Daisy:* claro que eu gostaria de sair, montar na minha bicicleta e pedalar pra lá e pra cá. Pedalar era uma coisa muito boa. Eu gostaria de andar de bicicleta de novo. Todo mundo conhece todo mundo na Ilha. Eu subia na minha bicicleta e dava minhas voltas, parando de hora em hora para conversar com os amigos.

Entrevistadora: e você acha que poderia andar de bicicleta de novo?

Daisy: não tenho certeza, eu gostaria, mas depois da coisa que tive nas pernas, não tenho certeza. Não tenho mais o sentido no meu corpo, às vezes não sinto nada, sinto aquela dormência. Eu não sei.

Entrevistadora: então, você não acha que é possível andar de bicicleta? (Entrevistador)

Daisy: talvez, mas não sei não. Eu sei que agora mesmo eu deveria ser capaz de sair e tudo, eu realmente gostaria de poder fazer todas essas coisas. Os médicos dizem que eu posso, mas eu não sinto que posso, por mais que eu queira. Andar de bicicleta era algo de que eu gostava muito. Eu gostava de ir nos bailes também. Eu amava dançar. Eu gostaria de poder fazer todas essas coisas de novo

them. I miss them. If I could I would visit them. I miss them. Nowadays, I just stay here at home, enclosed. Yeah, I would visit them, family is everything⁹⁰ (Lily)

Needs

Individuals commonly have perceived needs and obligations to themselves and to others in order to support desires and to influence the ordering of priorities. In this section I present participants' assessment of their own needs and requirements to achieve their desired mobility. The first key issue highlighted by a few participants was **material resources**. Sky described not having enough resources to acquire a walker. In Sky's situation, a walker would be useful for her recovery. Sky had surgery two years before our interview and used a wheelchair as her main means of mobility. During my first interview and follow up visit I kept returning to the walker issue because it was quite pertinent to my understanding of participants' needs and adaptation methods:

Sky: my desire would be to get out and walk, and I will succeed, I will succeed by the power of Jesus I will be able to walk. I did not get up before, I already get up and everything. The doctor said, "it will take long", but I will get it, God willing.

Interviewer: and you told me that the only thing that is missing now for you to be able to work on your walking skills is the walker, right?

Sky: it is the walker. Because I had one here that the lady lent me, but the lady had surgery again, she had surgery so she is using it, I had to give it back to her, but she said that when she is not using it anymore, she will give it to me, but then I do not know when. I have to see if I can get one, rent one for me, but it is difficult.

⁹⁰ Eu não posso mais sair sozinha. Eu já estou velha, mas gostaria de visitar meus irmãos e sobrinhas e sobrinhos. Ninguém vem me visitar mais. Se eu pudesse sair, eu ia visitar eles. Eu sinto falta deles. Se eu pudesse eu ia visitar eles. Eu sinto falta deles. Hoje em dia, só fico aqui em casa, enclausurada. Sim, eu iria visitar eles, família é tudo

Interviewer: is it? So how will you do it?

Sky: I have the impression that with a crutch I can walk, but he [her son] do not think so, that I can fall. I do not need to take a tumble because of my back wound, but every once in a while, I try to walk with my crutches.

Interviewer: it seems very dangerous for you to try to use crutches at this time. Crutches would be useful if you had good balance, and after two years between the bed and the wheelchair there was a loss of balance. We would not want anything to happen, right?

Sky: no, God forbid. But it is not easy not to have the things that help. I want to try, I want to get out, I want to walk, and how do I do it without having the walker? ⁹¹

Improvement of **built environment** was also mentioned as requirement for participants' mobility. Participants dwelling were often cited:

You know, if I could, I wanted to have that thing to hold on so we would not lose balance in the bathroom [handrail]. I already walk hunched forward, you know. That would help a lot. Actually, the shower [base] could be bigger, without the curb on the floor, because

⁹¹ *Sky:* meu desejo seria sair e andar, e eu vou conseguir, e vou lá, pelo poder de Jesus eu vou conseguir andar. Eu já não levantava, eu já levanto e fico em pé e tudo. A médica falou: “vai demorar”, mas eu vou conseguir se Deus quiser

Entrevistadora: e a senhora me disse que a única coisa que está faltando agora para a senhora poder trabalhar no seu andar é o andador, né?

Sky: é o andador. Porque eu tinha um aqui que a dona me emprestava, mas a dona operou de novo, teve que operar então está usando, eu tive que devolver, mas ela disse que quando não estiver usando mais, ela me dá, mas aí eu não sei quando. Tem que ver se consegue arrumar um, alugar um para mim, mas está difícil.

Entrevistadora: É? E aí como é que faz?

Sky: eu tenho impressão que com muleta eu consigo andar, mas ele [filho] acha que não, que eu posso cair. Eu não preciso levar tombo por causa da minha ferida nas costas, mas de vez em quando eu tento andar com as muletas.

Entrevistadora: me parece bem perigoso para a senhora nesse momento tentar usar muletas. Muletas seriam uteis se você tivesse um equilíbrio legal, e depois de dois anos entre a cama e a cadeira de rodas há uma perda de equilíbrio. Nós não gostaríamos que nada acontecesse, né?

Sky: não, Deus me livre. Mas não é fácil não ter as coisas pra ajudar. Eu quero tentar, sair, andar, e como é que eu faço isso sem ter o andador?

then I could go into the shower with the walker. My thing was to be able to wash my head in the bath, but I cannot, I told you, right?⁹²(Acacia)

Sidewalk surfaces and quality were also often mentioned:

You know, it is not easy to go out to run errands. Have you seen the sidewalks? They are terrible. It would be nice to have good sidewalks, free of tree roots, free of potholes, cracks. Trees grow in the middle of the sidewalk, they are not wide enough to begin with. I do not know if the administration does not have money, or what. I know that it would be easier to go out if we had accessible paved sidewalks.⁹³

Other participants felt that they needed more **information** regarding their health and mobility in order to more fully understand and choose their own paths to recovery:

I have done all the exams I should do, I already did it all. All the exams I could do I already did. I have done computed tomography of the spine, I have already done a magnetic resonance imaging, I have done electromyography to film the leg, I have done an electrocardiogram. But I do not know, I do not know, some doctors say one thing, others say another. How am I going to take care of myself like that? I was even taking medicine for the head, it is not that I was crazy, I took medicine that is not to heal the leg, it is for the brain. Because I am not understanding. I say one thing, she says, one says

⁹² Sabe, se eu pudesse eu queria ter aquele negócio de segurar pra gente nao perder o equilíbrio no banheiro [barra de apoio]. Eu já ando entrevada, sabe. Isso iria ajudar bastante. Na verdade o box poderia ser maiorzinho, sem o parapeito no chão, porque aí eu poderia entrar no chuveiro com o andador. Minha coisa, minha vida era poder lavar a cabeça no banho, mas eu não aguento, já te falei, né.

⁹³ Você sabe, não é fácil sair lá fora para resolver nossos abacaxis. Você já viu as calçadas? Um horror. Seria bom se elas fossem decentes, sem essas raízes enormes, buracos, trincos. As árvores brotam no meio da calçada, e as calçadas não são largas para começo de conversa. Eu não sei se a administração da ilha não tem dinheiro, ou o quê. Eu sei que seria mais fácil sair a gente tivesse essas calçadas endireitadas com cimento

another here, and I do not understand it. They say anything, how will I get better, how am I going to do something if even the doctors do not decide what I have?⁹⁴ (Daisy)

Some participants voiced the need of better **health** to work on their mobility:

I want to walk, I want to, I say “my God, I see others running, I want to run but I cannot”. But one of these days I am going to walk. I would like to lose weight. I am eating little to see if I lose weight because they say it is because of the weight that I am not able to walk much, but the weight I do not know, the scale was showing I do not know how much. I have to lose a little. I want to lose weight so I can walk. I am doing everything to lose weight.⁹⁵ (Flora)

Other participants voiced the need for better **psychological support** to work on their mobility

I just do not walk because I am afraid to fall. Because I fell and broke the femur and it has already been two years. I fell in the sitting position here. I sat down, then I felt a pain like fire, I got scared and I got up, I got up fast, then when I got up quickly my legs crossed over each other and I fell on the sitting position and broke the femur. I want to start walking, I want to walk. I had surgery and became afraid to walk after that to this

⁹⁴ Já fiz todos os exames que eu deveria fazer, eu já fiz tudo. Todos os exames que eu poderia fazer eu já fiz. Já fiz tomografia computadorizada da coluna, já fiz ressonância magnética, já fiz eletromiografia para filmar a perna, já fiz eletro doppler. Mas eu não sei o porque disso, não sei, uns médicos falam uma coisa, outros falam outra. Como eu vou me cuidar assim? Eu estava até tomando remédio para a cabeça, não é que eu seja biruta, eu tomei remédio que não é para curar a perna, é para o cérebro. Porque eu não tô entendendo. Eu digo lá uma coisa, ela diz, você aqui diz outra, e eu não tô entendendo. Eles falam qualquer coisa, como é que eu vou melhorar, como eu vou fazer algo se nem os médicos decidem o que eu tenho?

⁹⁵ Eu quero andar, eu quero, eu digo: “meu Deus, eu vejo os outros correndo, eu quero correr mas não posso”. Mas nesses dias eu vou andar. Eu gostaria de emagrecer. Eu estou comendo pouco para ver se eu emagreço porque diz que é o peso, que eu não estou conseguindo andar muito por causa do peso, mas o peso sei lá, a balança estava dando não sei quanto. Eu tenho que perder um pouco. Eu quero perder peso para poder andar. Eu estou fazendo de tudo para perder peso

day. I have never been to a psychologist, no, maybe it would help, do you think I need to?

I do not know, maybe it would help. If I lost this fear, I could walk again.⁹⁶ (Eva)

Summary

Participants' expectations towards mobility were related to their desire to engage in activities of daily living, being more active, and being more participative. To accomplish these expectations, they voiced a need for material, informational, psychological, built-in, and health resources. Participants past experiences, as well as individual, social and environmental structures seemed to affect their perceptions, values, and behaviors towards mobility. Their mobility identities and behaviors were negotiated within a framework emerging from their experiences, interpersonal encounters, and their internal dynamics.

Feelings participants attributed to mobility challenge were mainly negative. Fear, lack of freedom, burden, anger, distrust, shame, hopeless and illness were prevalent. However, when participants articulated their own mobility, they attributed more positive properties to it. On one hand, they were fatalistic, rejected their condition, and felt their body appearance and functioning were declining; on the other hand, they felt informed, motivated, and open to negotiating barriers, adapting and adjusting to live better with their mobility challenges. Finally, contextual factors played an important role in participants' perceptions and experiences with mobility challenges. Participants found themselves living without proper structural resources inside and outside their homes; however, the social support from their networks played an essential part in participants' adjustment to their challenged mobility.

⁹⁶ Eu só não ando porque eu tenho medo de cair. Porque eu caí e quebrei o fêmur e operei já tem dois anos. Caí sentada aqui. Eu estava sentada, aí veio uma dor e deu fogo, levei esse susto e fui levantar, levantar rápido, aí quando eu fui levantar rápido minhas pernas cruzaram uma na outra e eu caí sentada e quebrei o femur. Eu quero começar a andar, eu quero andar. Eu operei e aí eu fiquei com medo de andar e até hoje eu tenho medo. Nunca fui na psicologa nao, talvez ajudaria, você acha que eu precisa? Não sei, talvez ajudaria. Se eu perdesse esse medo, eu poderia andar de novo.

The relationships between mobility challenge (an activity limitation) and the other dimensions of the International Classification of Functioning, Disability and Health Framework are complex. Findings regarding factors related to participants' perceptions and experiences with mobility are essential for understanding individuals' mobility challenge. Within the International Classification of Functioning, Disability and Health Framework perceptions and experiences belong to the personal factor dimension. Therefore, this information regarding participants' sets of cognitive, emotional and motivational states of mind will assist us in having a greater understanding of older persons' mobility challenge in the functioning – disability continuum and better capture how older persons, as agents, dynamically respond and renegotiate the meaning of disability.

CHAPTER SIX: FINDINGS OF OLDER PERSONS' EXPERIENCES WITH THE SIT-TO-STAND ACTIVITY

The second focus of this research was to examine urban Brazilian community-dwelling older persons' perceptions about a sit-to-stand activity. From the 23 participants who agreed to take part in the first interview, 21 agreed to perform the sit-to-stand activity once a day, for four weeks. Only one participant interrupted participation in the sit-to-stand activity due to physical decline. In the end, 20 participants completed the 4-week sit-to-stand activity.

During the 4-week activity, I visited participants on a weekly basis. Almost all participants received four follow-up visits in between the first and second interview. When participants were not able to schedule a visit during a given week, we caught up on the following visit. On average, the follow-up visits took 5-10 minutes, of which I engaged in participant observation and informal interviews. At the end of the four-week activity, I conducted the last face-to-face interview.

This chapter presents analysis of the data from participant observations and interviews. Two themes emerged from the analysis: (1) 'To join, or not to join: that is the question'; (2) 'How did it go?' Each one of the two themes, and their respective sub-themes, are described with supporting excerpts from the transcripts and field notes.

Theme One: To join, or not to join: that is the question

After the first interview, I introduced the sit-to-stand activity to participants. If participants were curious about the activity, I was curious about their first impressions of the activity. I paid attention to participants initial reactions after the introduction of the activity, I wondered about which aspects of the activity were of interest to participants, I tried to

understand participants' motivation and reasoning to join, or not, the sit-to-stand activity. Sub-themes related to their first impressions of the sit-to-stand activity are outlined in Table 7.

Table 7. To join, or not to join: that is the question

Sub-themes	Categories
Structural aspects	Having flexible schedule Trying something new Changing routine Having someone to do it with
Individual influence	Having physical limitations Stigmatization associated with exercises targeting older people Intentioning Having goals

Structural Aspects

Participants' perceptions of the elements of the sit-to-stand activity affecting their perceptions of the intervention are described here. Structural aspects were related to the elements of the sit-to-stand activity. Participants usually anticipated the proposed activity offered them **flexibility** to schedule it according to their pre-established routine. Ella, for example, reasoned that she could fit it in her usual daily activities:

I think it will not be hard to do this exercise. You said once a day for a couple of minutes?

It seems doable. I can do it after lunch, or maybe after breakfast. Let's see. Let's see.

Sometimes we join the gym but it is not easy to show up every time. Something always

comes up and at the end, each day we are go less and less. Maybe with this exercise at home will be easier.⁹⁷ (Ella)

Another factor for those who expressed interest in pursuing the activity was the excitement of engaging in **something new**. Usually these participants were retired and their lives had a slower pace than it used to have previously. Sonata, for instance, spent her days by herself. She worked her whole life outside her home, but after she retired, her life changed. While she lived with her daughter, her daughter went out early in the morning and came back home late in the evening. According to her, she could benefit of some changes here and there:

If it is to help, I will do it. I will challenge myself with it, that is it. I feel a lot of back pain, but I will try it out. I tried many different things throughout the years, different drugs, compression socks, I even went to the physiotherapist a couple of times. To be honest my life is pretty much the same boredom now. Before I used to do everything, up and down. So, it is always good to try new things, it helps.⁹⁸ (Sonata)

On the other hand, a few participants hesitated to join the activity due to the changes it could impose on their previously established routine. Pre-established daily rituals were meaningful to participants and suggesting a **routine change** was a source of discomfort for some participants:

Florian: I already have my things, things I already to do during the day. I am not sure I like it [the activity]. I do not need it in my life.

⁹⁷ Eu acho que não vai ser difícil não pra fazer esse exercício. Você disse uma vez por dia por alguns minutinhos? Acho possível. Eu posso fazer isso depois do almoço, ou talvez depois do café da manhã. Vamos ver. Vamos ver. Às vezes a gente vai e se inscreve na academia, mas não é fácil sempre ir. Sempre surge algo e no fim das contas, cada dia que passa a gente vai cada vez menos. Talvez com esse exercício na casa da gente mesmo seja mais fácil

⁹⁸ Se é para ajudar, eu faço isso. Eu vou me desafiar a fazer isso, tá aí. Eu sinto muita dor nas costas, mas vou tentar. Eu já tentei tantas coisas diferentes de uns anos pra cá, diferentes remédios, usei meias de compressão, até no fisioterapeuta algumas vezes fui. Pra falar a verdade a vida fica nesse tédio agora. Antes eu fazia de tudo, pra lá e pra cá. Mas aí sempre é bom tentar umas coisinhas novas, isso ajuda.

Interviewer: how come? It would take just five minutes of your time. You could do it after you wake up, before taking a shower.

Florian: I am not sure, I have my life on a schedule, I like to do my stuff, I already organized my life with other things.⁹⁹

Another pertinent concern raised by some participants was their fear of doing the activity by themselves. Overall, participants who were alone during the day, had a poor perception of their health, or were in the oldest old age group and voiced that having **someone to do the activity with them** was an important element:

I am afraid, I am afraid of falling down and breaking my femur again. I need someone to do it with me. I do not feel well, it has been a while since I used the walker; my son carries me around. Before he leaves for work, he puts in the living room. Maybe my son can help me after he gets home from work. If you explain that to him, he will do it with me. It has been a while since I used the walker, I do not feel safe doing it by myself.¹⁰⁰

(Eva)

Individual Influence

Factors within individuals affecting their perceptions of the sit-to-stand activity, including ways of thinking, feeling, and acting when I invited them to do the sit-to-stand activity are

⁹⁹ *Florian:* já tenho minhas coisinhas, as coisinhas que eu já faço durante o dia. Não sei se gosto disso. Eu não preciso, preciso fazer isso, não preciso disso na minha vida.

Entrevistadora: Como assim? Isso tomaria apenas cinco minutos do seu tempo. Você poderia fazer isso depois de acordar, antes de tomar um banho.

Florian: não sei não, tenho minha vida cronometrada, gosto de fazer minhas coisas, já sistematizei minha vida com outras coisas

¹⁰⁰ Eu tenho medo de cair e quebrar meu fêmur de novo. Eu preciso de alguém para fazer comigo. Eu não me sinto legal, já tem um tempinho que eu não uso o andador, meu filho me carrega por aqui. Antes de ir para o trabalho, ele me põe sentada na sala. Talvez meu filho me ajuda depois que ele chegar do trabalho em casa. Se você explicar tudo direitinho pra ele, ele faria comigo. Já tem um tempo que eu não uso o andador, eu não me sinto segura fazendo isso sozinha não

described here. When participants perceived themselves as having **physical limitations**, they were more resistant to engage in the sit-to-stand activity:

I am not sure about this exercise. The thing is my leg. I have a lot of pain, a lot of pain, my dear, on the knee. It hurts when I move, when I get up, when I get down because of this arthrosis, very high arthrosis. I still feel a little pain from the varicose veins. The varicose veins hurt a little. When the weather warms up, they start to heat up, to burn. It is hard for me. I feel like I just cannot, what if I falter and fall?¹⁰¹ (Rose)

It was not only participants' physical limitations and health conditions that permeated their assumptions about the sit-to-stand activity, but also the perceived **stigma of exercises targeting older people** was also highlighted:

But this [sit-to-stand activity] is for people who do not walk or anything, it is for seniors or people who already are very sick. Thank you very much, but I do not want to take your time. This is not for me. I am old but that is not for me, that is enough. I am 80, but I am still good.¹⁰² (Summer)

Referrals from health care providers also influenced participants' **intention** to perform the sit-to-stand activity. When health care providers from the family health strategy had previously talked to participants about performing some physical activity or the benefits of sit-to-stand activity, they were more inclined to join the activity:

¹⁰¹ Eu não sei sobre esse exercício. O negócio é as minhas pernas. É muita dor, muita dor mesmo, minha filha, no joelho. Dói quando me movimento, levanto, abaixo. Por causa dessa artrose, artrose bem alta. Eu ainda sinto um pouquinho de dor por causa das varizes. As varizes doem um pouco. Quando o tempo esquenta, elas começam a esquentar, arder. Fica difícil pra mim. Eu sinto que não dá, se eu titubear e cair?

¹⁰² Mas isso são para gente que já não anda, nem nada, é para velhos ou gente já muito doente. Muito obrigada e tal, mas eu não quero tomar o seu tempo. Isso não é pra mim não. Eu estou velha mas isso não é pra mim, aí já é demais. Eu estou com 80 anos, mas ainda estou inteira

I will try to do [physical activities] as the doctor of the family health strategy asks me to do. And the other doctors also say: “you have to walk, walking is good, your muscles will thank you, you will see”. So, I think I can start with this exercise that you said.¹⁰³

(Acacia)

Furthermore, participants’ families also played an important role in participants’ **intention** to perform the sit-to-stand activity:

My daughter always tells me to be more active. She works at home and takes care of my granddaughter and me. I want to help by washing the dishes, doing any small thing, but she does not allow me to do any chores at home, she is afraid something will happen, an accident. She is being silly. I will do the exercise, she always tells me to do something like that and with her around it is easier.¹⁰⁴ (Ella)

In addition, when participants had **goals**, they agreed to participate in the activity more promptly. For instance, Juliette was housebound and her daughter and son in law assisted her with some activities of daily living. After she started doing the sit-to-stand activity, she voiced feeling less pain in her legs. Despite the proposed activity goal not being to reduce pain, but to strengthen muscles and assist with balance, her own perceptions and goals had a positive effect on her engagement in the sit-to-stand activity:

Oh, I really want to be able to sit down and get up without pain, without problems.

Sometimes when I sit down, get up, sit down, get up, my leg pops. But I already felt it

¹⁰³ Vou tentar fazer [atividades físicas] como a doutora da estratégia saúde família me pede. E os outros doutores também dizem: “você tem que caminhar, caminhar é bom, os músculos vão agradecer, você vai ver”. Então acho que já posso começar com esse exercício que você falou

¹⁰⁴ Minha filha sempre fala pra eu ser mais ativa. Ela é do lar e cuida de mim e da minha neta. Eu até quero ajudar lavando a louça, fazendo qualquer coisinha, mas ela não me quer que eu faça nada de casa, ela tem medo que algo aconteça, um acidente assim. Ela está de bobica. Eu vou fazer o exercício, ela sempre me manda fazer as coisas assim e com ela por perto fica mais fácil

before, it has been a while [that I feel the pop]. I think it keeps popping, for now ... But like, when I go to the bathroom, to climb the step there in the bathroom, I say: “oh, my knee popped. I heard a crack”. But this is normal. The thing is to do the exercise as you said. Better days will come, right. Sit down, get up, sit down again, get up, right? We have to look forward to something, hold onto something and move on.¹⁰⁵ (Juliette)

Theme Two: How Did It Go?

During my weekly follow-up visits, participants and I talked about the sit-to-stand activity, their progress, their impressions of it, and if there were any unexpected events from the previous week. On the second and last interviews, I was interested in knowing participants’ experiences with the sit-to-stand activity. Thus, this last formal interview served as an opportunity to summarize and debrief with participants the progressions of the 4-week activity. This interview was an opportunity I had to take my hunches and ideas back to participants so we could discuss and negotiate meanings. Sub-themes related to their completion of the 4-week activity are outlined in Table 8.

¹⁰⁵ Ah, eu queria mesmo era poder sentar e levantar sem dor, sem caso nenhum. Quando eu sento, levanto, sento, levanto, a perna estala às vezes. Mas eu já sentia antes, já tem um tempo. Eu acho que continua estalando, por enquanto... Mas assim, quando assim, eu vou sair para ir no banheiro, para subir o degrau ali do banheiro, eu digo assim: “ih, o meu joelho estalou. Escutei um estalo”. Mas isso é normal. O negócio é fazer o exercício conforme você falou. É bola pra frente, né. Senta, levanta, senta de novo, levanta, não é? Meu objetivo é poder levantar, sentar, talvez se eu fizer esse senta e levanta dá certo. A gente tem que mirar em algo, se apegar a algo e seguir em frente.

Table 8. How did it go?

Sub-themes	Categories
Drivers	Cost Privacy Perceived benefits in mental and physical health Going at own pace and adapting the activities Sense of achievement Having a supportive system Easily integrated into daily routine
Obstacles	Present health condition No perceived need Fatalism Fear of worse outcome Lack of companion Lack of motivation Competing demands Routine challenge/Discipline Safety concern Weather

Drivers

Participants highlighted different elements of the sit-to-stand activity that sustained their participation. Its low **cost**, which was translated into no gym membership fees, specialized equipment or travel costs; these were perceived as advantageous to participants:

You know, I enjoyed doing it, I did it every time I could and every time I remembered.

Sometimes we forget to do it and when we remember it is already bed time. But the thing of just using the chair was pretty nice. If we go to the gym classes on the beach, we have to pay. If we go there in the healthcare center's gym, we do not have to pay but to get

there we have to spend money on the rickshaw [transportation]. But that sitting and standing activity can be done at home, that is cool. We do at home.¹⁰⁶ (Star)

Another positive component of the sit-to-stand activity was the possibility of doing it in the participants' own home, which offered them some **privacy** to perform the activity without feeling judged or observed:

You do not have to get dressed and leave the house. I even do it wearing my old and ripped clothes. People look at you when you are there at the gym. It is easier to exercise because you do not have to worry about clothes, getting dressed, and such. When we are at home, it is just us.¹⁰⁷ (Ella)

Furthermore, participants emphasized how the activity made them feel. When participants could envision or feel an **improvement in their mental or physical health**, they seemed more disposed to keep performing the sit-to-stand activity:

Sonata: This week was not easy because sometimes I feel this pain in the morning and at night. During the day, the pain alleviates a little because I also have a lot to do. Oh my God. So, I have to do it according to what I can, I am doing something.

Interviewer: Did you notice any benefit from exercising?

Sonata: Oh yes. Because I did not get up from the chair with ease. I had to hold it here. If I sat on this stool, it was difficult to get up. So, I had to help myself up with both my hands on the chair, and sometimes it would take longer because of the pain. My whole

¹⁰⁶ Sabe, eu gostei de fazer isso, fiz toda vez que pude e toda vez que lembrei. Que às vezes a gente esquece de fazer e quando a gente lembra já está na cama. Mas o negócio de só usar a cadeira mesmo foi bem legal. Se a gente vai para a academia na praia tem que pagar. Se a gente vai lá na academia do hospital, não tem que pagar mas pra chegar lá tem que gastar com o eco-táxi. Mas isso de sentar e levantar dá para fazer em casa, aí fica legal. A gente faz em casa mesmo

¹⁰⁷ Você não tem que se arrumar e sair de casa. Eu faço com as minhas roupas velhas e rasgadinha mesmo. Os outros olham quando você está lá na academia. Ficou mais fácil fazer isso porque a gente não precisa se preocupar com roupa, se arrumar, e tal. Quando a gente está em casa, é só a gente mesmo.

body hurts. Oh, but my daughter was so happy. I surprised her, right? She got home, because I always have to wait for her to help me. Then she came and I said, “stay here close to me, close your eyes”. Then she said: “what happened?” I said, “a very good thing happened”. She said, “was the girl [researcher] here?” I said, “she was”. “What happened?” She asked. I said, “wait”. Then I said, “you can turn around”. Then I got up by myself. “Huh? You did not hold there”, she said. And then I came and did it once, twice, sometimes up to three times, I could not stand. It was not easy, but thank God, I am getting there.¹⁰⁸

The easiness of the activity and participants’ ability to **adapt** the activity to their reality coupled with the opportunity to pursue the sit-to-stand activity at their **own pace** also positively influenced adhesion to the activity:

The exercise is easy. I am going, I am going. I am doing. Once in a while, it is not easy to get up, okay. I can sit down... I go slowly and surely. I really wanted to sit without pain, right? And sometimes, there are times that hurt more, there are times that hurt less, right. The exercise is actually good. It is easy. It is not unpleasant, no. Every day I do a little. I sit there in that chair. Yesterday I did it. Sit down, get up, sit down, get up. Sometimes, I need assistance from my daughter or my son in law to do it, and I also use my hands to

¹⁰⁸ *Sonata*: Essa semana não foi fácil não, por que as vezes é de manhã, e a noite essa dor. Durante o dia ainda alivia um pouquinho porque eu também tenho muito coisa pra fazer. Ah, meu Deus. Então eu tenho que ir conforme o que eu posso, e eu vou fazendo alguma coisa

Entrevistadora: A senhora observou algum benefício do exercício?

Sonata: Ah, sim. Porque eu não levantava da cadeira muito bem. Tinha que segurar aqui. Se eu sentasse nesse banquinho, aí pra levantar era difícil. E aí, assim, tinha que ajudar com as duas mãos ali na cadeira, e às vezes tinha que esperar um pouquinho mais por aí dóia. O meu corpo todo dói. Ah, mas a minha filha ficou tão feliz. Ah. Eu fiz surpresa, né? Ela chegou. Porque eu tenho sempre que esperar pra ela ajudar. Aí ela chegou e eu falei: “fica aqui perto de mim, fecha os olhos”. Aí ela: “o que que aconteceu?” Eu falei: “aconteceu uma coisa muito boa”. Ela falou: “a menina [pesquisadora] esteve aqui?” Eu falei: “esteve”. “O que que aconteceu?”, ela perguntou. Eu falei: “pera”. Aí, falei: “pode virar”. Aí levantei sozinha. “Ué? Você não segurou ali”, ela falou. E aí vim aqui e fiz uma, duas, às vezes até três vezes, eu não conseguia ficar em pé. Era fácil não, mas graças a Deus estou conseguindo

get up. But I do it. When I do not feel like doing in that chair, I do here at the sofa. But I do it. The important thing is that I am trying.¹⁰⁹ (Juliette)

Another important element was participants' **sense of achievement**. When participants felt they crossed self-imposed milestones, they were more confident about the future.

Interviewer: Have you noticed any benefit after having done this exercise? What do you notice about yourself? Are you walking a little more?

Sky: No, not walking yet. Now I am going to start walking here. I am not walking yet. I just stand, but I am already stretching more. After you got the walker for me, I started doing the sit and stand thing. I tried and because I felt safe doing this, I do it every day. I am already stretching further. I believe I will improve more. I could not even stretch like that. One step at a time.¹¹⁰

Having **supportive system** also influenced participants' engagement in the activity. In most instances participants lived with **family members** and these family members were quite supportive of their engagement in the sit-to-stand activity. Family members would assist participants when they needed help to accomplish the activity. They would encourage and remind participants of the activity. They would also work as participants' advocates inquiring

¹⁰⁹ O exercício é moleza. Vou indo, vou indo. Estou fazendo. Uma vez ou outra. É ruim de levantar, né. Sentar eu sento...Vou devagar e sempre. Eu queria muito sentar sem dor, né. E às vezes, têm vezes que dói mais, têm vezes que dói menos, né. O exercício até que é bom. É fácil. Não é sacrificado não. Todo dia eu faço um pouco. Sentar aqui nessa cadeira. Ontem eu fiz. Senta, levanta, senta, levanta. Às vezes, preciso de ajuda da minha filha ou do meu genro para fazê-lo, e também uso minhas mãos para me levantar. Mas eu faço isso. Quando eu não sinto vontade de fazer isso, eu faço aqui no sofá. Mas eu faço isso. O importante é que estou tentando. Às vezes, preciso de ajuda da minha filha ou do meu genro para fazer, eu também apoio nas mãos para levantar. Mas eu estou fazendo. Quando eu não sinto vontade de fazer na cadeira, eu faço aqui no sofá. Mas eu faço. O importante é que eu tento fazer.

¹¹⁰ *Entrevistadora:* E você observou algum benefício depois de ter feito esse exercício? O que você observa em você? Anda um pouquinho mais?

Sky: Não, andar ainda não. Agora que eu vou começar a andar aqui. Andar ainda não. Só fico em pé, mas já estou me esticando mais. Depois que você conseguiu o andador pra mim, eu comecei a fazer o negócio do sentar e levantar. Eu tentei, tentei, e como eu senti segurança pra fazer isso, eu faço todo dia. Já estou me esticando mais. Eu acredito que vou melhorar mais. Eu nem esticava assim. Um passo de cada vez.

about the research and participants' development throughout the weeks. Support of participants' social circle showed to be an important ingredient in their positive experience of the activity:

Interviewer: Carnation, what would encourage you to do more of this activity? Is your son pushing you?

Carnation: My son ain't easy, when he sees me he says: "you have to do this and that". Sometimes, when he walks by and I am hanging outside, he says, "you are going out, at last, huh. Way to go". I say, "fine, fine". Then he gets all happy, then I do things when he is around. But when he is not around, I do not do anything.

Interviewer: So, he encourages you to exercise more?

Carnation: Very much, he wants me to go to the gym. What am I going to do at the gym? No gym. My son supports me. I am the one not taking it seriously, it is just that, because that exercise was a cool thing, but practically everything for health is a good thing. I even talked to my daughter, she said like that, "mom, that is right, do the exercise. Are you doing it?" Every now and then I do not do it, and my daughter says, "mom, you have to do it every day, every time". Not every time, I cannot. But that [the sit-to-stand activity] was good for me, to cheer me up. My family supports me. ¹¹¹

¹¹¹ *Entrevistadora:* Dona Carnation, e o que te encorajaria a fazer mais essa atividade? Seu filho dando em cima?

Carnation: Meu filho é fogo, quando ele me vê ele fala: "você tem que fazer isso, não sei o que lá". Quando às vezes ele passa por aqui e eu estou dando uma volta, ele fala, "vai sair, até que enfim hein. É isso mesmo". Eu falo, "tá beleza, tá bom, pode deixar". Aí ele fica todo feliz, aí eu faço as coisas quando ela está me vendo. Mas quando ele não vê, eu não faço é nada.

Entrevistadora: Então ele te encoraja né, a se exercitar mais?

Carnation: Bastante, ele quer que eu vou lá para a academia. O que vou caçar em academia, academia nada. Só meu filho mesmo na causa né, só meu filho na causa. A enrolação toda sou eu mais nada, que o exercício até que foi uma coisa legal, mas praticamente tudo para a saúde é coisa boa. Ainda falei com a minha filha, ela disse assim, "mãe, é isso mesmo, faz mesmo. Está fazendo?" De vez em quando não, e ela fala: "mãe, tem que fazer todo dia, toda hora". Toda hora também não, não tenho saco não. Mas isso [a atividade de sentar e levantar] foi bom para mim, levantar esse astral. A minha família me dá uma força.

However, the influence of supportive networks extended beyond participants' friends and family. A **supportive health care system** also determined participants' positive experience with the sit-to-stand activity. When participants felt that they were well cared for by health care professionals and well served by the healthcare system, they were more prone to engage in the sit-to-stand activity:

Last week the girls [nurses] were here, they came here to change the dressing on my leg. It went well. I really like them, because they are very cool. They changed the dressing. They do it very well. They are precious. To tell you the truth, I had a big callus, the size of my toe, here. Then I asked the nurse to clean it a little bit. Oh, she took the scissors, cut and cleaned it. I do not feel anything anymore. But it was a big callus and I could not even put my shoes on or walk straight. A miracle was done, eh? She cut here and cleaned it. She passed a lot of medicine. It is dry. She cut everything. I do not know if she cut it with razor or scissors. But it hurt a lot before. I put my foot on the floor and it hurt. After they cleaned everything and took off the callus, it stopped hurting, so I was more comfortable to do this sit and stand thing.¹¹² (Juliette)

Another factor relating to the health care system influencing participants' experience with the sit-to-stand activity was their ability to manage participants' medication regime and disease. During my interactions with Butterfly, she frequently diverted our conversations to her current health

¹¹² Semana passada as meninas estavam aqui, vieram aqui para fazer curativo na minha perna. Correu tudo bem. Eu gosto muito delas, porque elas são legais pra caramba. Fizeram um curativo. Elas fazem muito bem feito. Elas são umas jóias. Para dizer a verdade eu estava com um calo grande assim, do tamanho do meu dedo no pé, aqui. Aí eu pedi à enfermeira para ela dar um jeitinho de fazer uma limpezinha. Ah, ela pegou a tesoura, pá, cortou e limpou. Não senti mais nada. Mas era um calo grande que nem dava pra calçar ou andar direito. Milagre se faz, hein? Ela cortou aqui, limpou. Passou uma porção de remédio. Está sequinho. Cortou tudo. Não sei se ela cortou com gilete ou com uma tesoura. Mas doía muito. Eu botava o pé assim e doía. Depois que elas limparam tudo e tiraram o calo, parou de doer, aí eu fiquei mais tranquila para fazer esse negócio de senta e levanta

needs. During the follow ups, Butterfly frequently voiced her need to get some prescription drugs from the health care center to better manage her disease:

I did the exercise, I did not feel anything. But the doctor was going to send me my medicine, he did not send it. I talked to the community health agent that day. She did not have it, she was here that day but the doctor did not send any medicine. It is an anti-inflammatory. Then the health agent said, “I will have it by Friday”. But she did not send it. I do not know why. Then my arm continues to ache. I did not feel anything with the [sit-to-stand] exercise, but when the arm hurts I cannot do it.¹¹³ (Butterfly)

One week later during our follow up, Butterfly was less anxious. The first thing she mentioned when she saw me was that she finally obtained her prescription drugs. It seemed that after getting her prescription drugs, she was able to refocus on the activity:

I want to say that I even improved, too, with this medicine too, the arm improved well. Then it takes the worry out of my head. I was worried. I said: “Phew, how am I going to do my things?” If it gets worse, it gets bad. I say, “I will not be able” and depending on others is very bad. But it is getting better, so I already do the exercises without this worry.¹¹⁴ (Butterfly)

Participants also had an easier time when they were able to **fit the activity into their daily routine**:

Interviewer: Tell me about the activity, how did it go, how did you do it?

¹¹³ Eu fiz o exercício, não senti nada não. Mas o doutor ia mandar o meu remédio, não mandou. Eu falei com a agente de saúde aquele dia. Não teve não, ela esteve aqui aquele dia mas o médico não mandou nenhum remédio. É um anti-inflamatório. Aí a agente de saúde falou assim: “sexta-feira eu trago”. Mas aí não mandou. Eu não sei por quê. Aí o braço continua doendo. Mas aí do exercício não senti nada não, mas quando o braço dói que não dá para fazer.

¹¹⁴ É. Eu quero dizer que até melhorou também, com esse remédio também, o braço melhorou bem. Aí já tira uma preocupação da cabeça. Eu estava até preocupada. Eu falei: poxa, como é que eu vou fazer minhas coisas? Se piorar, aí fica ruim. Eu digo: “não vai dar.” E a gente depender dos outros é muito ruim. Mas está melhorando, aí eu já faço os exercícios sem essa preocupação.

Carnation: I did it and went for a walk. What I did, I always take a morning walk, so to not forget to do this stand up and sit down, I do it before my walk. I get up feeling so lazy, but I get up. I drink my coffee, I do the thing, then, I go for a walk. It was easy to do it [sit-to-stand activity] because I do it before my walk, but if I do not walk I forget to do it¹¹⁵

Obstacles

Participants highlighted different elements of the activity that hindered their participation in the sit-to-stand activity. Many participants related the impact of their **present health conditions** and its symptoms such as lack of balance, lack of strength, fatigue and pain as factors hindering their ability to do the sit-to-stand activity:

I had a hard time last Thursday. I got sick, I was sick like never before. I feel a lot of pain, I have no strength for anything, nothing. I no longer had [strength] but I got even worse. I went to bed I could not sleep, I was short of breath. I was without strength for nothing. I no longer had, now you see, I went under seven surgeries, and I have scoliosis. I could not do anything last week. The doctor told me that the Tandrilax that takes away my pain when it is too bad for me. So yesterday I did not take Tandrilax, not today, so I am in more pain, more in the knee, old folks you know, in the spine, on the shoulders. I cannot

¹¹⁵ *Entrevistadora:* E aí? Me diz sobre o exercício, como foi, como você fez?

Carnation: Fiz e dei uma caminhada. O que eu fiz, eu sempre dou uma caminhada de manhã, aí para não esquecer de fazer esse senta e levanta, eu faço isso antes da caminhada. Eu assim levanto com preguiça, mas eu levanto. Tomo meu café, depois faço a coisa. Aí depois eu dou uma caminhada. Foi fácil de fazer [a atividade de sentar e levantar] porque eu faço antes da caminhada, mas se eu não caminhar eu esqueço

even think about doing what you asked me with all this, not even think about it.¹¹⁶

(Acacia)

According to ANVISA, the government National Sanitary Surveillance Agency, Tandrilax is a drug composed by Diclofenac Sodium, Carisoprodol, Paracetamol and caffeine. It acts as a muscle relaxant, anti-inflammatory and analgesic. It is usually prescribed for the treatment of rheumatism (a set of diseases that can affect the joints, muscles and skeleton, characterized by pain, restriction of movement and, possible, presence of inflammatory signs). The most common examples of this disease are: low back pain, osteoarthritis, acute rheumatoid arthritis or other rheumatic arthritis, acute gout crisis (a disease characterized by deposits of crystals of uric acid at the joints and in other organs), post-traumatic and postoperative acute inflammatory states.

At times, participants did **not perceive a need** to pursue the activity. Participants who were not able to visualize the benefits of the activity engaged in it less frequently:

Interviewer: And what does motivate you to exercise? Or what would better motivate you to do the sit-to-stand activity?

Florian: I do not feel pain on the knee, I feel nothing. I do not feel anything, I have this thing in the knee, I walk with a cane; but I do not feel pain. The knee is practically normal. I do not need to do anything else, right. I am in this phase where I do not feel pain, I do not feel anything, the only thing I do is walk in the house, I do not leave the

¹¹⁶ Eu passei mal quinta feira. Passei mal, passei mal como nunca. Eu sinto muita dor, eu não tenho força para nada, nada, nada. Eu já não tinha [forças] mas fiquei ainda pior. Fui para a cama não conseguia dormir com falta de ar. Eu fiquei sem força para nada, nada, nada. Eu já não tinha, agora você veja, eu já fiz sete cirurgias, contando com a escoliose. Eu não pude fazer nada na semana passada. O doutor me disse que o Tandrilax que tira minha dor é muito ruim para mim. Então ontem eu não tomei o Tandrilax, nem hoje, então estou com mais dores ainda, mais no joelho, gente velha você sabe, na coluna, nos ombros. Eu não posso nem pensar em fazer o que você me pediu com essas dores, nem pensar

house, I do almost nothing. No, I do not need to do this exercise. I am ... I am fine, I have nothing. There is no catch, no, I do not feel I have to do it.¹¹⁷

Also, participants who believed that regardless of their actions or deeds, there are some things in life that are predestined to occur, had more difficulties to engage in the activity. This sort of **fatalism** is illustrated by Juliette when I asked her about her thoughts while doing the sit-to-stand activity:

Juliette: Honestly, in the beginning [of the activity] I did not feel any hope. I did not know if I was going to get there, but ... it has to be. We have to accept everything. I did not know if I would be able to do it, because I cannot sit down and stand up because of my knee, right? That was my thought.

Interviewer: How are you now, Mrs. Juliette?

Juliette: I am going. I am going. That is life.¹¹⁸

Likewise, when participants were **fearful of reaching a worse outcome**, they had more difficulties when engaging in the activity. For example, when asked to tell me about her experience with the sit-to-stand, Lily responded with the following:

I did very little. For example, now I am not feeling anything in my knee. But if it [the activity] starts to disturb it, then I start, I already start feeling the knee. I say to myself:

¹¹⁷ *Entrevistadora:* E o que te motiva a fazer exercício físico, e tal? Ou o quê que te motivaria mais a fazer a atividade de sentar e levantar?

Florian: Eu não sinto dor no joelho, não sinto nada. Eu não sinto nada, eu tenho esse troço no joelho, eu ando de bengala; mas eu não sinto dor. O joelho é normal, praticamente. Não preciso fazer mais nada, né. Eu estou nessa fase de coisa assim, não sinto dor, não sinto nada, a única coisa que eu faço é andar dentro de casa, eu não saio de casa, eu não faço quase nada. Não, não precisa de fazer esse exercício não. Estou... estou bem assim, não tenho nada. Não tem nenhum empecilho não, não acho que preciso fazer isso não.

¹¹⁸ *Entrevistadora:* Então, quais foram os seus pensamentos ao realizar essa atividade, assim?

Juliette: Sinceramente, no início eu não sentia esperança nenhuma. Não sei se vai se ia chegar lá... mas tem que ser. Isso a gente tem que ser conformado com tudo. Eu não sabia se ia conseguir, como eu não consigo ficar sentando e levantando por causa do meu joelho, né? O meu pensamento foi esse.

Entrevistadora: Como é que você está agora, Dona Juliette?

Juliette: Estou indo. Estou indo. É a vida que se leva

then I will not push myself. My knee does not swell. No, no. It only hurts. Last week, it was on Tuesday, out of nowhere, I do not know what happened, I had a little strain here. So, I prefer not to force or anything because it can get worse, then, how do I do? I am in my nineties, I have to be very careful not to make things worse.¹¹⁹ (Lily)

Another recurrent complaint was the **lack of companion** to do the activity. The majority of participants lived with or close to their family members but a few of them spent the day by themselves. Because their family members worked during the day and their significant other was deceased. For instance, in one of our interviews, Acacia conveyed that her late husband was her companion for travel and to do physical activities, but since his passing she had lost the person who used to do these activities with her:

Ohhh my dear I already did so much, I ran, I did aerobics, I ran a lot. Me and my old man [late husband] every morning, early in the morning we went for a walk. Yeah, both of us went to walk early in the morning. We woke up and didn't even drink coffee, but once in a while we had some coffee. We walked for an hour. He sometimes sat down at the beach bench and I would say, "it is okay", I had some friends who were also walking there. I stayed there for an hour, walked for an hour. It was good, I felt good and it was good for my health. Then after he passed away, my husband, I did not walk anymore, I did nothing else. He was such a good, wonderful person. Sixty-three years of happiness. He was my

¹¹⁹ É. Eu fiz muito pouco. Por exemplo, agora eu não está sentindo nada no joelho. Mas se começar a mexer muito, aí começa, eu já sinto o joelho. Eu digo: então eu não vou forçar. Não incha. Não coisa não. Só dói. Na semana retrasada, foi na terça-feira, do nada, não sei que jeito eu dei, que deu uma distensãozinha aqui. Então eu prefiro nem forçar nem nada porque pode piorar, ai como é que eu fico? Eu estou pra lá dos meus noventa anos, tenho que tomar muito cuidado para não piorar as coisas

partner in everything, if he were here maybe we would be doing it together, both of us, that exercise that you passed on. He was very good, he is missed.¹²⁰ (Acacia)

Some participants mentioned **lack of motivation** to keep doing the activity:

Ah, I have not done the exercise. I forget ... Oh, I do not know. It is laziness, it is everything, everything together. I have not even done it. I feel discouraged. Some days we feel like that, right. I will do it later. Yeah, but my laziness also gets in the way, laziness. I have to get smarter, be more alert and feel that I have to move, but then when I lie down I do not get up for anything. It is the same old thing, my dear, it is laziness here, I have to throw that laziness away. The whole laziness is with me, it is my fault, nothing else.¹²¹ (Carnation)

Sometimes participants were not able to perform the activity due to **competing demands** in their lives. Issues varied from family problems to health concerns:

But it is funny than the prescription medicine provided by the hospital, Losartan, did not arrive, it looks like they are out of it. But then, today I ordered [Losartan out of pocket]. I will get it soon. I sent [someone] to buy it in [downtown] Rio. I still have a crazy granddaughter. It is just that I cannot ... I am going to worry about her for what? I will not worry. But we always get annoyed sometimes, right? It is a lot of stress, sometimes we

¹²⁰ Ahhh minha filha eu já fiz tanto, eu corria, eu fazia ginástica, eu corri muito. Eu e meu velho [falecido marido] todos os dias de manhã, de manhã cedo íamos caminhar. É, aí íamos nós dois de manhã cedo. A gente acordava nem tomava café, uma vez ou outra ainda tomava um cafezinho. Caminhávamos ali por uma hora. Ele às vezes ficava sentado no banco da praia e eu: “está bom”, eu tinha umas amigas que caminhavam também ali. Mas eu ficava ali uma hora, caminhava uma hora. Era gostoso, eu me sentia bem e era bom para a saúde. Aí depois que ele se foi, meu marido, não caminhei mais, não fiz mais nada. Ele era uma pessoa tão boa, maravilhoso. Foram sessenta e três anos de felicidade. Ela era o meu parceiro de tudo, se ele estivesse aqui talvez estaríamos fazendo juntos, nós dois, esse exercíciuzinho que você passou. Ele era muito bom, ele faz muita falta

¹²¹ Ih, não tenho feito o exercício não. Eu esqueço... Ah, não sei, não sei. É preguiça, é tudo, tudo junto. Eu não tenho feito mesmo não. Eu estou desanimada. Alguns dias a gente fica, né. Logo mais eu faço. É, mas a preguiça também bota na frente, a preguiça. Tem que ficar mais esperta, acordar mais e sentir que eu tenho que fazer movimento, mas aí quando eu fico deitada não levanto é nada. É a mesma coisa mesmo, amada, é preguiça que está aqui, eu tenho que jogar essa preguiça fora. A preguiça toda é comigo, o defeito sou eu, mais nada

forget our lives, forget about doing things. When these stressful things happen, I get pissed off. On these days, I forget to do the sit-to-stand activity. It is a lot of preoccupation in the head.¹²² (Butterfly)

One of the most cited reasons hindering participants' engagement in the activity was their inability to insert the activity into their **routine**:

I am fine. I did the exercise only a couple of times, it is so much to do. I am by myself. Sometimes I forget. I do it when I remember. I even forget about this exercise, I really forget about it. Some things I do on auto-pilot, I just do them without thinking. But this sit-to-stand activity I am having trouble to remember.¹²³ (Flora)

A few participants voiced **safety concerns**:

It is just how I told you, when I get up, the first thing that gets me is that I have a lot of imbalance, you know. So, it is as if I were going to fall, but I do not fall, I never fell because of it, but I feel like that, a thump.¹²⁴ (Daisy)

Finally, when the **weather** was warmer, participants felt discouraged to perform the sit-to-stand activity:

¹²² Mas engraçado que o remédio do hospital, então, não veio o Losartana, parece que está em falta. E alguém falou assim: "eu acho que é da diabete que está faltando". Da diabete não é não. Já veio o da diabete. É Losartana que está faltando. Mas aí, hoje eu encomendei. Mas vai chegar daí a pouco. Mande para comprar no Rio. Eu ainda tenho uma neta maluca aí. É que eu não posso... eu vou me preocupar com ela para quê? Não vou me preocupar. Mas a gente sempre, às vezes, fica chateado, né? É muito estresse, aí às vezes a gente até esquece da vida, esquece de fazer as coisas. Quando esses estresses vem, eu fico com a cabeça azucrinada. Nesses dias eu esqueço de fazer o senta e levanta que você falou. É muita preocupação na cabeça

¹²³ Eu estou bem. Eu fiz exercício só umas duas vezes, que é tanta coisa para fazer. Eu sozinha. Às vezes eu esqueço. Eu faço quando lembro. Eu até esqueço desse exercício, que eu esqueço mesmo. Tem coisas que faço no piloto automático, eu faço sem mais. Mas este de de senta e levanta não esta sendo fácil de lembrar.

¹²⁴ É que nem eu falei, eu quando, assim, levanto a primeira coisa que me pega muito é quando eu levanto eu tenho muito desequilíbrio, sabe. Assim, como se eu fosse cair, mas não caio, nunca caí por causa disso, mas sinto assim, um baque

I have done it. I do the exercise and I walk around, today I did not because there is too much sun, very hot. I always do it in the morning. But this week no, it is very hot, right now, it is very hot today. When it is hot, it is not possible.¹²⁵ (Carnation)

Sit-to-stand activity within the International Classification of Functioning, Disability and Health

All findings were defined in view of the possible items enclosed within the International Classification of Functioning, Disability and Health in order to ensure a common language for interdisciplinary teams. The sit-to-stand activity was considered a personal factor, and its main associations with health conditions, body functions and structure, and activity and participation were modeled (Figure 10). To facilitate the understanding, all factors were grouped according to the International Classification of Functioning, Disability and Health, as shown in Table 9. To better understand the relevance of these findings, I describe how codes are constructed. Codes in the International Classification of Functioning, Disability and Health begin with a letter representing different domains. Body functions begin with a ‘b’, body structures with a ‘s’. Activity and participation codes are not distinguished and always start with a ‘d’ and environmental codes begin with an ‘e’. Personal factors, given the number and complexity of personal factors in individuals’ lives, are not presently coded. In each case, the code and its meaning can be identified based on its connection with the behaviors, skills, or attributes believed to be an integral part of human life. Coding becomes more specific as numbers are added to indicate levels of greater specificity. For example, b1 is considered a first-level item and refers to ‘body function, first chapter’, which is ‘mental functions’. b125 is a second-level item

¹²⁵ Eu tenho ido. Faço o exercício e dou a minha voltinha, agora eu não fiz porque está muito sol né, muito quente. Eu sempre faço isso na parte da manhã. Mas essa semana não, estão uns dias bem quentes né, hoje está bem quente. Quando está quente não dá\

and is the code for ‘dispositions and intra-personal functions’. b1250 extends the specificity to the third-level and now refers to ‘adaptability’.

Figure 10. Model of the sit-to-stand activity within International Classification of Functioning, Disability and Health and Mobility

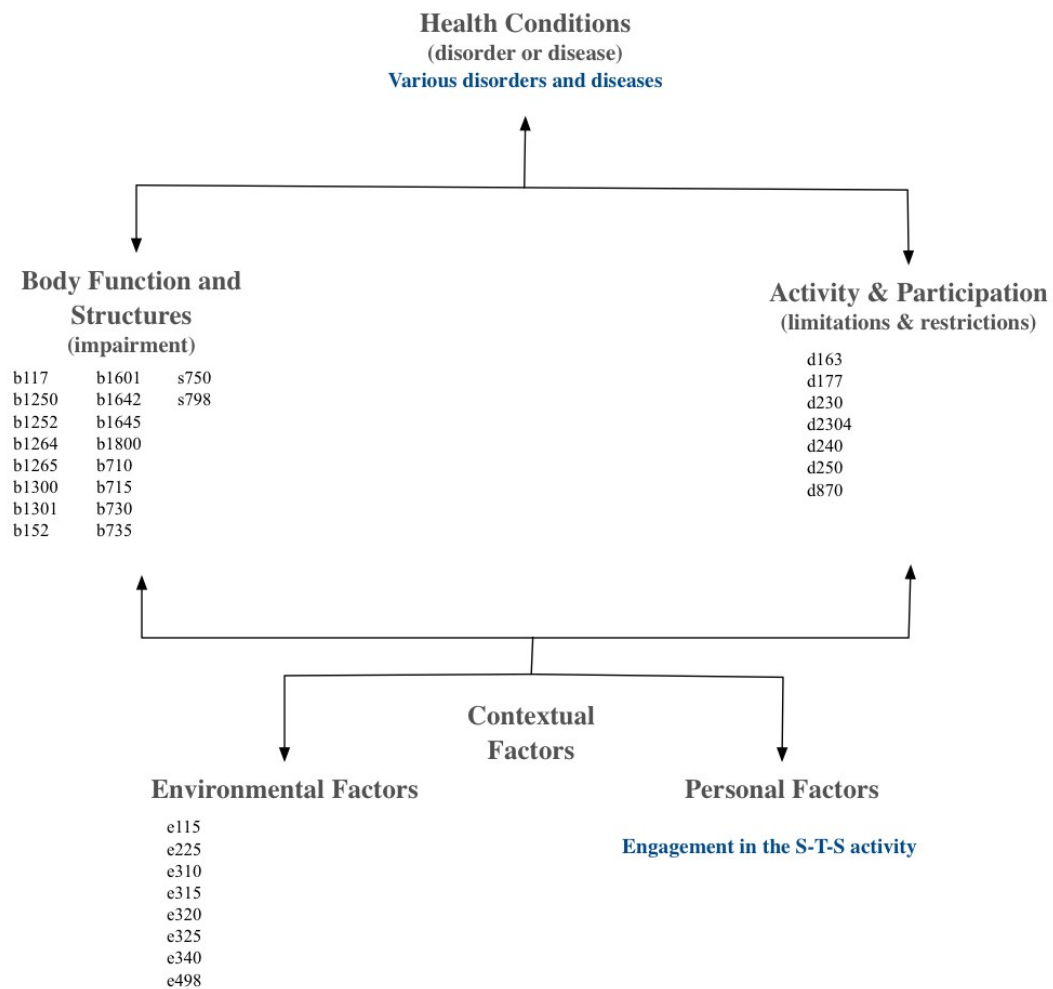


Table 9. Sit-to-stand activity within International Classification of Functioning, Disability and Health

ICF coding	Component	Chapter	Blocks	2nd level item	3rd level item
b117	Body function	Mental functions	Global mental functions	Intellectual function	N/A
b1250	Body function	Mental functions	Global mental functions	Dispositions and intra-personal functions	Adaptability
b1252	Body function	Mental functions	Global mental functions	Dispositions and intra-personal functions	Activity level
b1264	Body function	Mental functions	Global mental functions	Temperament and personality functions	Openness to experience
b1265	Body function	Mental functions	Global mental functions	Temperament and personality functions	Optimism
b1300	Body function	Mental functions	Global mental functions	Energy and drive functions	Energy level
b1301	Body function	Mental functions	Global mental functions	Energy and drive functions	Motivation
b152	Body function	Mental functions	Specific mental functions	Emotional functions	N/A
b1601	Body function	Mental functions	Specific mental functions	Thought functions	Form of thought
b1642	Body function	Mental functions	Specific mental functions	Higher-level cognitive functions	Time management

b1645	Body function	Mental functions	Specific mental functions	Higher-level cognitive functions	Judgement
b1800	Body function	Mental functions	Specific mental functions	Experience of self and time functions	Experience of self
b710	Body function	Neuromusculoskeletal and movement-related functions	Functions of the joints and bones	Mobility of joint functions	N/A
b715	Body function	Neuromusculoskeletal and movement-related functions	Functions of the joints and bones	Stability of joint functions	N/A
b730	Body function	Neuromusculoskeletal and movement-related functions	Muscle functions	Muscle power functions	N/A
b735	Body function	Neuromusculoskeletal and movement-related functions	Muscle functions	Muscle tone functions	N/A
s750	Body structures	Structures related to movement	N/A	Structure of lower extremity	N/A
s798	Body structures	Structures related to movement	N/A	Structures related to movement, other specified	N/A
d163	Activities and participation	Learning and applying knowledge	Applying knowledge	Thinking	N/A
d177	Activities and participation	Learning and applying knowledge	Applying knowledge	Making decisions	N/A
d230	Activities and participation	General tasks and demands	N/A	Carrying out daily routine	N/A
d2304	Activities and participation	General tasks and demands	N/A	Carrying out daily routine	Managing changes in daily routine

d240	Activities and participation	General tasks and demands	N/A	Handling stress and other psychological demands	N/A
d250	Activities and participation	General tasks and demands	N/A	Managing one's own behaviour	N/A
d870	Activities and participation	Major life areas	Economic life	Economic self-sufficiency	N/A
e115	Environmental factors	Products and technology	N/A	Products and technology for personal use in daily living	N/A
e225	Environmental factors	Natural environment and human-made changes to environment	N/A	Climate	N/A
e310	Environmental factors	Support and relationships	N/A	Immediate family	N/A
e315	Environmental factors	Support and relationships	N/A	Extended family	N/A
e320	Environmental factors	Support and relationships	N/A	Friends	N/A
e325	Environmental factors	Support and relationships	N/A	Acquaintances, peers, colleagues, neighbours and community members	N/A
e340	Environmental factors	Support and relationships	N/A	Personal care providers and personal assistants	N/A
e498	Environmental factors	Attitudes	N/A	Attitudes, other specified	N/A

Summary

Before engaging in the sit-to-stand activity, participants' preliminary intentions and goals, as well as the activity's novelty and flexibility seemed factors positively affecting their view of the proposed activity. However, the required routine change and personal need for having somebody to do the activity with, as well as self-perceived physical limitations, and stigmatization associated with the activities targeting older persons were perceived as negatively affecting participants' engagement in the sit-to-stand activity.

After the 4-week of sit-to-stand activity, participants suggested that factors positively influencing their experience with the sit-to-stand activity were its low cost, the privacy of doing it in their own homes and at their own pace, and its easy integration into their daily routine. When participants had a reasonably supportive system, it was easier to start and continue pursuing the activity. After engaging in the sit-to-stand activity, participants reported health benefits and a sense of achievement. Conversely, if participants had a fatalistic standpoint, lacked motivation and social support, feared a worse outcome, had safety concerns, did not feel the need to pursue the activity, and saw their health condition as restricting their activity, it was harder for them to start the activity and continue to engage in it.

Relationships between the sit-to-stand, a physical activity, and mobility disability are complex. Engagement in physical activity has been shown to delay the onset of disability among older people (Bangsbo et al., 2019). However, a multilateral relationship is possible, i.e., as older persons start to encounter difficulty in functioning at the body, person, or societal levels, in one or more life domains, they are also likely to reduce their engagement in physical activity. Difficulties in performing some activities (e.g., mobility, domestic tasks or work), when measured in time or energy expenditure, might be integrated into the International Classification

of Functioning, Disability and Health framework as a contextual personal factor (Geyh et al., 2011).

CHAPTER SEVEN: DISCUSSION

Using an ethnographic methodology, this pre-feasibility study sought to examine perceptions and experiences of urban Brazilian community-dwelling older persons with both mobility challenges and the sit-to-stand activity. The *raison d'être* for this study lies in the fact that the older adult population faces a higher prevalence of functional limitations and physical disability compared to younger age groups, and, at the same time, this population has one of the lowest rates of participation in physical activity, which places them at high risk for experiencing negative health outcomes. In addition, most of the research regarding functional limitation, particularly on mobility challenges, with older persons has been conducted in developed countries. Therefore, I sought to answer the following research questions: 1) what are Brazilian older persons' perceptions and experiences with mobility challenges? 2) how do Brazilian older persons with mobility challenges experience the sit-to-stand activity?

The key findings from this study are that perceptions of urban Brazilian community-dwelling older persons with mobility challenge are culturally transmitted and influenced by the social, physical and health environments of which they are a part. Older persons' experiences with mobility challenges were an integral part of their sense of self and strongly related to contextual factors. The experience of mobility-challenged older persons with the sit-to-stand activity was dependent on their mobility expectations involving many factors that worked together to influence their activity beliefs and attitudes, preferences, behaviors, and cultural perceptions. Participants of this study seemed to find the activity enjoyable; however, the most noticeable shortcomings for participants' engagement in the sit-to-stand activity emerged as gaps in their personal and intrapersonal needs.

In this chapter, I further discuss the responses to my research questions and then examine these findings in light of the International Classification of Functioning, Disability and Health presented in Chapter 2. Strengths and limitations of the study, and specific implications for practice and research arising from this study are found at the end of the chapter. This study provides new information to the field of inquiry on mobility of older persons as it focuses on the perceptions of a specific age group, and attends to the interrelationships between health conditions and contextual factors affecting the mobility of older persons in Paquetá, Rio de Janeiro, Brazil.

Perceptions and Experiences with Mobility Challenges

In this section I discuss these study findings in relation to the first research question and consider them within the context of extant literature in the field. Four key components are brought into the discussion to shed light on Brazilian older persons' perceptions and experiences with mobility challenges: (a) culturally transmitted perceptions of mobility; (b) mobility as an integral part of sense of self; (c) (dis)abling environments, and; (d) mobility expectancies.

Culturally Transmitted Perceptions of Mobility

My analysis of the data revealed that participants' previous experiences with mobility had significant implications on values – i.e., a person's principles or standards of behavior – they attributed to mobility challenges. In particular, the transference of cultural information (e.g., attitudes, beliefs, coping defenses, cultural scripts, values and behaviors) from one generation to the next played an important role in how participants perceived their mobility challenge as it did in research conducted by Schönplflug (2009). These findings regarding the effect of early experiences on participants' current experiences of mobility challenge fit with studies on human development, where scholars agree that close family members are an important source of cultural

values early in life (Kagan, 1999). According to Goodnow (1996) family members' beliefs and ideas are inserted into the context of child development and are the heart of processes of cultural transmission. When exploring the body of knowledge that is available on the effects of early experience on later behaviour, it becomes apparent that these effects can be long lasting (Carlson, 2017; Dawson, Ashman, & Carver, 2000; Salk, 1966; Spitz, 1945; Thompson, 1960; Weininger, 1956).

Participants of this study experienced structural limitations early in life. These included restricted resources, demanding family responsibilities, and limited access to healthcare services, which, in turn, created values regarding mobility and prevented or restricted activities and participation. It was also noted that fatalism was not an uncommon belief within participants of this study. A sizable body of literature points out the linkage between structural limitations and fatalism, with fatalism being not entirely a cause of health inaction itself, but rather a response to conditions that constrains individual ability to act (Mayo, Ureda, Parker, 2001; Peek, Sayad & Markwardt, 2008; Perfetti, 2018).

Furthermore, structural limitations early in life may have also influenced individuals' care-seeking behavior (Feikin et al., 2009; Chuma, Okungu & Moyneux, 2010). In this study, structural limitations such as lack of resources, proximity and access to healthcare influenced participants' perceptions and attitudes towards their mobility. This finding is linked to previously published literature. Feikin et al. (2009) explored the impact of distance on utilization of peripheral health facilities for sick individuals' visits in rural Kenya by using demographic surveillance system. These researchers found that for every 1 km increase in distance of a residence from a clinic, the rate of clinic visits decreased by 34% (95% CI, 31–37%) from the previous kilometre.

Yet, the family environment is not the only central axis for the development of cultural values. Seidl-de-Moura et al. (2004) highlight the role of different social, cultural and historical aspects. Beyond the transfer of cultural information regarding mobility through the family, it is relevant to observe the influence of the school setting. For most children, experiencing the school environment expands their world beyond the scope of their family. Before children attend school, the values, rules, and expectations they experience are, for the most part, largely those expressed within the family. However, as they enroll in school, they become exposed to a larger social environment. Not only do they learn ideologies, but they also get in touch with different behaviors, values, expectations and norms. Nevertheless, most participants in this study did not attend school further than grade four, which might have limited their opportunities to be exposed to different views of mobility and ways of dealing with a mobility challenge. Participants of this study were born between the 1910's and 1950's and had childhood family responsibilities, which precluded them from fully experiencing the school environment.

Note that it is necessary to recognize that what we call 'childhood' and its outcomes ('child', 'family affection', 'school education') are historical-cultural constructions, varying according to periods of time and customs, as well as child protection laws (Marchi, 2013). Child labor is not a historical novelty. During most of the 20th century Brazil was an agricultural rural country and it was not uncommon for children in rural areas to participate in the agricultural work of families and communities, instead of going to school.

All things considered, the exploration of participants' early memories served to illuminate some of their perceptions and experiences with mobility challenges that were created through culturally transmitted values, beliefs, representations, norms, and behaviors. They also served to

preface the next section, since part of participants' childhood experiences with mobility assisted them in constructing a sense of themselves.

Mobility is an Integral Part of Sense of Self

When asked about their mobility challenges, participants often attempted to express what mobility meant to their identity. As incisive as the notion of culture, identity implies the production of discourses bearing signs of identification. The identity of an individual and of a collectivity is constituted, among other things, from their recollections: it is from past experiences we construct the narrative that organizes our subjectivity. Through our past experiences, we organize and give meaning to the present, and it is through past experiences that we project our future (Araújo, 2011).

Identities help people make sense of different and distinct parts of their self-concepts (Oyserman, Elmore, & Smith, 2012). Thus, to a greater or lesser degree, participants incorporated their mobility challenges into their self-definitions and/or identities. I use the terms self, self-concept, and self-definition interchangeably to refer to how participants think about themselves. The concept of identity is closely related to that of self. Thus, disability identity is used here not as a political definition but to refer to that part of the self-concept that emerges from the disability-related self-definitions that exist within individuals.

Disability identity is generated when there is an unfavorable change in the functioning – disability continuum. It captures how individuals, as agents, dynamically respond and renegotiate the meaning of functioning and disability. Thus, when confronted with a disability, in this case a challenged mobility, individuals attempt to comprehend what that means to their identity in order to create or regain a coherent sense of self (Charmaz, 1995, Leventhal, Idler, & Leventhal, 1999). For individuals with disabilities, an identity should comprise relevant content and goals linked to

disability (Dunn & Burcaw, 2013). Strictly speaking, they need to integrate their disability into their identity because the process of recovery involves an engagement with the disability to learn about its management and symptoms – adopting a “disability identity” is a part of this immersion process (Charmaz, 1995).

In this study, some participants’ self-concept as individuals with mobility challenges were dominated by a fatalistic view of their mobility challenge; feeling fearful, distressed, ashamed, helpless, discouraged, stigmatized and like a burden, and having a negative view of themselves in comparison to their peers. These participants generally defined themselves in terms of their mobility challenges (Morea, Friend & Bennett, 2008). This group was comprised of participants whose disability was linked to their overall self-concept, which was impacted negatively by their disability. This finding fits with a study by Pereira (2014) who found that Brazilian older persons attributed to their disability, meanings of ‘being able/not being able to’ of doing something or ‘being a burden’ to someone. ‘Not being able’ referred to the functional loss inherent to the ageing process, whilst ‘being a burden’ were seen as a permanent pain and suffering generating status to both patient and caregiver.

It is interesting to note the link between self-identity and stigma. Stigma is understood generally as “an attribute that is deeply discrediting” and that reduces an individual “from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p.3). Participants in this study felt the impact of their mobility challenge on their identity to the point where their sense of self was defined by their perceived “tainted” mobility status. Yet, participants felt not just stigmatized by their mobility challenge, but also by their age, which may also have contributed to the lack of integration between their mobility challenges to their self-identity. It is known that older persons living with mobility challenges may be particularly stigmatized, as they are

branded by both their age and their disability status (Orel, Spence & Steele, 2005). In this study, participants' mobility experiences were linked not just to ageism, but also to an internalized ageism. Levy (2001) and Levy and Banaji (2002) indicates that during their lives, older persons are exposed to ageist stereotypes opening the doors to turning such stereotypes inward. Therefore, making possible the coexistence of different stereotypes, such as aging and disability.

Conversely, few participants completely rejected their self-identity as mobility challenged individuals. This rejection of their identity as mobility challenged emerged with assertions of no perceived need to engage in physical activities: *"I do not need, need it, I do not need it in my life"* (Florian). Later on, most of these individuals, who did not perceive the need to engage in physical activities, were the ones who engaged less in the sit-to-stand activity and I had more difficulty retrieving from them more in-depth responses. These study results build on those of Oris et al. (2016) who concluded that some individuals tend to neglect their disability, resulting in suboptimal treatment adherence, as well as Tilden et al. (2005) who found that these individuals also try to avoid thinking and talking with others about their disabilities.

On the other hand, being informed, having a sense of hope, and having impetus was identified by participants who accept the disability positively and as part of their identity. According to Morea et al. (2008) health conditions and disabilities play a peripheral role in one's identity and functions beside other personal, relational, and social self-assets, and does not pervade all life domains. Within the state of acceptance, individuals try to lead as normal a life as possible; yet, at the same time, they do not deny having a disability (Adams, Pill & Jones, 1997).

Though ideas about what it meant to be 'mobility challenged' varied among individuals and across gender, age groups, physical ability, and belief systems, participants in this present study fluctuated between positive and negative perceptions; they had ambivalent feelings

regarding their challenged mobility. Yet, most of these study participants did not positively integrate their mobility challenge with their self-identity, with just a few accepting their challenged mobility as part of themselves. One possible explanation is that an important variable in determining whether individuals view their disabilities positively is the point in the lifespan at which the disability was acquired (Darling, 2013). In a study by Darling & Heckert, (2010), they found that both chronological age and age at disability onset appear to be important in shaping one's orientation toward disability. According to the authors, individuals with lifelong disabilities were much more likely to have a more positive identity of disability, whereas those who acquired their disabilities later in life had views that are more negative.

(Dis)abling Contexts

Participants in this study perceived their surrounding contexts as capable of potentiating or contributing to their mobility challenge. They reflected on various components of the built-in and socio-economic environment they perceived as influential for them. Constraining aspects of participants' physical, built-in environment were similar to environmental issues described by older persons in other studies such as presence of stairs, noise, sidewalk hazards, and climate (Ferrer, 2018).

One of the most pertinent environmental factors hindering participants' mobility was the presence of staircases in their homes. As noted elsewhere, when participants lived in two-storey homes, their bedrooms were usually located on the second floor. According to Reid, Novak, Brouwer and Costigan (2011) stair ambulation is one of the most challenging and hazardous types of locomotion for older persons. In this present study, some participants mitigated the issue of not being able to use stairs by rearranging their home to have single-floor living (as opposed to stair use), as well as requiring help from others. These results are similar to those reported by

Smith, Brett, Straker, Snell, Jackson and Ulmer (1994) who found that community dwelling older persons (60+) living in multistorey houses and apartment buildings with stairs employed two kinds of strategies to allow continued living with stairs despite problems, namely home modifications and help from others. Similar to my study, Smith et al.'s (1994) study participants modified their houses by relocating their bedroom and bathroom to the first level of their houses to avoid stair ambulation.

If negotiating stairs was a task participants of this present study encountered, using a handrail to climb stairs was also a compensatory gait strategy to overcome mobility difficulties. Handrails, or the lack thereof, was another commonly mentioned environmental feature affecting participants' mobility in indoor and outdoor spaces. For this study participants, handrails aided stair ambulation and hill roads/alleys ascent and descent. According to Studenski et.al (1994) and Startzell, Owens, Mulfinger and Cavanah (2000), a handrail is a multipurpose tool that provides both physical and psychological support that may prevent falls after a trip or slip, decrease loads through the lower limb, or simply augment stability while negotiating stairs.

In addition, participants in this study indicated the importance of chairs and stools when moving around their homes. The existence of stools and chairs in participant's homes positively contributed to their mobility experiences by serving as a resting point to extend their potential area of locomotion. Previous studies have highlighted how outdoor benches influence older persons' experiences of mobility and well-being by supporting and even encouraging movement (Brookfield, Ward, C., & Scott, 2017; Ottoni, Sims-Gould, Winters, Heijnen, & McKay, 2016). According to Brookfield, Ward and Scott (2017), benches provide a welcome resting point, helping to facilitate longer trips. Ariza-Vega et al. (2019) corroborate these findings by suggesting that the indoor environment of acute care facilities may support older persons to be

active. The authors advocate that risks of functional decline are minimized if older persons are compelled to break up prolonged sitting with periods of light activity over the day via destination rooms and or clear hallways with handrails, and benches or chairs for rest stops, for example.

The lack of specific home features such as shower chairs in the shower pan were also highlighted. Participants of this study voiced inability to independently perform daily activities, such as bathing. Older persons may benefit from adequate bath features and devices to cope with the effects of mobility challenges, e.g., joint limitations, impaired balance, and decreased strength. Used appropriately, adequate bath features and devices can enhance safety and provide the prospect for bathing when it would otherwise be difficult or impossible. This finding is connected to the Stineman, Ross, Maislin and Gray (2007) study. The authors found a strong association between the perception of unmet need for accessibility features in the home among community dwelling persons and the likelihood of mobility limitations – with the odds of an activity of daily living difficulty being 3.7 times larger (95% confidence interval, 2.9 – 4.6) among people who perceived an unmet need for accessibility feature(s).

Regarding the outdoor space, participants also found that lack of well-designed, continuous, barrier-free curb cuts (depressed curbs that act as ramps in sidewalks) were barriers preventing their independence. This is in keeping with Beard et al. (2009) who found that negative neighborhood characteristics were associated with higher prevalence of both ‘physical’ disability and ‘going outside the home’ disability. Debnam, Harris, Morris, Parikh, and Shirey (2002) also found that poor-quality and inconsistent sidewalks contributed to older persons’ inability to walk independently outside their homes.

Some participants described feeling unsafe in their neighborhood which decreased their outdoor mobility. These results are congruent with studies indicating a relationship between

perception of neighborhood safety and mobility decline in older persons (Clark et al., 2009; Sun, Stijacic, Kao, Ahalt, & Williams, 2012). In a longitudinal cohort study of 2,812 community-dwelling elders aged 65 and older in the United States to examine effects perceived neighborhood safety hazards on participants' incident mobility disability, Clark et al. (2009) found that perceiving a safety hazard due to neighborhood crime was associated with increased risk of incident mobility disability among older persons. Therefore, asking older persons about their perceived neighborhood safety may provide important information about their perceived mobility boundaries.

The environmental natural factors had an important impact on participants' mobility. Heat and humidity were often mentioned as an important environmental factor hindering their ability to move around. As reported by Gronlund, Zanobetti, Schwartz, Wellenius and O'Neill (2014), older persons are more vulnerable to heat-related mortality and morbidity. These results built on those of Clarke, Yan, Keusch and Gallagher (2015) who found that heat was a problematic summer weather condition most likely to change the way individuals went about their day-to-day activities, particularly for older persons.

Noise was also an issue for participants' mobility. Previous studies confirmed that noise in the environment was associated with the older persons' disability (Annear et al., 2014; Ferrer, 2018). The relationship between excessive noise and disability is not established, but other research finds that noise is particularly disruptive to older persons (Evans, 1997). Noise may come from the neighborhood into the home and interfere with privacy, sleep, hearing, and other vital tasks (Balfour, Kaplan & Diez Roux, 2002). Given the connection between noise and mobility found in this study, there is a need to understand more about the sources of neighborhood noise in urban areas and the pathway through which it might affect mobility.

In addition to built-in environments, participants perceived their socio-economic context as contributors to their mobility. Study participants underscored social networks, participation, peer-comparison, and financial status as important to their mobility experiences. The association between social networks and health has been extensively documented in different cultures (Berkman, 1985; Berkman, Glass, Brissette, & Seeman, 2000; Chen & Silverstein, 2000; Sugisawa, Liang, & Liu, 1994). Older persons are particularly more vulnerable to the influence of various socio-environmental factors (Li & Zhang, 2015). In this study, social networks were formed by participants' family members (e.g., children and partners), extended family members (e.g., siblings), fictive kinships (e.g., friends and neighbors), and formal caregivers. For the most part, participants social network assisted them to accomplish activities of daily living and to remain socially connected. The association between mobility and social engagement has been reported in previous studies. Rosso et al. (2013) found that there is an association between low mobility and lower level of social engagement of all forms in older persons (OR=0.59, CI: 0.41–0.85 for organizations; OR=0.67, CI: 0.42–1.06 for senior center; OR=0.47, CI: 0.32–0.70 for phone; OR=0.38, CI: 0.23–0.65 for internet). Similarly, Gontijo et al. (2016) found that older persons with low levels of social capital had more chances of presenting some kind of difficulty in performing activities of daily living.

For participants in this study, their uncertainty regarding their finances affected their experience with mobility. For instance, multiple participants described how being unsure of their pension payments and the uncertainty of being able to make ends meet played a role in how they experience their mobility challenges. These results are not new. There has been long-standing recognition of the role of financial status on health and well-being (Weisbrot & Ray, 2011), with health outcomes being strongly correlated to income levels and relative income security (Pickett

& Wilkinson, 2015). In a study aimed at analyzing differentials in the prevalence rates of mobility disability among older persons in Brazil, the authors have concluded that the higher prevalence of mobility disability are associated to the areas with less satisfactory socioeconomic conditions (Parahyba & Veras, 2008).

Mobility Expectancies

The participants in this study described that having better mobility meant being able to improve their capacity to engage in activities of daily living, to become more active, and participate in social life. According to Schwarzer and Luszczynska (2008), having goals and intentions is essential to behavioral change. Outcome expectancies are subjective perceptions and impressions of the consequences and effectiveness of particular actions. Indeed, Schwarzer and Luszczynska (2008) said that outcome expectancies were also extremely crucial to motivate and help individuals make decisions in the process of performing a health behavior. This is congruent with Snippe, Scroevers, Tovote, Saderman, Fler and Emmelkamp (2015) who stated that positive outcome expectancies result in higher intention to engage in physical activities among chronic patients. Other research also suggests that cancer survivors who realized the potential benefits of physical activity on survival outcomes were more likely to embrace physical activity as an additional means of taking control and preserving hope during the cancer experience (Karvinen & Vallance, 2015). Thus, my findings suggest that if older persons with mobility challenges had more positive outcome expectations and believed that the efforts they put in improve their mobility would work, health behavior intention (such as performing the sit-to-stand activity) would also be more likely.

However, to achieve their own goals, these study participants felt they needed material and informational resources, and better health and psychological assets. Lack of material

resources have frequently been identified as a limiting factor to improved health (Jones & Jones, 1997; Morris, Kerr, Wood & Haughey, 2000). Dahlberg and McKee (2018) examined the association between social exclusion and well-being in older persons from urban and rural areas. The authors found that for material resources, income discomfort and lack of financial resources both had stronger associations with well-being and poor self-reported health in urban areas (well-being: rural $r_{pb}(616) = -.07$, $p = .079$, urban $r_{pb}(614) = -.17$, $p < .001$; poor self-reported health: rural $r(610) = .15$, $p < .001$, urban $r(614) = .17$, $p < .001$). The authors employed a cross-sectional survey design, where exclusion from material resources was measured by asking if participants were prevented from doing the things that they wanted to do by each of thirteen factors, with response options ‘a significant problem’, ‘a slight problem’, and ‘not a problem’. One factor, ‘activities are too expensive’, was used as a measure of low financial resources. It is also worth mentioning that the majority of research participants were widowed or divorced. Divorce and widowhood have been found to contribute to reduced financial means. Dealing with life’s challenges with a restricted income is an added burden that often needs to be addressed before health promotion activities can be pursued (Morris et al., 2000).

Informational resources were also highlighted by participants of this study as necessary for achieving their mobility goals. Lack of knowledge about their mobility challenges, familiarity with organizational systems, information and processes that allow individuals to navigate and thrive in society were emphasised. These findings are congruent with Zhan, Cloutterbuck, Keshian and Lombardi (1998) who discussed the necessity of available health information for older persons. The authors indicated that failure to achieve optimal benefits from health promotion strategies is often related to a lack of understanding. As a participant in the Zhan et al. (1998) research study commented “you got to know how to take care of yourself!” (p.37). This is

corroborated by Shin's (1997) research who also emphasized the need for education regarding their health and health promotion strategies for older women, who viewed the lack of such information as a barrier to health promotion strategies.

Study participants also highlighted that better health and psychological support were desired resources to achieve their mobility goals. It is noteworthy that participants who voiced a need for better healthcare support also identified pain and other physical barriers associated with musculoskeletal conditions as factors affecting their mobility. Chronic pain is highly prevalent in older persons, with estimates as high as 70% in community settings (Karttunen, Turunen, Ahonen & Hartikainen, 2015; Patel, Guralnik, Dansie & Turk, 2013). Previous research has established that musculoskeletal pain is associated with disability (Leveille et al, 2001) mobility limitations (Mottram, et al., 2008; Karttunen et al., 2012) and functional decline (Dunlop, Song, Manheim, Semanik, Shih & Chang, 2005) in older persons. More recently, research has started to consider the influence of chronic pain on psychological concerns related to falls (Stubbs, Eggermont, Patchay & Schofield, 2014; Stubbs, West, Patchay & Schofield, 2014). Psychological concerns related to falls, such as fear of falling, avoiding activities due to fear of falling, and reduced fall efficacy and balance confidence, are common and troublesome phenomena among community-dwelling older persons (Kempen, van Haastregt, McKee, Delbaere, & Zijlstra, 2009; Scheffer, Schuurmans, van Dijk, Rooij, 2008). This finding is consistent with published literature stating that a range of psychological concerns related to fear have been identified and commonly include fear of falling and avoiding activities due to fear of falling, reduced fall efficacy and balance confidence, and disproportionate concerns about the consequences of falling (Moore & Ellis, 2008; Moore et al., 2011). For older persons with mobility challenges, one focus of prevention and rehabilitation is considering the underlying

causes that lead to mobility decline and disability. Focusing on the mechanisms by which older persons have difficulty with mobility is particularly relevant.

Experiences with the Sit-to-stand Activity

In this section, I discuss these study findings in relation to the second research question and consider these findings within the context of extant literature in the field. Four key components are brought into the discussion to shed light on Brazilian older persons' experiences with the sit-to-stand activity: (a) establishing intentions, (b) the experience with the components of the activity, (c) the personal experience with the activity, and (d) the interpersonal experience with the activity.

Establishing Intentions

Before engaging in the sit-to-stand activity, participants referred to perceived barriers and benefits of engaging in this activity. Leung (2013) has suggested that perceived benefits and perceived barriers may shed some light into individuals' motives of performing and adopting the sit-to-stand activity.

Changes in participants' routine and the perceived need to have someone to do the activity with were observed as obstacles to engaging in the sit-to-stand activity. However, having flexibility to fit the activity into participants' preferred times and the opportunity to try something new were perceived as catalysts to participants' engagement in the sit-to-stand activity. This information helped me to consider how the many elements of the activity itself may have influenced the adoption process. This knowledge had important applications as it informed me about sit-to-stand activity's potential areas for refinement. For example, to overcome participants fear of change in their routine, we discussed the severity of their mobility challenge, the risks of developing other health conditions, the required skills and possible benefits in

pursuing the activity. Similarly, to address their need to have support from a companion, I assessed participants' self-efficacy; we discussed their fears, and the severity of their mobility challenge. Conversely, knowing that participants perceived activity elements such as having flexibility to fit the activity into their preferred times and having the opportunity to try something new as positive, I gained confidence in fostering these points to participants, which I believe assisted me with the adoption process by emphasizing specific concerns for this group, thus saving time, energy, and resources.

The above-mentioned findings are congruent with recent studies of perceived barriers and facilitators in undertaking physical activity (McPhail, Schippers, Marshall, Waite, & Kuipers, 2014) and a systematic review of experiences and views on physical activity around the transition to retirement (Barnett, Guell & Ogilvie, 2012). McPhail et al. (2014) noted that participants reported flexible work schedules or scheduling physical activity into their daily routine was beneficial for fostering physical activity. Barnett et al. (2012) noted that for many retirees' engagement in physical activity formed part of or comprised the whole of their new routine. According to Beck, Gillison and Standage (2010), some older persons feel the need to replace their working-day routine with new routines in retirement and intend to re-establish a sense of control and purpose in their lives.

Besides being able to explore perceived structural aspects of the sit-to-stand activity that worked as barriers and facilitators, I was also able to observe perceived barriers and facilitators of an individual nature. Having physical limitations, and having or suffering negative stigmatization of exercises targeting older individuals were perceived as obstacles to engage in the sit-to-stand activity. When participants raised their physical limitation as a concern to engage in the sit-to-stand activity, I tried to identify the reasons their perceived physical limitation would

preclude their engagement in the activity. Mostly, it was associated with their fear of falling and pain. After getting to know their reasons, I talked to them about their fears and together we made plans to reduce the risks and set small achievable goals to help them feel more confident.

A few participants voiced having or suffering negative stigmatization of growing old and exercising. There is mounting evidence to suggest that older persons constitute a stigmatized group in in most Western societies. Indeed, 'ageism' reveals the stigma and negative attitudes associated with advanced age and are linked to mental and physical health consequences, including less desire to live a healthy lifestyle (Dionigi, 2015; Robertson, 2017). This is corroborated by the literature on stereotype threat suggesting that stigmatized individuals avoid the negative experience of stereotype threat by disengaging from important activities (Major, Spencer, Schmader, Wolfe & Crocker, 1998; Von Hippel, Kalokerinos and Henry, 2013). When participants voiced that ageism was hindering their engagement in the sit-to-stand activity, I employed reflective talk. Not only was talk a significant way of exchange information, more importantly, it helped us to learn, make sense, and reflect. These functions of talk, which seem to be particularly significant in the context of change, in which participants must work out different ways of acting, have also been recognized by scholars (Bertholet, Faouzi, Gmel, Gaume, & Daepfen, 2010; Lombardi, Button, & Westra, 2014; Thurlow & Mills, 2009; Ybema, 2010).

Finally, showing intention to engage in the sit-to-stand activity and having goals were perceived as facilitators to engagement in the sit-to-stand activity. Both of these factors are aligned to several social psychological models, including the theory of reasoned action (Fishbein, 1980; Fishbein & Ajzen, 1975), the theory of planned behavior (Ajzen, 1985, 1991), Triandis's (1980) attitude-behavior theory, and protection motivation theory (Rogers, 1983). These theories

concur with the proposal that the most immediate and important predictor of a person's behavior is his/her intention to perform it and having goals.

The Experience with the Components of the Activity

Identifying the structural elements of a future intervention is a crucial part of unpacking the “intervention black box”. Knowledge of individuals' perceptions of structural elements can be used to identify specific practices that promote adoption and optimize interventions. During and after engaging in the sit-to-stand activity, participants of this study reported the low cost for this activity since it is home-based, the possibility to go at their own pace, and its ease of integration into a daily routine as components of the activity that supported its adoption. However, it is also important to consider other components of the activity that undermined its adoption, such as safety concerns and lack of a companion. In the following paragraphs, I explore these seemingly conflicting findings to uncover how participants experienced the components of the sit-to-stand activity.

The results of this study indicate there was a range of factors that contributed to participants' engagement in the sit-to-stand activity. The activity's low-cost was attributed to the non-requirement of specialized equipment and travel, which, in turn, is connected to the activity accessibility. This result built on those of Devereux-Fitzgerald, Powell, Dewhurst and French (2016) who pursued a meta-synthesis of qualitative studies of independently living older persons' (+65 years old) experiences of physical activity interventions in nonclinical contexts and found that keeping costs to a minimum was important as many older persons have limited incomes. Likewise, in a systematic review of qualitative studies on the perspectives of physical activity among individuals aged 60 years and over, Franco et al. (2015) found that costs associated with physical activity programmes were considered a major barrier to participation in

24% of the studies. Some participants said that they were unable to afford the high costs associated with these programmes but some participants expressed their unwillingness to spend money on physical activity, suggesting that free or government subsidised exercise classes could increase physical activity uptake. It would appear to be an overriding assumption that most community-dwelling older persons have the financial means to participate in home-based exercises (Hawley, 2009); yet, this may not be the case, as different activities require some types of initial investment, which may be prohibitive and serve as barriers to attendance. However, there appeared to be a consensus among participants that the minimal cost of the sit-to-stand activity was a facilitator to participation.

In this study, some of the participants described the home-based scope of the sit-to-stand activity as sensible to their needs, particularly because it allowed participants to enjoy their privacy while pursuing the activity. This result is in alignment with previous researchers who also found that completing exercises at home allowed participants the privacy to perform exercises without feeling judged or observed (Jansons, Robins, Haines, & O'Brien, 2018). On the other hand, few participants felt that the home-based scope of the activity was disadvantageous because it removed from them the opportunity of social integration. However, it has been suggested that while group-based programs are more effective in the short term, home-based programs appear to be more effective when it comes to physical activity maintenance in older persons (Ashworth, Chad, Harrison, Reeder & Marshall, 2009).

For these participants, the possibility of doing the sit-to-stand activity at their own pace, its adaptability, and easy integration into their daily routine worked as facilitators. This result is also consistent with Devereux-Fitzgerald et al., (2016) who asserted that “older adults should be encouraged to go at their own pace, but should also be supported to increase intensity or duration

when they are able to do more. This is important, as they may have self-limiting expectations that need to be addressed but that need handling sensitively” (p.22). Also, the ability to integrate the sit-to-stand into participants’ daily routine was previously mentioned in other studies as a driver to the activity engagement. In a study to examine how standardized interventions can be adjusted to fit individuals’ specific needs, capacities, and circumstances, Kerkelä, Jonsson, Lindwall, and Strand (2015) found out that it was crucial to make the exercise fit in with participants’ everyday routines. Therefore, a collaborative and mindful approach to physical activity seems more acceptable to older persons.

The Personal Experience with the Activity

Perceived health benefits, having goals, being motivated, having a sense of achievement were individual factors facilitating the sit-to-stand activity. Conversely, the impact of comorbidities, fatalism, no perceived need, and fear of worse outcome and lack of motivation were individual factors hindering the activity. Different studies that have examined outcomes of physical activities suggest that certain factors in the activity may be predictors of subsequent action decisions (Dishman, Sallis & Orenstein, 1985; Koeneman, Verheijden, Chinapaw & Hopman, 2011; Sallis & Hovell, 1990; Sherwood & Jeffery, 2000).

A key facilitator for performing the sit-to-stand activity was participants’ observations of personal benefits because of the activity. That was possible when participants set small achievable goals, which, in turn, motivated them and gave them a sense of achievement. The role of experiencing personal benefit as a result of the activity was previously discussed in a study conducted by Salehi, Shokrvash, Jamshidi and Montazeri (2010) with older persons to identify the facilitator and barrier factors of physical activity. The authors found that higher perceived health benefits and greater self-efficacy were associated with physical activity among older

persons. Thus, the potential benefits of engaging in a lifestyle that incorporates regular physical activity are to improve physical function, independence and quality of life (Stessman, Hammerman-Rozenberg, Cohen, Ein-Mor, & Jacobs, 2009). These changes have been shown to be of benefit even when physical activity is started at a later stage in life (Stessman et al., 2009).

In a reverse situation, participants comorbidities, fear of worse outcomes, lack of motivation, fatalistic view and no perceived need were key barriers for performing the sit-to-stand activity. These results are similar to findings of multiple other investigators who reported that the major barriers to physical activity are poor self-rated health (Booth, Bauman, Owen, & Gore, 1997; Clark, 1999; Grossman & Stewart, 2003; Hirvensalo, Lampinen, & Rantanen, 1998; McPherson & Yamaguchi, 1995; O'Neill & Reid, 1991; Satariano, Haight, & Tager, 2000; Whaley & Ebbeck, 1997) and symptoms of diseases such as pain and fear of pain (Clark, 1999; Hays & Clark, 1999). Many older persons are afraid of falls or injury while doing exercises and, thus, avoid them (Booth et al., 1997; Garber & Blissmer, 2002; Howland et al., 1998; McPherson & Yamaguchi, 1995; O'Brien Cousins, 2000; Satariano et al., 2000; Whaley & Ebbeck, 1997). Lack of energy and motivation is also often mentioned among frailer older persons (King et al., 2000). In addition, fatalism and no perceived need have also been found to be barriers to physical activity (Bunn, Dickinson, Barnett-Page, McInnes, & Horton, 2008; Child et al., 2012; Horne & Tierney, 2012; O'Hare et al., 2017).

Although having comorbidities was probably the most often mentioned barrier to engaging in the sit-to-stand activity among participants, perceived health benefits from engaging in the activity were the most often reported motivators for the activity. This finding is congruent with the literature. Bethancourt, Rosenberg, Beatty and Arterburn (2014) revealed that perceived

health benefit is a factor that can work in both directions. It can be viewed as a facilitator motivating physical activity or as a barrier detracting from physical activity.

In addition, when these study participants had set goals for themselves, it fostered sit-to-stand activity participation. Goals are defined as internal representations of desired outcomes, events or processes (Austin & Vancouver, 1996). According to Swann and Rosenbaum (2018), goal setting is one of the most widely applied and universally accepted strategies used to increase physical activity. These results are similar to those reported by Farhney, Kelley, Dattilo and Rusch (2010) who stated that goal-setting intervention seemed to have a positive effect on physical activity as seen by an increase in steps walked per session when the intervention was initiated and an increase in mean steps walked when intervention performance was compared to baseline.

Over time, satisfactory feelings such as motivation and achievement appeared to positively influence participants' engagement in the sit-to-stand activity. Other researchers have shown that similar remarks predict higher levels of adherence to physical activity and exercise (Devereux-Fitzgerald et al., 2016; Franco et al, 2015; Graf, 2013; Irizarry, 2017; King, Taylor, Haskell, & Debusk, 1988). According to Graf (2013), individual's motivation is a key factor that influencing mobilization, especially if they are able to safely walk by themselves or with family members.

The Interpersonal Experience with the Activity

The participants in this study described having a supportive system, lack of companion, having competing demands as interpersonal factors influencing participants' experience with the sit-to-stand activity. Family and friends had a role in encouraging participation in, and adherence to, the sit-to-stand activity. Both the importance of concrete support, such as being able to push

and help participants, as well as emotional support was emphasized. Others researchers have shown that support from family, friends, peers, and caregivers is considered critical to promoting and maintaining engagement with any exercise/activity intervention (Bunn, et al., 2008; Cameron & Quine 1994; Grossman & Stewart, 2003; Horne & Tierney, 2012; Jansons, et al., 2018; Moore, Moore, & Murphy, 2011; Sharon, Hennessy, Brandon, & Boyette, 1997). Participants choice in accepting engagement in a physical activity is framed by the physiological and psychological impacts of the intervention and also by the social and cultural structures in which the patient is living (Child, et al., 2012; Munro et al., 2007). Thus, social and cultural factors appear to shape expectations of engagement in the sit-to-stand activity.

The meaning of social networks was also demonstrated by feelings of obligation in relation to the family. Perceived obligations to the family resulted in competing demands hindering participants' engagement in the sit-to-stand activity. Difficulties in balancing and prioritizing among important factors in life and lack of support from the family have been found to arouse feelings of guilt and duty, often resulting in decreased adherence and dropout from interventions (Huberty et al., 2013; Podlog & Dionigi, 2009). It is noteworthy that in numerous studies, one common reported barrier by underprivileged groups of older persons was competing family responsibilities (Henderson & Ainsworth, 2000; Malpede et al., 2007; Nies, Vollman & Cook, 1999, Wilcox, Bopp, Oberrecht, Kammermann & McElmurray, 2003).

Findings in light of the International Classification of Functioning, Disability and Health

Several factors in this study were found to affect participants' engagement in the sit-to-stand activity. In an attempt to translate the categories retrieved from the content analysis into codes of the International Classification of Functioning, Disability and Health, 33 codes were identified in connection to the perceptions and experiences of the sit-to-stand activity. These

findings should be used to add to a coherent body of evidence that would more quickly advance the science in the area of mobility. The adoption of the International Classification of Functioning, Disability and Health framework can ensure a common language for interdisciplinary teams and allow future standardization and comparison between different studies. Working within this framework may allow researchers to go further than merely describing the mechanisms of mobility challenges and intervention to include important contextual factors.

While these findings are informative, the ultimate goal is to implement an intervention to increase physical activity performance in community-dwelling older persons with mobility challenge. These findings in light of the International Classification of Functioning, Disability and Health framework allow the comparison of the activities carried out in different services, helping the adequacy of the sit-to-stand activity for each patient. After all, this framework was developed with the main objective of providing a standardized language to assist the communication, exchange and recording of information.

Finally, besides the possibility of strengthening the participation of different professionals within healthcare teams, the employment of a universal and standardized language by nurses can provide support for more individualized, assertive, resolute and holistic decision-making focused on the functional potentialities of the individual and thus improve patients' adherence to the proposed activity. The implementation of the sit-to-stand activity based on the International Classification of Functioning, Disability and Health framework can also contribute to better clinical management, solvability and humanization, based on the real needs of patients.

Implications

Implications for Patient Care and Nursing Practice

It was expected that findings from this study would provide important clues on how to improve the strategies used by nurses to assist older persons in effectively managing their mobility challenges. Among the tasks of the Family Health Strategy team, home visits are one of the pillars of the program. It allows healthcare providers to know the social context and identify patients' health needs to support actions aiming at preventing diseases and promoting community health. Thus, an important finding of this study was that nurses were the ones in the healthcare team who frequently performed home visits. These community health nurses from the Family Health Strategy program had increased access to the home environment of patients, which allowed frequently observations of their living conditions.

The access nurses have to older persons' context offer them opportunity to further their role as patients' advocates. Advocacy has been described as participating with patients in pleading their cause (Mitty, 1991); protecting patients from unnecessary worry (Malin & Teasdale, 1991); valuing, appraising and interceding (Baldwin, 2003), and; providing information and supporting patients in their decisions (Kohnke, 1982). Because the course of mobility challenges is so dynamic (one can distinguish different periods, which bring different problems, questions, and needs), nurses have the opportunity to offer a timely approach to better meet the changing needs of patients. As unmet mobility needs may ultimately result in disability for the older person, these nurses from the Family Health Strategy program are well positioned to provide the most thorough assessments and culturally appropriate strategies for community-dwelling older persons with mobility challenges. Based on these findings, it is suggested that nurses advocate for: (a) improvement of mobility conditions in the outdoor environment; (b)

adaptation of indoor environment for older persons with mobility challenges; (c) provision of information to older persons about their mobility challenge, and (d) connection of faith communities with older persons with mobility challenges. The support of occupational therapists and other relevant health professionals could also be sought in advocating for older persons.

Community activism in promoting safe and accessible dwellings and neighborhoods should be part of a community-based nursing practice initiative. It was evident from the findings that there is a need for more appropriate environmental conditions for older persons to be more mobile. Nurses are in a unique position to not only provide bedside care but also to advocate for change within the community at large. More precisely, furnished with the results of this study and having knowledge of their clientele living conditions and needs, nurses are able to talk to the city representatives about environmental barriers impeding older persons' mobility. It also could be argued that these environmental barriers not only hinder older persons' ability to move; other groups could also benefit from better environmental conditions, for instance, new mothers with strollers would also benefit from having better planned sidewalks. Not to mention that a decayed outdoor environment may be a safety hazard to anyone. According to Taylor (1995), the World Health Organization states that "health professionals, with their expert knowledge and influence with politicians and the general public, can be an important force in mobilizing support and initiating change".

Nurses also were often the health care providers in contact with patients who needed someone to answer their questions and help them deal with their problems. Participants of this study raised their need to know more about their health, risk factors, mobility challenge, and appropriate health behaviors in order to more fully understand and choose their own paths to recovery. With this in mind, nurses should be prepared to support the educational preferences of

patients by providing a variety of educational mediums, specifically supplementing oral education with written material and handouts. Additionally, patients should be directed to appropriate health information websites that have been evaluated for accuracy, bias, and of course patient utility. However, it is necessary to understand nursing workload, workflow, and time allocation practices beforehand in order to evaluate the possibility of adding the task of preparing supportive educational materials to patients.

Finally, spirituality was a significant component in the life of many of the older persons who participated in the present study. According to Olson (2015), “spirituality, whether expressed through religious or secular means, is an important component of patients’ quality of life, affecting their healthcare decisions and outcomes” (p.3). Therefore, nurses need to be attentive to patients’ faith needs being met. Some participants may be appreciative if nurses are able to connect them with their community of faith. In this research, most of the participants considered themselves members of a community of faith; however, they were not able to participate due to their mobility challenge. Nurses, then, could rekindle the connection between their clients and their community of faith. Understandably, faith is deeply personal and culturally linked to behavior. As Brazilian older persons represent a diverse group of religious affiliations, it would be important to ask patients about preferences, and consider the demographics of the geographic area so that care may be culturally appropriate.

Furthermore, community health nurses could forge connections with other sectors of the community that are involved in the health and well-being of people in the community, such as faith communities. When visiting faith communities, nurses could discuss with them mobility challenges encountered by individuals in the community and see if they have ideas about things they could do to assist their parishioners. By employing community participation approaches and

utilizing available collaborations and partnerships, it is possible to optimize community health promotion and disability prevention (Quad Council of Public Health Nursing Organizations, 2011).

There are many opportunities for improvements to the care of individuals with mobility challenges. Nurses are in a prime position to facilitate changes in practice and education that could reduce disability, improve mobility and increase trust between patients and healthcare providers. Additionally, the holistic nature of nursing care adequately prepares nurses to serve as liaisons between patients and healthcare services facilitating integration across all domains of care. Nurses should not underestimate their ability to influence access to appropriate, efficient, and effective quality care. They are in excellent positions to share with various constituencies the importance of appropriate healthcare services available. Nurses are also well positioned to work with other sectors of society, including municipalities.

Implications for Nursing Education

It is important that health and culture-related issues that are relevant to older persons be addressed in nursing curricula since people are living longer – especially in countries in development where the older population is now growing more rapidly than those from developed countries. As research begins to close the gap in knowledge regarding health issues in Brazilian older persons, current research and trends in disability (and mobility challenges) should be current topics in nursing education. To my knowledge, most of the current nursing curricula at the universities in Brazil is focused on the health of older persons in hospital-care. However, the vast majority of older persons served by the healthcare system are not hospitalized. They spend most of their lives in the community setting being served by community health initiatives. Physical and psychosocial issues affecting Brazilian older persons' health and physical activity

practices should be presented as part of older persons' health curriculum content. Thus, a reframing of nursing curricula with a focus on health promotion and primary healthcare for the older population with health disparities is warranted. According to Baumbusch, Dahlke and Phinney (2012) one possibility is to not develop stand-alone courses in gerontology, but integrate this knowledge across different courses to foster sustainability.

Implications for Nursing Research

The current study suggests the need for producing more research on mobility and physical activity behaviours of older persons in developing countries. Cultural preferences and norms regarding physical activity facilitators and barriers revealed in this study should function as a point of departure for future research. As revealed by the current findings, older persons' cultural values and norms regarding mobility were important to the physical activity behaviours of the participants in this study, which suggests that future research on marginalized and stigmatized groups needs to avoid lumping different ethnocultural groups together in order to better understand the influence of distinct cultures on behaviour.

Future research should focus on the feasibility of implementing and sustaining the sit-to-stand activity. One of the outcomes of this study was the possibility to assess the prospects for successful implementation of the sit-to-stand intervention in urban Brazilian community dwelling older persons. This study was the first step in systematically studying how to design and evaluate a set of activities to facilitate successful uptake of the sit-to-stand activity – an evidence-based health intervention – in the real world. 'Evidence-based' refers to interventions that have undergone sufficient scientific evaluation to be considered effective and are recommended by healthcare providers and organizations. Thus, taking into consideration these findings, I believe that a full feasibility study should be undertaken now that the cultural, social,

physical, and health environments affecting older persons' mobility and home-based physical activity is better known.

In order to ensure that the intervention is clinical, academic, and culturally relevant and rigorously evaluated, I suggest that the design, development and evaluation of the sit-to-stand intervention be guided by The United Kingdom Medical Research Council framework (Medical Research Council, 2000). The United Kingdom Medical Research Council framework for complex interventions provides a common framework and language for the development and evaluation of complex interventions. This framework offers a way to systematically design an intervention, accumulate evidence, and integrate it into practice employing four, non-linear stages of intervention design. In this framework, greater emphasis is put on early phase piloting/feasibility, integration of process and outcome evaluation, the importance of tailoring interventions to the local context, and to consider experimental and non-experimental approaches for evaluating complex interventions (Kastner & Straus, 2012).

Knowledge Sharing Strategies

To share knowledge generated in this study with my peers, these findings will be presented at one or more nationally recognized conferences following the completion of the study. Publication outlining the findings of the study will then be published in two peer-reviewed journals in Portuguese and English. In addition, I will provide a technical report to my research funding agency outlining my research project.

Aiming to share these findings with a broader audience, I will adapt the technical report outlining this research project using the 1:3:25 approach (Canadian Health Services Research Foundation, 2001). The 1:3:25 approach suggests that research summaries should contain one page of main messages, a three-page executive summary, and a 25-page report. Using the 1:3:25

technical report as auxiliary material, an oral presentation will be offered to the healthcare center and the faith communities at Paquetá Island to discuss the results and practical implications of the study.

Study Strengths and Limitation

There are several strengths to this study. Qualitative research methods are ideal when little is known about the nature of the research problem (Creswell, 2009). Since I spent some months in the field before collecting data, it was possible to establish strong contacts and relationships. The selected methodology used in the study—focused ethnography, led me to obtain rich and comprehensive information. The acquired comparability of findings between different methods of data collection lent credence to the rigour of this study. In addition to interviews, participant observation was used to strengthen the analysis by identifying actions that conflicted with the interview data or required clarification, and allowed the researcher to observe the barriers and facilitators to mobility in person. This additional data helped more fully illuminate the experience of with mobility challenges and the sit-to-stand activity amongst Brazilian older persons.

This study is the first study of its kind to capture perceptions and experiences of mobility challenges and the sit-to-stand activity in urban Brazilian community-dwelling older persons. As other researchers begin to evaluate populations of older persons with mobility challenges from countries in development and those managing multiple comorbidities, data from this study may be used as a means of comparison. Findings of this study are rich because there was wide variation among the participants' social class, age, and mobility capacity. Thus, findings from this study will advance understanding of how factors relating to their cultural, psychosocial, physical, and health environments affect their expectations, norms, values and behaviors around

mobility as well facilitate or hinder the appropriateness and usefulness of the sit-to-stand activity in their daily lives. Findings from this study also support the International Classification of Functioning, Disability and Health for understanding mobility within the functioning – disability continuum.

Despite this study's valuable findings concerning older persons' perceptions and experiences with mobility challenges and the sit-to-stand activity, as with any research study, there are limitations. Recruitment was limited to older persons with mobility challenges who consented to participate. Participants who volunteer are more likely to be interested in remaining active and are more likely to have higher levels of physical activity. The perceptions and experiences of older persons who declined to participate may differ from those who willingly participated. It has been demonstrated that people with higher activity levels are more likely to be recruited for studies on physical activity (Crombie et al., 2004). In addition, the perceptions and experiences of healthcare providers, family members, and policy makers were not examined.

Lastly, there were limitations due to my position as a novice researcher conducting a study of this nature for the first time. My lack of familiarity with ethnographic studies coupled with the transition from theoretical to hands-on research was not without troubles. These factors lead to a couple of challenges at different stages of the research and misunderstandings occurred. It took some personal effort to meet expectations from academia, participants, and myself. In such situations, I sought guidance from my supervisors, who assisted me in carrying out research more independently, taking the initiative to seek knowledge in an active way, and constructing my moral identity as a nurse researcher. I believe that the findings from this research far outweigh the challenges.

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Appendices

APPENDIX A

HEALTH CARE CENTER CONSENT TO PARTICIPATE IN THE STUDY



PREFEITURA DA CIDADE DO RIO DE JANEIRO
SECRETARIA MUNICIPAL DE SAÚDE
UNIDADE INTEGRADA DE SAÚDE MANOEL ARTHUR VILLOBOIM
PRAÇA BOM JESUS, 40- ILHA DE PAQUETÁ - RJ
TEL:3397-0123 - uismav@smsdc.rio.rj.gov.br

DECLARAÇÃO

Eu, Diego Willer Ribeiro Oliveira diretor da Unidade Integrada de Saúde Hospital Municipal Arthur Villaboim, venho por meio desta manifestar meu apoio ao projeto de pesquisa da pesquisadora Uirá Duarte Wisnesky.

Em nossa instituição, nossa missão é oferecer uma experiência contínua através do Sistema Único de Saúde/SUS para as pessoas de nossas comunidades, proporcionando acesso equitativo e cuidados de saúde de qualidade. Nossa organização oferece um ponto de acesso central para trabalhar com pacientes idosos com problema de mobilidade física. Como tal, estamos bem posicionados para contribuir com o projeto da pesquisadora, confirmando assim que a mesma está autorizada a desenvolver o seu projeto de pesquisa em nossas instalações.

Rio de Janeiro, 24 de março de 2017.

Diego Willer Ribeiro Oliveira
11/283979-3 SMS-UISMAV
Diretor

Diego Willer Ribeiro Oliveira

Diretor

APPENDIX B

INFORMATION SHEET AND CONSENT FORM

INFORMATION LETTER

Study Title: Functional Mobility of Community Dwelling Older Persons: An Ethnographic Pre-Feasibility Study

Investigator: Uirá Duarte Wisnesky
Faculty of Nursing
University of Alberta
Edmonton, Alberta, Canada
Phone # in Brazil: (21) 97653-4629
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Co-supervisors: Dr. Pauline Paul
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Dr. Joanne Olson
Professor, Faculty of Nursing, University of Alberta
Telephone number: +1 (780) 492-6252
e-mail: joanne.olson@ualberta.ca

Why are we asking you to take part in this research study?

We are asking you to be part of this study because you are an older person living at home. We would like to know your views about mobility and a “sit-to-stand” activity.

What is the reason for doing the study?

We are doing the study to learn about the views and experiences of mobility challenges for urban older persons who live at home in Brazil. We also want to look at views about a “sit-to-stand” activity.

What will we ask you to do?

Being part of the study will take you about 5 hours and 20 minutes. You will spend about 2 hours and 20 minutes doing an activity by yourself. I will be with you for about 3 hours. This is what we will do if you agree to be in this study:

- I will ask you about age, education, etc.
- I will ask you to take some photos.
- I will ask you to participate in a “sit-to-stand” activity for four weeks. It will take you 5 minutes each day. I will come once a week to observe you doing this activity.
- I will visit you weekly and/or contact you by telephone.

I will interview you twice during the study.

Process for Photographs

On the first visit to your home, I will ask you to take photos. The photos will be of things that affect your ability to move around. Examples include your favorite spaces and chairs. Overall, taking photos should take 20 minutes. I will give you a copy of the photos. If you want, we will talk about the photos during the first interview.

Process for Observations

Once a week, for four weeks, I will come to see you and observe how you do the “sit-to-stand” activity.

The “sit-to-stand” activity is an exercise where you sit then stand a few times. I will want to see how you

do it and will take some notes. I will be with you for around 20 minutes each time.

Process for Interviews

I will do two interviews at a place and time that is good for you. Each interview will take around 30 to 40 minutes.

In the first interview, I will ask you questions about your mobility. If you agree, I will tape-record the interview.

In the second interview, I will ask you questions about the “sit-to-stand” activity. If you agree, I will tape-record the interview.

After each interview, I will summarize our talk and see if you agree with what I heard.

What are the risks and discomforts?

There are few risks to being in this study. During the “sit-to-stand” activity, it is possible to experience:

- A mild muscle soreness and knee pain
- Fatigue and shortness of breath

Although unlikely, you may feel uncomfortable during the interviews and observations. If you feel any distress, I can help you connect with a health care provider, or someone of your choice to assist you. You are free to stop an interview at any time. You are free to stop taking part in the study at any time. You are free to refuse to answer any question. At any time, you may cancel a visit.

It is not possible to know all of the risks that may happen in a study. I have taken all reasonable safeguards to lower any known risks to you.

What are the benefits to you?

You may enjoy doing the “sit-to-stand” activity and talking with me. However, you may not get any benefit from being in this study. The results of the research may help other people who have challenges moving around.

Do you have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in it at any time. It will in no way affect the care you receive from the health care centre.

You are also free to refuse to answer any question, or to participate in the sit-to-stand activity. If you decide to leave the study two weeks after the second interview, I will not use your information in the research.

Will your information be kept private?

During the study, I will be collecting data about you. I will do everything I can to make sure that this data is kept private. No data relating to this study that includes your name will be released to other people. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

I will not use your name and information that could identify you when writing about the research in a dissertation or publications. I will store the data from this study for five years in a locked filing cabinet

and a secure computer.

What if I have questions?

If you have any questions about the research now or later, please contact Uirá Duarte Wisnesky. You can reach her at 97653-4629

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board in Canada at +1 (780) 492-2615. If it is easier for you may contact the Health Research Ethics Board in Brazil at (61)3704-8851. Both offices have no affiliation with the study investigators.

CONSENT FORM

Study Title: Functional Mobility of Community Dwelling Older Persons: An Ethnographic Pre-Feasibility Study

Investigator: Uirá Duarte Wisnesky

Telephone # in Brazil: (21) 97653-4629

Co-supervisors: Dr. Pauline Paul

Telephone number: +1 (780) 492-7479

Dr. Joanne Olson

Telephone number: +1 (780) 492-6252

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you agree to take some photos of your favorite spaces and chairs	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐
Who explained this study to you? _____		
I agree to take part in this study:		
Signature of Research Participant _____		
(Printed Name) _____		
Date: _____		

APPENDIX C
DEMOGRAPHIC DATA SURVEY

SURVEY

Participant #: _____

SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

1. Name _____

2. Age _____

3. Biological Sex ☐ Male ☐ Female ☐ Other: _____

4. Race/Color/Ethnicity

☐ White ☐ Black ☐ Pardo ☐ Asian ☐ Other ☐ Not

declared

5. Marital Status

☐ Married ☐ Divorced ☐ Separated ☐ Single ☐ Widowed

☐ Not declared

6. Religion _____

If religious, how much do you participate

☐ Never ☐ Sometimes ☐ Frequently

7. Level of education _____

8. Do you currently work: ☐ Yes ☐ No

9. What is/used to be your professional occupation?

10. Do you live by yourself? ☐ Yes ☐ No

If yes, how long have you been living by yourself?

☐ Less than 1 year ☐ Between 1 and 5 years ☐ More than 5 years

If not, how many people live with you? _____

If not, who are living with you? (Family members, friends, etc.)

11. What kind of dwelling do you live in?

☐ House ☐ Apartment ☐ Other: _____

12. Do you need help from third parties to perform any activity?

☐ Yes ☐ No

If yes, of whom? _____

13. Have you experienced any major loss in this last year (partner, friends, financial)

☐ Yes ☐ No

HEALTH

14. How do you evaluate your general health?

☐ Excellent ☐ Good ☐ Fair ☐ Poor

15. Have you seen any health provider in this past month?

☐ Yes ☐ No

If yes, how many times have you visited a health provider in the past month?

If yes, what was the reason for the visit? _____

16. Do you have any health problems that prevent you from participating in any physical activity?

☐ Yes What: _____

☐ No

MOBILITY

17. Mobility challenge linked to:

- | | | | | | |
|--|---|---|-------------------------------------|-----------------------------------|-------------------------------|
| ☐ Arthritis | ☐ Arthroses | ☐ Stroke | ☐ Depression | ☐ Diabetes | ☐ Pain |
| ☐ Inferior limbs numbness | ☐ Lower limb edema | ☐ Multiple Sclerosis | | | |
| ☐ Fractured femur | ☐ Hypertension | ☐ Spinal cord injury | | | |
| ☐ Lymphedema | ☐ Obesity | ☐ Knee Surgery | | | |
| ☐ Osteoporosis | ☐ Cardiac problems | ☐ Lung Problems | | | |
| ☐ Rheumatism | ☐ Impaired Vision | ☐ Others: _____ | | | |

18. Do you use any accessories to get around? ☐ Yes ☐ No

- If yes, which one(s)? ☐ Cane ☐ Wheelchair ☐ Walker
- ☐ Prosthesis

APPENDIX D
1st INTERVIEW GUIDE

1st Interview guide

1. Can you tell me how do you feel about your mobility capabilities?

Prompt: What happened to you that you are having these mobility challenges?
How did that come about? When?

Prompt: How did you feel when that happened? For example, what were your thoughts when you saw yourself with your impaired physical mobility?

Prompt: How has this mobility problem changed your activities of daily living and your lifestyle?

Elicitation: Ask participants if they are able to eat, bath or go to the bathroom without help; or push tables or perform household repairs; or, stoop, kneel or bend, or; climb stairs, or; walk 100 meters?

If the participant has any of these challenges, ask them how do they feel?

Elicitation: I would like to know more about your routine now that you have this mobility challenge?

Prompt: What most influenced this change

Prompt: Is there anything you do not do because of your challenged mobility? Or are there new things you're doing now? For example, therapy.

Prompt: How do you see yourself in the future? With an improved or worsen mobility?

2. Can you tell me about the pictures we took together?

Prompt: what do the spaces and/or objects in the photograph represent and mean to you?

Prompt: how do you feel about them?

Prompt: where have they come from?

Prompt: what elements might be missing in this picture?

3. Could you describe in as much detail as possible a situation in which was very frustrating to have a mobility challenge?

Prompt: Has being a mobility challenged older person caused you any frustration or trouble?

4. Can you think about how your life would be if you could have better mobility?
5. What factors influence your mobility?

Prompt:

- Economic (income, financial support, debts, employment)
- Neighborhood and physical environment (housing, transportation, safety, walkability)
- Education (literacy, higher education)
- Psychological (emotional, behavior)
- Food (hunger, access to healthy options)
- Community and social context (social integration, support systems, community engagement, discrimination)
- Health care system (health coverage, provider availability, provider cultural competence, quality of care)
- Political (public government support and systems)

6. What do you think you/we could do to decrease your mobility challenge?
7. These are all my questions for this interview. Would you like to add something, or say something that you think is important but it was not discussed, before we end this interview?

APPENDIX E
2nd INTERVIEW GUIDE

2nd Interview Guide

1. Can you tell me using as many details as possible about the sit-to-stand activity you have performed the last 4 weeks?

Prompt: What are your thoughts on (or how do you feel about) this activity? How satisfied are you with the activity?

Prompt: How frequently did you do the activity?

Prompt: How did the sit the stand activity fit with your daily-life activities?

Prompt: What benefits did you observe after enrolling for this activity program? (Interviewer conducts the question towards appropriate intensity, frequency, and duration of the intervention)

Prompt: Would you say you observed any disadvantage or burden for joining this activity program? Interviewer conducts the question towards appropriate intensity, frequency, and duration of the intervention

Prompt: Can you think of any possible barriers you encountered that prevented you to do the activity?)

2. Did you talk to any community members about positive or negative effects of the activity?
3. How do you feel in regards to your mobility after completing the activity?
4. Do you intend to keep doing the activity after the study ends?
5. Do you have any comments on the content and design of the sit-to-stand activity? Anything we could do better? Anything that would encourage you to do it?
6. These are all my questions for this interview. Would you like to add something, or say something that you think is important but it was not discussed, before we end this interview?

**QUESTIONS TO PARTICIPANTS WHO DECIDED THEY NO LONGER WANT
TO DO THE SIT-TO-STAND ACTIVITY BUT STILL WANT TO BE INTERVIEWED**

1. Can you tell me, using as much detail as possible, your thoughts on sitting to stand activity?

Prompt: How do you feel about the sit-to-stand activity?

2. Can you foresee any disadvantage or burden when doing this activity?

Prompt: Interviewer conducts the question towards appropriate intensity,
frequency, and duration of the intervention

Prompt: In what ways do you think this activity is not appropriate, satisfying, or
attractive to someone with mobility challenges?

3. Could you offer me some suggestions to improve anything regarding the sit-to-stand activity?

If you can, you will help me to improve some features of the activity.

APPENDIX F

**SUMMARY OF THE CONNECTIONS BETWEEN RESEARCH QUESTIONS,
VEHICLES FOR DATA GENERATION, DATA TO BE GENERATED, PROCEDURES,
AND DATA ANALYSES**

Research Questions	Data produced	How data was generated (procedures)	Data Analysis
What are Brazilian older persons' perceptions and experiences with mobility challenges?	1. Field notes 2. Audio-recordings	1.1 Participant Observation (i.e., myself, the researcher) 1.2. Informal conversations 2.1. Interview	Qualitative content analysis
How do Brazilian older persons with mobility challenges experiences the sit-to-stand activity?	3. Field notes 4. Audio-recordings	3.1Participant Observation (i.e., myself, the researcher) 3.2. Informal conversations 3.3. Sit-to-stand activity 4.1. Interview 4. 2. Sit-to-stand activity	

APPENDIX G

DESCRIPTION OF THE SIT-TO-STAND ACTIVITY

Sit-to-stand activity

The researcher will instruct the participants on how to complete the sit-to-stand activity. The sit-to-stand activity will be performed by older persons, with or without the help of their caregivers, once a day and the duration of the activity will vary according to participants' ability and fatigue. Participants will be supported by the researcher following the first day of activity by telephone calls and/or weekly visits over the four-week program. The duration and frequency of the program (four weeks and once a day, respectively) is based on Pollock's (2014) findings that performing the sit-to-stand activity three times a week for two to three weeks may be enough to have a beneficial effect (Pollock, 2014). Participants and family members will be reminded that when a participant's condition deteriorates they should consult with a health care provider about the appropriateness of continuing with the activity.

Carrying out the sit-to-stand activity will require an armless, standard height chair with straight back and 16-18 inches high, as studies have shown that rising from a lower seat results in greater hip and knee movements than when rising from a higher seat (Burdett, Habasevich, Pisciotto, & Simon, 1985; Rodosky, Andriacchi, & Anderson, 1989). If the participants have balance problems, they will be encouraged to use a chair with arms. The chair height will ensure that the challenge posed by the activity to each participant will be similar and consistent across the intervention. Therefore, the effects of this important environmental feature influencing the sit-to-stand behavior is standardized and minimized. To avoid any potential safety hazard, participants will be directed to place the chair against the wall so it does not move away from them and result in their fall to the floor. If a wheelchair is used, then participants will be directed to place it against the wall with the wheels in the locked position. Participants will be directed not to complete the sit-to-stand activity using the seat of a wheeled walker.

Participants will be directed to start the movement in a standardized position as there is evidence that one's initial position can affect the performance of the sit-to-stand activity (Fleckenstein, Kirby, & MacLeod, 1988; Linden, Brunt, & McCulloch, 1994; Stevens, Bojsen-Moller, & Soames, 1989). This initial standardized position will require participants to sit with one third of their thigh length on the chair; thigh length will be measured as the distance between the greater trochanter and the lateral knee joint line. They also will be directed to place their feet flat and in parallel with the medial border of the heels 10-15cm apart. The desired knee angle in sitting is approximately 90 degrees of flexion.

Sequentially, participants will be asked to keep their back straight, and their arms against their chest. A target will be placed on a wall 3 meters in front of them and 1.5 meters above the floor surface to minimize head movement. Looking at the target straight ahead, participants will be instructed to perform a safe, controlled independent rise, at a self-paced speed, from a sitting to standing position. When necessary, due to lack of balance or lower limb instability, pushing off with hands will be encouraged.

Once participants reach the standing position, they will be instructed to perform the opposite movement, to sit down on a chair from their standing position. It is known that during sitting down the movement pattern is inverted (Mourey et al., 1998). If trunk angular displacements in space are considered, standing up and sitting down can be considered inverse movements. Although the initial position and mechanical conditions related to gravitational effects differ between standing up and sitting down, acromion trajectories in the sagittal plane show similar forms. Thus, up and down acromion trajectory does not vary in movement planning (Mourey et al., 1998).

However, the movement of sitting down requires fine postural control and precision in the final part of the movement, which is affected by aging (Mourey et al., 1998). Thus, participants will be directed to pay close attention to their stability, as the transition between forward and backward trunk movements are associated with a discontinuity in knee flexion. Finally, they will be encouraged to repeat the task as many times they can, as well as to maximize the number of sit-to-stand repetitions increasingly lowering of the chair height.