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Self-identified Social Participation Restriction among Community-dwelling Older Adults in the United States

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Abstract

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United States

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Background: Social participation (SP) is believed to positively contribute to health and well-being of older adults and has been identified as a central contributor for successful aging.

Available research on SP provides evidence on the associations of SP with demographic and health characteristics, but we know the least about the extent of social participation restriction (SPR) in older adults and whether SPR changes over time.

Objective: The primary aim of this research was to determine the prevalence of SPR, SPR incidence at one-year follow-up, and SPR recovery rate at one-year follow-up in U.S.

community-dwelling older adults. A secondary aim of this research was to determine the correlates of SPR incidence and recovery at one-year follow-up.

Methods: This study used data from the 2015 and 2016 rounds of the National Health and Aging Trends Study (NHATS). Inclusion criteria of community-dwelling older adults who had

completed SP survey items in 2015 resulted in a sample of 7,492. Participants were considered to have SPR if they reported restriction in at least one social activity and it was reported as “somewhat important” or “important”. The measured social activities were visiting in person with friends or family; attending religious activities; going out for enjoyment; and participating in clubs, classes, or other organized activities.

Results: In 2015, the overall prevalence of SPR was 17.0% (95% Confidence Interval [CI]: 16.0-18.0). SPR prevalence increased with advancing age and was more common in women than in men. SPR incidence was 10.5% (95% CI: 9.72-11.3). The one-year incidence of SPR was associated with having more medical conditions, worse physical functioning, fatigue, bothersome pain, and cognitive decline at baseline. SPR recovery was 39.9% (95% CI: 36.7-43.1), and it was associated with having reporting no pain and better physical functioning at baseline.

Conclusions: SPR is common in community-dwelling older adults in the U.S. SPR prevalence is expected to increase as the number of older adults increases with the baby-boomers aging. The identified SPR incidence risk factors can help healthcare providers identify those who are vulnerable to developing SPR and provide them with the services and resources that can support continued SP. More research is needed to design programs that facilitate and promote SP in community-dwelling older adults.

Plain Language Summary

Participating in valued social activities in older age contributes positively to health and well-being. Participating in social activities has been connected to a lower risk of developing problems in memory and getting around the house or the community. However, researchers do not know how many older people face problems in participating in social activities. They also do not know if older people recover from such problems. The purpose of this study was to learn about the extent to which older people who live in the United States have problems participating in social activities.

This study used data from the 2015 and 2016 National Health and Aging Trends Study (NHATS). NHATS is a nationwide study that has been interviewing people 65 years and older annually since 2011 to learn what ways their daily life, health, and function change with age. The interviews included questions about health, family, and everyday tasks. The interview sessions also include tests for memory, orientation, balance, walking speed, and the ability to get up from a chair.

Each participant in the NHATS study reported on whether they participated in any of the following activities in the past month and how important each of the activities was to them: (1) visiting in person with friends or family; (2) attending religious activities; (3) going out for enjoyment (examples: going out to dinner, movie, gamble, concerts, or plays); and (4) participating in clubs, classes, or other organized activities. Problems in participating in social activities were defined as the inability to participate in at least one of the measured activities that were “important” or “somewhat important” to the participant.

The major findings of this study were:

1. In 2015, 17.0% of older people in the United States reported problems in participating in social activities that they value. These problems were connected with increasing age and were more common in females.
2. Problems in participating in social activities were connected with balance problems, reduced walking speed, and problems in getting up from a chair.
3. Among older adults who did not report problems in social activities in 2015, 10.5% of older people in the United States developed these problems one year later. Developing these problems was connected with having more medical conditions, balance problems, reduced walking speed, fatigue, pain, and memory and orientation problems.
4. Of older adults who had problems participating in social activities in 2015, 39.9% of them recovered one year later. This recovery was connected with having pain, better balance, normal walking speed, and no pain.

This study improved our understanding of how participating in social activities changes with time in older age. The findings suggest that problems in participating in social activities are common in older people, and they are connected with many health factors. These findings can support efforts to develop and improve programs that focus on improving health and well-being of older people.

Human Subjects Statement

The Human Subjects Division of the University of Washington determined that the proposed activity does not involve human subjects, as defined by federal and state regulations.

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TABLE OF CONTENTS

Chapter 1. General Introduction	1
Research Aims and Hypothesis	31
Chapter 2. The Prevalence of Social Participation Restriction in Community-dwelling Older Adults in the United States	33
Abstract	33
Introduction.....	34
Methods.....	36
Results.....	41
Discussion.....	46
Chapter 3. Recovery and Incidence of Social Participation Restriction in Community-dwelling Older Adults in the United States	51
Abstract	51
Introduction.....	52
Methods.....	54
Results.....	60
Discussion.....	70
Chapter 4. Concluding Statements and Future Directions.....	74
Bibliography	79

LIST OF FIGURES

Figure 1. Flow of the Participants During the Study Period	27
Figure 2. Distribution of Social Participation by Short Physical Performance Battery.....	45

LIST OF TABLES

Table 1: Demographic and Health Characteristics Associated with Social Participation in Older Adults, Summary of Empirical Evidence.	12
Table 2: Prevalence of Social Participation Restriction According to Demographic and Health Characteristics in Adults 65 years and Older in the United States: National Health and Aging Trends Study, 2015	42
Table 3: Prevalence of Social Participation Restriction in the Measured Social Activities	44
Table 4: Total Number of Restricted Social Activities.....	44
Table 5: Association of Social Participation Restriction and Housing Type.....	45
Table 6: Association of Social Participation Restriction and Short Physical Performance Battery in adults 65 years and older	45
Table 7: Overall Social Participation Restriction Change in 2016.....	60
Table 8: Social Participation Change by Each Activity.....	61
Table 9: Sample Characteristics by Social Participation Restrictions at One-Year follow-up.....	62
Table 10: Rate Ratio Estimates for the Incidence of Social Participation Restriction	65
Table 11: Rate Ratio Estimates for Recovery from Social Participation Restriction	67

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Chapter 1. General Introduction

In the United States (U.S.), there were 47.8 million adults 65 years and older as of May 2015, comprising 14.9% of the total population (United States Census, 2017). It is expected that, by the year 2030, older adults 65 years and older will comprise 20% of the U.S. population (Institute of Aging, 2018). This increase in the proportion of older adults can be explained by the increased emphasis on preventive medicine, the decrease in mortality rates, major historical events, and the decline in fertility rates (He, Goodkind, & Kowal, 2016; McCrindle & Wolfinger, 2010; Ortman, Velkoff, & Hogan, 2014). The return of the military personnel home after the Second World War was associated with 18 years of elevated fertility rates and is considered one of the main influential events contributing to the current increase in the older population. The fertility rates in the U.S. remained elevated between the years of 1946 and 1964; for example, the National Center for Health and Statistics recorded 2.9 million births in 1945 and 3.4 million births in 1946. The sudden increase in the birth rates resulted in a phenomenon known as baby boom and the cohort that was born in that period is known as the baby-boomers. In the U.S., the total number of the baby-boomers is 72.5 million; the oldest baby-boomers turned 65 in 2011 (Colby & Ortman, 2014; McCrindle & Wolfinger, 2010).

Typically, a change in life roles occurs at an older age; many roles such as work and child-rearing end which, in turn, frees more time for older adults to participate in other valued activities such as social activities or leisure and recreation (Heaven et al., 2013; Herzog, Ofstedal, & Wheeler, 2002). Social participation (SP) is an important component of health-related quality of life and a key health outcome (Hemmingsson & Jonsson, 2005; Jette, Haley, & Kooyoomjian, 2003; Law, 2002; Levasseur, Desrosiers, & Whiteneck, 2010; Piškur et al., 2014). SP is believed to positively contribute to health, well-being, and quality of life (Law, 2002;

Levasseur, Desrosiers, & Noreau, 2004). Indeed, high mortality and morbidity rates have been shown to be associated with limited SP (Berkman, Glass, Brissette, & Seeman, 2000; Holt-Lunstad, Smith, & Layton, 2010).

James, Wilson, Barnes, and Bennett (2011) suggest that older adults who participate in socially enjoyable activities are less likely to develop dementia, are better prepared to cope with loss, and are able to maintain or even enhance their cognitive skills. The mechanism of how SP impacts cognitive skills is not known, but it is hypothesized that SP challenges older adults to participate in complex personal exchanges that can promote or maintain efficient neural networks (James, Wilson, et al., 2011; Wang, Karp, Winblad, & Fratiglioni, 2002). James, Wilson, et al. (2011) study followed 1,138 older adults for 12 years and their analyses attempted to account for reverse causation and confounding between SP and cognitive decline; however, it is not possible to rule out the alternative scenario of the reciprocal relationship between cognition and SP due to the observational nature of the study. Furthermore, several empirical studies have reported that social participation restriction (SPR) is correlated with multiple individual characteristics including older age, being single (marital status), rural residence (versus urban), restricted mobility, and activities of daily living (ADL) disability (Anaby, Miller, Eng, Jarus, & Noreau, 2009; Arnadottir, Gunnarsdottir, Stenlund, & Lundin-Olsson, 2011; Desrosiers et al., 2009).

Participation versus Social Participation

The concept of SP has been widely used in the healthcare literature since 1960, whereas the concept of participation has been widely used since 2001 (Piškur et al., 2014). The introduction of participation in the International Classification of Functioning Disability and Health (ICF) spiked the use of this term and improved the understanding of the concept of

participation in public health and healthcare (Piškur et al., 2014; World Health Organization, 2001). The widespread use for both concepts started a debate on whether participation and SP are distinct concepts (Piškur et al., 2014; Whiteneck & Dijkers, 2009). Therefore, the first section of this introduction will start by briefly discussing the concept of participation according to the ICF. A discussion on whether SP is different from participation will follow.

There are many approaches to measuring disability. The ICF framework uses disability as an umbrella term for abnormal functioning at three levels: (1) body function (impairment), (2) individual level (activity limitation), and (3) and societal level (participation restriction) (World Health Organization, 2001). Impairments are defined as problems in body functions. Activity limitations are defined as problems in activity execution, and participation restriction is defined as problems in the involvement in life situations (Üstün, 2002; World Health Organization, 2001). An individual who has a medical condition does not necessary suffer from all three levels of disability. i.e., impairment, activity limitation, and participation restriction. An individual might have an impairment and no activity restriction or participation restriction. On the contrary, an individual might have participation restriction and no impairment (e.g. participation restriction due to low motivation or personal factors). Of the three disability levels, we know the least about participation restriction. Participation restriction is hypothesized to result from the interaction between health conditions, the individual, and contextual factors such as the physical, social, and cultural environment (World Health Organization, 2001).

Participation is one of the main positive indicators in the ICF model, which, in turn, encouraged many health organizations and institutions to include it as a key concept in their mission statements and policies (Matsuura, 2005; Prout, 2003; Williams, Stern, Mellow, Safer, & Greifinger, 2012). The participation domains in the ICF are: (1) learning and applying

knowledge, (2) general tasks and demands, (3) communication, (4) mobility, (5) self-care, (6) domestic life, (7) interpersonal interactions and relationships, (8) major life areas, and (9) community/social/civic life. Each participation domain is divided further into subdomains that cover the full range of life areas (World Health Organization, 2001). The ICF model specifies that those domains and subdomains are shared with the activity limitations.

The concept of participation, according to the ICF, has been extensively critiqued in the literature for being too broad and failing to capture the objective state and the subjective experience of persons' involvement with others (Levasseur, Richard, Gauvin, & Raymond, 2010). Many claimed that everything a person would be involved in between their birth and death would be a life situation (Dijkers, 2010; Piškur et al., 2014). Furthermore, participation is often critiqued for using the same domains and subdomains as activity limitations, which adds to the challenge of understanding and measuring both concepts (Dijkers, 2010; Levasseur et al., 2010; Piškur et al., 2014).

The ICF does not define SP, nor does it describe how participation differs from SP, which has led many researchers to use the two concepts interchangeably. Using the two concepts interchangeably started a discussion in the health research community on whether they can be used interchangeably or if there is a need to distinguish between them (Levasseur et al., 2010; Piškur et al., 2014). Many researchers argued that there is a substantial overlap between the two concepts, especially that the ICF lists many social opportunities under participation (i.e., community life, recreation and leisure, and civic life). A distinction between the two concepts can be built on the basis that the ICF does not necessarily put the participation in the perspective of societal engagement, whereas SP emphasizes the importance of the social interactions with others. At the same time, the ICF lists many areas under participation that are not social in nature

such as self-care (i.e., dressing and toileting). Accordingly, SP can be viewed as a domain of participation or a concept under the umbrella of participation (Dijkers, 2010; Levasseur et al., 2010; Piškur et al., 2014). Based on this argument, this dissertation will focus on SP rather than the broad area of participation.

Defining Social Participation

In an attempt to improve our understanding of SP as a concept in older adults, Levasseur et al. (2010) presented a content analysis for the SP definitions in the aging literature. The authors identified 43 original definitions for SP within the public health, rehabilitation, psychology, sociology, social work, and gerontology literature using the following keywords combined with seniors or elderly: community involvement, community participation, social engagement, social involvement, or SP. The authors extracted the conceptual definitions from the identified studies and analyzed their content according to seven interrogative pronouns: who, how, what, where, with whom, when, and why. The majority of the extracted definitions described only four of the seven pronouns: who, how, what, and where. “Who” refers to a person or population depending on the perspective of the author. “How” refers to the focus of the definition, i.e., if it was on engagement, involvement, or performance. “What” refers to the exact social activities mentioned in the definition. Lastly, “Where” refers to the environment in which the social activity takes space. Engagement means a commitment and a guarantee to participate in a social activity, where engagement is stronger than involvement. Involvement means taking part in a social activity. Performance refers to the objective outcome of the social activity. Most rehabilitation definitions focused on the performance of activities that are social in nature. This focus on performance resulted in quantifying SP in rehabilitation as accomplished with or without (1) difficulty and (2) human or technical assistance.

Levasseur et al. (2010) used most of the common keywords that are used interchangeably with SP in their literature search; however, they also missed many other keywords such as civic/societal participation, social activity, social contact, and social integration. Further, this analysis excluded studies that focused only on productive/paid activities and recreational activities. They acknowledged that those activities are mostly social in nature, but they only focused on a narrow aspect of SP. Excluding those studies possibly resulted in losing a significant amount of the literature and also underrepresented two of the essential social areas of SP. Despite those limitations, the Levasseur et al. (2010) is the only recent study that systematically investigated SP definitions. Hence, this dissertation will use the same SP definition that Levasseur et al. (2010, p. 10) adopted: “a person’s involvement in activities that provide interaction with others in society or the community”. Further, SPR will be defined as a problem experienced by an individual in the involvement in valued activities that provide interaction with others in society or the community.

An expert panel within the patient-reported outcomes measurement information system (PROMIS) provided another definition for SP. Social health was one of the National Institutes of Health Roadmap Initiative domains that have been incorporated in the National Institutes of Health Roadmap Initiative (Ader, 2007). To that end, a social health working group was formed to define social health and to create an assessment tool to measure it (Bode, Hahn, DeVellis, Cella, & Group, 2010). This working group created a social health framework that identified social function and social relationships as two subdomains for social health. Social function was defined as “involvement in, and satisfaction with, one’s usual social roles in life’s situations and activities” (Bode et al., 2010, p. 2). The expert panel acknowledged that social function could be used interchangeably with SP, and it was further broken down into “ability to participate” and

“satisfaction-with-participation”. Identifying social health as one of the key domains in PROMIS resulted in the development of multiple item banks that can be used to measure SP in general population and in adults with chronic conditions (Bode et al., 2010).

Similar to participation, the concept of SP has been critiqued for the lack of a widely accepted definition (Piškur et al., 2014). Many researchers use the concept of SP interchangeably with many other concepts such as social network, social engagement, and social inclusion (Piškur et al., 2014). Social inclusion and SP are often used interchangeably within the context of social-rights; the human right to participate in the community (Bathgate & Romios, 2011). Specifically, social inclusion is defined as “a situation in which individuals are integrated into the economic, social, and political framework of society” (Bathgate & Romios, 2011; Oxoby, 2009, p. 1). Social network is often referred to as “a web of social relationships that surrounds an individual and the characteristics of those ties ” (García, Banegas, Perez-Regadera, Cabrera, & Rodriguez-Artalejo, 2005, p. 511). Lastly, social engagement is defined as “maintenance of many social connections and a high level of participation in social activities” (Bassuk, Glass, & Berkman, 1999, p. 165). According to the available definitions of each of the previously mentioned definitions, they overlap, but are not interchangeable.

Measures of Social Participation

It is not surprising that the lack of agreement on definitions for participation and SP has led to inconsistency in the measurement of both concepts. The majority of the available outcome assessment tools, for example, the Craig Handicap Assessment and Reporting Technique (CHART), the Keele Assessment of Participation (KAP), and the Short Form Survey (SF-36) (McHorney, Ware, & Raczek, 1993; Whiteneck, 1992; Wilkie, Peat, Thomas, Hooper, & Croft, 2005), measure SP as a subdomain of participation. Only a few, such as the PROMIS “ability-to-

participate” item bank (Bode et al., 2010), focus solely on SP. It is important to note that the vast majority of the available participation assessment tools were designed to measure participation in the years following rehabilitation, not in population-based research (Eyssen, Steultjens, Dekker, & Terwee, 2011). For example, the CHART was one of the early measures that were developed to measure the degree in which impairment affected participation after a range of physical or cognitive impairments. The subdomains of the CHART that focus on SP are: (1) ability to occupy time in the manner customary to that person's sex, age, and culture, and (2) ability to participate in and maintain customary social relationships (Whiteneck, 1992).

Eyssen et al. (2011) conducted a meta-analysis of all instruments available at that time that assessed participation. The participation definition that the author used in this review was “performing roles in the domains of social functioning, family, financial, work/education, or in a general domain” (Eyssen et al., 2011, p. 984). The search yielded 103 instruments (2,445 items) where at least 50% of the items measured participation. The 2,445 items were further categorized into 619 items that measured participation, 217 undetermined items, and 1,609 items that measured non-participation items. The participation items measured the following domains: work/study (27%), social life (27%), general participation (19%), and home participation (11%). The undetermined items measured transportation, shopping, and sexual participation. Lastly, the non-participation items focused mostly on health. Furthermore, among the 103 instruments, only two instruments solely measured participation: the Activity Participation Questionnaire (APaQ) and the Personal and Social Performance (PSP). The APaQ is a two-item instrument that was developed to measure participation for people with rheumatoid arthritis (Li, Wells, Westhovens, & Tugwell, 2009 & Tugwell, 2009). The PSP is a one-item instrument that was developed to measure participation for people with schizophrenia (Juckel et al., 2008). The short nature of

both instruments, their focus on a specific population, and the limited psychometric studies on each have negatively affected their use in empirical studies on participation. Of the instruments with more items overall, 73% of Keele Assessment of Participation (KAP) items measured participation.

The KAP was developed to measure self-reported participation restriction within the past four weeks in population-based research including community-dwelling older adults. The KAP has 11 items, and each item is scored using a five point ordinal scale. Specifically, the items of KAP measure mobility within the home, mobility outside the home, self-care, looking after home, looking after belongings, looking after dependents, interpersonal interaction, managing money, work, education, and social activities. The KAP was developed and standardized in the United Kingdom. The KAP's face validity, content validity, construct validity, and test-retest reliability have been established (Wilkie et al., 2005 Hooper, & Croft, 2005). Eyssen et al.'s (2011) meta-analysis focused on identifying the items that measured participation in available instruments and identifying what subdomains of participation are commonly measured without discussing the psychometric properties of any of the tools. Most available measures of participation, including the APaQ, PSP, and KAP, are based on the assumption of "more is better", ignoring the subjective aspects of participation, such as the value or satisfaction of participation for individuals (Eyssen et al., 2011; Piškur et al., 2014). An adequate measure for SP should be an individual's report of their own SP according to their own values and needs that incorporates their own environmental and personal factors (Wilkie et al., 2005). One way for measuring SP according to a person values and needs would be by incorporating the perceived value of each activity into the scale while defining SPR only by the inability to participate in the activities of importance to an individual. Considering a person's values and needs in participation and SP

measures might improve the validity and reliability of the measures (Perenboom & Chorus, 2003; Whiteneck & Dijkers, 2009).

The social health PROMIS working group created two of the few assessment tools that assess SP. They utilized a rigorous methodology to develop multiple item banks to measure SP and test their validity. The development of each item bank included a comprehensive literature search, cognitive interviews, and validity studies (Ader, 2007; Bode et al., 2010). A comprehensive literature review yielded all existing instruments that measure SP and match the PROMIS definition for SP. A focus group reviewed and revised the relative items to include in an item bank to use in subsequent cognitive interviews and validity studies. These efforts yielded two item banks to measure SP: one to measure the “ability-to-participate” and one to measure “satisfaction-with-participation” in social activities. Both item banks were validated in adults with chronic illness (Hahn, Cella, Bode, & Hanrahan, 2010).

The National Health and Aging Trends Study (NHATS) team developed a set of items to assess SPR to include in their disability measurement protocol. The SPR items were developed over 2 years by an expert panel and several rounds of cognitive testing and then validated using a purposive sample of older adults 65 years or older ($N = 326$) (Freedman et al., 2011). The NHATS SPR items examine if the participant carried out the following activities in the past month: (1) visiting in person with friends or family, (2) attending religious activities, (3) going out for enjoyment (examples: going out to dinner, movie, gamble, concerts, or plays), and (4) participating in clubs, classes, or other organized activities. Each question is followed by a question about the importance of the activity (i.e., very important, somewhat important, or not so important). A summary dichotomous score of any-restriction/no-restriction can be created based on those items. Any-restriction is defined as reporting restriction in one of the measured

activities that is perceived as “somewhat important” or “very important”. No restriction is defined as reporting no restriction in any of the measured activities or reporting a restriction in one or more of the measured activities that is perceived as “not so important”. Construct validity was established for SPR items through correlations with demographic characteristics, frailty, memory, and performance-based mobility. Test-retest reliability has been found to be adequate (Kappas ranged from 0.56-0.91). Lastly, a confirmatory factor analysis confirmed that the four items fit into one domain (Freedman et al., 2011). Measuring both the participation in each activity and its perceived value makes the NHATS items of SPR stand out from other SP measures. However, it is still a new measure and has not been used in studies other than the annual waves of NHATS.

Predictors of Social Participation

Many variables have been found to be associated with SP in older adults. The remainder of this introduction will briefly present the key findings of current empirical studies on the association between SP and age, sex, living arrangements, education, chronic health conditions, physical function, and psychosocial health. See Table 1 for a summary of the key empirical evidence on the association of SP with demographic and health characteristics of older adults 65 years and older. Please note that the items that measured SP are listed only for the studies that did not use a standardized tool to measure SP. A discussion of the presented empirical evidence will follow the table.

Table 1: Demographic and Health Characteristics Associated with Social Participation in Older Adults, Summary of Empirical Evidence.

Study	Study Design	Participants	Social Participation Measure	Primary Findings Related to Social Participation	Country
Agahi, Ahacic, and Parker (2006)	- Longitudinal observational study - Data collection rounds 1986, 1991, and 2002	495 adults 43-65 years on baseline	- Participation in 9 leisure activities - The activities: reading books, hobby activities, gardening, cultural activities, fishing or hunting, restaurant visits, study circles and courses, religious activities, and dance - Response categories: yes/no	- SP was reported based on the following activities: cultural activities, restaurant visits, study circles and courses, religious activities, and dance - SP in 2002 was a continuation of participation in earlier life - SPR in 2002 was associated with lower educational levels	Sweden
Anaby et	Cross-sectional	200 older adults 65	Assessment of Life Habits and	- Mobility and	Canada

al. (2009)		years or older with 2 or more chronic medical conditions, mean age = 75	Interpersonal Support Evaluation	balance explained 24% of the participation variance in social roles - Depression was not associated with participation in social roles	
Arnadottir et al. (2011)	Cross-sectional	186 older adults 65 years or older, mean age = 73.9	Late Life Function and Disability	- Higher participation levels were associated with living in urban communities rather than rural communities. - Lower participation levels were associated with older age and with depression	Iceland
Avlund, Lund, Holstein,	- Longitudinal observational study	1396 older adults 75 years and older	- Participating in 3 social activities - The activities: paying visits to others, receiving visitors at home, and	- Higher SP associated with decreased risk of the onset of mobility	Denmark

and Due (2004)	- Follow-up after 1.5 year of baseline		participating in other social activities outside the home. - Based on the answers, participants were categorized into low SP or high SP	disability	
Bukov, Maas, and Lampert (2002)	- Longitudinal observational study - Data collection rounds 1990 and 1995	206 older adults 70 years or older	- Participation in 11 activities - The activities: hobby, travelling, day trips, sports, culture, games, education, art, dancing, voluntary social engagement, and politics - Response categories: yes/no with a follow-up question if the person participated in each activity with others	- SP was defined as socially oriented sharing of individual resources - Lower SP levels were associated with advancing age and lower educational level	Germany
Buchman et al. (2009)	- Longitudinal observational study - Annual data collection between 1997-2008	906 older adults 65 years or older, mean age = 78.7. The average follow-up period = 4.9 years	Late Life Function and Disability	- Each 1-point decrease in social activity was associated with about a 33% more rapid rate of decline in motor function	Chicago, United States

(Motor function was measured using 9 measures of muscle strength and 9 motor performance tests)

Levasseur et al. (2004)	Cross-sectional	46 adults aged 60 years or older, mean age = 72.6	Assessment of Life Habits	- Lower “social roles” score was associated with decline in quality of life	Canada
Desrosiers et al. (2009)	Cross-sectional	350 older adults 65 years and older	Assessment of Life Habits	- SPR was associated with advancing age - SPR was more common in men	Canada
Desrosiers, Noreau, and Rochette (2004)	Cross-sectional	189 adults aged 55 years and older, mean age = 72.6	Assessment of Life Habits	- Lower SP with advancing age - No differences in SP between men and women - Higher SP was	Canada

Gagliardi et al. (2007)	Cross-sectional	3950 adults ages 55 years or older, mean age = 71.7	<ul style="list-style-type: none"> - SP in 4 social activities - The activities: Religious events, activities in clubs, meeting friends, receiving visits at home, and being cozy at home - Response categories: yes/no - The activities we 	<p>associated with living with a spouse</p> <ul style="list-style-type: none"> - SP restriction was associated with advancing age - Women participated more in home activities - Living in urban environment was associated with higher SP 	Germany, Finland, Hungary, Netherlands, and Italy
Glass, De Leon, Bassuk, and Berkman (2006)	- Longitudinal observational study - Data collection rounds 1982, 1985, and 1988	2,812 older adults 65 years and older	<ul style="list-style-type: none"> - Social engagement in 5 social activities - The activities: going to a movie, restaurant, or sporting event, going on day trips and overnight trips, playing cards, games, or bingo, attending religious services, and participating in social and community groups. 	<ul style="list-style-type: none"> - Social engagement restriction was associated with depressive symptoms as measured by CES-D. This association was present cross-sectionally but not longitudinally 	New Haven, United States
Griffin	Cross-sectional	104 older adults 65	Modified Leisure Satisfaction Scale	- Restriction in	Australia

and McKenna (1999)		years and older, mean age = 74	(included a subscale of social leisure activities)	leisure activities was associated with older age and less access to transportation	
Ishikawa et al. (2006)	Cross-sectional	239 older adults aged 65 years and older, mean age = 76.7	1-question about the frequency of participation in social activities outside the home such as shopping, hospital, bank, meeting place for hobby or amusement, friend's home, workplace, teahouse, a walking to neighborhood	- Higher frequency of SP in activities outside the home was associated with being a man and actively employed women. - Lower frequency of SP outside the home was associated with depression.	Japan
James, Wilson, et al. (2011)	- Longitudinal observational study - Annual interviews for 12 years	- 1138 older adults 65 years and older, mean age = 79.6 - Average follow-up period = 5.1 years	- Participation in 6 social activities - The activities: go to restaurants, go on day trips or overnight trips, do unpaid community or volunteer work, visit relatives or friends houses, participation in groups or senior center, and attend religious activities.	- Higher SP was associated with less cognitive decline in older adults	Chicago, United States
James,	- Longitudinal	- 954 older adults 65	- Participation in 6 social activities	- Higher SP was	Chicago,

Boyle, Buchman, and Bennett (2011)	observational study - Annual interviews for 13 years	years or older, mean age = 79.6 - Follow-up period = 5.1 years	- The activities: go to restaurants, go on day trips or overnight trips, do unpaid community or volunteer work, visit relatives or friends houses, participation in groups or senior center, and attend religious activities.	associated with decreased incidence of IADL disability	United States
Mendes De Leon and Rajan (2014)	- Longitudinal observational study - 3-years cycle interviews between 1997-2010	5,306 older adults 65 years or older, mean age = 79.0	- Participation in 3 social activities and 1 item about participating at paid work - The activities: religious services, went to a museum, participated in activities or groups outside the home - The response categories: 3-point ordinal scale	- Higher social engagement scores were associated with decreased risk of developing ADL disability, and with decreased progress of ADL disability	Chicago, United States
Rosso, Taylor, Tabb, and Michael (2013)	Cross-sectional	676 older adults 65 years or older, mean age = 72.8	- Participation in 2 social activities - The activities: participation in organizations and use of senior centers and talking by phone and use of internet - Frequency of telephone conversations with friends or family was recorded as several times per day, once a day, a few	- The overall social engagement restriction was associated low mobility even with the absence of disability	Philadelp hia, United States

times per week, or once a week or less frequently

Sørensen, Axelsen, and Avlund (2002)	- Cohort longitudinal study - Interviewed twice with 5 years gap in between	442 older adults aged 75 at baseline	- Participating in 3 social activities - The activities: paying visits to others, receiving visitors at home, and participating in other social activities outside the home. - Based on the answers participants were categorized into low SP or high SP	- In men, no depression and no home help predicted high SP at follow-up - In women, good functional abilities and normal mood predicted high SP at follow up	Denmark
Wilkie, Peat, Thomas, and Croft (2006)	Cross-sectional	7,878 older adults aged 50 years or older, mean age = 66.3	Keele Assessment of Participation	- SPR was associated with advancing age and women	United Kingdom

SPR = Social Participation Restriction; IADL= Instrumental; ADL= Activities of Daily Living; CES-D= Center for Epidemiologic Studies Depression

Decline in SP with advancing age is a consistent finding in current literature (Bukov et al., 2002; Desrosiers et al., 2004; Desrosiers et al., 2009; Gagliardi et al., 2007; Griffin & McKenna, 1999; Wilkie et al., 2006). Older adults who are older than 85 years consistently report lower SP levels than older adults who are 65-84 years old (Desrosiers et al., 2004; Desrosiers et al., 2009). One study from Sweden followed a cohort of 495 older adults for 34 years; participants were aged 34-65 at baseline and aged 77-99 at the last follow-up. Data collection was done in three rounds (1968, 1991, 2002). The outcome measure of this study was the interest and frequency of participation in nine leisure activities. Many of the measured leisure activities in this study were social in nature (e.g., attending religious services and restaurants visits). The authors presented the data for each activity separately, which allowed for examining participation in the social activities. They found that participating in leisure activities, including those that are social in nature, declined over time. For instance, attending religious activities rate dropped from 23.3% in (give year) to 20.2% in 2002. The participation patterns in the social activities did not differ by sex (Agahi et al., 2006). Agahi et al.'s (2006) extended follow-up period is a clear strength of the study; however, the extended period between the follow-up rounds is a major weakness. The extended period between the data collection points prevented the researchers from studying the trajectories of the investigated activities. Furthermore, although the study protocol specified that the participants were asked how often they participated in each activity (i.e., never, sometimes, and often), in the analyses, the data were converted to a binary variable without factoring the frequency of participation into the analysis.

Differences in SP by sex in older adults have not been found to be as conclusive as age differences. Two studies found that older men report higher SP rates than older women (Ishikawa et al., 2006; Wilkie et al., 2006). However, multiple studies have found no significant

difference in SP according to sex (Agahi et al., 2006; Bukov et al., 2002; Desrosiers et al., 2004; Sørensen et al., 2002). In contrast, Gagliardi et al. (2007) found that SP differs between older men and older women according to the type of the activity with older women participating more in home social activities and men participating more in social activities that involved sports. The studies that found no difference between SP and sex had significantly smaller sample sizes than the ones that reported differences between sexes. The small sample size of those studies increased their margin of error, which may have influenced the results.

One study reported on the association of SP with living arrangement and found that living with a spouse or another person was associated with higher SP (Desrosiers et al., 2004). Two studies found that living in an urban setting is associated with higher SP (Arnadottir et al., 2011; Gagliardi et al., 2007). Many studies found that higher levels of education are associated with higher levels of SP. Specifically, more than 8 years of schooling has been significantly associated with better SP (Agahi et al., 2006; Bukov et al., 2002; Gagliardi et al., 2007). Chronic health conditions are another variable that has been found to be associated with SP in older adults. For example, osteoarthritis, hearing deficit, visual function, hypertension, mobility problems, and respiratory problems were associated with SPR (Agahi et al., 2006; Bukov et al., 2002; Desrosiers et al., 2004; Gagliardi et al., 2007; Griffin & McKenna, 1999; Sørensen et al., 2002).

The correlation between physical health variables and SP is well documented in the literature (Anaby et al., 2009; Mendes De Leon & Rajan, 2014; Rosso et al., 2013). Physical health variables include mobility and balance. A cross-sectional study of 200 community-dwelling older adults found that mobility (measured using Timed Up and Go) and balance (measured using Activities-specific Balance Confidence) explained 24% of the variance in

participation in social roles measured with the Assessment of Life Habits (Anaby et al., 2009). Another cross-sectional study of 676 community-dwelling older adults living in Philadelphia showed that mobility limitations, even in the absence of disability, were correlated with low social engagement (Rosso et al., 2013). Mobility in this study was measured using Life-Space Assessment, and disability was measured using a questionnaire created by the research team. Disability was defined as dependency in one or more activity of ADL or instrumental activities of daily living (IADL). Social engagement was measured using the total number of social organizations in which the person participated and the frequency of telephone conversations with friends and family (Rosso et al., 2013).

A population-based longitudinal study of 5,306 older adults living in Chicago found that less social engagement was associated with higher incidence and progression of ADL disability. ADL disability was measured by the ability to perform six basic ADLs, and social engagement was measured based on whether older adults participated in organizations or used senior centers and the frequency of telephone conversations with family and friends. The researchers found that social network was negatively associated with ADL disability. Social network was measured using a survey that focused on the number of relationships with children, relatives, and friends and the frequency of interaction within each type (Mendes De Leon & Rajan, 2014).

Similar to physical function, the correlation between depression and SP is well documented in literature (Anaby et al., 2009; Ang, 2018; Arnadottir et al., 2011; Ishikawa et al., 2006; Sørensen et al., 2002). For example, in one study of 186 community-dwelling older adults, lower participation frequency was associated with reporting depressive symptoms as measured by the Geriatric Depression Scale (Arnadottir et al., 2011).

In addition to the aforementioned variables that correlate with SPR, it is hypothesized that housing type would be associated with SPR. Typically, older adults reside either in traditional community housing, residential/assisted-living housing, or nursing homes. Residential/assisted-living is “an aggregation of housing units within clearly demarcated geographic boundaries, intentionally planned for older people that offers some level of common services or leisure amenities” (Glass & Skinner, 2013, p. 68). Usually, residential/assisted-living housing do not offer personal care services, on the contrary, nursing homes are settings that offer a range of supportive personal care services (e.g., self-care assistance and medication assistance).

In 2011, over 5.5 million older adults, 15% of the total older adult population, lived in settings other than traditional community housing (Freedman & Spillman, 2014). Residential/assisted-living housing and nursing homes facilities offer and plan a wide range of social activities for their residents. According to the NHATS, 98.6% of older adults living in senior living facilities and nursing homes reported having access to social activities planned at their facility (Freedman & Spillman, 2014). Further, most assisted-living housing and nursing home facilities offer transportation services, which might facilitate older adults’ SP (Freedman & Spillman, 2014). However, no studies have investigated whether older adults’ SP differs according to their resident type. Such evidence would help us to understand any difference in older adults’ SP patterns living in different residents, which can help in planning SP programs for older adults.

Social Participation Recovery, Incidence, and Prevalence

All of the empirical studies presented above solely explored SPR risk factors. Many theoretical papers have discussed SP as a potentially modifiable and dynamic health factor (De Leon, 2005; Dijkers, 2010; Levasseur et al., 2010; Rowe & Kahn, 1997). However, the patterns

of SP change over time, SPR prevalence, SPR incidence, and SPR recovery are still poorly understood. No studies have reported on SPR recovery in the general population of older adults, although multiple studies have reported on SPR recovery in older adults after fractures or stroke (Ekström, Ivanoff, & Elmståhl, 2013; Kim, Chang, & An, 2014; Miller et al., 2009; Ryan, Enderby, & Rigby, 2006). For example, Miller et al. (2009) reported a linear improvement in SP at 2 months, 6 months, and 12 months post hip fracture. To my knowledge, only one study has estimated SPR prevalence and another SPR incidence.

In the United Kingdom, SPR prevalence in adults 50 years and older in 2002 was found to be 13.6% as measured by the KAP. The tested sample in this study was 7,878 community-dwelling older adults. SPR prevalence increased with advancing age, and it was more frequent in women (Wilkie et al., 2006). A follow-up study using the same population found that SPR incidence at 3-year follow-up was 10.1%. Similar to the SPR prevalence, SPR incidence increased with advancing age and in women; however, no other SPR incidence risk factors were tested in this study (Wilkie, Thomas, Mottram, Peat, & Croft, 2008). Both the prevalence and the incidence studies expanded on current literature by providing evidence on SP change over time in older adults, although, no risk factors beyond demographic characteristics were discussed. To my knowledge, no studies have provided an estimate of SPR recovery in older adults.

Narrow population characteristics are among the most common limitations in healthcare study designs. Most of the studies that were summarized earlier used convenience samples in narrow geographical areas, which potentially limits the validity and generalizability of the results. Furthermore, most of the explored studies were cross-sectional in nature, which limits our ability to draw any causal relationships based on the provided results. Lastly, the items and instruments that were used to measure participation were diverse, and most studies did not

provide the SP operational definition they used to develop their outcome measure. The longitudinal studies also had many limitations. Most longitudinal studies had smaller samples than the cross-sectional studies; furthermore, many of the longitudinal studies had extended periods between follow-ups. Meaningful transitions can be lost because of the extended periods in follow-up. To overcome those limitations, the NHATS began to collect data annually in 2011 to facilitate our understanding of trends in late-life health and functioning.

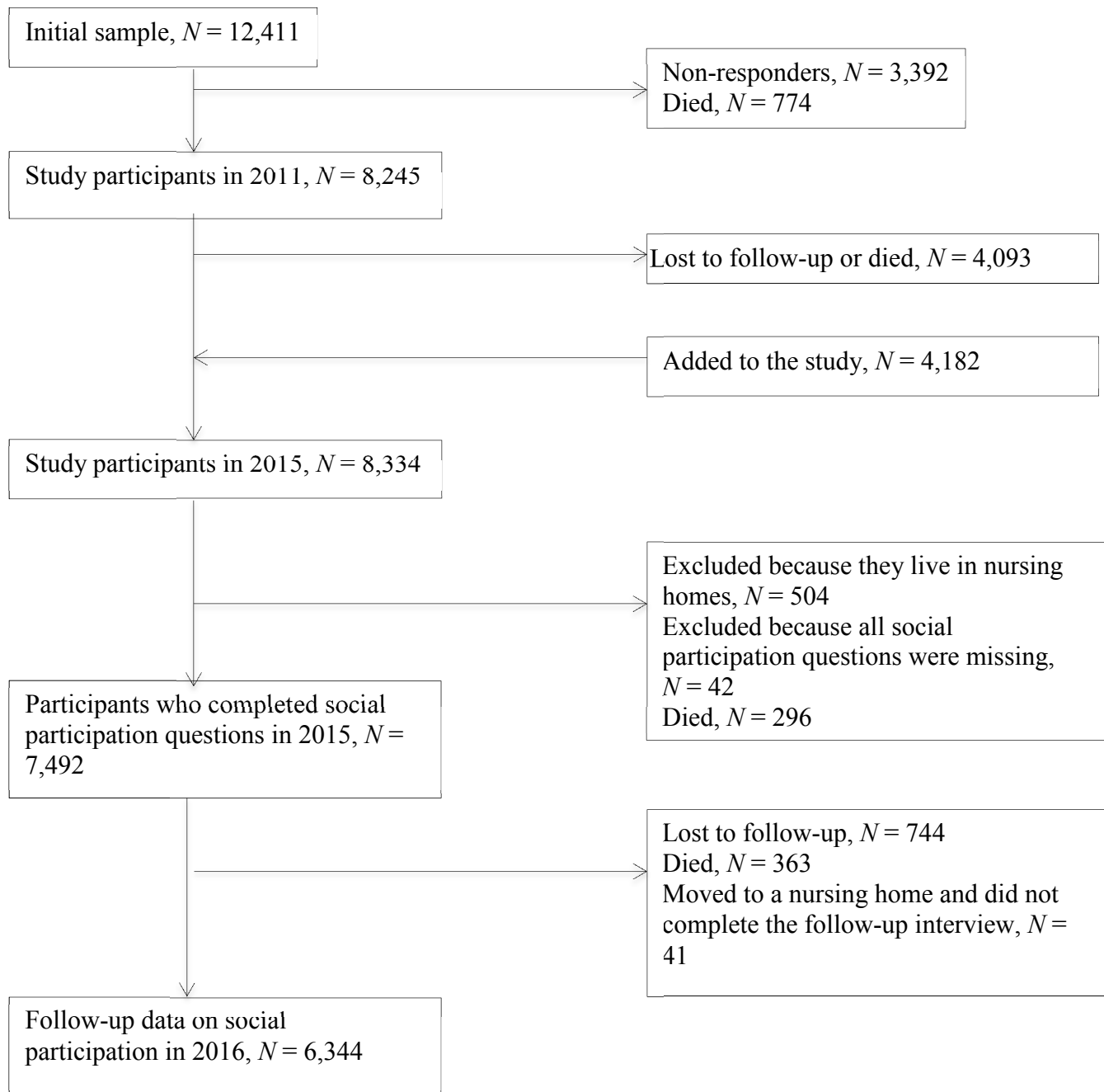
Introduction to National Health and Aging Trends Study

The NHATS study sample is based on Medicare data in 2011 (Round 1) and 2015 (Round 5). Medicare enrollment data represent 96% of all adults 65 years and older in the U.S. According to the U.S. census, there were 40.3 million older adults aged 65 years and older in 2010. NHATS researchers used the census data to calculate the effective sample sizes that needed to be recruited to represent the older adult population in the U.S. by age and race/ethnicity. According to the effective sample size calculations, a sample of 8,500 was the target sample that should be recruited; however, 12,411 beneficiaries were identified as eligible participants in order to account for nonresponse. More information on the effective sample sizes and the sample selection process can be found in Montaquila, Freedman, Edwards, and Kasper (2012a). To better understand the sampling method of the NHATS, a breakdown for the three-stage sampling that was used to recruit the final sample is presented below.

The first stage of sampling included choosing 95 random sampling units (individual counties or group of counties), the second stage involved choosing 655 secondary sampling units (ZIP codes and ZIP code fragments), and the third stage was beneficiaries who were 65 or older as of September 30, 2010 with oversampling Black non-Hispanic persons and persons aged ≥ 90 years. In 2011, 8,245 beneficiaries were recruited with a 71% response rate (Montaquila et al.,

2012a). In 2015, the sample was replenished, resulting in 4,182 (50.1%) new participants in addition to 4,152 from the original sample (74% overall weighted response rate) (Montaquila, Freedman, Spillman, & Kasper, 2017). Analytical weights were developed to account for survey nonresponse and oversampling of Black Non-Hispanic older persons and adults aged ≥ 90 years (Montaquila, Freedman, Edwards, & Kasper, 2012b). Thus, the provided analytical weights of any round allows researchers to reproduce those who were alive and eligible for NHATS at that same round (Montaquila, Freedman, Edwards, & Kasper, 2017). See Figure 1 for a diagram showing the flow of the study participants between 2011 and 2016 according to the inclusion criteria for this dissertation.

Figure 1: Flow of the Participants During the Study Period



A multidisciplinary team of researchers from the fields of demography, geriatric medicine, epidemiology, health services research, economics, and gerontology developed the NHATS study procedures and the survey items. Trained survey research staff collected the data through a single in-person interview at the study participants' homes. In most cases, the respondents for the survey questions were the participants themselves; however, a proxy was identified as the main responder when the participant was unable to provide responses due to health or memory problems. The reasons for using a proxy respondent included dementia or cognitive impairment, severe illness, speech or hearing impairment, and language barrier (Kasper & Freedman, 2012). In the initial rounds, the interviews were administered for the participants who lived in traditional community housing and residential/assisted-living housing, but not to participants who lived in nursing homes (Kasper & Freedman, 2012).

The Center for Medicare and Medicaid Services (CMS) sent a letter and a study brochure for the participants who were selected for the NHATS. The letter and the study brochure announced the study, stated the study's purpose, and asked for the participants' cooperation. Prior to the initial interview, a welcoming letter and a welcoming package were sent to each participant informing them that a study representative would be visiting them soon for data collection. A phone number for scheduling appointments was provided for those who preferred to set up an appointment instead of waiting for a visit. On the interview day, a trained survey research staff visited the participant. Each survey research staff had introductory scripts to use and follow throughout the interview. The research staff obtained consent prior to the interview. Each interview took approximately two hours, and, at the end of the interview, each participant received an incentive check for \$40 (Kasper & Freedman, 2012).

The NHATS is funded by the U.S. National Institute on Aging, National Institutes of Health. The Johns Hopkins University Institutional Review Board approved the study protocol (Montaquila et al., 2012a). All non-sensitive NHATS data are publicly available at www.nhats.org. However, it is possible to link the study data to Medicare data with the approval from the NHATS investigative team and appropriate institutional review boards. The NHATS data is a unique dataset that offers longitudinal representative data about older adults' health and functioning that can be used to bridge many of the gaps in SPR research.

Summary

SP is a health factor of particular interest for those investigating older populations, as well as those who are interested in reducing the impact of chronic conditions, because it is considered a modifiable health factor (Levasseur et al., 2010; Whiteneck & Dijkers, 2009). Additionally, it is a concept of particular interest in healthcare because designing programs to prevent SPR and to facilitate SP are potentially cost-effective (Veenhuizen et al., 2015).

Despite the growing research on SP and its effect on health among older adults, there is still a considerable amount of ambiguity in the literature. Much of this ambiguity stems from the lack of empirical studies that examine the extent of SPR in older adults. Further, there remains the need to reach an agreement on a definition of SP in this population. This dissertation is an effort to build on the theoretical and empirical understanding of SPR in older adults. The purpose of this study is to further our knowledge of the relationships between SPR and demographic and health characteristics, housing status, and physical function of older adults.

This dissertation will be presented in the format of two-linked papers. The first paper will determine the prevalence of SPR in older adults in the U.S. The second paper will investigate the incidence and recovery rates of SPR in older adults in the U.S. This dissertation will improve

upon prior research by determining the overall prevalence for SPR in older adults, using a valid measure collected in a nationally representative sample of community-dwelling older adults in the U.S., and by examining SPR incidence and recovery in community-dwelling older adults in the U.S. A better understanding for SPR in older adults can provide important information for healthcare professionals and health policy as well as clinical interventions to improve older adults' quality of life.

Research Aims and Hypothesis

Aim 1: Determine the prevalence and correlates of SPR in older adults in the U.S.

Aim 1A: Determine the prevalence of SPR in older adults in the U.S. by age and sex.

Hypothesis 1A:

- It is hypothesized that the prevalence of SPR will increase with advancing age.
- It is hypothesized that SPR prevalence will be higher in females than in males.

Aim 1B: Determine the association of housing status (traditional community housing vs. residential/assisted-living community) with SPR among older adults in the U.S.

Hypothesis 1B: It is hypothesized that SPR will be positively and significantly associated with living in residential/assisted-living community.

Aim 1C: Determine the association of physical functioning with SPR in older adults in the U.S.

Hypothesis 1C: It is hypothesized that SPR will be associated with worse physical functioning.

Aim 2: Determine the incidence and recovery rates of SPR among older adults in the U.S.

Aim 2A: Determine the one-year incidence and risk factors of SPR in older adults in the U.S.

The incidence of SPR is defined as the proportion of older adults who reported SPR at one-year follow-up among those who did not report SPR at baseline.

Hypothesis 2A:

- It is hypothesized that more than 10% of older adults will develop SPR at one-year follow-up.
- It is hypothesized that older age, being a female, lower physical functioning, and living in residential/assisted-living housing will be associated with developing SPR.

Aim 2B: Determine the one-year SPR recovery rate and correlates of SPR recovery in older adults in the U.S. The SPR recovery is defined as the proportion of older adults who do not report SPR at one-year follow-up among those who reported SPR at baseline.

Hypothesis 2B:

- It is hypothesized that more than 10% of older adults will recover from SPR at one-year follow-up.
- It is hypothesized that younger age, being male, better physical functioning, and living in traditional community housing will be associated with SPR recovery at one-year follow-up.

Chapter 2. The Prevalence of Social Participation Restriction in Community-dwelling Older Adults in the United States

Abstract

Objectives: To (1) determine the prevalence of social participation restriction (SPR) by age and sex among community-dwelling older adults ages ≥ 65 years in the United States and (2) the association of SPR with residence type and physical functioning.

Methods: This cross-sectional study analyzed data from the 2015 National Health and Aging Trends Study ($N = 7,492$). Adjusted Wald statistics were used to determine SPR prevalence across age and sex. Poisson regression was used to test the association of SPR with residence type and physical functioning (measured using the Short Physical Performance Battery).

Results: The overall prevalence of SPR was 17.0% (95% Confidence Interval [CI]: 16.0-18.0). SPR increased with advancing age and was more common in women than in men (21.4% vs. 11.4%, $P < 0.001$). The residence type was not associated with SPR after adjusting for demographic and potential covariates. Worse physical functioning was associated with SPR (adjusted prevalence ratio = 0.90 [95% CI: 0.88-0.92]).

Discussion: SPR is common among community-dwelling older adults in the U.S. and is associated with advancing age, female sex, and lower physical functioning. Identifying SPR risk factors could help develop and refine programs that aim to improve older adults' participation in social activities that they value.

Introduction

Between 2015 and 2030, the proportion of older adults aged 65 years and older will rise from 15% to 24% of the total population in the United States (U.S.) (Crimmins & Beltrán-Sánchez, 2010; Mather, Jacobsen, & Pollard, 2015). Social participation (SP) has been identified as a key component of successful aging (De Leon, 2005). SP has been positively associated with well-being and quality of life (Law, 2002; Levasseur et al., 2004). Moreover, SP is associated with a decreased risk of mobility limitations, cognitive decline, morbidity, and mortality (Berkman et al., 2000; Buchman et al., 2009; Holt-Lunstad et al., 2010).

Many empirical studies have measured SP and its correlates in the older adult population; however, most of those studies used convenience samples in narrow geographical areas (Anaby et al., 2009; Buchman et al., 2009; Levasseur et al., 2004). Furthermore, most of the empirical studies on SP in older adults have been conducted in countries other than the U.S. (Gagliardi et al., 2007; Griffin & McKenna, 1999; Ishikawa et al., 2006; Sørensen et al., 2002), and several of the published papers on SP used the same datasets (James, Boyle, et al., 2011; James, Wilson, et al., 2011; Wilkie et al., 2006; Wilkie et al., 2008).

Social participation restriction (SPR) is defined as a problem experienced by an individual in the “involvement in activities that provide interaction with others in the society or community” (Levasseur et al., 2010, p. 10). To our knowledge, there is one study that estimated SPR prevalence in adults 50 years and older in the United Kingdom, but none in the U.S. Wilkie et al. (2006) estimated the prevalence of the overall participation restriction in the past four weeks using the Keel Assessment of Participation (KAP) in 7,878 adults aged 50 years or older. The KAP is a broad participation measure with only one item on SP. It was found that 51.8% of the participants reported restriction in at least one area of participation, and about 13.6% of the

participants reported participation restriction in social activities. Furthermore, the overall participation restriction prevalence increased with advancing age and was higher in women. Considering the limitations in previous studies, the growing older adult population, and the impact of SP on older adults' health, it is important to expand on the existing SP literature by determining the prevalence of SPR and its correlates using nationally representative samples of the older adult population.

Now more than ever, older adults are considering living arrangements other than traditional community housing such as residential/assisted-living communities. Over 5.5 million older adults, 15% of the total older adults population in the U.S., are living in settings other than traditional community housing (Freedman & Spillman, 2014). Residential/assisted-living facilities typically offer and plan a wide range of social activities for their residents and facilitate SP by providing services such as transportation. Nonetheless, the current literature does not provide much information on whether SPR differs according to residential status.

In this study, we sought to determine the prevalence and correlates of SPR in a large nationally representative sample of older adults in the U.S. Specifically, the aims and the hypotheses of this study were to: (1) determine the prevalence of SPR in older adults in the U.S. by age and sex; it was hypothesized that the prevalence of SPR will increase with advancing age and will be higher in women than in men; (2) determine the association of housing status (traditional community-dwelling vs. residential/assisted-living housing) with SPR among older adults in the U.S.; it was hypothesized that association between SPR will be positively and significantly associated with living in residential/assisted-living housing; and (3) determine the association of physical functioning with SPR in older adults in the U.S.; it was hypothesized that SPR will be associated with worse physical functioning.

Methods

Study Design and Population

This study is a cross-sectional analysis of the 2015 National Health and Aging Trends Study (NHATS). The University of Washington Institutional Review Board deemed this study exempt as NHATS consists of publically available non-identifiable data. NHATS is funded by the U.S. National Institute on Aging, National Institutes of Health. The Institutional Review Board of Johns Hopkins University approved the study protocol (Kasper & Freedman, 2012).

NHATS is an annual survey, administered through in-person interviews, designed to investigate trends in late life functioning. Trained research staff conduct the interviews in the participants' homes. Annual data collection began in 2011 (i.e., Round 1). Three-stage sampling was used to recruit 8,245 out of 12,411 eligible participants with a 71% response rate. The sample was drawn randomly from Medicare beneficiaries ages 65 years and older residing in the U.S. The first stage of sampling involved choosing 95 random sampling units (individual counties or group of counties), the second stage involved choosing 655 random secondary sampling units (ZIP codes and ZIP code fragments), and the third stage consisted of randomly selecting Medicare beneficiaries who were 65 years or older as of September 30, 2010. In 2015 (i.e., Round 5), the sample was replenished, resulting in 4,182 (50.1%) new participants in addition to 4,152 from the original sample for a total sample of 8,334 (74% overall weighted response rate) (Montaquila, Freedman, Spillman, et al., 2017). The NHATS study survey items, including the SP items, were validated prior to data collection (Freedman et al., 2011). More information on the NHATS procedures can be found at www.nhats.org (Kasper & Freedman, 2012). Community-dwelling older adults, including those living in traditional community housing and those living in residential/assisted-living housing, with complete data on SP were

included in this study, resulting in a sample size of 7,492 participants (504 living in nursing homes and 42 missing data on SP were excluded).

Measures

Social participation.

Participants were asked if their health ever kept them from participating in four major social activities in the past month, including: (1) visiting in person with friends or family; (2) attending religious activities; (3) going out for enjoyment (examples: going out to dinner, movie, gamble, concerts, or plays); and (4) participating in clubs, classes, or other organized activities. Each question was followed up by a question about the importance of the activity (i.e., very important, somewhat important, and not so important) (Kasper & Freedman, 2012). Participants were considered to have SPR if they reported restriction in one of the aforementioned activities, and it was rated as “somewhat important” or “very important”. This dichotomous summary of SPR was developed and validated by Freedman et al. (2011).

Demographics and characteristics.

Age and sex were extracted from the Medicare enrolment files and confirmed at the NHATS interviews. Participants were asked to identify their race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and others), marital status, the highest level of education attained, and income. Interviewers identified the participant’s residence type as a traditional community housing or residential/assisted-living housing based on observation and asking the participants whether their house was part of a facility or not. Traditional community housing was defined as private residences such as freestanding houses. Residential/assisted-living housing was identified in two ways: (1) if the participant lived in a multi-unit building or a retirement community and indicated that the place he/she lived at had areas they can move to if care is needed or (2) if the

participant lived in a freestanding or attached home and reported living in a “group home/board and care/supervised housing” or “assisted living facility or continuing care retirement community” (Kasper & Freedman, 2012, p. 17). The study participants were the preferred respondents for the interview questions; however, a proxy respondent answered the interview questions when the participant was unable to respond due to health, memory problems, or language barrier. The proxy respondent needed to be familiar with the participant’s health, daily routine, and care.

Medical conditions and symptoms.

Participants reported if they ever received a medical diagnose of arthritis, osteoporosis, hip fracture (since age 50), cancer, myocardial infarction, diabetes, stroke, dementia, or others. The total number of medical conditions was used in this current analysis rather than the specific conditions. The Body Mass Index (BMI) was calculated using the measured weight and height with 4-BMI categories defined according to accepted standards (< 18.5 , $18.5-24.99$, $25.00-29.99$ and, ≥ 30). Obesity was defined as $BMI \geq 30 \text{ kg/m}^2$ (National Institutes of Health, National Heart Lung, & Blood Institute, 1998). Participants were asked if they had fallen in the past month (response categories: yes/no), if they had low energy in the last month or if they were easily exhausted (response categories: yes/no), and if they were bothered by pain in the last month (response categories: yes/no). These measurements of falls, fatigue, and bothersome pain were operationalized and validated in previous studies (Patel et al., 2013; Patel et al., 2019; Patel et al., 2014). Lastly, participants reported on their sleep quality using a series of questions. They reported how often it took them more than 30 minutes to fall asleep at night and how often they had trouble falling back asleep on nights they woke up. Response categories were every night, most nights, some nights, rarely, and never. Participants were considered to have sleeping

difficulties if they answered “every night”, “most nights” or “some nights” to at least one of the questions. This method of defining sleep problems is consistent with sleep problem definition in prior studies (Leggett, Polenick, Maust, & Kales, 2018; Patel et al., 2019).

Physical functioning.

The Short Physical Performance Battery (SPPB) was used to measure physical functioning. The SPPB is a widely used physical capacity measure of lower-extremity function in older adults. It consists of 3 components: (a) balance, (b) gait speed, and (c) chair stand testing (Guralnik, Ferrucci, Simonsick, Salive, & Wallace, 1995; Guralnik et al., 1994). For balance assessment, participants were asked to stand with their feet together (side-by-side) for 10 seconds. If they were able to complete the side-by-side test, they were asked to perform a semi-tandem stand (the heel of one foot touching the big toe of the other foot) for 10 seconds. If they were able to complete the semi-tandem test, participants were asked to perform and maintain a tandem stand (the heel of one foot in front and touching the big toe of the other foot) for 10 seconds. Gait speed was assessed by asking the participant to walk 3 meters (from a standing start) at his/her usual speed. Participants were allowed to use their walking aids during the test. This test was performed twice, and only the faster trial was analyzed. The last component of the SPPB was chair stands. Each participant was asked to rise from a chair and return to the seated position with his or her hands folded over their chest for 5 times. The examiner recorded the time needed to complete 5 chair stands. Each test was scored on a scale from 0 to 4 with 0 indicating the inability to perform the test and 4 indicating the highest performance. The final score of the SPPB is the sum of the three test scores, ranging from 0 to 12 with higher values indicating better lower extremity function. The SPPB has acceptable psychometric properties (Guralnik et al., 1994; Kasper, Freedman, & Niefeld, 2012; Ostir, Volpato, Fried, Chaves, & Guralnik, 2002).

Current literature supports the use of SPPB as an indicator of physical functioning as it has been shown to be a powerful predictor for older adults' hospitalization, disability, and mortality (Cooper, Kuh, & Hardy, 2010; Guralnik et al., 1995; Guralnik et al., 1994; Studenski et al., 2011).

Cognitive function and depressive symptoms.

Cognitive function was measured by assessing memory and orientation. Memory was assessed using word recall tests. Ten common words were read aloud to the participants, and they were asked immediately to list as many as they can remember. After approximately 5 minutes, they were asked to list the same 10 words. Orientation was tested by asking participants to list the date, month, year, day of week, the name of the current U.S. President, and the name of the Vice President. The final score for cognitive function was the sum of the 3 subtests. The score ranged from 0 to 24 with 10 points for immediate recall, 10 points for delayed recall, and 4 points for orientation. A higher score indicates higher cognitive performance (Kasper & Freedman, 2012). Depressive symptoms were assessed using two questions from the Patient Health Questionnaire -2. Participants were considered to have depressive symptoms if their score was ≥ 3 (Kroenke, Spitzer, & Williams, 2003).

Statistical Analysis

In the current study, all analyses including the estimation for SPR prevalence were performed using Stata version 14.2 (StataCorp, 2015). Analytical weights were used to account for survey nonresponse and oversampling of adults age ≥ 90 years and Black non-Hispanic older adults (Montaquila, Freedman, Spillman, et al., 2017). Variance estimates [95% Confidence Intervals (CI)] were calculated using a Taylor series linearization that incorporated the complex sample design of the survey. For all analyses, $P < 0.05$ was considered statistically significant.

Adjusted Wald statistics were used to test differences in SPR prevalence across demographic and participant characteristics (Table 2). Survey commands were used to calculate weighted frequencies of restriction in specific activities and the total number of activity restriction (Tables 3 and 4). Poisson regression was used to estimate the association of SPR with housing type. The first model was adjusted for age, sex, ethnicity, marital status, income, and reporting status. The second model was additionally adjusted for the total number of health conditions, falls, BMI, fatigue, pain, and sleep quality. ; The third model was also adjusted for physical functioning and cognition (Table 5). Poisson regression was used to assess the association between SPR and physical functioning. The first model was an unadjusted model. The second model adjusted for age, sex, ethnicity, marital status, income, reporting status, total number of chronic conditions, bothersome pain, obesity, sleep problems, and fatigue. The third model was additionally adjusted for cognition (Table 6). Age was used as a categorical variable because the NHATS public data file only provides researchers with the age category of the participants and not their birthdates to protect their identity.

As expected, proxy respondents reported higher rates of SPR than the study participants themselves. Therefore, all final regression models were adjusted for reporting status.

Results

The final sample size was 7,492, representing 40.7 million older adults aged 65 years and older in the U.S. The overall prevalence of SPR in the last month was 17.0% (95% CI: 16.0-18.0%), affecting 6.9 million older adults in the U.S. Table 2 shows the distribution of SPR according to major demographic and health characteristics. SPR prevalence increased with advancing age ($P < 0.001$) and was higher in women (21.4%) than in men (11.4%) ($P < 0.001$). The SPR prevalence in adults 90 years and older was more than double the SPR prevalence in

the age group of 65-69 years. SPR prevalence was the highest in non-Hispanic Black older adults in comparison to other race/ethnicities. There was a decrease in SPR prevalence with higher levels of education and income. Older adults living in residential/assisted-living housing had a higher SPR prevalence in comparison to those who were living in traditional community housing ($P < 0.05$). Older adults who were obese ($BMI \geq 30$) and older adults who were underweight ($BMI < 18.5$) had higher SPR prevalence than older adults in the normal weight and overweight groups ($P < 0.001$). SPR prevalence was higher in older adults with depressive symptoms ($P < 0.001$) and those who reported bothersome pain ($P < 0.001$). A linear increase of SPR prevalence was observed with an increase in the total number of medical conditions ($P < 0.001$).

Table 2: Prevalence of Social Participation Restriction According to Demographic and Health Characteristics in Adults 65 years and Older in the United States: National Health and Aging Trends Study, 2015

Characteristics	No.in the United States with SPR	% Prevalence of SPR (95%CI)
Total in the older adults population	6,899,000	17.0 (16.0-18.0)
Age**		
65-69 years	1,648,000	13.8 (11.5-16.5)
70-74 years	1,468,000	13.5 (11.7-15.6)
75-79 years	1,247,000	16.4 (14.3-18.7)
80-84 years	1,104,000	21.5 (19-24.2)
85-89	872,000	26.4 (22.9-30.2)
≥ 90 years	559,000	30.1 (26.7-33.6)
Sex**		
Men	2,074,000	11.4 (10.1-12.8)
Women	4,824,000	21.4 (19.9-23.0)
Race/Ethnicity*		
Non-Hispanic White	5,243,000	16.6 (15.4-17.7)
Non-Hispanic Black	665,000	20.1 (18.1-22.2)
Hispanic	509,000	17.7 (14.0-22.2)
Other	481,000	16.9 (12.7-22.0)
Education*		
<9 years	455,000	20.8 (16.6-25.9)
9-11 years	399,000	17.4 (13.1-22.7)
High school graduate	1,341,000	19.0 (16.7-21.6)

Some college/vocational	1,235,000	15.1 (12.8-17.8)
College degree	681,000	16.3 (13-20.3)
Masters or professional degree	356,000	9.7 (7.5-12.5)
Income \$*		
<15,000	4,626,000	17.3 (16.1-18.5)
15,000-29,999	919,000	22.1 (18.7-25.9)
30,000-59,999	790,000	17.0 (14.1-20.3)
>60,000	564,000	11.1(8.48-14.4)
House Type*		
Community	6,409,000	16.5 (15.5-17.5)
Assisted Living	490,000	25.9 (21.0-31.6)
BMI*		
<18.50	650,000	18.1 (12.0-25.7)
18.50-24.99	9,879,000	17.4 (15.8-19.1)
25.00-29.99	12,537,000	14.3 (12.6-16.1)
≥ 30	10,050,000	19.1 (17.5-20.9)
Pain in the last month **		
Yes	5,340,000	24.4 (23.1-25.7)
Depressive symptoms**	1,834,000	36.8 (33.6-40.1)
Total No. of medical conditions**		
0	267,000	6.2 (4.5-8.6)
1	705,000	8.3 (6.7-16.2)
2	1,579,000	14.2 (12.4-16.2)
3	1,738,000	19.7 (17.6-22.1)
≥4	2,610,000	32.8 (30.1-35.6)

SPR=Social Participation Restriction; CI= Confidence Interval; BMI = Body Mass Index; * = $P < 0.05$; ** = $P < 0.001$

Table 3 shows the frequency and the weighted percentage of restriction in each of the measured social activities. Attending religious activities was the activity with the highest percentage of restriction (10.3%; $n = 965$) followed by visiting family and friends (6.8%; $n = 546$). Table 4 reports the overall weighted percentage of the total number of activity restriction. Among participants who were classified with any SPR approximately half reported restriction in multiple activities. Only 1% reported restriction in all four activities.

Table 3: Prevalence of Social Participation Restriction in the Measured Social Activities

Activity		Frequency	Weighted % (95% CI)
Visiting Family and friends	No restriction	6,924	93 (92.2-93.7)
	Restriction	546	6.8 (6.1-7.5)
	Missing	22	0.2 (0.1-0.4)
Attending religious activities	No restriction	6,505	89.4 (88.5-90.2)
	Restriction	965	10.3 (9.6-11.1)
	Missing	22	0.3 (0.2-0.5)
Going out for enjoyment	No restriction	6,941	93.1 (92.4-93.8)
	Restriction	529	6.6 (5.9-7.3)
	Missing	22	0.3 (0.2-0.5)
Participating in clubs, classes, or other organized activities	No restriction	6,996	94.2 (93.7-94.8)
	Restriction	477	5.6 (5.0-6.0)
	Missing	19	0.2 (0.1-0.3)
Any restriction	No restriction	6,011	83 (82.0-84.0)
	Restriction	1,481	17.0 (16.0-18.0)
	Missing	0	0

CI = Confidence Interval

Table 4: Total Number of Restricted Social Activities

Total number of activity restriction	Frequency (weighted%)
0	6,053 (83.0%)
1	816 (9.1%)
2	384 (4.5%)
3	191 (2.4%)
4	90 (1.0%)

There was no association between housing type and SPR after adjusting for possible confounding variables ($P = 0.31$). The association of SPR with SPPB scores remained significant [Model 3: PR: 0.90 (95%CI, 0.88-0.92)] after adjusting for demographics, reporting status, BMI, the total number of medical conditions, depressive symptoms, pain, sleep problems, and fatigue

(Table 6). According to Model 3, every one-unit increase in the SPPB decreases the likelihood of SPR by 10%. Figure 2 illustrates that participants with a SPPB score < 4 comprise the largest proportion of those with SPR. In contrast, the participants with SPPB scores 10-12 comprise the largest proportion of those with no SPR.

Table 5: Association of Social Participation Restriction and Housing Type

	Model 1 PR (95% CI)	Model 2 PR (95% CI)	Model 3 PR (95% CI)
Housing type			
Residential assisted-living	1.01 (0.82-1.26)	1.08 (0.91-1.30)	0.89 (0.71-1.12)
<i>P</i> value	0.86	0.37	0.31

PR=Prevalence Ratio; CI=Confidence Interval

Model 1 was adjusted for age, sex, race/ethnicity, marital status, income, education, and reporting status

Model 2 was additionally adjusted for chronic health conditions, falls, BMI, fatigue, pain, and sleep quality

Model 3 was additionally adjusted for physical functioning and cognition problems

Table 6: Association of Social Participation Restriction and Short Physical Performance Battery in adults 65 years and older

	Model 1 PR (95% CI)	Model 2 PR (95% CI)	Model 3 PR (95% CI)
SPPB			
Per 1 unit of SPPB score	0.85 (0.84-0.86)	0.85 (0.84-0.86)	0.90 (0.88-0.92)
<i>P</i> value	< 0.001	< 0.001	< 0.001

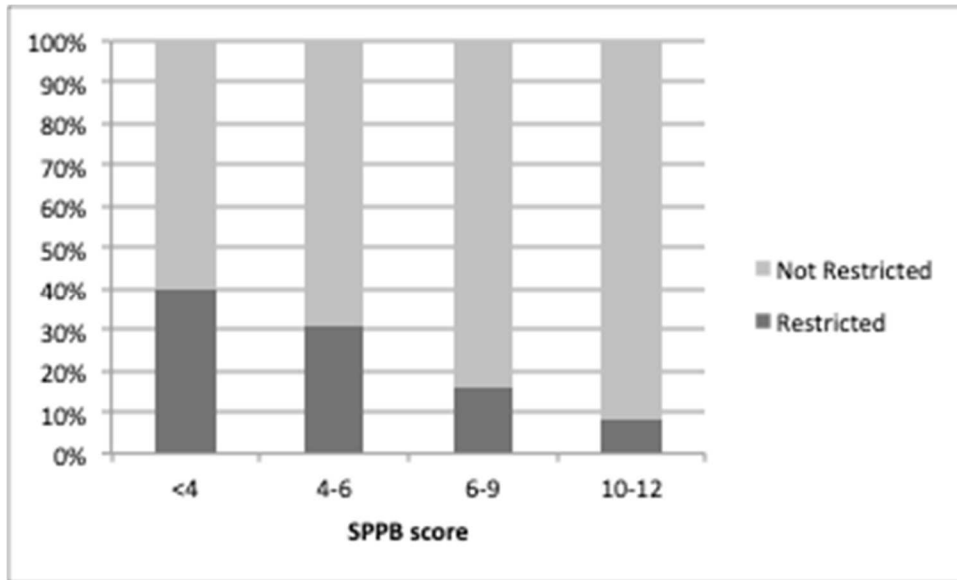
PR= Prevalence Ratio; CI=Confidence Interval

Model 1 was unadjusted

Model 2 was adjusted for age, sex, income, race/ethnicity, marital status, income, education, reporting status, comorbidity, pain, obesity, sleep problems, fatigue

Model 3 was additionally adjusted for cognition problems

Figure 2. Distribution of Social Participation by Short Physical Performance Battery



Discussion

This study found that an estimated 6.9 million community-dwelling older adults in the contiguous U.S. reported SPR in 2015. A linear increase in SPR was observed with advancing age with women reporting higher SPR rates than men. Non-Hispanic black older adults were more likely to report SPR. Higher socioeconomic status, as measured by education and income, was associated with lower rates of SPR. Unadjusted comparison of SPR according to housing type showed that older adults living in residential/assisted-living housing reported higher SPR. However, this association did not hold after adjusting for demographic and health characteristics. Lastly, worse physical functioning was associated with SPR.

The overall estimated SPR prevalence of 17.0% in this study was higher than the estimated SPR prevalence of 13.6% found by Wilkie et al. (2006) as measured by the KAP. This is likely explained by the younger population (50+ years) in the Wilkie et al. (2006) study in comparison with the population in this study. Consistent with prior studies, SPR increased with advancing age and was higher in women than in men (Agahi et al., 2006; Bukov et al., 2002; Desrosiers et al., 2004; Desrosiers et al., 2009; Gagliardi et al., 2007; Griffin & McKenna, 1999;

James, Boyle, et al., 2011; Wilkie et al., 2006). Higher mortality rates in older men, higher disability rates in women, and lower disability recovery rates in women likely explain the sex differences in SPR (Gill, Gahbauer, Lin, Han, & Allore, 2013). Another possible explanation is the education and income gap between men and women over the past decades (Bobbitt-Zeher, 2007). This gap puts many women in lower socioeconomic status, which was associated with SPR (Lindström, Hanson, & Östergren, 2001). Furthermore, the caregiving burden that is higher in women might be reducing the opportunities for women to go out and enjoy social activities (Chappell, Dujela, & Smith, 2015).

Analyzing the restriction in each measured activity revealed that attending religious activities had the highest rates of restriction. Numerous factors might be playing a role in this high restriction rate. First, many environmental factors can play a role in participation in religious activities such as the availability of transportation and the accessibility of the building. Second, religious activities are often held according to fixed schedule (often in the morning time), which might mean that older adults need to adjust their morning routines to be able to participate in those activities. The results of this study clearly point out that high restriction prevalence in attending religious activities, warranting further investigations into the barriers and factors that hinder older adults from attending religious activities. In contrast, participating in “clubs, classes, or other organized activities” was the activity with least restriction according to this analysis. At the first glance, it seems that the demands for attending organized activities are very similar to the demands of attending religious activities (i.e., fixed schedules and transportation). This difference may reflect that older adults value participating in religious activities more than participating in clubs, classes, or other organized activities. Alternatively, attending religious services typically requires driving, whereas other social activities can be

carried out at home or a nearby setting. Furthermore, attending religious activities are more likely to be long-standing habitual activities for older adults, while the various clubs, classes, or other organized activities may be newer in their lives.

A growing body of literature has focused on the value of religious activities in older age. For example, a qualitative study in 17 different assisted-living facilities found that older adults use religious activities to maintain identity, relief of emotional strains, to increase socialization, to provide a sense of purpose, and to prepare for death. Furthermore, older adults used religious activities to socialize with both family friends and church friends. Older adults reported that they maintained contact with many family members through attending religious activities. At the same time, they identified a number of barriers for attending religious activities including physical discomfort (i.e., hard benches), unavailability of caregivers, specific impairments (i.e., vision problems), transportation availability, and the unavailability of religious facility programs that are appropriate for older adults (Patterson, King, Ball, Whittington, & Perkins, 2003).

Contrary to the second study hypothesis, there was no association between SPR and housing type after adjusting for demographic and health characteristics. Freedman et al. (2011) also showed no significant association between SPR and housing type. Older adults living in residential/assisted-living housing are on average 85 years or older, predominantly women, have at least two medical conditions, and need assistance in one or more activities of daily living (Caffrey et al., 2012). Thus, it was expected that those who live in residential/assisted-living housing would have significantly higher rates of SPR. This study finding might indicate that the social opportunities and services (i.e., transportation) provided by residential/assisted-living housing are fulfilling their mission of bridging the gap in SPR between their residents and those who live in traditional community housing. Accordingly, it is important to study the

effectiveness and reach for such programs and start exploring how those programs can accommodate the expanding population of older adults.

Consistent with prior studies, physical functioning had a significant association with SPR above and beyond demographics, health characteristics, symptoms, housing type, and cognition (Anaby et al., 2009; Mendes De Leon & Rajan, 2014; Rosso et al., 2013). A subgroup of interest was identified in figure 2, i.e., the older adults who had a SPPB score < 4 , but were still participating in valued social activities. This finding indicates that, even with the progressive association between SPR and worse physical functioning, many are still able to maintain participating in valued social activities. Future studies that investigate what factors facilitate the continued participation of this group could add to our understanding of SPR.

Strengths and Limitations

Several strengths and limitations should be considered when interpreting these study results. First, only four major categories of SP were examined. Although there are likely other social activities not included in the NHATS questionnaire, the four categories capture a wide range of social activities. The NHATS items that were used to measure SPR demonstrated good test-re-test reliability, construct validity, and face validity (Freedman et al., 2011). The definition of SPR used assessed not only a broad range of social activities, but also specifically assessed whether health interfered with these activities and whether participants found these activities meaningful or important. In addition to the measurement strengths of SPR, the NHATS collects information on a wide range of other health and functional tasks that are valuable for investigating SPR. The robust sampling methods and the generalizability of the study results are other major strengths of this study. Finally, the comprehensive study protocol allowed for adjusting the regression models to many confounding variables.

On the other hand, the cross-sectional nature of this study limits our ability to test causality and longitudinal changes in SPR. Although the study sample generalizes to older adults enrolled in the Medicare program, it does not represent uninsured or undocumented older adults in the U.S. It also does not represent those who live in Alaska, Hawaii, and Puerto Rico. Moreover, the study results cannot be generalized to older adults who live in nursing homes who were not asked the SP question and, therefore, not included in the analysis. Presumably the prevalence of SPR is high in the nursing home population. Lastly, the BMI data was not adjusted for sex and age; therefore, the BMI categories used in this study might have a higher margin of error.

Conclusion

This is the first nationally representative study that estimated the overall prevalence of SPR in the U.S. This study highlights the large number of community-dwelling older adults who might benefit from programs that are designed to improve SPR. Moreover, it identifies women, older adults 85+ years, Non-Hispanic blacks, individuals with lower socioeconomic status, and individuals with depressive symptoms and bothersome pain as more vulnerable to SPR. Identifying the characteristics of older adults who will most likely have SPR can support efforts to develop and refine programs that target improving older adults' SP.

Chapter 3. Recovery and Incidence of Social Participation Restriction in Community-dwelling Older Adults in the United States

Abstract

Objectives: To determine social participation (SP) change among community-dwelling older adults in the United States over a one year period through determination of the incidence and recovery rates of social participation restriction (SPR) and their correlates.

Methods: The study sample was a nationally representative sample of 7,492 Medicare beneficiaries from the National Health and Aging Trends Study (NHATS) (Round 5 and 6). Poisson regression was used to determine the factors associated with SPR incidence and recovery.

Results: The one-year incidence rate of developing SPR was 10.5% (95% Confidence Interval [CI]: 9.7-11.3), and the rate of SPR recovery was 39.9% (95% CI: 36.7-43.1). SPR incidence was associated with more self-reported medical conditions, worse physical functioning, self-reported fatigue, worse cognitive functioning, and bothersome pain. SPR recovery was associated with reporting no bothersome pain and better physical functioning.

Discussion: A considerable proportion of older adults move in and out of SPR at one-year follow-up. The identified SPR incidence risk factors can help healthcare providers identify those who are vulnerable to developing SPR and provide them with services and resources that can support continued participation.

Introduction

Social Participation Restriction (SPR) is defined as a problem experienced by an individual in the “involvement in activities that provide interaction with others in society or the community” (Levasseur et al., 2010, p. 10). SPR is associated with increased risk of mortality and reduced quality of life (Holt-Lunstad et al., 2010; Law, 2002; Levasseur et al., 2004). SPR is common among older adults with a prevalence rate of 17.0% according to a recent U.S. nationally representative study (Jarrar, 2019). SPR is considered a modifiable health outcome and a key aspect of successful aging (De Leon, 2005; Holt-Lunstad et al., 2010; Levasseur et al., 2010; Rowe & Kahn, 1997).

Cross-sectional studies investigating SPR have found that SPR is associated with advancing age and being a woman (Desrosiers et al., 2004; Desrosiers et al., 2009; Gagliardi et al., 2007; Griffin & McKenna, 1999; Ishikawa et al., 2006; Jarrar, 2019; Wilkie et al., 2006). Furthermore, many studies have reported that SPR is correlated with depressive symptoms, presence of pain, cognitive decline, and lower physical functioning (Anaby et al., 2009; James, Wilson, et al., 2011; Jarrar, 2019; Mendes de Leon & Rajan, 2014; Rosso et al., 2013). Longitudinal studies have expanded on the cross-sectional findings by showing that SPR is correlated with decline in motor function (Buchman et al., 2009). Further, a longitudinal study over 13 years found that participation in religious activities, going out to museums, and participation in activities or groups outside the home were associated with a decreased risk of developing disabilities in activities of daily living (ADL) and instrumental activities of daily living (IADL) (Mendes De Leon & Rajan, 2014).

The available evidence on SPR and its correlates has been expanding steadily in the past two decades, but there are still many gaps and limitations. Most available studies on SPR are

within narrow populations (i.e., geographically and age range), and conducted outside the U.S. The areas with most ambiguity in SPR literature are the patterns of SPR change over time, SPR incidence rates, and SPR recovery rates. One study found that SPR incidence at three-year follow-up in adults 50 years and older in the United Kingdom was 10.1% as measured by the Keel Assessment of Participation (KAP). Wilkie et al. (2008) showed that SPR incidence increased with advancing age and in women. This study expanded on current literature by providing evidence on SPR change over time in older adults; however, no risk factors beyond demographic were discussed. To our knowledge, no studies have estimated SPR recovery rate in older adults in the U.S or internationally.

To better understand the etiology of SPR, it is essential to estimate SPR incidence and recovery together with identification of SPR risk factors. This need will become even more significant as the numbers of older adults with SPR increases as the proportion of the older adult population increases (Institute of Aging, 2018). Furthermore, better understanding of SPR in older adults can provide perspective on the potential need for effective interventions to improve SPR. Developing and delivering programs to improve access to social participation (SP) opportunities and increase SP have been challenging because the key risk factors associated with SPR incidence are yet to be identified. Identifying the key risk factors associated with SPR incidence could assist healthcare professionals in screening older adults who are at risk of developing SPR. At the same time, understanding the factors correlated with recovery can help in developing programs to facilitate older adults' SP.

This study sought to determine the SPR incidence and recovery among community-dwelling older adults in the contiguous U.S. The first aim was to determine the rate and risk factors of SPR incidence at one-year follow-up in older adults in the U.S. SPR incidence was

defined as the proportion of older adults who reported SPR at one-year follow-up among those who did not report SPR at baseline. It was hypothesized that more than 10% of older adults will develop SPR at one-year follow-up and that SPR incidence would be associated with older age, being a women, lower physical functioning, and living in residential/assisted-living housing. The second aim was to determine SPR recovery rate at one-year follow-up and SPR recovery rate correlates in older adults in the U.S. The SPR recovery rate was defined as the proportion of older adults who do not report SPR at one-year follow-up among those who reported SPR at baseline. It was hypothesized that more than 10% of older adults would recover from SPR at one-year follow-up and that SPR recovery would be associated with younger age, being male, better physical functioning, and living in traditional community housing.

Methods

The current study is an analysis using data from Rounds 5 (collected in 2015) and 6 (collected in 2016) of the National Health and Aging Trends Study (NHATS) public dataset. The NHATS study is funded by the U.S. National Institute on Aging, National Institutes of Health (Kasper & Freedman, 2012). Johns Hopkins University Institutional Review Board approved the study protocol (Kasper & Freedman, 2012). The University of Washington Institutional Review Board deemed the current study exempt because NHATS consists of publically available non-identifiable data.

Study Design and Population

The NHATS annual data collection began in 2011 (Round 1) with sample replenishment in 2015 (Round 5). In 2011, three-stage sampling was used to recruit 8,245 out of 12,411 eligible participants with a 71% response rate. In 2015, the sample was replenished, resulting in 4,182 (50.1%) new participants in addition to 4,152 from the original sample (74% overall weighted

response rate). The overall weighted response rate in 2016 was 88.5% (Freedman et al., 2011; Montaquila et al., 2017). See Montaquila et al. (2017) for more information on the three-stage sampling and dataset replenishment. In the initial rounds (2011 and 2015) nursing home residents were not eligible for the interviews. However, all participants were included in the follow-up interviews in the subsequent rounds even if they had moved to a nursing home. Only community-dwelling older adults, including those who were living in traditional community housing and those who were living in residential/assisted-living housing, with complete data on SP in Round 5 were included in this study, resulting in a sample of 7,492 (504 living in nursing homes and 42 missing data on SP excluded). More information on NHATS study procedures can be found at www.nhats.org (Kasper & Freedman, 2012).

Measures

All of the self-report measures used in this analysis were developed and validated by experienced researchers from the fields of demography, geriatric medicine, epidemiology, health services, economics, and gerontology (Freedman et al., 2011). Standard physical and cognitive performance measures were collected to complement the self-report data. Trained survey research staff collected the study data through in-person interviews in the study participants' homes (Kasper & Freedman, 2012).

Social participation.

Participants were asked if their health ever prevented them from participating in four different social activities in the past month using a dichotomous scale (yes/no), including: (1) visiting in person with friends or family, (2) attending religious activities, (3) going out for enjoyment (examples: going out to dinner, movie, gamble, concerts, or plays), and (4) participating in clubs, classes, or other organized activities. Each question was followed by

another question about the importance of the activity (very important, somewhat important, and not so important) (Freedman et al., 2011; Kasper & Freedman, 2012). SPR was defined as reporting activity restriction in at least one of the social activities that was rated as “somewhat important” or “very important”. This summary SPR score was developed and validated by Freedman et al. (2011).

For the purposes of this study, SPR incidence was defined as the proportion of older adults who reported SPR at one-year follow-up in 2016 among those who were not socially restricted in 2015. SPR recovery was defined as the proportion of older adults who reported no restriction at one-year follow-up in 2016 among those who were socially restricted in 2015.

Demographic and characteristics.

Age and sex were extracted from the Medicare enrolment file and confirmed in the interviews. Participants were asked to identify their race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and other), marital status, highest educational level attained, and income. The research staff identified the participant’s housing type during the interview as a traditional community housing or residential/assisted-living housing. Traditional community housing was defined as a private residence such as a freestanding house, while residential/assisted-living housing was defined as a residence that is part of a community/facility with an area the participant can move to if care is needed (Kasper & Freedman, 2012). Group home/board and care/supervised housing were considered residential/assisted-living housing. If a study participant was not able to respond to the interview questions, a proxy respondent, who was familiar with the participant’s health, daily routine, and care, was surveyed. The proxy respondents were included in this study to avoid selection bias (Skolarus et al., 2010).

Medical conditions and symptoms.

The total number of chronic medical conditions a participant reported including arthritis, osteoporosis, hip fracture (since age 50), cancer, myocardial infarction, diabetes, stroke, dementia, or others was used in the analysis. The Body Mass Index (BMI) was calculated using the measured weight and height with 4-BMI categories and obesity were defined according to accepted standards. BMI categories were < 18.49 , $18.5-24.49$, $25-29.99$, and ≥ 30 , and obesity was defined as $\text{BMI} \geq 30 \text{ kg/m}^2$ (National Institutes of Health et al., 1998). Additionally, participants reported if they had fallen in the past month (yes/no), if they had low energy in the last month or if they were easily exhausted (yes/no), and if they were bothered by pain in the last month (yes/no). This method of defining falls, fatigue, and bothersome pain is consistent with other studies (Patel et al., 2013; Patel et al., 2019; Patel et al., 2014). Finally, participants reported on their sleep quality using a series of questions. Participants were asked how often it took them more than 30 minutes to fall asleep at night and how often they had trouble falling back asleep on nights they woke up. Response categories were every night, most nights, some nights, rarely, and never. Participants were considered to have sleeping difficulties if they answered “every night”, “most nights” or “some nights” to at least one of the questions. This method of defining sleep problems is consistent with sleep problem definition in prior studies (Leggett et al., 2018; Patel et al., 2019).

Physical functioning.

The Short Physical Performance Battery (SPPB) was used to measure physical functioning in this study. The SPPB is a widely used physical capacity measure to assess lower extremity function in older adults. It consists of three components: balance test, gait speed test, and chair stand testing (Guralnik et al., 1995; Guralnik et al., 1994). For balance assessment, participants were asked to stand with their feet together (side-by-side) for 10 seconds. If the participants were

able to complete the side-by-side test, they were asked to perform and maintain a semi-tandem stand (the heel of one foot touching the big toe of the other foot) for 10 seconds. If the participants were able to complete the semi-tandem stand, the participants were asked to perform and maintain a tandem stand (the heel of one foot in front of and touching the big toe of the other foot) for 10 seconds. In the gait speed assessment, participants were asked to walk three meters from a standing start at their usual speed. Participants were allowed to use their walking aids during the test. This test was performed twice and only the faster trial was recorded. For the timed chair stands assessment, participants were asked to rise from a chair and return to the seated position with their hands folded over their chest for five times. Each test was scored on 0 to 4 scale with 0 indicating the inability to perform the test and 4 indicating the highest performance. The final score of the SPPB is the sum of the three test scores. It ranges from 0 to 12 with higher scores indicating better lower-extremity function. The SPPB has acceptable psychometric properties (Guralnik et al., 1994; Kasper et al., 2012; Ostir et al., 2002). The balance test, gait speed test, and the timed chair stands have been found to be powerful predictors of older adults' hospitalization, disability, and mortality (Cooper et al., 2010; Guralnik et al., 1995; Guralnik et al., 1994; Studenski et al., 2011).

Cognitive function and depressive symptoms.

Cognitive function was measured by assessing immediate and delayed 10 word recall; orientation to day, date, month, and year; and naming the current U.S. President and Vice President. The cognitive function final score ranged from 0 to 24. The final score is the sum for the items mentioned above with 10 points for immediate recall, 10 points for delayed recall, and 4 points for orientation (Kasper & Freedman, 2012). Depressive symptoms were assessed using

two screening questions from the Patient Health Questionnaire -2 (PHQ-2). A participant was considered to have depressive symptoms if their PHQ-2 score was ≥ 3 (Kroenke et al., 2003).

Statistical Analysis

All analyses were performed using Stata Crop 14.2 (StataCorp, 2015). All analyses were weighted to account for survey nonresponse and oversampling of adults aged greater than 90 years and black persons (Montaquila et al., 2017). Variance estimates [95% Confidence Intervals (CI)] were calculated using a Taylor series linearization. For all analyses, $P < 0.05$ was considered statistically significant.

Four SPR groups were defined according to the change in SPR between 2015 and 2016. Group 1 represents the participants who stayed restricted in 2015 and at one-year follow-up. Group 2 represents the participants who recovered from restriction (i.e., they were restricted in 2015, but not at one-year follow-up). Group 3 represents the participants who developed restriction (i.e., those participants who were not restricted in 2015, but reported restriction at one-year follow up). Group 4 represents the participants who did not report restriction in either 2015 or 2016.

Incidence and recovery data are presented in Table 7, along with the percentage of participants who were lost to follow-up or deceased. Wald statistics were used to calculate differences in SPR change at one-year follow-up (Table 7). Survey commands were used to calculate weighted frequencies of SPR change at one-year follow-up in each measured social activity according to the defined groups (Table 8). Sample characteristics were stratified by SPR groups and presented in Table 9. Adjusted Wald statistics were used to test the differences in SPR groups across participants' demographics and characteristics.

Rate Ratios (RRs) and 95% CIs were estimated using Poisson regression to model the association of SPR incidence at one-year follow-up with possible risk factors (Table 10). Model 1 presents 10 separate models that assess the unique association of SPR incidence with each of its risk factors. The tested risk factors were housing status, obesity, depressive symptoms, pain, fatigue, sleep problems, history of falls, physical functioning, cognitive functioning, and the total number of medical conditions. Each model was adjusted for age, sex, race/ethnicity, marital status, education, and reporting status. All risk factors along with demographics were entered into one model and presented in model 2. Similarly, RRs and 95% CIs were estimated using Poisson regression to model the association of SPR recovery at one-year follow-up with possible correlates (Table 11). Model 1 presents 10 separate models that assess the unique association of SPR incidence with each of its correlates. The tested correlates were housing status, obesity, depressive symptoms, pain, fatigue, sleep problems, history of falls, physical functioning, cognitive functioning, and the total number of medical conditions. Each model was adjusted for age, sex, race/ethnicity, marital status, education, and reporting status. All correlates along with demographics were entered into one model and presented in model 2.

Results

There were 7,492 participants included in this study. Table 7 presents the SPR change at one-year follow-up. The overall prevalence of SPR in 2016 was 18.1% (95% CI: 16.9-19.3). The SPR incidence was 10.5% (95% CI: 9.7-11.3), and the SPR recovery was 39.9% (95% CI: 36.7-43.1). Older adults who were restricted at Round 5 were more likely to die, move to a nursing home, or be lost to follow-up than those who were not restricted.

Table 7: Overall Social Participation Restriction Change in 2016

		Round 6		
Restricted	Not	Died	Moved to	Lost to

		restricted		Nursing home		follow-up
Round 5	Total No. (weighted%)	No. (weighted%)	No. (weighted%)	No. (weighted%)	No. (weighted%)	No. (weighted%)
Restricted	1,481 (18.1)	590 (38.7)	572 (39.9)	145 (7.1)	17 (0.9)	157 (13.4)
Not restricted	6,011 (81.9)	699 (10.5)	4,483 (75.2)	218 (2.4)	24 (0.4)	587 (11.6)
Total	7,492					

Note: Participants who moved to nursing homes in Round 6 were asked about social participation; however, there were 41 participants in nursing homes at Round 6 who had missing data

Table 8 displays SPR change according to the four measured social activities. The highest incidence of restriction was in attending religious activities (6.2%), and the least incidence of restriction was observed in participating in clubs, classes, or other organized activities (4.1%). The incidence of restriction was higher than the recovery rate in each activity.

Table 8: Social Participation Change by Each Activity

Activity	Group 1: Stayed restricted	Group 2: Recovered from restriction	Group 3: Developed restriction	Group 4: Never restricted
	No. (weighted%)	No. (weighted%)	No. (weighted%)	No. (weighted%)
Visiting Family and friends	133 (1.9)	283 (4.1)	329 (5.1)	5,557 (88.9)
Attending religious activities	366 (4.6)	386 (5.1)	449 (6.2)	5,098 (84.1)
Going out for enjoyment	116 (1.6)	281 (4.3)	314 (4.9)	5,609 (89.2)
Participating in clubs, classes, or other organized activities	118 (1.7)	252 (3.6)	313 (4.1)	5,630 (90.1)

Table 9 shows the variations in demographic and health characteristics according to the SPR change at one-year follow-up. The group who stayed restricted was older than those who were never restricted. However, there is no apparent difference in age between those who

recovered from SPR and those who developed SPR. Women were more likely to stay restricted or to develop restriction. Among the women in this study, the survey-weighted proportion for SPR change in women was as follow: 10.4% stayed restricted, 12.1% developed SPR, 9.8% recovered from SPR, and 67.6% were never restricted (not shown). SPR status did not vary by race/ethnicity. The proportion of older adults with less education was higher among those who developed SPR in comparison with those who recovered from SPR. The group of older adults who stayed restricted reported less income in comparison to those who were never restricted, but there was no clear difference in income between people who developed SPR and those who recovered from SPR. The proportions of SPR change according to housing type were approximately the same across the different groups. The majority of those who stayed restricted had bothersome pain.

Table 9: Sample Characteristics by Social Participation Restrictions at One-Year follow-up

Characteristics	Group 1: Stayed restricted	Group 2: Recovered from restriction	Group 3: Developed restriction	Group 4: Never restricted	<i>P</i>
	No. (weighted%)	No. (weighted%)	No. (weighted%)	No. (weighted%)	
Weighted total (N)	2,668,620	2,751,655	3,547,087	25,420,570	
Age					< 0.001
65-69 years	61 (26.1)	56 (22.4)	85 (27.0)	672 (30.8)	
70-74 years	94 (19.0)	114 (25.4)	138 (23.3)	1,204 (29.1)	
75-79 years	118 (18.1)	117 (18.5)	124 (16.3)	1,004 (19.2)	
80-84 years	118 (14.6)	115 (15.6)	146 (15.2)	794 (11.5)	
85-89	114 (13.5)	99 (11.2)	127 (12.3)	491 (6.2)	
≥ 90 years	85 (8.6)	71 (6.9)	79 (5.9)	318 (3.2)	
Sex					< 0.001

Men	137 (25.9)	179 (32.4)	237 (35.0)	2,118 (49.5)	
Women	453 (74.1)	393 (67.6)	462 (65.0)	2,365 (50.5)	
Race/Ethnicity					0.104
Non-Hispanic White	380 (76.8)	377 (78.7)	471 (77.7)	3,156 (79.8)	
Non-Hispanic Black	148 (10.1)	140 (9.7)	151 (9.6)	854 (7.3)	
Hispanic	33 (7.3)	34 (6.6)	44 (6.9)	257 (6.8)	
Other	29 (5.7)	21 (5.1)	33 (5.9)	216 (6.1)	
Education					< 0.05
< 9 years	75 (10.9)	77 (9.3)	71 (9.8)	403 (7.1)	
9-11 years	90 (11.4)	58 (8.0)	88 (10.0)	476 (8.3)	
High school graduate	158 (27.7)	150 (26.3)	187 (27.7)	1,157 (24.8)	
Some college/vocational	157 (29.4)	142 (27.5)	180 (27.6)	1,169 (28.6)	
College degree	59 (11.6)	77 (17.5)	73 (9.3)	630 (16.2)	
Masters or professional degree	44 (9.0)	64 (11.4)	90 (15.5)	588 (15.1)	
Income \$					< 0.001
< 15000	414 (69.4)	389 (65.4)	419 (60.3)	3,047 (68.4)	
15000-29000	76 (11.0)	71 (13.6)	105 (12.9)	464 (8.3)	
30000-59999	66 (13.9)	56 (8.79)	96 (13.6)	477 (10.7)	
> 60000	34 (5.7)	56 (12.2)	79 (13.2)	495 (12.6)	
Housing Type					< 0.05
Community	558 (93.9)	530 (93.2)	641 (93.4)	4,289 (96.6)	
Residential/assisted living	32 (6.1)	42 (6.8)	58 (6.7)	194 (3.4)	
BMI					< 0.05
<18.49	13 (2.3)	9 (1.1)	16 (2.3)	74 (1.4)	

18.5-24.49	168 (27.7)	185 (33.2)	199 (27.8)	1,357 (28.9)	
25-29.99	180 (29.9)	178 (31.6)	244 (35.1)	1,683 (38.9)	
≥ 30	212 (40.2)	181 (34.2)	214 (34.8)	1,269 (30.7)	
Depression					< 0.001
Yes	167 (27.8)	123 (21.7)	96 (14.4)	401 (8.1)	
Bothersome pain					< 0.001
Yes	478 (83.0)	394 (70.4)	447 (67.1)	2,137 (46.9)	
Total No. of medical conditions					< 0.001
0	14 (3.4)	27 (5.2)	30 (4.9)	507 (13.0)	
1	43 (7.81)	43 (14.2)	105 (16.9)	1,051 (24)	
2	138 (22)	138 (26.3)	221 (29.2)	1,334 (28.8)	
3	150 (23.8)	150 (26.0)	165 (19.9)	961 (21.0)	
≥4	245 (42.9)	245 (28.3)	178 (29.1)	630 (13.2)	

BMI = Body Mass Index

Table 10 displays the adjusted RRs of SPR incidence and possible risk factors. The tested risk factors were the number of medical conditions, obesity, SPPB, fatigue, depression, cognition, sleep problems, falls in the past month, and housing type. All the unique associations were significant. The RR of SPR with having more than four medical conditions was the highest 3.77 (95% CI: 2.49-5.70), followed by fatigue 2.26 (95% CI: 1.84-1.76). The lowest RR of incidence of SPR was observed with physical functioning 0.88 (95% CI: 0.86-0.91). A follow-up model of SPR incidence was fitted with all the possible risk factors and presented in Table 10 as model 2. The factors that remained significant other than demographics were pain, fatigue, SPPB, and the number of medical conditions.

Table 10: Rate Ratio Estimates for the Incidence of Social Participation Restriction

	Model 1 RR (95% CI)	<i>P</i> Value	Model 2 RR (95% CI)	<i>P</i> Value
Age				
65-69			1.00	
70-74			0.79 (0.62-1.01)	0.05
75-79			0.79 (0.58-1.07)	0.12
80-84			1.00 (0.73-1.34)	0.98
85-89			1.22 (0.92-1.63)	0.15
≥90 years			0.87 (0.59-1.27)	0.47
Sex				
Men			1.00	
Women			1.51 (1.23-1.85)	< 0.001
Race/Ethnicity				
Non-Hispanic White			1.00	
Non-Hispanic Black			1.01 (0.78-1.31)	0.93
Hispanic			0.91 (0.66-1.24)	0.54
Others			0.75 (0.42-1.36)	0.34
Education				
< 9 years			1.00	
9-11 years			0.91 (0.65-1.28)	0.58
High school graduate			0.86 (0.61-1.21)	0.38
Some college/vocational			0.94 (0.65-1.35)	0.71
College degree			0.72 (0.48-1.06)	0.09
Masters or professional degree			1.27 (0.88-1.82)	0.19
Income				
< 15,000			1.00	
15,000-29,000			1.26 (1.00-1.59)	0.05
30,000-59,000			1.27 (1.02-1.57)	0.09

> 60,000			1.38 (1.04-1.83)	< 0.05
Marital status				
Married/living with a partner			1.00	.
Separated/divorced			1.11 (0.84-1.46)	0.45
Widowed			0.83 (0.67-1.02)	0.06
Never married			1.20 (0.76-1.88)	0.42
Reporting Status				
Sample person			1.00	
Proxy			0.87 (0.52-1.45)	0.58
Housing Status				
Traditional community housing	1.00		1.00	
Residential/assisted living	1.39 (1.06-1.82)	< 0.05	1.17 (0.87-1.54)	0.26
Obesity				
No	1.00	< 0.05	1.00	
Yes	1.32 (1.08-1.60)		1.09 (0.90-1.33)	0.37
Depressive Symptoms				
No	1.00		1.00	
Yes	1.55 (1.20-2.00)	< 0.05	0.93 (0.72-1.22)	0.60
Bothersome Pain				
No	1.00		1.00	
Yes	1.99 (1.66-2.39)	< 0.001	1.55 (1.27-1.89)	< 0.001
Fatigue				
No	1.00		1.00	
Yes	2.26 (1.84-1.76)	< 0.001	1.63 (1.33-2.01)	< 0.001
Sleep Problems				
No	1.00		1.00	
Yes	1.45 (1.19-1.76)	< 0.001	1.12 (0.91-1.37)	0.27
Falls				
No	1.00		1.00	
Yes	1.62 (1.25-2.10)	< 0.001	1.19 (0.92-1.55)	0.18
SPPB (1 unit increment)	0.88 (0.86-0.91)	< 0.001	0.93 (0.90-0.96)	< 0.05
Cognition (1 unit increment)	1.14 (1.06-1.22)	< 0.001	1.09 (1.01-1.17)	< 0.05
Total No. of medical conditions				

0	1.00		1.00	
1	1.71 (1.13-2.58)	< 0.05	1.47 (0.94-2.30)	0.09
2	2.21 (1.47-3.34)	< 0.001	1.64 (1.06-2.55)	< 0.05
3	2.04 (1.29-3.22)	< 0.05	1.33 (0.81-2.18)	0.24
≥ 4	3.77 (2.49-5.70)	< 0.001	1.98 (1.21-3.24)	< 0.05

RR= Rate Ratio; SPPB=Short Physical Performance Battery

Under Model 1 all 10 models adjusted for age, sex, race/ethnicity, marital status, education, and reporting status

Table 11 shows the adjusted RRs of SPR recovery and possible associated factors. The tested factors were identical to those tested in the incidence model. There were significant associations with number of the medical conditions, pain, SPPB, and fatigue. SPR recovery was found to be 5% higher with every unit increase in SPPB. A follow-up model of SPR recovery was fitted with all the possible factors and presented as model 2 in Table 11. The factors that remained significant other than demographics were pain and SPPB.

Table 11: Rate Ratio Estimates for Recovery from Social Participation Restriction

	Model 1 RR (95% CI)	P Value	Model 2 RR (95% CI)	P Value
Age				
65-69			1.00	
70-74			1.18 (0.87-1.60)	0.29
75-79			1.09 (0.79-1.51)	0.59
80-84			1.11 (0.79-1.55)	0.55
85-89			0.95 (0.64-1.40)	0.80
≥90 years			1.02 (0.65-1.61)	0.93
Sex				
Men			1.00	
Women			0.91 (0.76-1.10)	0.34
Race/Ethnicity				

Non-Hispanic White			1.00	
Non-Hispanic Black			1.11 (0.94-1.31)	0.21
Hispanic			1.18 (0.87-1.60)	0.27
Others			0.80 (0.53-1.22)	0.30
Education				
< 9 years			1.00	
9-11 years			0.91 (0.63-1.33)	0.64
High school graduate			0.99 (0.76-1.29)	0.95
Some college/vocational			0.93 (0.72-1.23)	0.64
College degree			1.14 (0.84-1.55)	0.38
Masters or professional degree			1.08 (0.97-1.46)	0.62
Income				
< 15,000			1.00	
15,000-29,000			1.24 (1.05-1.46)	< 0.05
30,000-59,000			0.83 (0.66-1.05)	0.12
> 60,000			1.18 (0.95-1.47)	0.14
Marital status				
Married/living with a partner			1.00	
Separated/divorced			1.07 (0.84-1.36)	0.60
Widowed			1.07 (0.87-1.33)	0.49
Never married			0.94 (0.60-1.49)	0.80
Reporting Status				
Sample person			1.00	
Proxy			0.95 (0.64-1.40)	0.78
Housing Status				
Traditional community housing	1.00		1.00	
Residential/assisted living	1.16 (0.88-1.53)	0.28	1.01 (0.70-1.47)	0.93
Obesity				
No	1.00		1.00	
Yes	0.86 (0.74-1.01)	0.07	0.95 (0.80-1.14)	0.60
Depressive symptoms				
No	1.00		1.00	
Yes			1.00 (0.79-1.24)	0.98

Bothersome pain				
No	1.00		1.00	
Yes	0.74 (0.65-0.85)	< 0.001	0.83 (0.71-0.97)	< 0.05
Fatigue				
No	1.00		1.00	
Yes	0.73 (0.61-0.86)	< 0.001	0.85 (0.70-1.03)	0.09
Sleep problems				
No	1.00		1.00	
Yes	0.95 (0.82-1.11)	0.53	0.97 (0.83-1.13)	0.66
Falls				
No	1.00		1.00	
Yes	0.86 (0.73-1.05)	0.15	0.87 (0.71-1.06)	0.16
SPPB (1 unit increment)	1.05 (1.02-1.07)	< 0.001	1.03 (1.01-1.1.06)	< 0.05
Cognition (1 unit increment)	1.00 (0.92-1.05)	0.61	1.03 (0.96-1.10)	0.43
Total No. of medical conditions				
0	1.00		1.00	
1	1.09 (0.81-1.47)	0.55	1.02 (0.76-1.38)	0.89
2	0.95 (0.73-1.23)	0.67	0.93 (0.71-1.20)	0.55
3	0.94 (0.71-1.25)	0.67	0.92 (0.70-1.22)	0.57
≥ 4	0.73 (0.56-0.93)	< 0.05	0.79 (0.60-1.05)	0.11

RR= Rate Ratio; SPPB=Short Physical Performance Battery

Under Model 1 all 10 models adjusted for age, sex, race/ethnicity, marital status, education, and reporting status

Discussion

In this nationally representative sample of Medicare beneficiaries, we demonstrated that SPR is highly dynamic with older adults moving in and out of SPR over a one-year period. This longitudinal analysis builds on a previous study that estimated the prevalence of SPR to be 17.0% among older adults in the U.S. (Jarrar, 2019). In the current study, approximately 1 in 10 older adults developed SPR over one year, while approximately four out of 10 recovered one year later from having SPR at baseline. In addition, the study identified a number of risk factors beyond demographics that are associated with SPR incidence including more medical conditions, worse physical functioning, fatigue, cognitive decline, and bothersome pain. In contrast, recovery was associated with reporting no bothersome pain and better physical functioning.

The evidence of SP change in this study is consistent with previous studies (Sørensen et al., 2002; Wilkie et al., 2008). The estimated SPR incidence of 10.5% is comparable to the 10.1% SPR incidence that was found in adults 50 years and older in the United Kingdom, although the 32.6% SPR persistence rate in that study was slightly lower than the 38.7% persistence rate in this analysis (Wilkie et al., 2008). SPR was measured using the KAP and the follow-up period was three years. This discrepancy in the persistence rate may be because the participants in Wilkie et al. study (2008) were younger than the participants in this analysis. There are no published studies on SPR recovery; however, one study reported on SP change over five years in a cohort of older adults aged 70 years (Sørensen et al., 2002). Sørensen et al., 2002 found that 25% of the men and 29% of the women improved their SP in 5-years follow-up, and 15% of the men and 11% of the women reduced their SP in five years. The proportion of older adults who improved their SP was higher than the proportion of older adults who reported decline in their SP is comparable to our findings of higher SPR recovery than SPR incidence.

To our knowledge, there are no studies to date that have directly explored the association between SPR incidence and SPR recovery correlates. However, there is evidence from previous cross-sectional and longitudinal studies that investigated associations between SPR with risk factors that is consistent with the findings in the current analysis. For instance, many studies have found an association between SPR and worse physical functioning (Anaby et al., 2009; Buchman et al., 2009; Jarrar, 2019; Rosso et al., 2013). SPR was associated with depressive symptoms (Arnadottir et al., 2011; Glass et al., 2006). Similarly SPR was associated with pain and reporting more medical conditions (Jarrar, 2019; Patel et al., 2019). No studies other than this one explored the association of SPR with sleep problems or fatigue. Often, sleep problems and fatigue overlap (Patel et al., 2019). For example, sleep problems can cause tiredness during daytime, which can manifest as difficulty in maintaining SP.

The SPR recovery rate in these analyses is consistent with the recovery rates in other forms of disability (Gill, Allore, Hardy, & Guo, 2006; Gill et al., 2013). This evidence of recovery is especially important because it indicates that SPR is potentially reversible even in the participants 85+ years. The factors that play a role in SPR recovery in community-dwelling older adults are likely to be numerous, and this study analyzed limited factors that contribute to SPR recovery. For example, medical interventions and environmental factors (i.e., transportation) can play a role in SPR recovery. In future studies, it is important to investigate the role of such factors in SPR recovery.

This evidence of SPR recovery highlights that SPR is a dynamic concept with some older adults moving in and out of SPR. This indicates that in most cases, the SPR at baseline was a form of short-term disability due to acute illness and injuries or it was related to traumatic accidents such as falls rather than a permanent form of disability. Accordingly, this recovery rate

might be reflecting the recovery of such conditions rather than improvement in function (Gill, Hardy, & Williams, 2002). On the contrary, the recovery can be a short-lasting recovery, and it will be followed by SPR recurrence.

Previous studies that investigated mobility disability recovery found that the highest rate of recovery often happens within the first six months of onset (Hardy & Gill, 2004). It was not possible to identify the exact timing of SPR in this study. Future studies that focus on identifying the onset of SPR and any related cause can improve our understanding for the process of SPR recovery. Furthermore, the long follow-up period of one year might have caused us to miss meaningful transitions in SPR. Long follow-up periods often contribute to underestimate the incidence and recovery rates (Deeg, 2005). Therefore, a longitudinal study with a shorter follow-up period could contribute to us understanding the dynamic process of SPR better.

Participants who were lost to follow-up, died, or moved to nursing homes in 2016 were more likely to report SPR in 2015. Therefore, it is possible that the SPR incidence rate and SPR persistence (Group 1) were both underestimated. Alternatively, some of the changes in SPR recovery can be contributed to participants restarting an activity while, in other instances, the value of the activity changed from important to non-important.

Strengths and Limitations

There were a number of strengths to this study. We used a nationally representative sample of older adults that provided a wide range of demographic and health data with SP variables that demonstrated good psychometric properties (Freedman et al., 2011). Unlike most of the cross-sectional studies on SP, the longitudinal nature of this study allowed us to examine SPR change over time. However, this study also had many limitations. Causal inferences were difficult to make due to the use of survey methodology. BMI data was not adjusted for sex and

age; therefore, the BMI categories used in this study might have a higher margin of error. This sample is composed of Medicare beneficiaries, and therefore, does not represent undocumented older adults in the U.S., those who remain on employment-related benefits, or those who were born in another country and never qualified for Medicare. Lastly, older adults living in nursing homes were excluded from this study due to the lack of data on SPR and the results cannot be generalized to those individuals.

Conclusion

The study findings suggest that SP in older adults is highly dynamic. Further, the results of this analysis suggest that SPR risk factors can be targeted with interventions to either prevent SPR or promote recovery. Whether more frequent assessments of SPR could provide useful prognostic information is not known, but should be considered in future studies.

Chapter 4. Concluding Statements and Future Directions

Previous literature on SP has mainly focused on studying factors associated with SP, the positive effects of SP, or the negative impact of SPR on older adults. These studies have agreed that, although SP is associated with higher survival rates, better health-related quality of life, and better physical functioning, SP tends to decrease with advancing age. Maintaining participation in valued social activities is of central importance to successful aging (De Leon, 2005).

SP is one of the main components of many operational definitions of successful aging. The other components of operational definitions of successful aging are: (a) physiological indicators (i.e., physical functioning), (b) well being (i.e., life satisfaction), (c) personal resources (i.e., coping), and (d) extrinsic resources (i.e., income) (Cosco, Prina, Perales, Stephan, & Brayne, 2014). For example, Rowe and Kahn (1997, p. 439) define successful aging as a multidimensional concept “encompassing three distinct domains: avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities”. This definition emphasizes that SP is only one component of successful aging. Hence, the association between successful aging and SP is more complex than a unilateral cause and effect relationship. Further, it is possible that this association involves reciprocal effects since many of the successful aging components are also associated with SP (i.e., physical functioning and income).

The precise mechanism on how SP is associated with better health (i.e., physical functioning) is not clear at this time. It is possible that the association between health and SP is mediated by activity gains rather than the social benefits of SP such as social support. However, the empirical studies to date do not support this hypothesis. Most studies support a more complex reciprocal relationship between health and SP in which physiological and psychological

mechanisms are likely involved. It is possible that one of the gains of SP is preserving physical functioning, which in turn supports continued SP (Bath & Deeg, 2005).

SP is often referred to as a modifiable health factor, but it is not clear what interventions can meaningfully change SP in community-dwelling older adults. Self-management and wellness programs have demonstrated potential positive effects on SP in older adults with arthritis. Self-management and wellness programs often use specific curriculum that focuses on problem solving, keeping the body healthy, and introducing medical resources (Peterson Bethea, Lovett, Cooks, & Bell, 2010; Theis, Murphy, Hootman, & Wilkie, 2013). It is not clear if similar programs can benefit older adults with SPR, but it is potentially an important aspect to explore. Moreover, promoting older adults' health should include programs that promote SP to a very advanced age. SP promotion programs are a possibly effective and low cost intervention. It is possible to create SP promotion programs that are low in cost by implementing them in already existing community facilities such as senior centers, and training community members to deliver the programs instead of healthcare professionals. The low cost of the SP promotion programs together with the positive effects on health might contribute to a decrease in health cost.

The many benefits of SP had made it an important health outcome to include as an intervention outcome. However, variety in the conceptualization, definition, and assessment methods of SP remain major barriers to incorporating SP as an intervention outcome. There is little consistency in the definition and usage of SP and SPR as concepts. This inconsistency in the conceptualization and definition is common in emerging areas of research. Many new initiatives are working to bridge this gap such as the social health-working group within the National Institutes of Health Roadmap Initiative. Nevertheless, the heterogeneity in SP definition and measurement should not be taken as a weakness to dismiss the available literature. Rather,

each of the different methods have contributed to establishing associations between health factors and SP, which in turn have established a literature base for future research.

Most health research focuses on SP at the individual level, whereas the socio-cultural context is a feature of SP that is broader than the individual level. The social environment influences SP through shared traditions and norms. Accordingly, understanding the socio-cultural context of SP may contribute to deepening our understanding of SP and allow us to compare SP across different cultures and countries.

Most studies on SP assessed SP that involved participating in activities that provide “real life” social interactions with others. However, the use of social media/social networking websites has been increasing steadily in older adults. In 2012, 67% of U.S. older adults used at least one social networking website (Duggan & Brenner, 2013). Exploring how the use of social media fit within our current understanding for SP might affect SP definitions and measurement methods.

The results of the current dissertation research add to the emerging evidence base on SPR in community-dwelling older adults. Specifically, this dissertation expanded on the current literature by identifying the prevalence of SPR in addition to SPR incidence and SPR recovery at one-year follow-up using the NHATS data from 2015 and 2016.

The first study (Chapter 2) estimated that the overall prevalence of SPR in community-dwelling older adults in the U.S. was 17.0%. SPR increased with advancing age and was higher in females. Non-Hispanic Black older adults reported higher SPR than other races/ethnicities. Moreover, SPR was associated with depressive symptoms, pain, and higher number of medical conditions. SPR did not differ according to housing type after adjusting for demographic and health characteristics. Further, SPR was associated with worse physical functioning as measured by SPPB.

The second study (Chapter 3) estimated that the SPR incidence was 10.5% and the SPR recovery was 39.9% at one-year follow-up. It also found that SPR incidence is associated with numerous risk factors including higher number of medical conditions, bothersome pain, worse physical functioning, fatigue, and cognitive decline. On the contrary, SPR recovery was associated with a no bothersome pain and better physical functioning.

According to the study findings presented in this dissertation, it is estimated that 6.9 million community-dwelling older adults experience SPR at any given time with 3.5 million new cases every year. However, we found that 2.8 million older adults recover from SPR every year. Collectively, these findings contribute to understanding SP in community-dwelling older adults, and they highlight the dynamic nature of SPR. More information is needed on the onset of SPR as it is expected that most of recovery happens on the first six months of restriction. Shorter follow-up periods such as monthly SPR assessment can add to our understanding of SP transitions and SPR recovery.

The reported restriction was highest in participating in religious activities in comparison to the other measured activities. Participating in religious activities also had the highest restriction incidence rate in comparison to the other measured activities. These findings highlight the value of participating in religious activities for the U.S. community-dwelling older adults. The majority of the factors that can influence participation in religious activities are environmental factors including transportation, religious facility programs that are appropriate for older adults, and the comfort of the physical space of the religious facility (Patterson et al., 2003). The studies that investigate such barriers are still limited. Understanding the demands of participating in religious activities would contribute to our understanding of SPR in older adults.

This could also be the first step towards designing programs to facilitate older adults participation in this valued activity.

Future Directions

This dissertation used data from the NHATS 2015 and 2016 rounds. Possible next steps for this body of work would be to extend this analysis to NHATS rounds 2011 to the present. Additionally, NHATS datasets could be used to tackle the following research aims: (1) determining SPR trajectories over multiple data rounds, (2) determining the risk factors of SPR persistence, (3) identifying the characteristics of those who have low physical functioning and yet have no SPR, and (4) studying the effects of transportation on SP.

Future studies beyond the NHATS should focus on:

- Studying the effects of environmental factors such as transportation and accessibility on SP.
- Studying the association between the socio-cultural context and SP.
- Studying how the use of social networking websites/applications fit within the current definitions of SP and how it might change the methods of measuring SP.
- Studying SPR incidence and recovery using monthly assessments.
- Designing SP promotion programs and studying their effects on SP within the community-dwelling older adult population.

The estimates reported in this dissertation represent a starting point and an important contribution to the limited nationally representative data on SP in community-dwelling older adults in the U.S. SPR is common in U.S. community dwelling older adults, but it is highly dynamic. SP may hold a promise to promote the health of older adults; however, more research is needed to facilitate the development of programs that can produce a meaningful change in SP.

Bibliography

- Ader, D. N. (2007). Developing the patient-reported outcomes measurement information system (PROMIS). *Medical Care*, 45(5),S1-S2
- Agahi, N., Ahacic, K., & Parker, M. (2006). Continuity of leisure participation from middle age to old age. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(6), S340-S346.
- Anaby, D., Miller, W., Eng, J., Jarus, T., & Noreau, L. (2009). Can personal and environmental factors explain participation of older adults? *Disability and Rehabilitation*, 31(15), 1275-1282.
- Ang, S. (2018). Social participation and health over the adult life course: Does the association strengthen with age? *Social Science & Medicine*, 206, 51-59.
- Arnadottir, S. A., Gunnarsdottir, E. D., Stenlund, H., & Lundin-Olsson, L. (2011). Participation frequency and perceived participation restrictions at older age: applying the International Classification of Functioning, Disability and Health (ICF) framework. *Disability and Rehabilitation*, 33(22-23), 2208-2216.
- Avlund, K., Lund, R., Holstein, B. E., & Due, P. (2004). Social relations as determinant of onset of disability in aging. *Archives of Gerontology and Geriatrics*, 38(1), 85-99.
- Bassuk, S. S., Glass, T. A., & Berkman, L. F. (1999). Social disengagement and incident cognitive decline in community-dwelling elderly persons. *Annals of Internal Medicine*, 131(3), 165-173.
- Bath, P. A., & Deeg, D. (2005). Social engagement and health outcomes among older people: introduction to a special section. *European Journal of Ageing*, 2(1), 24-30.

- Bathgate, T., & Romios, P. (2011). *Consumer participation in health: Understanding consumers as social participants*. Paper presented at the Institute for Social Participation Seminar Series.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*(6), 843-857.
- Bobbitt-Zeher, D. (2007). The gender income gap and the role of education. *Sociology of Education*, *80*(1), 1-22.
- Bode, R. K., Hahn, E. A., DeVellis, R., Cella, D., & Group, P.-R. O. M. I. S. S. D. W. (2010). Measuring participation: the patient-reported outcomes measurement information system experience. *Archives of Physical Medicine and Rehabilitation*, *91*(9), S60-S65.
- Buchman, A. S., Boyle, P. A., Wilson, R. S., Fleischman, D. A., Leurgans, S., & Bennett, D. A. (2009). Association between late-life social activity and motor decline in older adults. *Archives of Internal Medicine*, *169*(12), 1139-1146. doi: 10.1001/archinternmed.2009.135
- Bukov, A., Maas, I., & Lampert, T. (2002). Social participation in very old age: Cross-sectional and longitudinal findings from BASE. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *57*(6), P510-P517.
- Caffrey, C., Harris-Kojetin, L. D., Moss, A. J., Park-Lee, E., Sengupta, M., & Rosenoff, E. (2012). Residents living in residential care facilities; United States, 2010. *National Center for Health Statistics*, (91), 1-8
- Chappell, N. L., Dujela, C., & Smith, A. (2015). Caregiver well-being: intersections of relationship and gender. *Research on Aging*, *37*(6), 623-645.
- Colby, S. L., & Ortman, J. M. (2014). The baby boom cohort in the United States: 2012 to 2060. *US Census Bureau*. 1-16

- Cooper, R., Kuh, D., & Hardy, R. (2010). Objectively measured physical capability levels and mortality: systematic review and meta-analysis. *British Medical Journal*, *341*(c4467), 1-12.
- Cosco, T. D., Prina, A. M., Perales, J., Stephan, B. C., & Brayne, C. (2014). Operational definitions of successful aging: a systematic review. *International Psychogeriatrics*, *26*(3), 373-381.
- Crimmins, E. M., & Beltrán-Sánchez, H. (2010). Mortality and morbidity trends: is there compression of morbidity? *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *66*(1), 75-86.
- De Leon, C. F. M. (2005). Social engagement and successful aging. *European Journal of Ageing*, *2*(1), 64-66.
- Deeg, D. J. (2005). Longitudinal characterization of course types of functional limitations. *Disability and Rehabilitation*, *27*(5), 253-261.
- Desrosiers, J., Noreau, L., & Rochette, A. (2004). Social participation of older adults in Quebec. *Aging Clinical and Experimental Research*, *16*(5), 406-412.
- Desrosiers, J., Robichaud, L., Demers, L., Gélinas, I., Noreau, L., & Durand, D. (2009). Comparison and correlates of participation in older adults without disabilities. *Archives of Gerontology and Geriatrics*, *49*(3), 397-403.
- Dijkers, M. P. (2010). Issues in the conceptualization and measurement of participation: an overview. *Archives of Physical Medicine and Rehabilitation*, *91*(9), S5-S16.
- Duggan, M., & Brenner, J. (2013). *The demographics of social media users, 2012* (Vol. 14). Washington, DC: Pew Research Center's Internet & American Life Project.

- Ekström, H., Ivanoff, S. D., & Elmståhl, S. (2013). Does informal support influence social participation of fractured elderly people? *Archives of Gerontology and Geriatrics*, *56*(3), 457-465.
- Eyssen, I. C., Steultjens, M. P., Dekker, J., & Terwee, C. B. (2011). A systematic review of instruments assessing participation: challenges in defining participation. *Archives of Physical Medicine and Rehabilitation*, *92*(6), 983-997.
- Freedman, V. A., Kasper, J. D., Cornman, J. C., Agree, E. M., Bandeen-Roche, K., Mor, V., . . . Wolf, D. A. (2011). Validation of new measures of disability and functioning in the National Health and Aging Trends Study. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, *66*(9), 1013-1021.
- Freedman, V. A., & Spillman, B. C. (2014). The residential continuum from home to nursing home: size, characteristics and unmet needs of older adults. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *69*(Suppl_1), S42-S50.
- Gagliardi, C., Spazzafumo, L., Marcellini, F., Mollenkopf, H., Ruoppila, I., Tacken, M., & Szemann, Z. (2007). The outdoor mobility and leisure activities of older people in five European countries. *Ageing & Society*, *27*(5), 683-700.
- García, E. L., Banegas, J., Perez-Regadera, A. G., Cabrera, R. H., & Rodriguez-Artalejo, F. (2005). Social network and health-related quality of life in older adults: a population-based study in Spain. *Quality of Life Research*, *14*(2), 511-520.
- Gill, T. M., Allore, H. G., Hardy, S. E., & Guo, Z. (2006). The dynamic nature of mobility disability in older persons. *Journal of the American Geriatrics Society*, *54*(2), 248-254.

- Gill, T. M., Gahbauer, E. A., Lin, H., Han, L., & Allore, H. G. (2013). Comparisons between older men and women in the trajectory and burden of disability over the course of nearly 14 years. *Journal of the American Medical Directors Association, 14*(4), 280-286.
- Gill, T. M., Hardy, S. E., & Williams, C. S. (2002). Underestimation of disability in community-living older persons. *Journal of the American Geriatrics Society, 50*(9), 1492-1497.
- Glass, T. A., De Leon, C. F. M., Bassuk, S. S., & Berkman, L. F. (2006). Social engagement and depressive symptoms in late life: longitudinal findings. *Journal of Aging and Health, 18*(4), 604-628.
- Griffin, J., & McKenna, K. (1999). Influences on leisure and life satisfaction of elderly people. *Physical & Occupational Therapy in Geriatrics, 15*(4), 1-16.
- Guralnik, J. M., Ferrucci, L., Simonsick, E. M., Salive, M. E., & Wallace, R. B. (1995). Lower-extremity function in persons over the age of 70 years as a predictor of subsequent disability. *New England Journal of Medicine, 332*(9), 556-562.
- Guralnik, J. M., Simonsick, E. M., Ferrucci, L., Glynn, R. J., Berkman, L. F., Blazer, D. G., . . . Wallace, R. B. (1994). A short physical performance battery assessing lower extremity function: association with self-reported disability and prediction of mortality and nursing home admission. *Journal of Gerontology, 49*(2), M85-M94.
- Hahn, E. A., Cella, D., Bode, R. K., & Hanrahan, R. T. (2010). Measuring social well-being in people with chronic illness. *Social Indicators Research, 96*(3), 381-401.
- Hardy, S. E., & Gill, T. M. (2004). Recovery from disability among community-dwelling older persons. *Jama, 291*(13), 1596-1602.
- He, W., Goodkind, D., & Kowal, P. R. (2016). An aging world: 2015. International Population Reports. *United States Census Bureau*.

- Heaven, B., Brown, L. J., White, M., Errington, L., Mathers, J. C., & Moffatt, S. (2013). Supporting well-being in retirement through meaningful social roles: Systematic review of intervention studies. *The Milbank Quarterly*, *91*(2), 222-287.
- Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health some critical remarks. *American Journal of Occupational Therapy*, *59*(5), 569-576.
- Herzog, A. R., Ofstedal, M. B., & Wheeler, L. M. (2002). Social engagement and its relationship to health. *Clinics in Geriatric Medicine*, *18*(3), 593-609.
- Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: a meta-analytic review. *Public Library for Science Medicine*, *7*(7), 1-20.
- Institute of Aging. (2018). Read how Institue of Aging views aging in America. from <https://http://www.ioaging.org/aging-in-america>
- Ishikawa, M., Tamakoshi, K., Yatsuya, H., Suma, K., Wada, K., Otsuka, R., . . . Kondo, T. (2006). Factors related to frequency of engaging in outside activities among elderly persons living an independent life at home. *Nagoya Journal of Medical Science*, *68*(3/4), 121-130.
- James, B. D., Boyle, P. A., Buchman, A. S., & Bennett, D. A. (2011). Relation of late-life social activity with incident disability among community-dwelling older adults. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, *66*(4), 467-473.
- James, B. D., Wilson, R. S., Barnes, L. L., & Bennett, D. A. (2011). Late-life social activity and cognitive decline in old age. *Journal of the International Neuropsychological Society*, *17*(6), 998-1005.

- Jarrar, M. (2019). *The Prevalence of Self-Identified Social Participation Restriction Due to Health Issues in Older Adults*. Unpublished manuscript.
- Jette, A. M., Haley, S. M., & Kooyoomjian, J. T. (2003). Are the ICF activity and participation dimensions distinct? *Journal of Rehabilitation Medicine, 35*(3), 145-149.
- Juckel, G., Schaub, D., Fuchs, N., Naumann, U., Uhl, I., Witthaus, H., . . . Brüne, M. (2008). Validation of the Personal and Social Performance (PSP) Scale in a German sample of acutely ill patients with schizophrenia. *Schizophrenia Research, 104*(1), 287-293.
- Kasper, & Freedman. (2012). National health and aging trends study round 1 user guide: Final release. . *Baltimore, MD: Johns Hopkins University School of Public Health*.
- Kasper, J., Freedman, V., & Niefeld, M. (2012). Construction of performance-based summary measures of physical capacity in the National Health and Aging Trends Study. NHATS technical paper #4. *Baltimore, MD: Johns Hopkins University School of Public Health*.
- Kim, W.-J., Chang, M., & An, D.-H. (2014). Effects of a community-based fall prevention exercise program on activity participation. *Journal of Physical Therapy Science, 26*(5), 651-653.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2003). The Patient Health Questionnaire-2: validity of a two-item depression screener. *Medical Care, 41*(11), 1284-1292.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy, 56*(6), 640-649.
- Leggett, A., Polenick, C. A., Maust, D. T., & Kales, H. C. (2018). “What Hath Night to Do with Sleep?”: The Caregiving Context and Dementia Caregivers’ Nighttime Awakenings. *Clinical Gerontologist, 41*(2), 158-166.

- Levasseur, Desrosiers, J., & Noreau, L. (2004). Is social participation associated with quality of life of older adults with physical disabilities? *Disability and Rehabilitation*, 26(20), 1206-1213.
- Levasseur, Richard, Gauvin, & Raymond. (2010). Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. *Social Science & Medicine*, 71(12), 2141-2149.
- Levasseur, M., Desrosiers, J., & Whiteneck, G. (2010). Accomplishment level and satisfaction with social participation of older adults: association with quality of life and best correlates. *Quality of Life Research*, 19(5), 665-675.
- Li, T., Wells, G., Westhovens, R., & Tugwell, P. (2009). Validation of a simple activity participation measure for rheumatoid arthritis clinical trials. *Rheumatology*, 48(2), 170-175.
- Lindström, M., Hanson, B. S., & Östergren, P.-O. (2001). Socioeconomic differences in leisure-time physical activity: the role of social participation and social capital in shaping health related behaviour. *Social Science & Medicine*, 52(3), 441-451.
- Mather, M., Jacobsen, L., & Pollard, K. (2015). Aging in the United States (Vol. 70): Population Reference Bureau.
- Matsuura, K. (2005). Appendix I UNESCO Universal Declaration on Cultural Diversity
UNESCO Universal Declaration on Cultural Diversity. *Diogenes*, 52(1), 141-145.
- McCrinkle, M., & Wolfinger, E. (2010). Generations defined. *Ethos*, 18(1), 8.
- McHorney, C. A., Ware, J. E., & Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care*, 31(3), 247-247.

- Mendes de Leon, C. F., & Rajan, K. B. (2014). Psychosocial influences in onset and progression of late life disability. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 69(2), 287-302.
- Miller, R. R., Ballew, S. H., Shardell, M. D., Hicks, G. E., Hawkes, W. G., Resnick, B., & Magaziner, J. (2009). Repeat falls and the recovery of social participation in the year post-hip fracture. *Age and Ageing*, 38(5), 570-575.
- Montaquila, J., Freedman, V. A., Edwards, B., & Kasper. (2017). National health and aging trends study round 1 sample design and selection. NHATS Technical Paper# 14. *Baltimore, MD: Johns Hopkins University School of Public Health.*
- Montaquila, J., Freedman, V. A., Edwards, B., & Kasper, J. D. (2012a). National health and aging trends study round 1 sample design and selection. NHATS Technical Paper# 1. *Baltimore, MD: Johns Hopkins University School of Public Health.*
- Montaquila, J., Freedman, V. A., Edwards, B., & Kasper, J. D. (2012b). National health and aging trends study round 1 sample design and selection. NHATS Technical Paper# 2. *Baltimore, MD: Johns Hopkins University School of Public Health.*
- Montaquila, J., Freedman, V. A., Spillman, B. C., & Kasper. (2017). National Health and Aging Trends Study round I development of round I survey weights. NHATS Technical Paper# 16. Baltimore, MD: Johns Hopkins niversity, Bloomberg of Public Health.
- National Institutes of Health, National Heart Lung, & Blood Institute. (1998). Evaluation, and Treatment of Overweight and Obesity in Adults. *Clinical Guidelines on the Identification*, 98-483.

- Ortman, J. M., Velkoff, V. A., & Hogan, H. (2014). *An aging nation: the older population in the United States* (pp. 25-1140). Washington, DC: United States Census Bureau, Economics and Statistics Administration, US Department of Commerce.
- Ostir, G. V., Volpato, S., Fried, L. P., Chaves, P., & Guralnik, J. M. (2002). Reliability and sensitivity to change assessed for a summary measure of lower body function: results from the Women's Health and Aging Study. *Journal of clinical epidemiology*, *55*(9), 916-921.
- Oxoby, R. (2009). Understanding social inclusion, social cohesion, and social capital. *International Journal of Social Economics*, *36*(12), 1133-1152.
- Patel, K. V., Guralnik, J. M., Dansie, E. J., & Turk, D. C. (2013). Prevalence and impact of pain among older adults in the United States: findings from the 2011 National Health and Aging Trends Study. *Pain®*, *154*(12), 2649-2657.
- Patel, K. V., Guralnik, J. M., Phelan, E. A., Gell, N. M., Wallace, R. B., Sullivan, M. D., & Turk, D. C. (2019). Symptom burden among community-dwelling older adults in the United States. *Journal of the American Geriatrics Society*, *67*(2), 223-231.
- Patel, K. V., Phelan, E. A., Leveille, S. G., Lamb, S. E., Missikpode, C., Wallace, R. B., . . . Turk, D. C. (2014). High prevalence of falls, fear of falling, and impaired balance in older adults with pain in the United States: findings from the 2011 National Health and Aging Trends Study. *Journal of the American Geriatrics Society*, *62*(10), 1844-1852.
- Patterson, V. L., King, S. V., Ball, M. M., Whittington, F. J., & Perkins, M. M. (2003). Coping with change: Religious activities and beliefs of residents in assisted living facilities. *Journal of Religious Gerontology*, *14*(4), 79-93.

- Perenboom, R. J., & Chorus, A. M. (2003). Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation, 25*(11-12), 577-587.
- Peterson Bethea, D., Lovett, A., Cooks, K., & Bell, J. (2010). Promoting social participation for adults through arthritis self-management: A pilot study. *Physical & Occupational Therapy In Geriatrics, 28*(3), 297-306.
- Piškur, B., Daniëls, R., Jongmans, M. J., Ketelaar, M., Smeets, R. J., Norton, M., & Beurskens, A. J. (2014). Participation and social participation: are they distinct concepts? *Clinical Rehabilitation, 28*(3), 211-220.
- Prout, A. (2003). Participation, policy and the changing conditions of childhood. In *Hearing the voices of children* (pp. 27-41). New York, NY: Routledge.
- Rosso, A. L., Taylor, J. A., Tabb, L. P., & Michael, Y. L. (2013). Mobility, disability, and social engagement in older adults. *Journal of Aging and Health, 25*(4), 617-637.
- Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *Gerontologist, 37*(4), 433-440. doi: 10.1093/geront/37.4.433
- Ryan, T., Enderby, P., & Rigby, A. S. (2006). A randomized controlled trial to evaluate intensity of community-based rehabilitation provision following stroke or hip fracture in old age. *Clinical Rehabilitation, 20*(2), 123-131.
- Skolarus, L. E., Sánchez, B. N., Morgenstern, L. B., Garcia, N. M., Smith, M. A., Brown, D. L., & Lisabeth, L. D. (2010). Validity of proxies and correction for proxy use when evaluating social determinants of health in stroke patients. *Stroke, 41*(3), 510-515.
- Sørensen, L. V., Axelsen, U., & Avlund, K. (2002). Social participation and functional ability from age 75 to age 80. *Scandinavian Journal of Occupational Therapy, 9*(2), 71-78.

StataCorp, L. (2015). Stata/SE 14.2.

Studenski, S., Perera, S., Patel, K., Rosano, C., Faulkner, K., Inzitari, M., . . . Connor, E. B.

(2011). Gait speed and survival in older adults. *Journal of the American Medical Association*, 305(1), 50-58.

Theis, K., Murphy, L., Hootman, J., & Wilkie, R. (2013). Social participation restriction among US adults with arthritis: a population-based study using the International Classification of Functioning, Disability and Health. *Arthritis Care & Research*, 65(7), 1059-1069.

United States Census. (2017). Facts for Features: Older Americans Month: May 2017.

Retrieved Jun 25, 2019, from <https://http://www.census.gov/newsroom/facts-for-features/2017/cb17-ff08.html>

Üstün, T. (2002). Towards a Common Language for Functioning, Disability and Health, ICF. *World Health Organization Geneva*.

Veenhuizen, Y., Cup, E. H., Groothuis, J. T., Hendriks, J. C., Adang, E. M., van Engelen, B. G., & Geurts, A. C. (2015). Effectiveness and cost-effectiveness of a self-management group program to improve social participation in patients with neuromuscular disease and chronic fatigue: protocol of the Energetic study. *BioMed Central Neurology*, 15(1), 58.

Wang, H.-X., Karp, A., Winblad, B., & Fratiglioni, L. (2002). Late-life engagement in social and leisure activities is associated with a decreased risk of dementia: a longitudinal study from the Kungsholmen project. *American Journal of Epidemiology*, 155(12), 1081-1087.

Whiteneck. (1992). Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Physical Medicine Rehabilitation*, 73(6), 519-26.

- Whiteneck, & Dijkers, M. P. (2009). Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation, 90*(11), S22-S35.
- Wilkie, R., Peat, G., Thomas, E., & Croft, P. (2006). The prevalence of person-perceived participation restriction in community-dwelling older adults. *Quality of Life Research, 15*(9), 1471-1479.
- Wilkie, R., Peat, G., Thomas, E., Hooper, H., & Croft, P. R. (2005). The Keele Assessment of Participation: a new instrument to measure participation restriction in population studies. Combined qualitative and quantitative examination of its psychometric properties. *Quality of Life Research, 14*(8), 1889-1899.
- Wilkie, R., Thomas, E., Mottram, S., Peat, G., & Croft, P. (2008). Onset and persistence of person-perceived participation restriction in older adults: a 3-year follow-up study in the general population. *Health and Quality of Life Outcomes, 6*(1), 92.
- Williams, B. A., Stern, M. F., Mellow, J., Safer, M., & Greifinger, R. B. (2012). Aging in correctional custody: setting a policy agenda for older prisoner health care. *American Journal of Public Health, 102*(8), 1475-1481.
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. World Health Organization